South Puget Intertribal Planning Agency

Serving the Tribal Nations of:

Chehalis

Nisqually

Shoalwater Bay

Skokomish

Squaxin Island

A Comprehensive Cancer Control Plan for the SPIPA Tribes 2005-2012

A Framework for Action To Reduce the Burden of Cancer for the SPIPA Tribes

Prevention Early Detection Treatment Survivor Support

Acknowledgements and Thanks

- **The SPIPA Cancer Advisory Committee**
- **SPIPA Board of Directors**
- **Tribal Councils of the five SPIPA Tribes**
- **The Chehalis, Nisqually, Shoalwater Bay, Skokomish and Squaxin Island Tribes and Tribal Health Clinics**
- **SPIPA's Breast and Cervical Cancer Early Detection Program**
- **National Cancer Institutes Cancer Information Service Partnership Program**
- **Spirit of the EAGLES at the Cancer Information Service**
- **The Center for Disease Control and Prevention**

Major Sources of Information

- Tribal and Community Members from the Five Tribes
- The SPIPA Cancer Control Advisory Committee
- The Chehalis, Nisqually, Shoalwater Bay, Skokomish and Squaxin Island Tribal Health Clinics
- SPIPA's Breast and Cervical Cancer Early Detection Program
- Washington State Cancer Registry
- The Centers for Disease Control and Prevention
- National Cancer Institute
- Intercultural Cancer Council
- Northwest Portland Area Indian Health Board's Behavior and Risk Factor Surveillance System and Racial Misclassification Study
- American Cancer Society
- US Preventive Services Task Force

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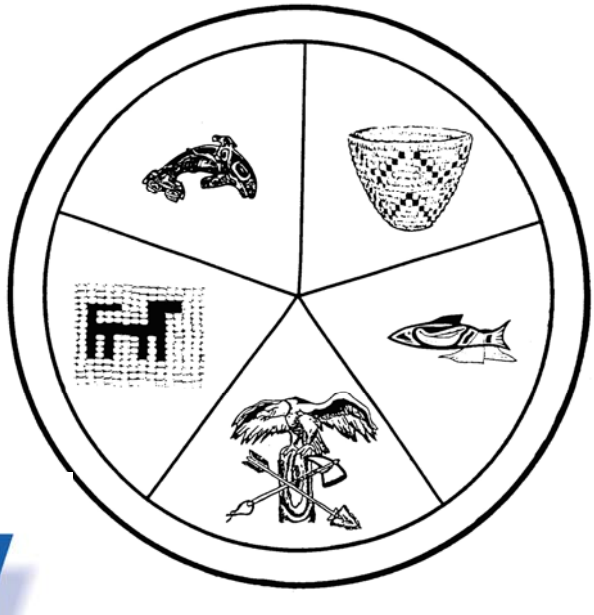


Northwest Portland Area Indian Health Board

American Cancer Society®

AMERICAN LUNG ASSOCIATION®

The Unbroken Circle

ARC NW Alliance For Reducing Cancer, Northwest

Table of Contents

Purpose of the Cancer Control Plan

This Plan is meant to be used by the South Puget Intertribal Planning Agency's (SPIPA) Tribal and community members, Tribal Councils and Tribal Health Clinic staff, by Tribal and SPIPA Planners and Administrators, by non-tribal partners including funding agencies and those providing technical assistance to the SPIPA Tribes.

This Cancer Control Plan is a roadmap covering the unified efforts of the SPIPA communities and partners to address, control and prevent cancer for all served by SPIPA. It encompasses cancer control and prevention activities from 2006 through 2011. This Cancer Control Plan includes "measures of effectiveness" and a timeline for carrying out cancer control activities so that we can monitor our success in cancer control as we journey down this path.

Cancer control will not be completed by 2011. Our work today is to create a strong foundation for current and future generations. These next five years will be a strong first step toward reaching our seventh-generation vision of cancer free communities.

Organization of this Document

This plan is organized in order of the four priorities outlined by the SPIPA Tribal communities. This plan provides the SPIPA Comprehensive Cancer Control Program (CCCP), the SPIPA Tribes and their partners with a roadmap for the journey towards cancer control and a cancer free community. An executive summary and overview is provided in the beginning of this plan. This document is organized to provide clarity on:

- Where we've been
- Where we are
- Where we are going, and
- How we are going to get there

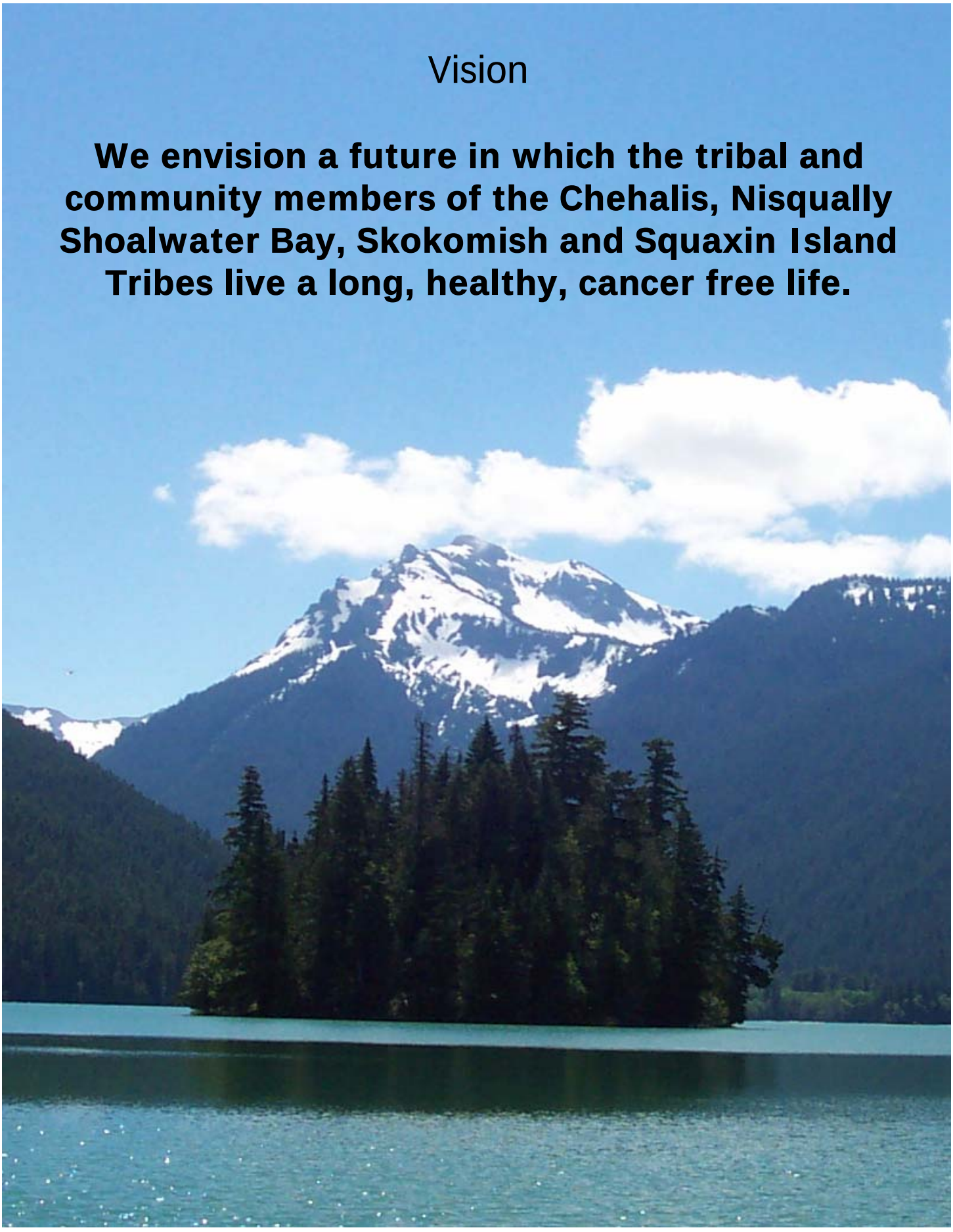
The actual cancer control plan starts on page 29 and provides information on the goals, objectives and activities in order of the four priorities that were outlined by the SPIPA tribal and community members (prevention, screening, treatment and survivor support). The work plan for each of these priorities is presented in an outline form with detailed information on objectives, activities, how we are going to measure the effectiveness of each activity, the time line for action and those responsible for each action. We present this level of detail in this plan so that all involved in cancer control for the SPIPA Tribes are aware of the strategies in place for achieving the vision of cancer-free communities. Those reading the plan are encouraged to provide feedback to ensure the success, appropriateness and feasibility of the plan.

The SPIPA CCCP and the Advisory Committee are committed to ensuring the words of this plan become a reality. The Plan is organized so that it is revisited and used as a roadmap for our journey throughout the life of the SPIPA Comprehensive Cancer Control Program.

Background information and data on the burden of cancer for the SPIPA Tribes is presented throughout this document. Further information on the burden of cancer for the SPIPA Tribes can be found in the SPIPA CCCP report entitled "Cancer Information for the Five Tribes, 2005". Details of all data and information sources can be found in the reference section of this plan.

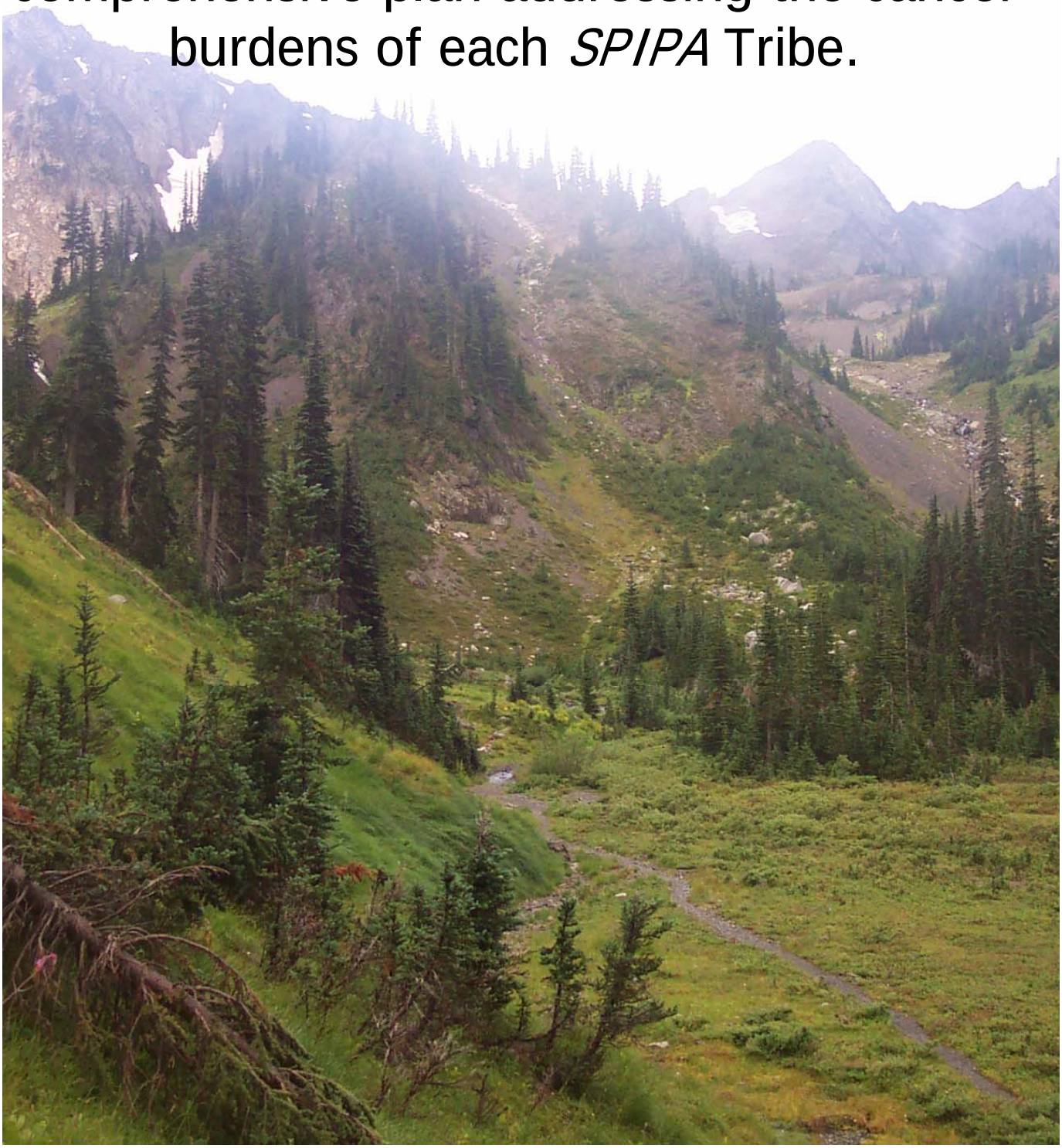
Vision

We envision a future in which the tribal and community members of the Chehalis, Nisqually Shoalwater Bay, Skokomish and Squaxin Island Tribes live a long, healthy, cancer free life.



Mission

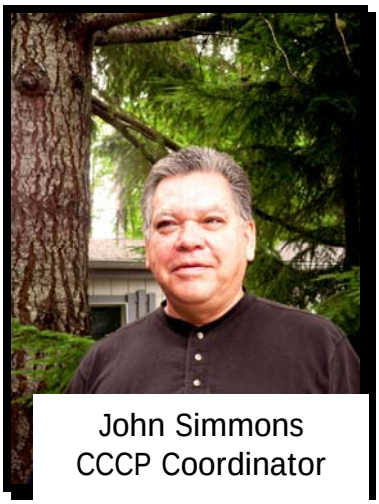
To implement a community-driven, comprehensive plan addressing the cancer burdens of each *SPIPA* Tribe.



Executive Summary

Executive Summary

The Comprehensive Cancer Control Project team adopted a project planning approach to develop the Cancer Control Implementation Plan. This plan was created through the partnership of the Advisory Committee, which is made up of Tribal and Community members from the Chehalis, Nisqually, Skokomish, Squaxin Island and Shoalwater Bay Tribes, including some very distinguished Professional Organizations residing in the State of Washington.



John Simmons
CCCP Coordinator

Obtaining detail information, at the grass roots level from the Tribal Communities, was the foundation for the development of this plan. What you will read here is the collaborative work of dedicated partners with four (4) Goals in mind that would reduce cancer incidence, morbidity and mortality within the SPIPA Tribes through prevention, early detection, treatment and survivor support.

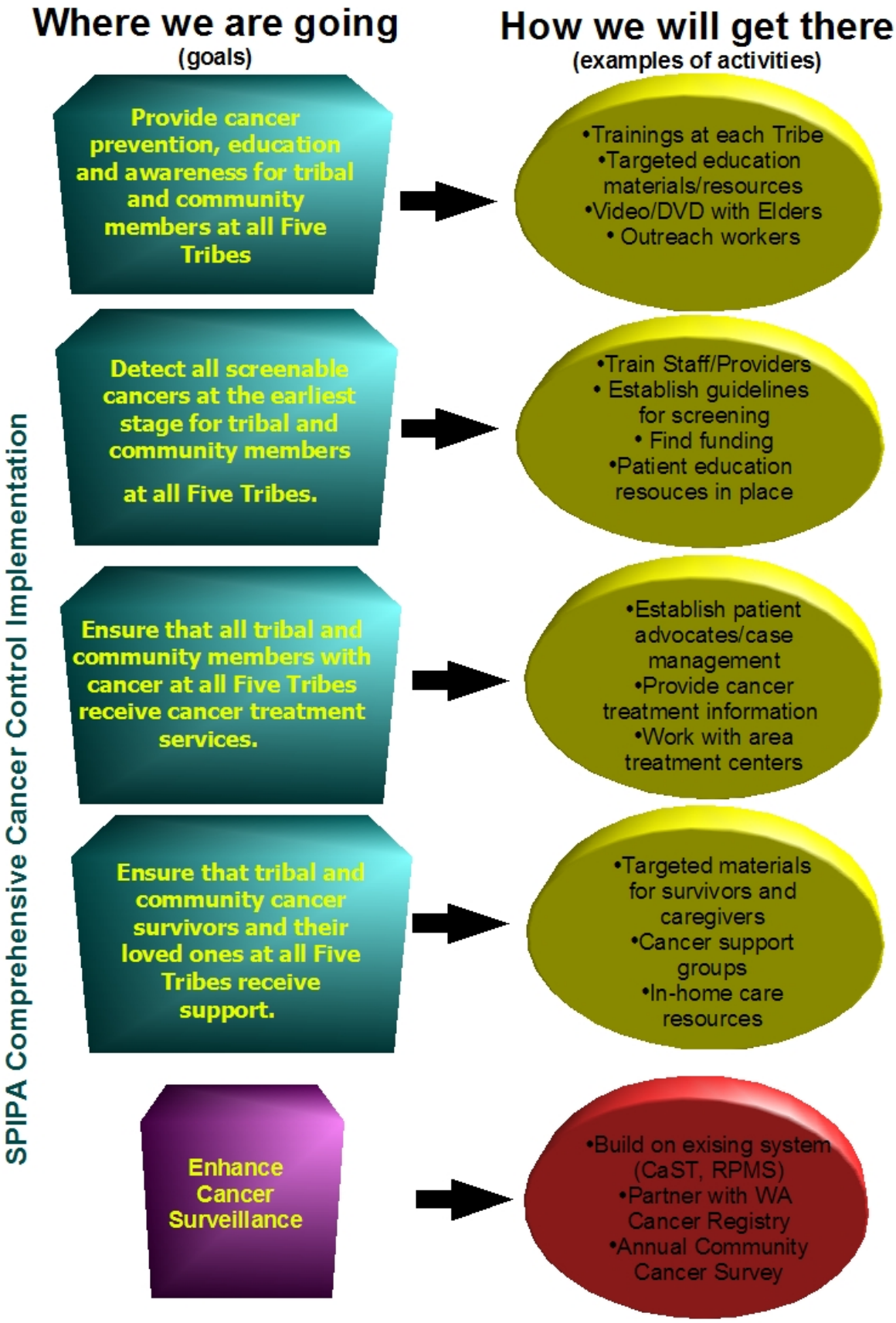
Awareness of Cancer was raised through educational trainings, survivors telling of real life stories that both helped and hindered their wellness activates for themselves, family members and friends. The challenges and success stories from survivors were identified and addressed as action items to ensure successes, understanding and involvement in early detection, follow up and treatment.

The collaborative effort of the partnership working on this comprehensive cancer plan recognized the tremendous burden of cancer within the SPIPA Tribes – it is the second leading cause of death in Indian Country. We have identified the following activities to bookmark where we are going with this plan:

- Provide cancer prevention, education and awareness for tribal and community members at the SPIPA Tribes,
- Detect all screen able cancers at the earliest stage for tribal and community members,
- Ensure that all tribal and community members with cancer at the Tribes receive cancer treatment services and
- Ensure that tribal and community cancer survivors and their loved ones at all five Tribes receive support.

The goals and strategies outlined for this effort will include targeted education materials, resources and outreach worker training at each tribal community. Training for clinical staff and providers, establish guidelines for screening at each clinic, establish patient advocates/case management, provide cancer treatment information and establish cancer support groups sensitive to the Native American traditional and cultural environment.

It is not possible to address all issues related to cancer control in one document. This plan is designed to be a living document that will guide collaborative efforts throughout the SPIPA tribes. This plan will be modified as the SPIPA Tribes move through the implementation phase and resources for this project change.


SPIPA Comprehensive Cancer Control Implementation
Where we are going
(goals)
How we will get there
(examples of activities)
Provide cancer prevention, education and awareness for tribal and community members at all Five Tribes
•Trainings at each Tribe
•Targeted education materials/resources
•Video/DVD with Elders
• Outreach workers
Detect all screenable cancers at the earliest stage for tribal and community members at all Five Tribes.
•Train Staff/Providers
• Establish guidelines for screening
• Find funding
•Patient education resouces in place
Ensure that all tribal and community members with cancer at all Five Tribes receive cancer treatment services.
•Establish patient advocates/case management
•Provide cancer treatment information
•Work with area treatment centers
Ensure that tribal and community cancer survivors and their loved ones at all Five Tribes receive support.
•Targeted materials for survivors and caregivers
•Cancer support groups
•In-home care resources
Enhance Cancer Surveillance
•Build on exising system (CaST, RPMS)
•Partner with WA Cancer Registry
•Annual Community Cancer Survey

Goals and Objectives

Goal#1: Provide cancer prevention, education and awareness for tribal and community members at all SPIPA Tribes.

Objectives to meet this goal:

#1: By 2012, the SPIPA CCCP, in coordination with the SPIPA Tribes, will create and implement activities that raise awareness and education of cancer prevention and screening.

#2 by 2012, the SPIPA CCCP will coordinate with each of Tribal Tobacco programs to strengthen Tobacco use prevention activities at each of the Five Tribes.

#3 by 2012, the SPIPA CCCP and the SPIPA Tribes will coordinate with each of the Tribal Tobacco programs to strengthen Quit smoking/chew programs.

#4 By 2012, the SPIPA CCCP and SPIPA Tribes will create and implement Activity and exercise programs, in coordination with existing efforts, at each of the SPIPA Tribes.

#5 By 2012, the SPIPA CCCP and SPIPA Tribes will create and implement Nutrition awareness (5 fruits and vegetables a day) for cancer prevention activities at each of the SPIPA Tribes.

#6 By 2012, the SPIPA CCCP and SPIPA Tribes will coordinate with the Native Women's Wellness Program (NWWP) and Tribal Clinics to create and implement activities related to Sexually Transmitted Disease (STD) prevention related to cancer.

Goal #2: Detect all screen able cancers at the earliest stage for tribal and community members at all SPIPA Tribes.

Objectives to meet this goal:

#1 The SPIPA's CCCP will work with the NWWP and Tribal clinics to increase Breast cancer screening (mammograms) rates by at least 10% each year.

#2 The SPIPA CCCP will coordinate with the Tribal Clinics and other Tribal services to annually screen at least 50% of the eligible population for prostate cancer by 2009.

#3 The SPIPA CCCP will work with the Tribal Clinics to screen at least 50% of the eligible population for skin cancer by 2009 at recommended time intervals.

#4 The SPIPA CCCP will work with the Tribal Clinics to screen at least 50% of the eligible population for Colon / Rectal cancer at the recommended time intervals.

#5 The SPIPA CCCP will work with the NWWP and the Tribal clinics to increase cervical cancer screening by at least 10% each year.

Goal #3: Ensure that all tribal and community members with cancer at all SPIPA Tribes receive cancer treatment services that are state of the art, timely, comprehensive, traditional, and affordable.

Objectives to meet this goal:

#1 by 2012, SPIPA's CCCP and the SPIPA Tribes will assess and implement systems that improve and track the timeliness of treatment (getting treated quickly) for SPIPA Tribal and community members.

#2 By 2012, SPIPA's CCCP and the SPIPA Tribes will assess challenges and opportunities for covering the cost of treatment, implementing policies and procedures that help cover the cost of treatment where applicable.

#3 by 2012 the SPIPA CCCP, in partnership with the NWWP and Tribal Health Clinics will assess the challenges and opportunities for access to the latest treatment options, implementing systems that improve access to the latest treatment options when applicable.

#4 by 2012 the SPIPA CCCP and the SPIPA Tribes will support opportunities to increase access to traditional/spiritual treatment, for cancer treatment for the SPIPA Tribes.

Goal #4: Ensure that tribal and community cancer survivors and their loved ones at all SPIPA Tribes receive support. (Cancer survivors include family, caregivers, friends and other support systems.)

Objectives to meet this goal:

#1 by 2012, SPIPA's CCCP will find/develop and implement Family support education and awareness activities for the families of those with cancer in the SPIPA Tribes.

#2 by 2012, SPIPA's CCCP will develop Cancer survivor support groups for the SPIPA Tribes.

#3 by 2012, SPIPA's CCCP will research and develop systems for giving financial assistance for on-going cancer related needs for cancer survivors within the SPIPA Tribes.

#4 by 2012, SPIPA's CCCP will assess the needs, find resources and develop systems for Home care for cancer survivors for the SPIPA Tribes.

#5 by 2012, SPIPA's CCCP will assess needs and implement activities that address Cancer related pain management for cancer survivors in the SPIPA Tribes.

#6 by 2012, SPIPA's CCCP will assess needs and implement activities that address End of life care and support for the SPIPA Tribes.

Cancer Control Planning

Where we've been.....

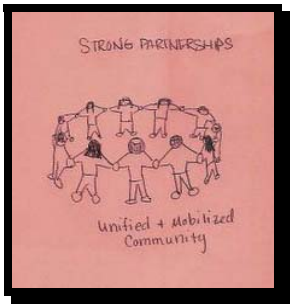
Commitment to Community-Driven Planning -

How the plan was developed

In many of the most effective health programs, activities that help people to develop their own skills and ownership of the solutions have become a key part in addressing the burden of disease. Health disparities continue to persist in Indian Country. The health burdens of the five SPIPA Tribes mirror those of other tribal communities throughout the nation.

SPIPA's Cancer Control Planning efforts are rooted in the notion that many successful programs in Indian Country have begun as small projects that gradually developed and evolved in response to the needs of the communities being served. Meeting the needs of our Five Tribes works best with small, local beginnings and strong partnerships that respect community-based planning and management. This means important planning and decision making still take place at the Tribal or community level.

Thanks to the CDC-sponsored Comprehensive Cancer Control Planning Program, community-driven planning has been supported and has given cancer control a strong foundation for the Five Tribes. This process has included involvement of Tribal and community members in each phase of the program. Local leaders and all members of the Tribal communities are given the opportunity to play a leading role in determining program priorities.



SPIPA has embraced an approach that views planning as a 'learning process'. Prior to soliciting input from the communities and the Cancer Advisory Committee appropriate training in cancer was provided. Planning will go on continually as a part of a learning process for the program, the partners and the communities served. Participants at every level (health care providers, Tribal Councils, and members of the community) are invited to help shape, change, and critique the plan. This allows the program to constantly evolve and adapt, in order to better meet people's changing needs. Planning and program evaluation will continue to be evidence-based, but will also be locally driven in order to most appropriately meet the needs of each community served.

SPIPA recognizes that good health can only be attained through helping Tribal and community members improve the entire situation in which they live. Through strong partnerships this program is linking health activities with other aspects of social development. Health is seen as a state of wholeness and well being in the Five Tribes. This program is committed to cancer control efforts that enable Tribal and community members from the SPIPA Tribes to work together to improve community wellness in a way that is self-reliant and responsive to ongoing needs.

Cancer Control Planning with the SPIPA Communities

Community Cancer Orientations
The Comprehensive Cancer Control Planning Project hosted a "Community Cancer Orientation" at each of the five SPIPA Tribes throughout the summer of 2004.

The purpose of the CCC Orientations was to:

- Increase community awareness of the project
- Remove barriers (mitigate fears) of cancer
- Increase the understanding of cancer, conduct basic training on cancer - "*Cancer 101*"
- Create Community Advocates (Advisory Committee) to help prioritize planning
- Provide opportunities for entire community to provide input on Cancer Control Priorities

Orientation at Shoalwater Bay, August 3-4, 2004

Community Cancer Survey
Surveys were distributed in each of the SPIPA Tribes at the end of each orientation and by outreach workers at each Tribe. Over 400 surveys were completed and provide the foundation for our cancer control priorities.

Cancer Control Advisory Committee
Each of the five SPIPA Tribes showed a continued commitment to cancer control through the formation of a community-centered Cancer Control Advisory Committee. This committee, made up of community and tribal members, clinic representatives, SPIPA and partners such as the National Cancer Institute's Cancer Information Services (Northwest Region), the Spirit of the E.A.G.L.E.S., the American Lung Association met over 10 times between November 2004 and July 2005.

Planning Retreat with Cancer Control Advisory Committee, Squaxin Island, May 2005

"Community-driven planning" was in full force during a two-day planning retreat held in May of 2005. The CCCP Advisory Committee convened to help craft this plan using information from a community cancer survey, evidence-based practices and their own expertise to craft a vision, mission, goals, objectives and activities for cancer control for the Five Tribes. Participants worked hard during the retreat to produce over 60 pages of "activities and strategies" to address cancer control.

This plan will be submitted to all five Tribal Councils for resolution and, finally, to the Center for Disease Control and Prevention. If approved, the CDC will fund cancer control implementation activities in 2006. In the meantime, the activities and goals outlined in this community-driven plan will be used to submit proposals to other granting agencies.

Current Environment for Cancer Control

Where we are.....

Where We Are

The Current Environment for Cancer Control – SOCKEYE Analysis

SPIPA's Cancer Control future success starts with the "know thyself" principle. Strengths, Opportunities, Challenges and Keys to cancer control were identified in the spring of 2005 by the CCCP Advisory Committee through an exercise entitled "SOCKEYE". The SOCKEYE analysis is designed to allow us to step outside the day-to-day biases and reflect on critical issues that will have an impact on the success of this program. It is also a time to look at the environment external to us and the opportunities and challenges we might encounter.

The background for this analysis depicts the journey of the Sockeye salmon from river to ocean and returning to the river. Like the salmon in their journey the SPIPA Tribes find strength, opportunities, challenges and keys to their vision of cancer-free communities.

Strengths

- Community awareness of cancer
- Active health programs and clinics
- NWWP – outreach workers!
- Good partnerships
- Good participation
- Spiritual Leaders
- Native Women's Wellness Program
- Family
- Prayer
- Clinic testing
- Women's doctor
- Mammograms at the Tribes
- Outreach workers that call and remind us of checkups
- Four generations
- NWWP Dream Catcher
- Canoe Journey
- Traditional activities – basket-weaving classes, gathering materials
- Doctors
- Spiritual Leaders
- Exceptional Program Staff
- Strong Partnerships
- Clear vision for SPIPA community
- Unified and Mobilized Community
- Friends and Family
- Language (Tribal)
- Tribal Council (strong)
- Inclusive sharing
- Spiritual prayers to support the sick
- Health education by trusted members of the community

Opportunities

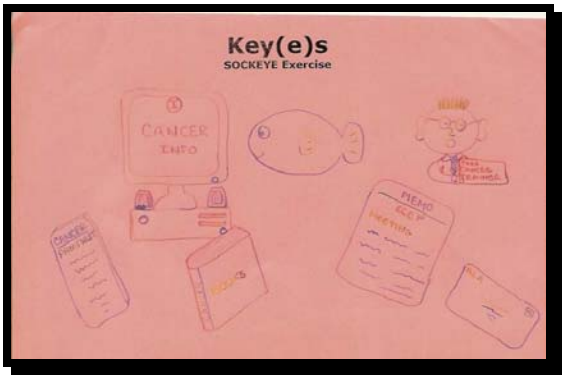
- Partnerships among the Five Tribes
- Women's Wellness data systems
- Community participation
- Fully use elders for education about cancers, including speaking, sharing of stories, wellness fairs, etc.
- Bring together five Tribes to work toward a common goal – to prevent cancer.
- To become a model for Indian Country
- Five Tribes coming together
- Women's and Girls Gathering
- Combining the health programs (tobacco, HIV/AIDS, CCCP, Diabetes, NWWP)
- SPIPA Cancer Advisory Committee to lobby or otherwise influence legislation and $$ allocation to strengthen cancer control
- Provide for the next seven generations by improving things now
- Strengthen Tribal Communities by improving health
- Health Fairs

Challenges

- Lack of awareness
- Misconceptions
- Financial challenges
- High smoking rates for adults and youth
- Getting any information to the whole community including elders, who are set in their ways and very unsure of the white man's way.
- Pollution - air quality
- Fear
- Resistance to screening
- Strained resources in clinics
- Treatment!
- Clinic policies re: not seeing non-tribal enrolled community members
- Need a Men and Boy's Gathering
- Scheduling appointments at the clinic
- Transportation
- Tribal clinic policies to include community members
- Money
- Information
- Modesty
- Support
- Not understanding treatment – confusing medications
- Not understanding the doctor
- $$$
- $$$$$
- Bringing all the different mindsets together
- Space issues (office and meeting rooms)

Keys to Success

- Outreach
- Community awareness and participation
- Clinic buy-in
- Dance, drum and sing-play-share – eat together – read - hugs – prayer – canoe paddle – sweat – live
- God's hand
- Trust and obey – there's no other way
- 5 strong tribal resolutions
- Secure funding (beyond CDC Grant)
- A Cancer specific employee at each tribe (education, outreach, navigator)
- Excellent treatment for SPIPA cancer patients
- Cancer information
- Tribal cancer trainer
- Communication



History/Background of SPIPA & the Five Tribes

SPIPA, driven by the values of service, collaboration and respect, has been serving the Five Tribes since 1976. SPIPA serves five Tribes in Western Washington. Each Tribe has their own respective characteristics that reflect their rich history and traditions as well as vision for the future. All Five Tribes have worked hard to develop community centers, health facilities, youth programs, elder services, tribal enterprises and more.

SPIPA's Vision Statement
Support each Tribe's vision of success and wellness.

SPIPA's Mission Statement
Deliver social, human and health services and provide training and technical assistance, resource development and planning to the Chehalis, Nisqually, Shoalwater Bay, Skokomish and Squaxin Island Tribal Communities.

The Shoalwater Bay Tribe is located on the Washington Coast at the mouth of the Willapa Bay. Reservation lands total about 2.59 square miles. This tight-knit resident community consists of a total Indian resident service population of 1,148, with 237 enrolled tribal members.

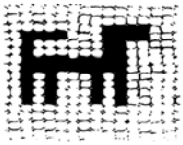
The Skokomish Tribe has a total Indian resident service population of 1,395. The reservation encompasses about 4,998 acres on the lower Hood Canal and Skokomish River. There are 825 enrolled tribal members.

The Squaxin Island Tribe has the second largest total Indian resident service population: 2,498, with 717 enrolled tribal members. The tribe is located in the Kamilche area near Shelton, a central location to the inlets where the original seven bands of people lived.

The lands of the Confederated Tribes of the Chehalis Reservation total about 4,315 acres. The reservation is bounded on the south by the Chehalis River and Black River. In 2004 Chehalis served a total Indian resident population of 3,436, with 688 enrolled tribal members.

The Nisqually Tribe is located near the Nisqually River 15 miles east of Olympia. The Tribe has a total Indian resident population of 4,450, with 505 enrolled tribal members. Tribal land holdings on and near the Nisqually reservation exceed 1,000 acres, all of which have been reacquired in the past 26 years.





Background and Need

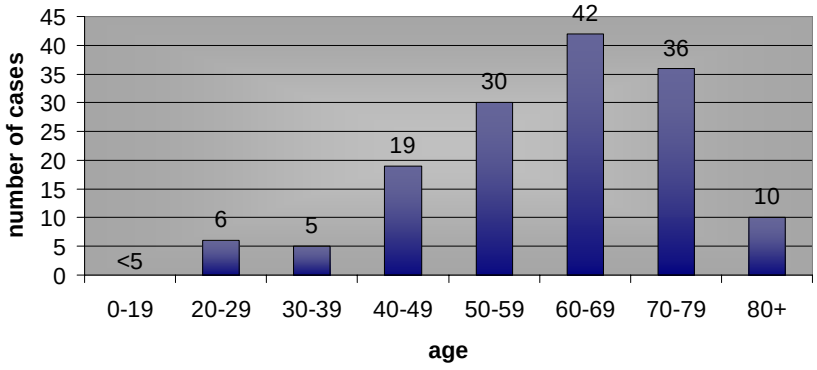
The five SPIPA Tribes of Chehalis, Nisqually, Shoalwater Bay, Skokomish and Squaxin Island are located in western Washington; with a combined total population of over 10,000.

Eliminating health disparities has been the goal of the U.S. Surgeon General's office for over a decade, yet inequalities in health outcomes and access to health resources for Native Americans remain. Advanced age is the main culprit behind cancer. Life expectancy at birth for Native Americans grew from 51 years to 71.5 years between 1940 and 1989 [60]. As those in the SPIPA communities live longer lives, cancer prevention and control becomes a higher priority.

According to current statistics, American Indians and Alaska Natives have a lower incidence of most cancers in Washington than the total population.[1,2] However, American Indians and Alaska Natives (AI/AN) have lower screening rates for cancer, higher risk factors for cancer and lower survival rates for those diagnosed with cancer than for the general population. In addition, rates of cancer for American Indians and Alaska Natives are showing a slight but steady increase over time. [1, 7] It is the goal of this project to control and ultimately prevent cancer in the five Tribes.

As with the general population, cancer incidence increases for those over 40 years old. Between 1996 and 2001 almost 80% of all cancers diagnosed in the AI/AN population in Southwest Washington occurred in those 50 and older [48]. Lung is the most commonly diagnosed cancer for Native Americans in Southwest Washington.

Total number of AI/AN cancer cases by age group, Southwest Washington, 1996-2001



Source: NPAIHB Cancer Registry Project, 2004

The journey of cancer control has already begun. Since 1994 SPIPA's Native Women's Wellness Program has provided breast and cervical cancer screening services for women in the SPIPA Tribes. This program has resulted in earlier detection of breast and cervical cancer along with increased awareness of healthy lifestyles and importance of routine breast and cervical cancer screening. In 2004 over 400 women were screened for breast and cervical cancer through this program.(3) The journey has started, now the path needs to be expanded to include all cancer related priorities identified by all five Tribes.

Most commonly diagnosed cancers for Native Americans in Southwest Washington in rank order (1996-2002)[1]

1. Lung	(27 cases; 17% of cancers)
2. Breast	(22 cases; 14% of cancers)
3. Prostate	(17 cases; 11% of cancers)
4. Colon/Rectal	(15 cases; 10% of cancers)
5. Leukemia/Lymphoma	(14 cases; 9% of cancers)
6. All other	(57 cases; 38% of cancers)

Source: Northwest Portland Area Indian Health Board Cancer Registry Project, 2004

Carmen Kalama, Nisqually Tribal Elder, CCCP Project Director, SPIPA Social Services Manager

"We've had a successful breast and cervical cancer screening program for the women, now we need to expand it for all tribal and community members, especially the men. Our Board of Directors and the communities have also stated that they would like us to focus on prevention. I think we will be able to do that through the Comprehensive Cancer Control grant."

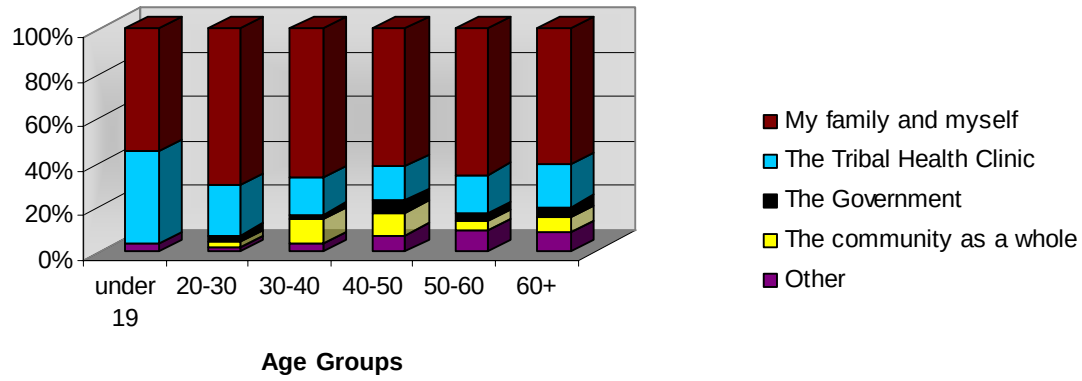
Community opinions strongly indicated that cancer is a key issue facing the five Tribes (4). Over 93% of Tribal and community members responding to the community cancer survey indicated that cancer was either a major problem or an important problem.

[1]"Southwest Washington" includes the counties of Thurston, Lewis, Mason, Grays Harbor, and Pacific.

As the SPIPA Tribes journey down this path of cancer control and prevention it is promising to see the strength of the communities and their commitment to healthy lifestyles. In the recent cancer control survey the majority (68%) of all respondents agreed that the responsibility of health and wellness lies with oneself and one's family. The Tribal Clinics and outside resources such as the U.S. government continue to be strong influences and resources for health and wellness in the tribal communities, but the ultimate strength is coming from the tribal members themselves.

It is the hope of the SPIPA CCCP that the groundbreaking efforts made by this program will be sustained for future generations. Through this program we aim to control cancer through early detection and quality treatment, support for those with cancer and their families and ultimately prevent cancer in future generations by adopting healthy lifestyles.

Opinions: Who is Responsible for Health/Wellness of Family & Self
SPIPA Tribes 2004



Source: SPIPA Community Cancer Survey, 2004

Data gathered & methodology of the cancer control planning process

The SPIPA Comprehensive Cancer Control Program and Plan is rooted in comprehensive data enabling evidence-based planning and decision making. Both qualitative (perceptions, ideas, priorities, etc.) and quantitative (health statistics, screening rates, risk factor data, etc.) information were gathered to inform participants during the planning process.

Qualitative Information (perceptions, knowledge, priorities, ideas, experiences, etc.)

- Community Orientations to provide basic knowledge of cancer, cancer statistics and background information on CCCP in order to provide informed input into CCCP planning efforts
- Community Cancer Survey – a survey of the needs and priorities of tribal and community members. A significant sample of community and tribal members responded to this survey, providing baseline information on the perceptions, needs and priorities. Questions from this survey will be repeated in future community surveys to measure change.
- Knowledge, Attitudes and Beliefs exercise conducted at beginning and repeated at end of each cancer orientation
- Interviews – Cancer survivors, Advisory Committee Members, Clinic and Program Directors were interviewed to further assess needs and priorities for cancer control.

Quantitative Information: (cancer screening, incidence, prevalence, mortality and morbidity information)

- SPIPA Native Women's Wellness Program for breast and cervical cancer screening information
- SPIPA Tribal Clinics – chart review and assessment of existing medical databases
- State Cancer Registry for information such as AI/AN cancer incidence and mortality, cancer incidence at the county and census track level
- Northwest Portland Area Indian Health Board
  - NW Tribal Behavior and Risk Factor Surveillance System (BRFSS)
  - Cancer Registry Project
- Other (Intercultural Cancer Council, literature review, etc.)

"People are more interested if they know the statistics of their particular Tribe. Otherwise, were not aware of the issue. Our Tribes will be more interested if the history of cancer, particularly for their own Tribe, were brought out. We recently found out that a prominent elder in our community has cancer, so there is awareness right now. I think the challenge is to get people interested in learning more. Classes might work. We need to increase awareness."

Harriet Gouley, PHN and Cancer Survivor, Skokomish Elder

Data Limitations and Strengths – current and future

Statewide data, instead of community data, is used to show incidence and mortality rates from cancer due to the small number of AI/AN with cancer in the service area covered by the five SPIPA Tribes. Actual cases for the AI/AN population for 1996 to 2002 are used in this plan and have been presented to the CCCP Advisory Committee with data limitations explained. The SPIPA CCCP is currently working with the Washington State Cancer Registry (WSCR) to track actual cases of cancer versus the expected number of cancer cases at the county and census tract level. Future reviews of cancer related data, with the assistance of the WSCR, will take into consideration the small numbers of cases when publishing results for the SPIPA community.

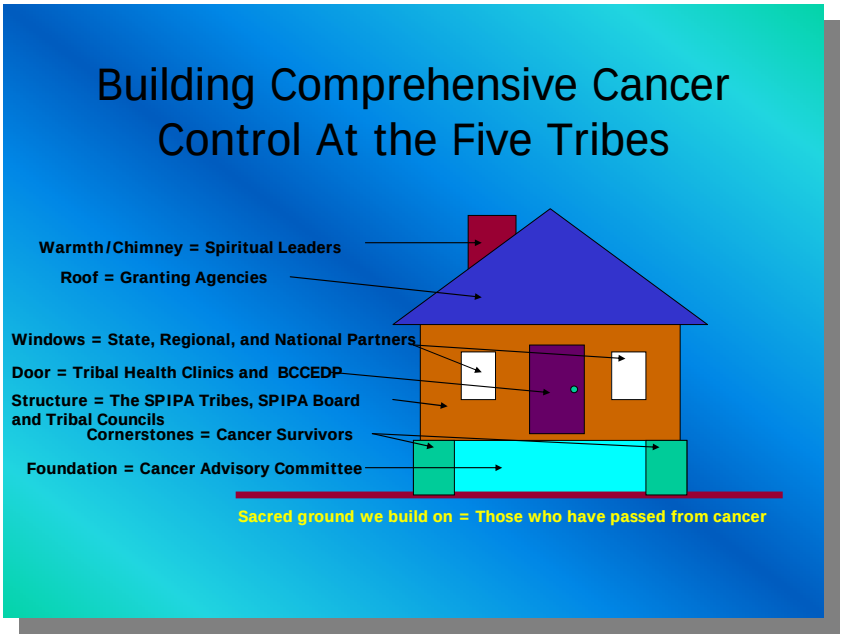
Community surveys and interviews will continue to be used throughout the length of the program. Due to the strong community ownership of this program we foresee strong participation in qualitative data gathering through such methods as community surveys, interviews and focus groups.

Each of the five SPIPA Tribes currently track various degrees of medical information for all patients seen at the Tribal Clinics. Most of the five clinics use the Resource and Patient Management System (RPMS) electronic medical tracking system supported by the Indian Health Service. Shoalwater Bay collects medical data on an alternative electronic records system. Screening rates, patient education and related data elements are not consistently tracked in an electronic records system at the five Tribal Clinics as of summer 2005.

SPIPA has been using the Cast system to track breast and cervical cancer screening and follow up services for women screened through the NWWP. The Cast system cannot be expanded to include screening for other cancers, such as prostate or colorectal. However, lessons learned from tracking screening and case management in Cast for the NWWP will be used when designing a system to track screening for other cancers.

Partners in Cancer Control Implementation

The partners who are involved with the SPIPA Comprehensive Cancer Control Project (CCCP) are members of the CCCP Advisory Committee. These key stakeholders have all been identified as the authors of this plan, see pages 2 and 3. The members of this partnership obtain expertise in Cancer education and training attributes, through knowledge in health programs being offered to Tribal members in each of the five Tribal Communities as well as Clinical knowledge on other chronic diseases affecting the Tribal Communities. These are strong partnerships that unify and stabilize the community. They are built on a strong foundation of those who have passed from cancer. There are cancer survivors who are the cornerstone of this effort and who share their experiences within each community. The five Tribal communities and Tribal Councils provide the structure that sits atop the cornerstone and foundation and provides direction. The Tribal health clinics and the BCCEDP program provide the entrance way into this project with their vast experience with cancer activities that take place on a weekly and monthly basis. The Cancer registry from the State of Washington and National Cancer Information Service along with the Spirit of EAGLES including the American Lung Association and the American Cancer Society provide the windows to see into the project with their tremendous pool of resources in the way of free brochures, pamphlets, free training and mini grants at the regional level. Advice is provided by all the partners depending on their expertise.



The vision of the SPIPA tribes is to be Cancer Free within each community. With this in mind the Advisory Committee members provide as much support in this effort as they can.

A strategic role has been identified for the partners and is listed below. With this plan to move towards implementation of the project activities we expect that these partners will remain with the project until implementation which is expected to be completed in July of 2012.

Partner	Strategic Role														
	Research	Surveillance	Policy	Community planning	Training	Outreach	Coordination	Cultural Awareness	Screening	Patient Advocacy	Treatment	Survivor Support	Hospice/End –f Life	Funding Search	
Shoalwater Bay Clinic		x		X	X	X			X			x			
Shoalwater Bay Tribal Council			X	X				X							
Shoalwater Bay Community				X				X	X						
Squaxin Island Clinic		x		X	X	X			X			X			
Squaxin Island Tribal Council			X	X				X							
Squaxin Island Community				X				X	X						
Nisqually Clinic		x		X	X	X			X			X			
Nisqually Tribal Council			X	X				X							
Nisqually Community				X				X	X						
Skokomish Clinic		x		X	X	X			X			X			
Skokomish Tribal Council			X	X				X							
Skokomish Community				X				X	X						
Chehalis Clinic		x		X	x	x			X			X			
Chehalis Tribal Council			x	X				X							
Chehalis Community				x				X	X						
CCCP Advisory Committee			x	x		x		X	X			X			
SPIPA Comp. Cancer Program	x	x	x	x	x	x	**X**	X	X			x	x	x	x
SPIPA Native Women's Wellness Program	x	x			X	X			X			x			
SPIPA HIV/AIDS program					X	X			X						
Tribal Tobacco Programs		x			X	X									
NCIS/Spirit of the E.A.G.L.E.S.					X	X						x	X		
Washington State Cancer Registry	x	x													
Northwest Portland Area Indian Health Board	x				X	X		x							
American Cancer Society	x				X	X							X		
American Lung Association	x				X	X									
Alliance to Reduce Cancer Northwest	x					X									
The Unbroken Circle					x	x		x				x	X		
Washington State Comprehensive Cancer Control Program		x	x				x								

The Plan

Where we are going.....

Cancer Prevention and Awareness

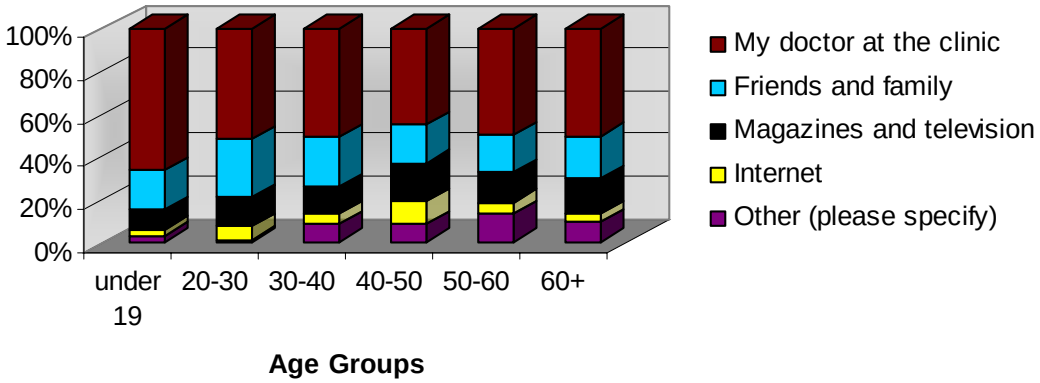
<u>Goal#1:</u> Provide cancer prevention, education and awareness for tribal and community members at all SPIPA Tribes.

Prevention, Education and Awareness

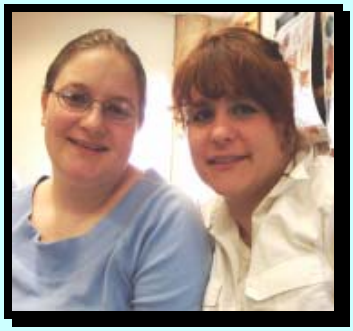
Cancer education and prevention is the number one priority related to cancer according to the 2004 SPIPA Community Cancer Survey.

Since 1995 the Native Women's Wellness Program has successfully raised awareness of the importance of early detection and screening for breast and cervical cancer. Each of the Five Tribes has begun to implement tobacco prevention activities with funding from the Washington Department of Health for Tobacco Prevention Program.

Source of Health/Wellness Information, SPIPA Tribes 2004



Source: SPIPA Community Cancer Survey 2004

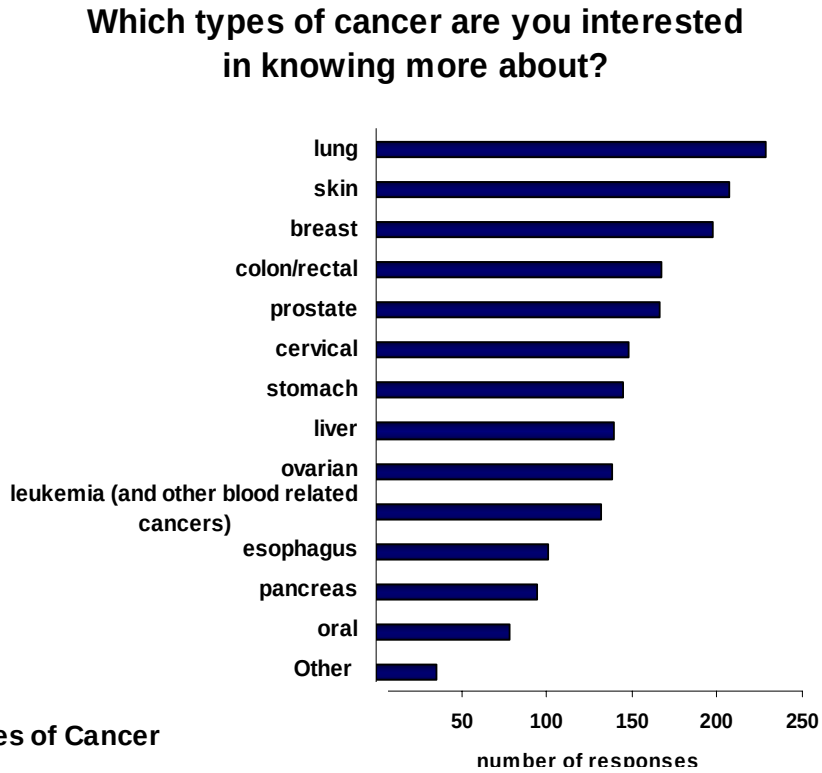


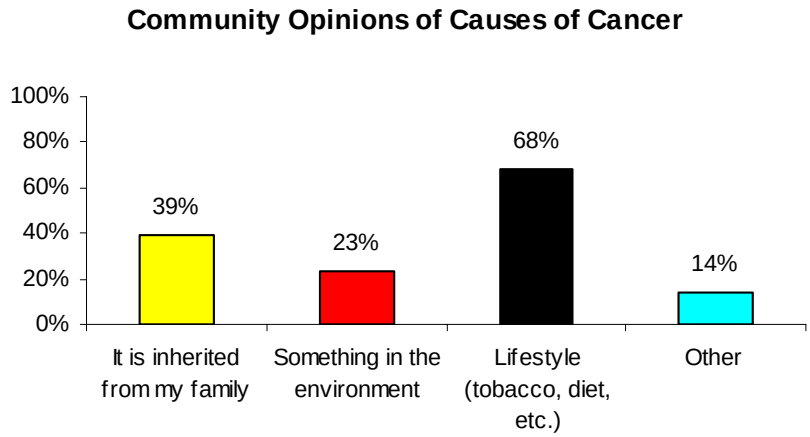
Lisa Shipman,
HIV program coordinator
and
Jennifer Taylor, CHR
Shoalwater Bay Tribal Members

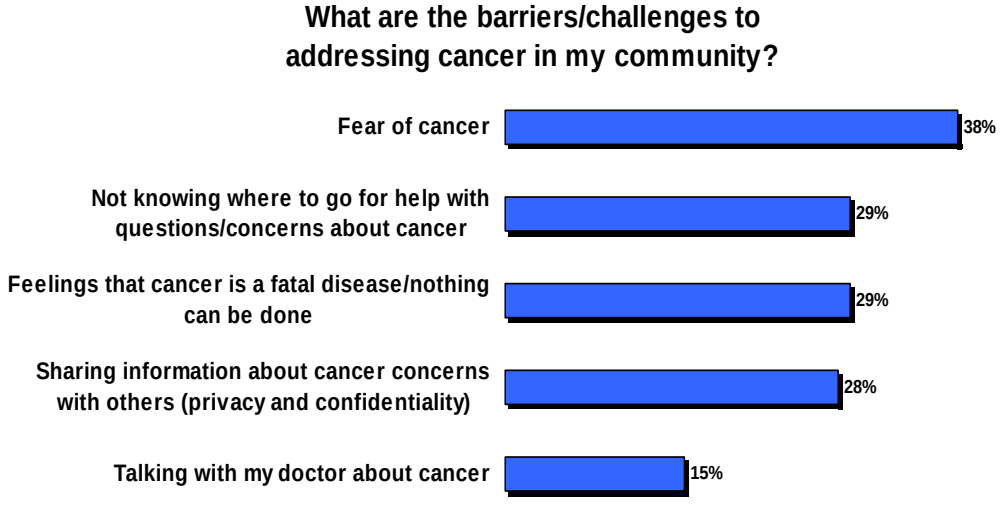
"More education is important so that community members learn the risk factors for cancer as well as more education on cancer prevention and screening. We would need additional resources, such as staff, training materials and give always to help them learn more. We currently have a strong support network in the community, hopefully it will stay strong. We have been talking for years about screening for men, maybe a "men's day" or activities specifically for the men. Clinic staff need to know about the resources, such as homecare assistance and places to stay for those going for treatment."

What the Community Says

Community Opinions[4,52]
Lung and skin cancer were the top two types of cancer Tribal and community members wanted to know more about. Most Tribal and community members from the Five Tribes agree that lifestyle factors such as smoking and diet are causes of cancer. Many (39%) also feel that cancer is inherited.





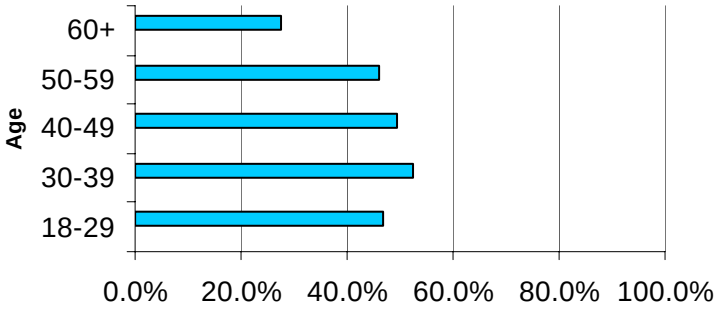


Source: SPIPA Community Cancer Survey 2004

Behavior and Risk Factors for Cancer

Tobacco use accounts for about one-third of all cancer deaths in the United States. Smoking causes almost 90% of lung cancers. Smoking also causes cancers of the larynx (voice box), oral cavity, pharynx (throat), and esophagus, and contributes to the development of cancers of the bladder, pancreas, liver, uterine, cervix, kidney, stomach, colon and rectum, and some leukemia's. (53, 57-59)

Percentage NW Tribal Members who are Current Smokers or Chewing Tobacco Users



Source: NW Tribal BRFSS

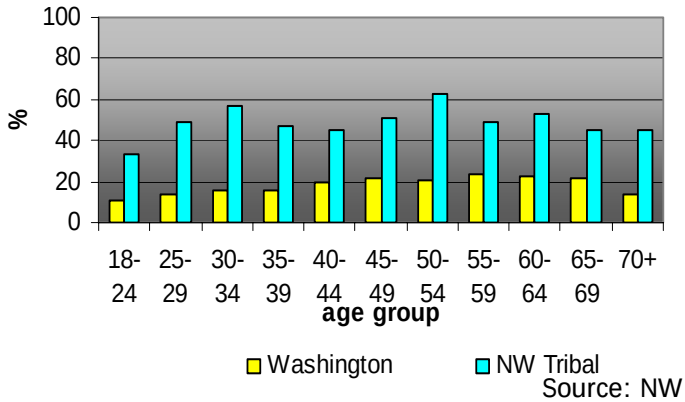
Based on trends in health and lifestyles, it is now thought that avoiding non-traditional use of tobacco, avoiding excessive alcohol consumption, being physically active, healthy eating and maintaining recommended body weight, may all contribute to reductions in risk of certain cancers. (44, 53, 54, 59)

Behaviors related to a higher risk of cancer include:

- tobacco use, alcohol consumption (associated with increased risk of oral, esophageal, and other cancers),
- physical inactivity (associated with increased risk of colon, breast, and possibly other cancers), and
- being overweight (associated with colon, breast, endometrial, and possibly other cancers).

In 2001, experts concluded that cancers of the colon, breast, endometrial (the lining of the uterus), kidney, and esophagus are associated with obesity. Some studies have also reported links between obesity and cancers of the gallbladder, ovaries, and pancreas.

Obesity Rates of Respondents, Washington & NW Tribes, 2001



Source: NW Tribal BRFSS

Goals and Objectives

Goal #1: Provide cancer prevention, education and awareness for tribal and community members at all SPIPA Tribes.

Objective #1: By 2012, the SPIPA CCCP, in coordination with the SPIPA tribes, will create and implement activities that raise awareness and education of cancer prevention and screening.			
Activities/Strategies	**Measures of Effectiveness/ Data**	**Time frame**	**Who is Responsible**
1. Create a video/DVD of cancer survivors, (work with The Evergreen State College's communication and media dept TCTV, Northwest Native Culture, advertising agencies that work with casinos)	Video/DVD completed and distributed	Winter 2007	SPIPA w/ SPIPA tribes
2. Cancer prevention and screening workshops (youth, mid age, elders) at each of the 5 tribes. Collaboration with other organizations: ACS, ALA, NCI's CIS, NPAIHB/NTCCP	Workshops completed	3-workshops per year	SPIPA w/TRIBES
3. Expand communication for cancer control issues and activities (i.e. newsletter)	Increase distribution	Quarterly	SPIPA w/ Tribes and other health projects (Diabetes/NW WP)
4. Collaborative planning/sharing resources with all SPIPA and tribal health awareness and prevention programs.	Increase communication /regular meetings take place	Quarterly	SPIPA and tribal health directors
5. Collectively (NWWP and CCCP) report back to the communities	Communication products are joint effort	Spring 2008	SPIPA CCCP and NWWP
6. Create and enhance infrastructure of each tribe (i.e. hire and train community health outreach workers/educators)	Dedicated FTE for cancer programs	Spring 2007	Tribal health departments
7. Utilize (and spread the word about) NCI's Cancer Information Service 1-800-4-CANCER hotline, ACS's 1-800-ACS-2345 info line.	track zip code call data	Annually	Collaboration between SPIPA, NCI & Tribal clinics
8. Train CHR's and outreach workers at each tribe to become certified to teach on *Cancer 101* issues in the community	Certify at least 5 per tribe initially and add an additional person/year	Annually	SPIPA w/ NPAIHB, NCI's CIS, SOE

Objective #1: By 2012, the SPIPA CCCP, in coordination with the SPIPA tribes, will create and implement activities that raise awareness and education of cancer prevention and screening.			
Activities/Strategies	**Measures of Effectiveness/ Data**	**Time frame**	**Who is Responsible**
9. Encourage tribal youth and community youth to participate in Hutch High and summer research programs for college students	# of youth & college students participating annually	Summer 2007 then annually	SPIPA social services & youth tribal programs w/SoE, NCI's CIS, FHCRC

#2 By 2012, the SPIPA CCCP will coordinate with each of the Tribal Tobacco Programs to strengthen Tobacco use prevention and lung cancer awareness activities at each of the SPIPA Tribes.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
1. Implement TATU (Teens Against Tobacco Use) and ACS Speak Out Youth Leadership trainings at each of the 5 Tribes	Trainings occur, # of trainers trained	Winter 2006	ALA, ACS with SPIPA and Tribal Tobacco program
2. Implement policies to create clean indoor atmosphere	Policies in place	Fall 2008	SPIPA and Tribal Councils
3. Challenge Tribal casinos & smoke shops to give a certain amount of money	Amount received	Fall 2006	SPIPA and Advisory Committee
4. Have video include elders speaking and teaching the traditional use of tobacco	Video completed/ distributed	Fall 2008	SPIPA and Advisory Committee
5. Activity of second-hand smoke prevention (can target parents and parents to be)	Activity completed/ survey of knowledge	Fall 2009	SPIPA and Tribal Tobacco Programs
6. Teen/Adult tobacco survey	Survey completed	Annual by Fall 2007	SPIPA and Tribal Tobacco Programs
7. Activity of chewing tobacco prevention	Activity completed/survey of knowledge	Summer 2008	SPIPA and Tribal Tobacco Programs

#3 By 2012, the SPIPA CCCP and the SPIPA Tribes will coordinate with each of the Tribal Tobacco Programs to strengthen quit smoking/chew programs.

Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
1. Implement smoking cessation program such as the Oregon Research Institute's smoking cessation program	Program, resources in place	Winter 2008	SPIPA, Tribal Tobacco and Health programs
2. Under medical supervision provide pharmaceutical such as patches & pills, Nicotine Replacement Therapy (NRT).	NRT available	Winter 2008	SPIPA, Tribal Tobacco and Health programs
3. Support groups or activities for quitting tobacco	Groups or activities in place and number of attendees	Summer 2009	SPIPA, drug and alcohol programs Tobacco and Health programs
4. Promote smoking quit lines, telephone line for tobacco use cessation support.	Use of smoke quit lines data by zip code	Fall 2007	WA tobacco program and SPIPA

#4 By _2010, SPIPA and SPIPA Tribes will create and implement activity and exercise programs, in coordination with existing efforts, at each of the Five Tribes.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
1. Hire certified staff at each tribe to certify other hired staff to coordinate walking, exercise activities and create incentive program for exercise and nutrition programs	Certified staff hired, trainings given, # Tribal staff	Spring 2008	SPIPA and Tribal Health Programs
2. Work with registered dieticians at each tribe to work on exercise and nutrition programs	Nutrition questions on community survey	Spring 2006	SPIPA and Tribal Diabetes Programs
3. Have an exercise arcade (for the youth)	Arcade in place at each Tribe	Summer 2010	SPIPA and Tribal Health Programs
4. Collaborate with other fitness organizations and develop policies (i.e. public gyms, Curves, Bally's, etc.)	Policies and procedures in place at each tribe	Summer 2007	SPIPA and Tribal Health Programs
5. Support and organize traditional activities (i.e. wood walks, berry picking, torch light walk, etc.)	Number of Activities completed	Spring 2010	SPIPA and Tribal Health Programs
6. Promote people to participate in events such as Komen's *Race for the Cure*, ACS's "Active for Life" and have conditioning opportunities available	Number of events promoted, # participating	Winter 2009	SPIPA and Tribal Health Programs

#5 By 2012, the SPIPA CCCP and SPIPA Tribes will create and implement nutrition awareness (5 fruits and vegetables a day) for cancer prevention activities at each of the Five Tribes.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
1. Nutritional cooking, nutritional eating choices and habits classes	# of classes given, # of participants	Fall 2010	SPIPA and Tribal Health Programs
2. Coordinate with diabetes education coordinators to review/create healthy foods list	Healthy food list complete	Fall 2007	SPIPA with Tribal Diabetes Programs
3. Encourage traditional food choices and eating habits (i.e.: through publications and educational events)	Survey of healthy habits	Summer 2006	SPIPA and Tribal Health Programs
4. Provide vouchers for farmers' market	# of Vouchers provided	Spring 2007	SPIPA and Elders Programs
5. Start up Tribal community gardens	# of active community gardens	Spring 2009	SPIPA and Five Tribes
6. Field trips to grocery stores for food label reading	Number of participants	Summer 2008	SPIPA and Tribal Diabetes programs
7. Have one article in each tribal paper annually to provide nutrition awareness	Article published annually	Winter 2007	SPIPA and Tribal Diabetes Programs
8. Expand the Squaxin Island Healthy eating concept habits	Existing at all Five Tribes	Winter 2010	SPIPA and Tribal Diabetes Programs

#6 By 2012, the SPIPA CCCP and SPIPA Tribes will coordinate with the NWWP and Tribal Clinics to create and implement activities related to Transmittable Disease prevention (Hepatitis C, Human Papiloma Virus).			
Activities/Strategies	**Measures of Effectiveness/ Data**	**Time frame**	**Who is Responsible**
Provide education and awareness (pamphlets, outreach worker training, provider training) of the transmission routes for Hepatitis C in order to decrease risky behaviors. Provide education and awareness (pamphlets, outreach worker training, provider training) of the transmission routes and testing HPV in order to decrease risky behaviors and promote screening (future vaccination).			

Cancer Screening and Early Detection

<u>Goal #2:</u> Detect all screen able cancers at the earliest stage for tribal and community members at all SPIPA Tribes.

Screening and Early Detection

Screening for cancer is an examination (or testing) of people for early stages of cancer even though they have no symptoms. Early detection of cancer through screening saves lives. For example, one- and five-year breast cancer survival rates are significantly lower among Southwest American Indian (AI) women compared with non-Hispanic whites, primarily due to late stage at diagnosis. By detecting cancers at an earlier stage, screening mammography can reduce breast cancer mortality by 30% among women ages 50-69 years.

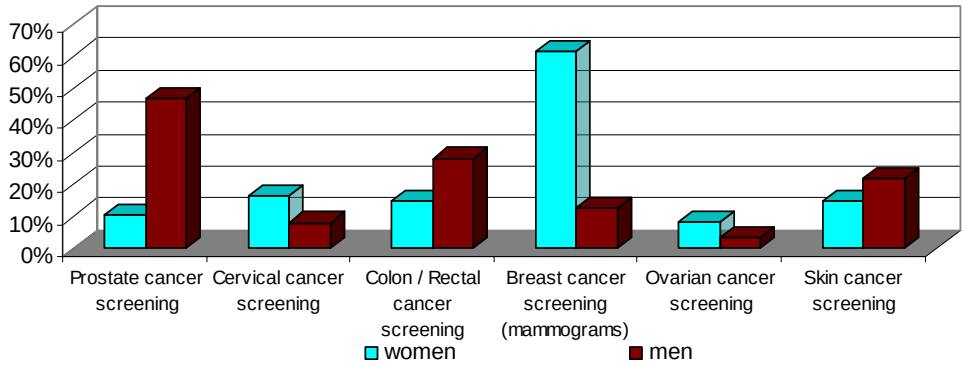
What's being done now?

SPIPA's Native Women's Wellness Program (NWWP) is a Center for Disease Control funded Breast and Cervical Cancer Early Detection Program (BCCEDP) for women at the Chehalis, Nisqually, Shoalwater Bay, Skokomish and Squaxin Island health clinics. It has been in place since late 1994. This program has successfully completed more than 2,800 screening tests for breast cancer and more than 3,700 screening test for cervical cancer for over 1,853 women from SPIPA Tribes. It is due to the success of this program that the SPIPA Tribes are now able to plan for comprehensive cancer control [(3)].

What the Community Thinks:

Breast cancer screening received the highest overall ranking for priorities for cancer screening. As illustrated below, women tended to give breast cancer screening a high priority, possibly due to the breast cancer screening and awareness activities that take place as part of SPIPA's Native Women's Wellness Program. Men, on the other hand, markedly ranked prostate cancer as their average highest priority [(4)].

Top Priorities for Cancer Screening,
Comparison of Men and Women Respondents, SPIPA 2004



Source: SPIPA Community Cancer Survey, 2004

Cancer Detection - Southwest Washington

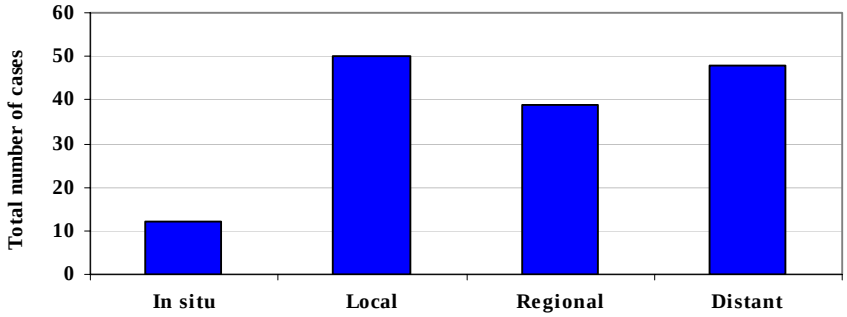
For Southwest Washington Native Americans, 35% of screen able cancers, including breast, cervical, prostate and colon cancer, were detected at late stages.

Stage at diagnosis for Screen able Cancers, Southwest Washington AI/AN, 1996-2001

Stage at diagnosis	Total number of AI/AN screen able cancers for SW Washington, 1996-2001	Percent of all cases
Early	39	65%
Late	21	35%

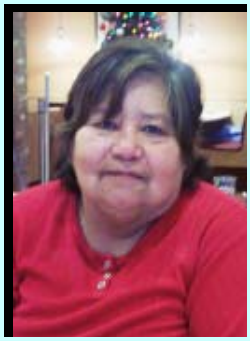
For Southwest Washington the majority of cancers for American Indians and Alaska Natives were diagnosed at the regional or distant stage.

Total number of AI/AN cancer cases by stage at diagnosis*, all sites, Western Washington, 1996-2001**



*Excludes cases with unknown stage at diagnosis

Source: NPAIHB Cancer Registry Project



Marjaorie Stepetin
Cancer Survivor
Nisqually Tribal Member

"I get my mammogram every year, but a couple of months after my last mammogram I felt a lump when doing my breast self exam. I probably would have put off getting it checked out if there had not been the mammogram day at the Nisqually clinic. They caught it early and I got treated right away. I have a good prognosis. "

Thoughts on cancer control
"It's important to know your own body, know when there are changes. More education is important. We all need to learn not to be afraid of getting checked. It's also important that we have support in place for those diagnosed with cancer."

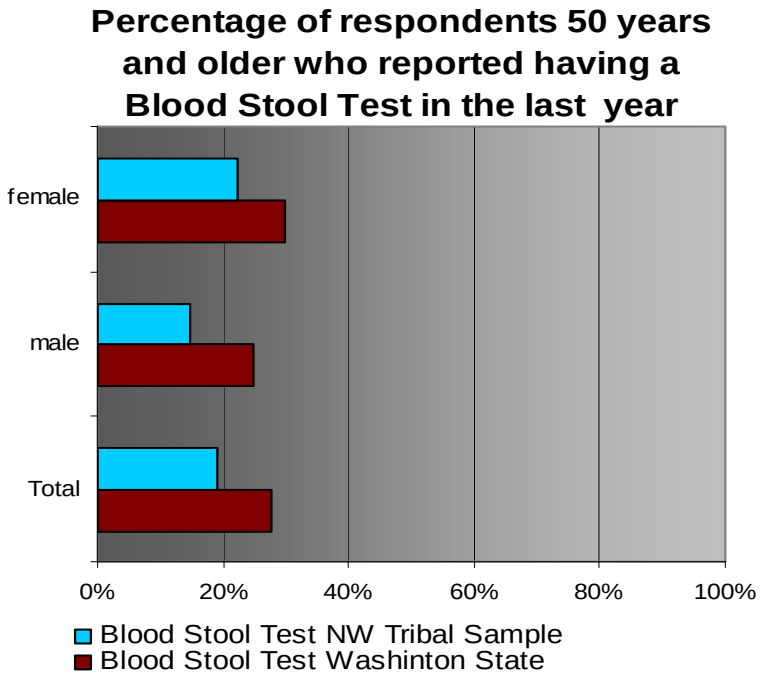
Screen able Cancers

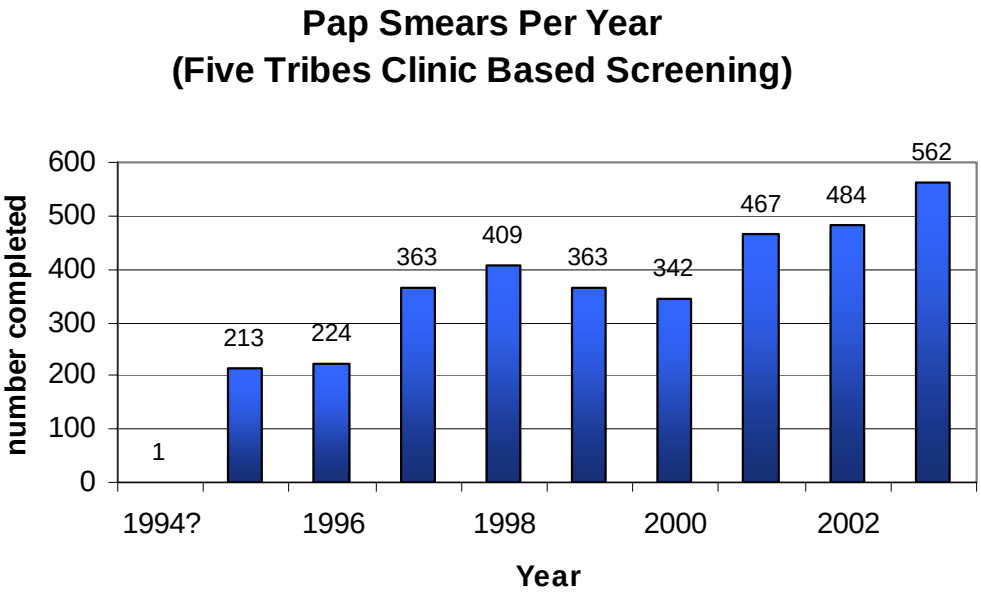
Colorectal cancer is the second leading cause of death from cancer in the United States.

Risk factors for colorectal cancer include diet (red meat consumption), physical inactivity, alcohol consumption, obesity, and smoking. Colon cancer is often linked to family history of colon cancer or polyps in the colon[7,47,58].

There are three screening tests for colorectal cancer:

1. Sigmoidoscopy
2. Colonoscopy
3. Fecal Occult Blood Stool test (FOBT)





source: SPIPA Native Women's Health Program, 2004

The SPIPA Tribes have had a successful Native Women's Wellness program providing cervical cancer screening since 1994. The number of women screened for cervical cancer at the five tribal clinics has increased to 562 in 2003[(3)]!

Lee Shipman,
Shoalwater Bay
Tribal Member

"My sister Joan walked on two years ago after battling cancer for several years. Lisa (CHR and relative) hounded her to get a mammogram. I think they needed one extra person to get the mammogram van to come out here. Thank God they found out when they did. I think God gave her three extra years because she was a fighter and had a mission. When she was first diagnosed she called me and made me promise to get my mammogram every year. I was in my 40s and had still never gone. Every year on her birthday she called and reminded me to get my screening. Now I honor her by going every year for my mammogram and women's exam. I get my colon cancer screen now as well. I'm a healthy person and I want to stay that way.

I'd like to see more education at the Tribal level, more awareness. We need more access to screening and follow up for all those in the community, both at the clinic and funds to send them for outside testing if needed. Everyone needs access to colonoscopy when they turn 50. We need to get more men screened, maybe a men's screening day. Skin cancer screening is needed as well. We need additional resources for home health care as well. A real exercise program and person to help out would be great.

We have a strong community now, everyone looks out for each other, and we'd like to keep it strong."

Goal #2: Detect all screen able cancers at the earliest stage for tribal and community members at all SPIPA Tribes.

#1 SPIPA's CCCP will work with the Native Women's Wellness Program and Tribal Clinics to increase breast cancer screening (mammograms) rates by at least 10% each year.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
1. Coordination and integration of activities (community-driven planning, events, patient advocacy) between NWWP and CCCP on an annual basis	Joint planning process in place	Winter 2007	SPIPA
Providers			
2. CCCP/NWWP Medical advisory committee for the Five Tribes to include representation from the Tribes and regional providers that serve the Tribes to focus on all cancer related issues.	Meeting notes, participant lists	Fall 2006	SPIPA
Patient			
3. Outreach about breast cancer screening (video, etc) to those not reached by NWWP.	# of outreach activities complete	Fall 2010	SPIPA NWWP and CCCP
4. Use State BCCEDP to serve those community members that are not currently receiving mammograms through the NWWP	# of women from this population served	annual	SPIPA NWWP and CCCP
5. Address patient confidentiality issues (HIPAA education, refer to other clinic, Women and Girls Gathering)	Trainings given, policies in place	Summer 2008	SPIPA NWWP and CCCP
6. Seek funding (possibly fundraising, seek volunteers) to provide breast cancer screening and follow up for all community and tribal members (those not covered by NWWP or other services).	Funding in place	Spring 2007	SPIPA NWWP and CCCP
7. Coordinate with NWWP to ensure all tribal and community members are receiving mammograms.			SPIPA NWWP and CCCP

#1 SPIPA's CCCP will work with the Native Women's Wellness Program and Tribal Clinics to increase breast cancer screening (mammograms) rates by at least 10% each year.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
8. Respect traditional beliefs, integrate traditional beliefs/ways into outreach – work with elders in order to understand best approach for outreach (work in a healing way).	Community wellness survey	Ongoing	SPIPA NWWP and CCCP
9. Address male breast cancer issues (education, awareness, screening and follow up, additional training for outreach workers).	Number of activities	Spring 2009	SPIPA NWWP and CCCP

#2 SPIPA CCCP will coordinate with the Tribal Clinics and other Tribal services annually to screen at least 50% of the eligible population for prostate cancer by 2009.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
Surveillance 1. Develop a system for tracking prostate cancer screening and follow up information for the Five Tribes.	Tracking system in place	Fall 2007	SPIPA and Tribal Clinics
2. Establish a baseline for prostate cancer screening education, rates (PSA, DRE) for the Five Tribes.	Baseline established	Fall 2008	SPIPA and Tribal Clinics
3. Provide technical support to Tribal Clinics for tracking the rates of screening and follow up.	Technical assistance in place	Summer 2006	SPIPA and Tribal Clinics

#2 SPIPA CCCP will coordinate with the Tribal Clinics and other Tribal services annually to screen at least 50% of the eligible population for prostate cancer by 2009.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
4. Develop system to track prostate cancer patient education, provider education (work with RPMS, PCC form, etc).	System in place	Fall 2006	SPIPA and Tribal Clinics
5. Work with NPAIHB, Washington State Cancer Registry and Surveillance, Epidemiology and end Results to track prevalence of prostate cancer for the Five Tribes.	Community cancer rates tracked and reported	Spring 2006, annually	SPIPA and partners
Providers/Clinic			
6. Existing CCCP/NWWP Medical Advisory Committee adopts guidelines for prostate cancer screening/education	Guidelines developed and accepted	Summer 2007	SPIPA and Tribal Clinics
7. Assess provider knowledge of prostate cancer; provide training (CMEs) to address gaps.	Trainings attended	Winter 2007, ongoing	SPIPA and Tribal Clinics
8. Ensure providers receive strong support (clinic staff, referral specialists, patient education resources, etc.) for addressing prostate cancer issues.	Provider survey results	ongoing	SPIPA and Tribal Clinics
9. Ensure adequate staffing at clinic (male providers available)	Male provider at each clinic	ongoing	SPIPA and Tribal Clinics
10. Ensure provider visit time adequate for prostate cancer screening.	Patient and provider surveys	Spring 2007	SPIPA and Tribal Clinics
11. Utilize other “teachable moments” in the clinic, i.e.: posters in waiting rooms, restrooms, exam rooms, MA and clinic staff to provide patient education.	Teaching activities in place and tracked	Fall 2009	SPIPA and Outreach workers

#2 SPIPA CCCP will coordinate with the Tribal Clinics and other Tribal services annually to screen at least 50% of the eligible population for prostate cancer by 2009.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
Patient			
12. Patient education on prostate cancer issues. Outreach (video, etc) for prostate cancer.	Education activity completed	Winter 2007	SPIPA and Advisory Committee
13. Patient advocacy and education in place when referred out to specialist.	Patient navigator in place, patient survey	Spring 2008	SPIPA and Tribal Health Clinics
14. Men's wellness clinic at least twice each year with great incentives.	Men's clinic participant lists	Winter 2008	SPIPA and Tribal Clinics
15. Address patient confidentiality issues (HIPAA education, refer to other clinic,)	Trainings and policies in place	Summer 2008	SPIPA and Tribal Clinics
16. Respect traditional beliefs, integrate traditional beliefs/ways into outreach – work with elders in order to understand best approach for outreach (work in a healing way).	Community Survey	ongoing	SPIPA and Five Tribes, Advisory Committee
17. Ensure all patients are treated with respect and dignity through education of clinic staff and referral clinics/providers.	Community Survey	ongoing	SPIPA and Tribal Clinics
Tribes/SPIPA			
18. Seek funding for incentives for men.	Funding in place	Spring 2006	SPIPA
19. Funding to hire a men's outreach worker – determine level of staffing needed.	Funding in place, staff hired	Spring 2007	SPIPA and Five Tribes
20. Seek funding (possibly fundraising, seek volunteers) to provide prostate cancer screening and follow up for all	Funding in place	Fall 2009	SPIPA and Tribal Clinics

#2 SPIPA CCCP will coordinate with the Tribal Clinics and other Tribal services annually to screen at least 50% of the eligible population for prostate cancer by 2009.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
community and tribal members (those not covered by other services).			
21. Ensure all tribal and community members are receiving prostate cancer screening education and services.	Community survey results	Winter 2009	SPIPA and outreach workers

#3 SPIPA's CCCP will work with the Tribal Clinics to screen at least 50% of the eligible population for skin cancer by 2009 at recommended time intervals.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
Provider/Tribal Clinic			
1. Make sun screen available to all community and Tribal members	Sunscreen available at each clinic	Spring 2007	SPIPA and Tribal Clinics
Patient			
2. Provide education on skin cancer prevention, screening, awareness (health fairs, clinics, etc.).	Education activities documented	Spring 2008	SPIPA and Tribal Health Clinics
3. Self exam education (ABCDs) available at all Tribal clinics	Available and tracked (in RPMS and patient survey)	Summer 2008	SPIPA and Tribal Health Clinics
4. Annual skin cancer screening day at each clinic (with specialist). Base on skin cancer awareness month.	Screening day participant list	Winter 2009	SPIPA and Tribal Health Clinics

#4 SPIPA will work with the Tribal Clinics to screen at least 50% of the eligible population for colorectal cancer screening at the recommended time intervals.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
Surveillance 1. Develop a system for tracking colorectal cancer screening and follow up information for the Five Tribes.	Tracking system in place	Fall 2007	SPIPA and Tribal Health Clinics
2. Establish a baseline for colorectal cancer screening education, rates (Sigmoidoscopy, colonoscopy, FOBT) for the Five Tribes	Baseline established	Fall 2008	SPIPA and Tribal Health Clinics
3. Provide technical support to Tribal Clinics for tracking the rates of screening and follow up.	Technical assistance in place and tracked	Summer 2006	SPIPA and Tribal Health Clinics
4. Develop system to track colorectal cancer patient education provider education (work with RPMS, PCC form, etc).	Tracking system in place	Fall 2007	SPIPA and Tribal Health Clinics
5. Work with NPAIHB, Washington State Cancer Registry and Surveillance, Epidemiology and end Results to track prevalence of colorectal cancer for the Five Tribes.	Community cancer rates tracked and reported	Fall 2006	SPIPA and partners
Providers/Clinic			
6. Existing CCCP/NWWP Medical Advisory Committee adopts guidelines for colorectal cancer screening/education.	Guidelines developed and accepted	Fall 2006	SPIPA and Tribal Clinics
7. Assess provider knowledge of colorectal cancer; provide training (CMEs) to address gaps.	Trainings attended	Fall 2007	SPIPA, ACS and Tribal Clinics

#4 SPIPA will work with the Tribal Clinics to screen at least 50% of the eligible population for colorectal cancer screening at the recommended time intervals.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
8. Ensure providers receive strong support (clinic staff, referral specialists, patient education resources, etc.) for addressing colorectal cancer issues.	Provider survey results	ongoing	SPIPA and Tribal Clinics
9. Ensure adequate staffing at clinic (providers available)	Male provider at each clinic	ongoing	SPIPA and Tribal Clinics
10. Ensure provider visit time adequate to address/refer for colorectal cancer screening (FOBT in house, colonoscopy and sigmoidoscopy referred out).	Patient and provider surveys	Spring 2009	SPIPA and Tribal Clinics
11. Utilize other "teachable moments" in the clinic, i.e.: posters in waiting rooms, restrooms, exam rooms, MA and clinic staff to provide patient education.	Teaching activities in place and tracked	Fall 2009	SPIPA, partners and Outreach workers
Patient			
12. Patient education on colorectal cancer issues. Outreach (video, health fairs, incentives, etc) for colorectal cancer.	Education activity completed	Winter 2008	SPIPA and Advisory Committee
13. Patient advocacy and education when referred out to specialist.	Patient navigator in place, patient survey	Spring 2008	SPIPA and Tribal Health Clinics
14. Address patient confidentiality issues (HIPAA education, refer to other clinic,)	Trainings and policies in place	Summer 2008	SPIPA and Tribal Clinics

#4 SPIPA will work with the Tribal Clinics to screen at least 50% of the eligible population for colorectal cancer screening at the recommended time intervals.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
15. Respect traditional beliefs, integrate traditional beliefs/ways into outreach – work with elders in order to understand best approach for outreach (work in a healing way).	Community Wellness Survey	ongoing	SPIPA and Five Tribes
16. Ensure all patients are treated with respect and dignity – (education of clinic staff and referral clinics/providers).	Community Wellness Survey	ongoing	SPIPA and Tribal Health Clinics
Tribes/SPIPA			
17. Seek funding for incentives.	Funding in place	Spring 2007	SPIPA
18. Funding to hire an outreach worker – determine level of staffing needed.	Funding in place, staff hired	Fall 2008	SPIPA and Five Tribes
19. Seek funding (possibly fundraising, seek volunteers) to provide colorectal cancer screening and follow up for all community and tribal members (those not covered by other services).	Funding in place	Fall 2009	SPIPA and Tribal Clinics
20. Ensure all tribal and community members are receiving colorectal cancer screening, education and services.	Community survey results	Fall 2009	SPIPA and outreach workers

#5 The CCCP will work with the NWWP and the Tribal clinics to increase cervical cancer screening by at least 10% each year.			
Activities/Strategies	**Measures of Effectiveness Data**	**Time frame**	**Who is Responsible**
1. Coordination and integration of activities (community-driven planning, events, patient advocacy) between NWWP and CCCP on an annual basis	Joint planning process in place	Winter 2007	SPIPA
Providers			
2. CCCP/NWWP Medical Advisory Committee for the Five Tribes to include representation from the Tribes and regional providers that serve the Tribes to focus on all cancer related issues.	Meeting notes, participant lists	Fall 2006	SPIPA
Patient			
3. Outreach (video, etc) to those not reached by NWWP.	# of outreach activities complete	Fall 2010	SPIPA NWWP and CCCP
4. Use State BCCEDP to serve those community members that are not currently receiving cervical cancer screening through the NWWP	# of women from this population served	annual	SPIPA NWWP and CCCP
5. Address patient confidentiality issues (HIPAA education, refer to other clinic, Women and Girls Gathering)	Trainings given, policies in place	Fall 2008	SPIPA NWWP and CCCP
6. Seek funding (possibly fundraising, seek volunteers) to provide cervical cancer screening and follow up for all community and tribal members (those not covered by NWWP or other services).	Funding in place	Spring 2008	SPIPA NWWP and CCCP
7. Coordinate with NWWP to ensure all tribal and community members are			SPIPA NWWP and CCCP

#5 The CCCP will work with the NWWP and the Tribal clinics to increase cervical cancer screening by at least 10% each year.			
Activities/Strategies	**Measures of Effectiveness Data**	**Time frame**	**Who is Responsible**
receiving cervical cancer screening.			
8. Respect traditional beliefs, integrate traditional beliefs/ways into outreach – work with elders in order to understand best approach for outreach (work in a healing way).	Community Wellness Survey	ongoing	SPIPA and Five Tribes

"I'm a 30 year cancer survivor. My husband passed from cancer. He would say "my cancer should wake our youth up to stay away from alcohol and smoking". The kids didn't like to see their Dad that way and didn't know how to help. We had a case worker from the clinic and hospice worker from the hospital to help us. The end of life was the hardest thing to deal with. The case worker helped us get medicine, helped with the transportation and all the paperwork. I couldn't have done it all without her help."

My thougths on cancer control:
"We need to get the awareness to the menfolk, let them know how important it is to get a check up. I would guess some people are hesitant to go to the doctor because they don't have a way to pay. The SPIPA Tribes could benefit from good case workers to help those diagnosed with cancer and their families".

Zelma McCloud, Nisqually Elder's Coordinator, Tribal Member

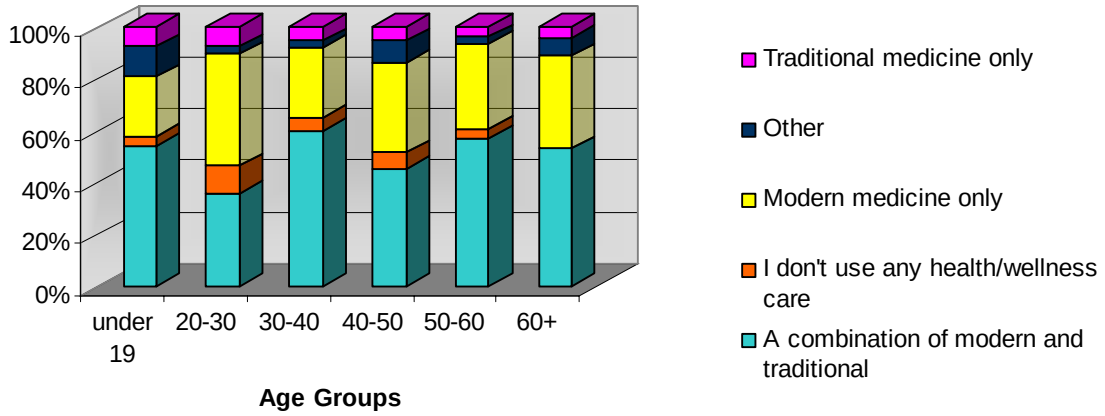
Cancer Treatment

<u>Goal #3:</u> Ensure that all tribal and community members with cancer at all SPIPA Tribes receive cancer treatment services. (state of the art, timely, comprehensive, traditional, affordable)

Cancer Treatment

Access and quality of cancer treatment services vary for each of the tribes served by SPIPA. Barriers to treatment include distance to treatment centers, financial concerns for treatment, holistic care to include traditional/spiritual medicine and lack of culturally appropriate patient advocacy at non-tribal health care facilities.

Type of Health Care Used by Age Group, SPIPA Tribes 2004



According to a recent community cancer survey [4], the majority of respondents call their tribal health clinic their primary source of health care. Over half of all respondents use a combination of modern and traditional health care.

Over 10,000 Tribal and community members are served by the SPIPA Tribal Health Clinics. These clinics provide primary and secondary care and public health programs. Most patients are sent to outside clinics for advanced care such as cancer diagnosis and treatment.

Cancer Facts for
American Indians and Alaska Natives
Source: Intercultural Cancer Fact Sheet

- The shortage of health care professionals working in American Indian and Alaska Native communities - fewer than 90 doctors for every 100,000 Indians, compared to 229 per 100,000 nationally - makes health care access an even more challenging issue to address among the population. (44)
- Contrary to the general opinion that the Indian Health Service (IHS) provides health care to all American Indians and Alaska Natives, IHS is under-funded by the US Congress on average by about 40% of the documented health care need, which results in the inability of Native patients to access health care. (31,45,)

Cancer Treatment – Financial Concerns and the Cost of Care

Tribal and community members have voiced concern over the financial impact of cancer on a family. Fear of the cost of cancer has deterred tribal and community members from seeking cancer screening or follow up services (49).

Contract Health Services (CHS) is the financial resource from the Indian Health Service for most of the care provided to Tribal members outside of the Tribal Clinic. The amount of CHS funds a Tribe receives from the federal government is largely dependent on the number of Native Americans actively using the Tribal clinic. For Tribes in the Northwest, the CHS fund was $504 per active patient in 2004. It is a challenge for smaller Tribes to cover all outpatient costs at this funding level. Most Tribes run short of funds well before the end of the fiscal year. The term "Priority One" is used for the status a Tribal Clinic finds itself in when CHS funds become limited. When a Clinic is in Priority One status only acute and emergent care is covered.

This fund is especially limited for the smaller Tribes. One or two cases of a catastrophic disease, such as cancer, for uninsured Tribal members can drain a Tribal clinic's Contract Health Services budget. The Catastrophic Health Emergency Fund (CHEF) is the safety net for Indian health programs. Its purpose is to fund catastrophic health care cases with large expenses. As of 2002, $21,700 must be spent on a case before it is considered for CHEF funding. This fund is also limited and has been depleted mid-way though the fiscal year for the past few years. **(50, 51)**

The bottom line is that funding for high cost cases is limited for the SPIPA Tribes. In Indian Country, Tribes must often find alternative sources of funds to fully address health services, such as cancer control. These alternative resources make up for the continued short fall in IHS funding for health services.

The Cost of Care

$504 *= The annual amount (per eligible patient) the Indian Health Service (IHS) funds each Northwest Tribal Health Clinic to provide all health care for Tribe and community.*(50)

$5,549 *= Total health care spending per capita, 2002 dollars.* (63)

$21,700 *= The amount that must be spent on a case before IHS will assist with additional funds through the Catastrophic Health Emergency Fund (CHEF)*(50,51)

1/2 *= Approximately the number of cases the CHEF has covered in years past before running out.*(50-51)

$20 to $40 *= The cost for prostate cancer screening test (PSA)*

$1200-$2000 *= The current medicaid rate for a colonoscopy*

$47,952 *= The average cost of treating the top seven cancers during 1999-2000*(61)

$35,264 *= The average cost of treating metastatic breast cancer in 2004*(62)

PRICELESS *= The cost of catching cancer at an early stage*

Cleo Frank, Nisqually Tribal Member and CHR

"Clinics need to make it easier for people to access the services. It is getting better with services such as the mammogram day. There is nothing for men's health. The clinic needs additional resources and people need to not be afraid to come in. Sometimes they don't come in because they are afraid of the financial burden it might cause. Lack of awareness is also a part of it. People think "Ignorance is bliss", or "if I don't know about it, It's not happening".

We need more training for family members and the community on the importance of early detection of cancer. We can get family members to get each other in for screening. We also need to make sure the clinic has the resources it needs for awareness and screening – to support a men's clinic with give-aways and a raffle. That should get them to come in. "

1) By 2012, the SPIPA CCCP and the SPIPA Tribes will assess and implement systems that improve and track the timeliness of treatment (getting treated quickly) for the SPIPA Tribes.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
1. (Secure funding to hire) Case manager/patient navigator/patient advocacy for those going through treatment to address all the issues. (care, financial, etc.)	Staff in place, patient survey	Winter 2008	SPIPA and Tribal Clinics
2. Conduct needs assessment: Follow cancer patients to find out how long it takes to get into treatment, interview cancer survivors for barriers and how to improve timeliness of treatment.	Assessment complete	Winter 2007	SPIPA, Tribal Clinics and Advisory Committee
3. Staffing to assist patient with applying for financial resources to get into treatment. (patient advocacy/patient navigator model).	Staff in place/trained, patient survey	Fall 2009	SPIPA and SPIPA Tribes
4. Assist tribal clinics with finding alternative financial resources and updating patient information for DSHS, especially before a clinic goes into Priority One status.	Resources found and in place	Summer 2009	SPIPA and Tribal Clinics
5. Provide CHR's and clinic staff with tools to assist with outside resources for cancer treatment.	Tools identified and in place	Spring 2008	SPIPA and Tribal Clinics
6. TANF workers trained/certified as Medical eligibility determiners at all Five Tribes or at SPIPA	Staff trained	Spring 2008	SPIPA and TANF program
7. Contract Health Services staff perspective on how to improve this system.	Staff interviewed or meeting held	Summer 2007	SPIPA and Tribal Clinics

1) By 2012, the SPIPA CCCP and the SPIPA Tribes will assess and implement systems that improve and track the timeliness of treatment (getting treated quickly) for the SPIPA Tribes.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
8. Increase local resources for cancer treatment (specialists available locally)	Distance traveled for treatment	Summer 2009	SPIPA and Tribal Clinics

#2 By 2012, the SPIPA CCCP and the SPIPA Tribes will assess challenges and opportunities for covering the cost of treatment, implementing policies and procedures that help cover the cost of treatment where applicable.			
Activities/Strategies	Measures of Effectiveness / Data	Time frame	Who is Responsible
1. Case manager/patient navigator/patient advocacy/"House Calls (Harbor view)" for those going through treatment to address all the issues. (care, financial, etc.); ACS Quality of Life Training	Staff in place, patient survey results	Winter 2008	SPIPA and Tribal Health Clinics, ACS
2. Follow cancer patients to find out financial barriers to treatment, interview cancer survivors for barriers and how to decrease the financial burden of treatment.	Assessment complete	Ongoing	SPIPA and Advisory Committee
3. Staffing to assist patient with applying for financial resources to get into treatment (patient advocacy/patient navigator model).	Staff in place, time from diagnosis to treatment	Fall 2009	SPIPA and Tribal Health Clinics
4. Assist tribal clinics with finding alternative financial resources and updating patient information for DSHS, especially before a clinic goes into Priority One status.	Resources found and in place	Summer 2009	SPIPA and Tribal Health Clinics

#2 By 2012, the SPIPA CCCP and the SPIPA Tribes will assess challenges and opportunities for covering the cost of treatment, implementing policies and procedures that help cover the cost of treatment where applicable.			
Activities/Strategies	Measures of Effectiveness / Data	Time frame	Who is Responsible
5. Provide CHR's and clinic staff with tools to assist with outside resources for cancer treatment.	Tools identified and in place	Spring 2008	SPIPA and Tribal Health Clinics
6. TANF workers trained/certified as Medical eligibility determiners at all Five Tribes or at SPIPA	Staff trained	Spring 2008	SPIPA and TANF program
7. Contract Health Services staff perspective on how to improve this system.	Staff interviewed or meeting held	Summer 2007	SPIPA and Tribal Health Clinics
8. Fund raising or seeking funds for cancer treatment and misc. needs related to cancer treatment	Funds raised and allocated based on need	Winter 2009	SPIPA
9. Resource book available for family during treatment (research existing)	Resource book complete, distributed	Fall 2007, ongoing	SPIPA
10. Support and advocate for enrolling community and tribal members into Basic Health (insurance coverage).	Policy and # enrolled in BHP	Summer 2006	SPIPA and Five Tribes
11. Raise awareness of option for clinical trials (to cover the cost of treatment, transportation, etc.).	Education activity completed	Summer 2006	SPIPA and NCIS, SOE
12. Connect with hospital social workers.	Contact made, procedures in place	Summer 2007	SPIPA and Tribal Health Clinics
13. Increase local resources for cancer treatment (specialists available locally)	Distance traveled for treatment	Summer 2009	SPIPA and Tribal Health Clinics

#3 By 2012 the SPIPA CCCP, in partnership with the NWWP and Tribal Health Clinics, will assess the challenges and opportunities for access to the latest treatment options, implementing systems that improve access to the latest treatment options when applicable.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
1. Knowledge of the latest treatment options available, what to expect. Patient Driven, helped by advocate or SPIPA with resources such as www.cancer.gov, 1-800-4cancer, wikipedia, University affiliated hospital, 1-800-ACS-2345.	Research completed per patient	Ongoing, In place by Fall 2007	SPIPA, Tribal Health Clinic
2. Find out the rating/level of quality of the treatment specialist.	Research, rating completed	Ongoing	SPIPA and Medical Advisory Committee
3. Primary providers aware of quality specialists, support through continuing education and communication on latest treatment options	Communication in place for latest cancer info/options	Spring 2008	SPIPA and med. Advisory Committee
4. Inform patients about clinical trials.	# of Awareness Activities complete	Summer 2006, Ongoing	SPIPA and NCIS, SOE
5. Participate in teleconferences, etc. on latest research, SPIPA can alert community and clinics of events	# of Communications with community	Winter 2006, Ongoing	SPIPA
6. List serve and communication system for community and providers for latest research, events, notices	List serve in place	Spring 2007	SPIPA

#4 By 2012 the SPIPA CCCP and the SPIPA Tribes will support opportunities to increase access to traditional/spiritual treatment, for cancer treatment for the SPIPA Tribes.			
Activities/Strategies	Measures of Effectiveness/ Data	Time frame	Who is Responsible
1. SPIPA and Tribal Clinics respect those who seek both traditional/spiritual and western approaches to healing for cancer.	Community Survey	Ongoing	SPIPA and SPIPA Tribes
2. Learn from each other about traditional/spiritual healing opportunities within the SPIPA Tribes.	Community Survey	ongoing	Cancer Advisory Committee

Cancer Survivor Support

<u>Goal #4:</u> Ensure that tribal and community cancer survivors and their loved ones at all SPIPA Tribes receive support. (Cancer survivors include family, caregivers, friends and other support systems.)

Cancer Survivor Rates for American Indians and Alaska Natives

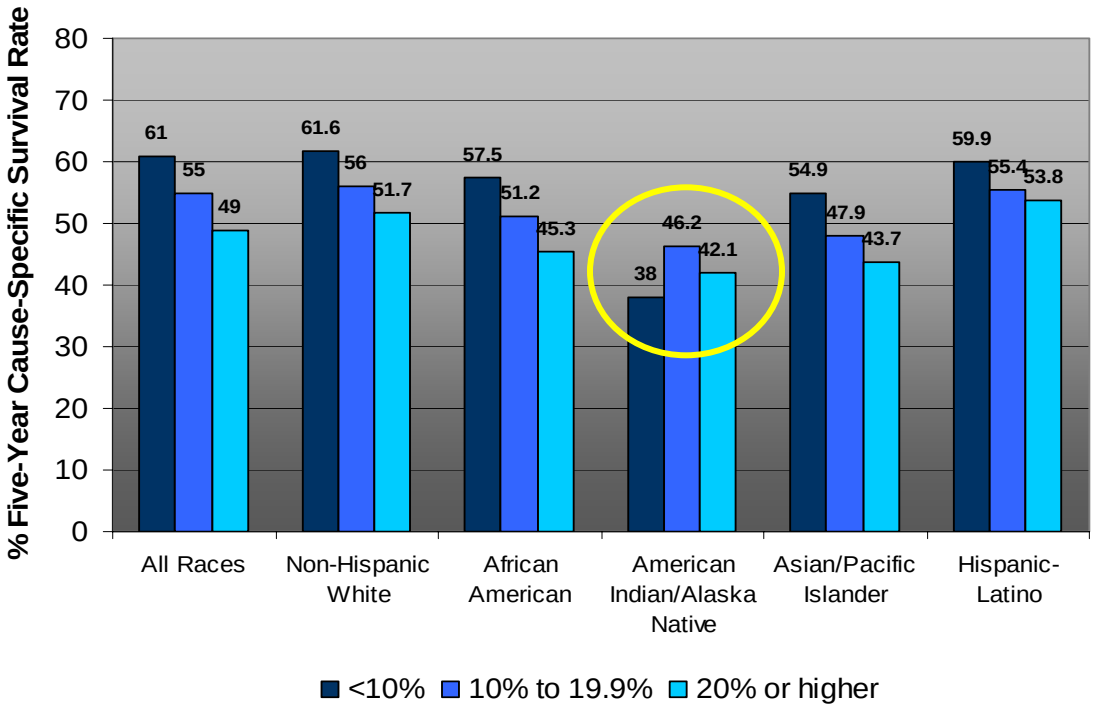
Native Americans and Alaska Natives have the lowest five-year relative survival rate of all U.S. populations. Only 38% of Native American males survive 5 years past diagnosis. In comparison, 61% of the overall U.S. male population survives 5 years past diagnosis.

Factors that may contribute to lower survival rates for cancer include stage of diagnosis, timelines and access to treatment, co-morbidities, lifestyle factors and ability to complete treatment regimen.

The survival rates shown here represent the probability of escaping death due to the underlying cancer in the absence of other causes of death. The survival rates are divided into race and also percent of the population below the poverty line in 1990. For example, for American Indian and Alaska Native men living in a census tract with less than 10% of the population below the poverty line, 38.0% of those diagnosed with cancer tended to survive at least 5 years. This compares with 61.5% of men diagnosed with cancer in the non-Hispanic white population living in a similar economic area surviving at least 5 years. [7, 11-13]

Five Year Cancer Survivor Rates

Males



Percent of Census Tract Population below Poverty Line in 1990

Source: SEER (All Sites Combined) Survival among Men and Women, 1988-1994 Cohort. [41, 4]

Support for Cancer Survivors

Those facing cancer in the SPIPA Tribes have had the support of their clinic, the communities and their loved ones. Yet, there remain gaps in support for those with cancer and their caregivers. Interviews conducted with tribal and community members reiterate the need for cancer support groups, patient advocacy, support and training for caregivers, end-of-life assistance, pain management and palliative care. These items and others are addressed in the work plan for cancer survivor support.

The strength of the SPIPA CCCP, as illustrated in the SOCKEYE analysis (page 18), includes the wisdom of the Elders and cancer survivors, unified and mobilized communities and a foundation of support through the Native Women's Wellness Program.

Caregiver support

"I was a care provider for an aunt who passed from cancer. One of our elders said he would lie in bed in pain and pray he could have the energy to chop wood. That was what was most important to him. He commented that the cancer was just in his body, not in his spirit. I watched another of our elders walk across the lawn one day. She was bent over from pain. When she saw me she straightened up to hide the pain that she was in. I didn't let her know that I had seen her bent over. I think seeing another community member that supported her gave her strength to get through her pain. I believe our community can impact and support one another just by being present. Just by giving a hug."

Charlene Krise,
Squaxin Island
Tribal Member

Roslynne Reed
Skokomish Tribal Member

I think our communities need more education. The reason I got involved was because of my mom. She didn't know the questions to ask when she had cancer. My sister was diagnosed as well. That is what I like about this program, it is starting with educating the people who are in the community. We are learning why it is important to know more about cancer. I realize now we need to know more of the details. For example, we need to know more about nutrition and how it is related to cancer. When the doctor says we need to start "eating right" we need to understand what that means. Also, you've taught us about the risk factors for cancer, now we need to know what we can actually do about it. What is practical and will actually work. I like that you are training and relying on community members for planning and outreach versus someone from the outside.

We're trained not to complain. As a child my mother trained us to grin and bear it. There is a big difference between the way the Elders where taught and how we need to talk to our doctors and family about illness. When we get off kilter it is important to understand what is going on with our bodies and to be able to talk about our pain and need for pain management. Prevention is also hard. Our culture is one that lives day to day. Planning and healthy living for tomorrow is something new.

Our needs include integrating the health programs so there is a common message. Right now each disease has its own program and I think they would be well received if the services and health messages were integrated.

I think the first priority is the emotional well being of patients and their families. We need to know how to deal with terminal illness. At first, when it hits you, we need help in how to deal with this. We also need assistance (both financial and training) for the caregivers of those with advanced illness. We need help in recognizing the last days of our loved ones. We, as advocates, can make sure there is help around at this time.

#1 By 2012, the SPIPA CCCP and the SPIPA Tribes will find/develop and implement **family support education and awareness** activities for the families of those with cancer in the SPIPA Tribes. Activities/Strategies	**Measures of Effectiveness / Data**	**Time frame**	**Who is Responsible**
1. Include health clinics, CHR's, survivors, and outreach workers in survivor support activities.	Number of staff trained, job descriptions	Fall 2007	SPIPA, Tribal Clinics, Advisory Committee
2. Create a pamphlet of stages of what to expect after diagnosis including	Pamphlet complete	Winter 2007	SPIPA, CIS, clinics and survivors
3. Provide coping, support, resources, etc. for cancer survivors created by survivors.	Resources available	Winter 2008	SPIPA and survivors, ACS
4. Create a handbook of stages of what to expect after diagnosis including coping, support, resources, etc. for cancer survivors created by survivors. (more detailed than pamphlet)	Handbook available	Spring 2008	SPIPA, SOE, Unbroken Circle, Survivors
5. Create a humor program	Program created	Summer 2008	SPIPA, clinics and Advisory Committee
6. Hold a retreat for cancer survivors.	# participants	Fall 2008	SPIPA, partners
7. Complementary & alternative medicine (example: Massage therapy)	Resources available	Summer 2007	SPIPA and Tribal Clinics
8. Look for additional funding	Funding available	Summer 2007	SPIPA and partners
9. Provide caregiver support, activities, retreat, resources for how the caregiver can care for themselves	Resources available	Fall 2008	SPIPA, Unbroken Circle
10. Have an annual cancer survivor day, Partnering with other organizations that help support cancer survivors.	Activities of survivor day	Fall 2009	SPIPA and partners

#2 By 2012, the SPIPA CCCP and the SPIPA Tribes will develop **cancer survivor support groups** for the SPIPA Tribes.			
Activities/Strategies	**Measures of Effectiveness/ Data**	**Time frame**	**Who is Responsible**
1. Provide education and awareness of existing issues.	Contact list available	Summer 2006	SPIPA and partners (ACS)
2. Include all SPIPA Tribes in the support group with transportation resources provided (for cancer survivors and loved ones).	List of participants, schedule of activities	ongoing	SPIPA and tribal clinics
3. Have separate activities for the cancer survivor and the caregivers/loved ones.	List of participants, schedule of activities	ongoing	SPIPA and tribal clinics
4. Include resources from the casino to provide funding, meeting spaces, refreshments, comedy show	Resources available	ongoing	SPIPA
5. Conduct home visits for homebound patients.	Number of visits (tracked)	Fall 2006	SPIPA and Tribal clinics
6. Have craft groups (including bead work).	Number of participants	Winter 2007	SPIPA and Adv. Comt.
7. Provide errand/daily life support (shopping, yard work, etc.).	Number of visits (tracked)	Winter 2008	SPIPA and tribal clinics
8. Offer spiritual support, prayer groups.			Advisory Committee
9. Develop an internet chat room for survivors.	Number of visitors	Spring 2008	SPIPA
10. Provide peer to peer support resources (age/gender sensitive, Reach to Recovery, Man to Man).	Resource system created	Fall 2008	SPIPA, Adv. Committee, ACS
11. Create a referral list linking newly diagnosed patients to talk with survivors.	List created	Fall 2006	SPIPA, Adv. Committee
12. Provide counseling support for children with cancer and children of cancer patients (LLS has free program).	Number connected w/ resource	Spring 2007	SPIPA and partners

#3 By 2012, the SPIPA CCCP and the SPIPA Tribes will research and develop systems for giving **financial assistance for on-going cancer related needs** for cancer survivors.			
Activities/Strategies	**Measures of Effectiveness/ Data**	**Time frame**	**Who is Responsible**
1. Provide transportation resources for cancer survivors and their families.	Resources documented	Summer 2007	SPIPA, clinics and partners
2. Identify housing resources during cancer treatment and follow up.	Resources documented	Fall 2007	SPIPA, clinics and partners
3. Create a booklet listing available financial services/assistance.			
4. Provide equipment and supplies not covered by insurance or CHS (i.e. diapers, nutritional supplements).	Funds available	Spring 2009	SPIPA, partners and clinics
5. Provide in home care services (cooking, cleaning, and babysitting).	Care available	Summer 2009	SPIPA, Clinics
6. Help with living expenses (rent, utilities, food).	Emergency funds available	Summer 2010	SPIPA, Tribal Councils
7. Create a system to determine eligibility and distribution of resources.	System created	Winter 2009	SPIPA and Tribal Clinics
8. Access available resources from casino (hotel, food, free pass to nightly show).	Resources available	Spring 2009	SPIPA and Tribal Councils
9. Provide pet care	Care available	Spring 2010	SPIPA, Tribal youth program?

#4 By 2012, the SPIPA CCCP and the SPIPA Tribes will assess the needs, find resources and develop systems for **home care for cancer survivors**.			
Activities/Strategies	**Measures of Effectiveness / Data**	**Time frame**	**Who is Responsible**
1. Develop checklist for survivors to identify their needs in the home.	Checklist complete	Fall 2006	SPIPA
2. Find and develop resources based on their needs (house cleaning tasks, shopping, errands, and childcare and activity transportation assistance).	Resources available	Fall 2009	SPIPA, Tribal Clinics
3. Create awareness and referral to in home care services (COPES).	Information distributed	Spring 2007	SPIPA, partners
4. Provide assistance with filling out forms.	Assistance available	Summer 2008	SPIPA, Tribal Clinics
5. Provide a personal financial helper.	Assistance available	Summer 2010	SPIPA, Tribal Clinics
6. Research and provide legal assistance resources (workshop for power of attorney, living will).	Assistance available	Summer 2009	SPIPA, Tribal Clinics, partners
7. Provide skilled nursing services.	Services available	Fall 2010	SPIPA and Tribal Clinics

#5 By 2012, the SPIPA CCCP and the SPIPA Tribes will assess needs and implement activities that address **cancer related pain management** for cancer survivors.			
Activities/Strategies	**Measures of Effectiveness / Data**	**Time frame**	**Who is Responsible**
1. Create a resource for pain management including complementary and alternative methods	Resource available	Fall 2006	SPIPA and partners
2. Partnering with established pain management resources.	Partnerships in place	Summer 2006	SPIPA

#6 By 2012, the SPIPA CCCP and the SPIPA Tribes will assess needs and implement activities that address **end of life care and support.**			
Activities/Strategies	**Measures of Effectiveness / Data**	**Time frame**	**Who is Responsible**
1. Provide counseling for patients.	Counseling serviced available	Spring 2009	SPIPA, Tribes
2. Research and Provide Legal assistance (workshop for power of attorney, living will) – address these issues early on in the end of life process.	Workshop attendance	Winter 2007	SPIPA and partners
3. Individual gifts			
4. Provide assistance with end of life costs and arrangements.	Assistance available	Winter 2009	SPIPA
5. Provide for hospice services in the home.	Services available	Fall 2008	SPIPA and partners
6. Partner/coordinate care with local hospice organizations and hospitals.	Partnerships in place	Fall 2007	SPIPA
7. Provide transportation/travel assistance for family members to visit patient.	Assistance available	Summer 2008	SPIPA and Tribal Clinics
8. Provide education and grief and loss counseling for family members.	Counseling available	Spring 2008	SPIPA and partners
9. Provide spiritual care in the hospital and home (and/or nursing home).	Care available	Summer 2008	SPIPA and Advisory Committee
10. Provide assistance with the grieving process for loved ones (support groups, what to do with personal items).	Support available	Spring 2008	SPIPA and Advisory Committee
11. Provide coordination among health care team, patient, family and loved ones; Opportunity for family, loved ones, patient & health care professionals to meet.	Protocol in place for coordination	Winter 2008	SPIPA, clinics, Adv. Committee
12. Create resource for time of passing – create list of things to do (i.e., important phone calls).	List created	Spring 2007	SPIPA, partners

Plan Implementation.

How we are going to get there....

Cancer control has a strong foundation with the success of the Native Women's Wellness Program and the strong commitment of tribal and community members to actively participate in the development of this plan. Comprehensive cancer services have been a desire of the SPIPA Tribes for many years. Those involved in the formation of the SPIPA Comprehensive Cancer Control Plan developed objectives and activities that are SMART (specific, measurable, achievable, realistic and timely). Because community members were used throughout the planning process the strategies are based on first-hand knowledge of the strengths, challenges and opportunities of the SPIPA tribes.

SPIPA and the SPIPA Tribes will implement the cancer control plan with the ongoing input and wisdom of our Advisory Committee, the support of Tribal Councils and the advice and assistance of a web of partners in the SPIPA Comprehensive Cancer Control Process.

With this plan we have a framework and mandate from the community to:

- Move forward to search for additional resources that will sustain comprehensive cancer control,
- Partner with the five Tribal Health Clinics on efforts such as
  - Community cancer awareness and education
  - Provider and staff training and education
  - Prostate, colorectal and skin cancer screening and follow up
  - Cancer surveillance and a community health assessments
- Partner with experts outside of the SPIPA Tribes in areas such as cancer survivor support, teen tobacco education and tracking cancer prevalence rates for the SPIPA Tribes

A timeline outlining when objectives and activities are to be achieved can be found in the appendix. The illustration on the next page is a summary look of where we are going and how we are going to get there.

Existing programs funded by other sources that will be critical to the successful coordination and integration of the plan:

Strategy for Evaluation of CCCP Plan Implementation

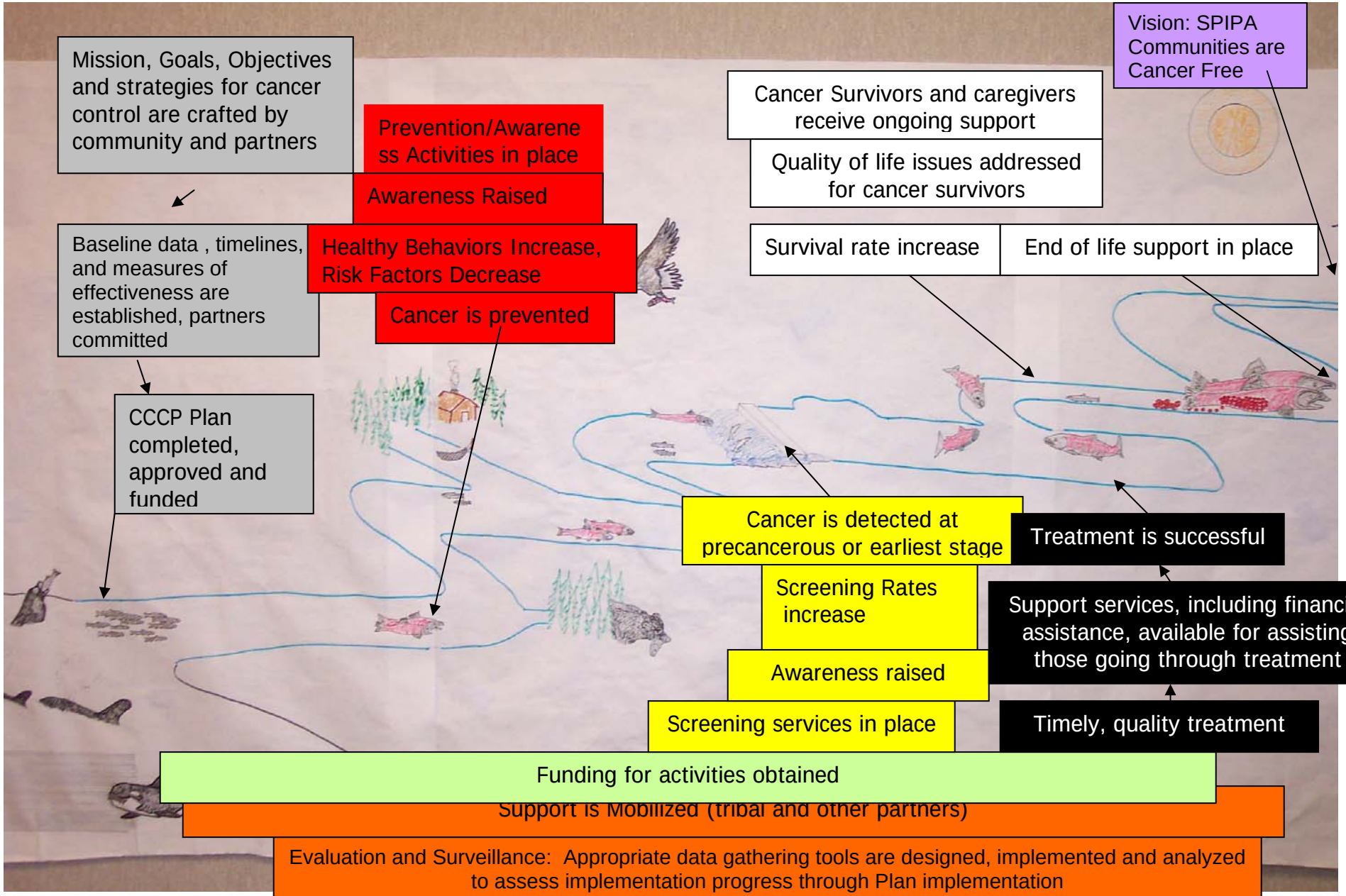
SPIPA Comprehensive Cancer Control Implementation Evaluation Plan and Criteria

The goal for evaluating SPIPA's comprehensive cancer control implementation process is to ensure that it is a measurably effective public health project true to the priorities and needs of the SPIPA Tribes. The evaluation will inform the implementation process and ensure that everything is unfolding according to the plan.

The evaluation includes assessing the implementation strategies of the SPIPA Comprehensive Cancer Control Plan. Evaluation measures and questions are crafted to ensure the evaluation process is feasible and useful during the implementation process. Data gathered for evaluation will routinely and appropriately inform ongoing decision making. The project aims to effectively use the evaluation to support the implementation process for accountability and continuous quality and process improvement. A periodic report of the status of the implementation process, including success and lessons learned, will be given to all partners, tribal clinics, tribal councils and other stakeholders. In accordance with the "plan-do-study-act" approach of continuous quality improvement, information gathered in periodic evaluations of the implementation process will be used to support continuation of plan strategies or will inform adjustments in strategies to most effectively reach the goals of the SPIPA CCCP Plan.

The following page is the SPIPA CCCP version of our "logic model". The model uses the journey of the salmon in their mission to return to spawning grounds to illustrate SPIPA's mission of a successfully implemented comprehensive cancer control program. Just as the salmon face barriers and challenges on their journey from the ocean to their goal, controlling cancer in the SPIPA communities will not be an easy journey. Though successful completion of activities such as raising awareness, increasing cancer screening and implementing cancer survivor support activities, step by step we will reach our outcome measures of controlling cancer. Through the comprehensive cancer control process will have strong partnerships and a unified vision. With this strength we begin our journey to comprehensive cancer control implementation.

Journey to Comprehensive Cancer Control (SPIPA's CCCP Logic Model)



Key Evaluation Questions for Quarterly and Annual Evaluation; Date of Evaluation: _____

	Evaluation Question	Evidence Documented?	Needs Improvement?
Mission, Goals, Objectives and strategies for cancer control are crafted by community and partners	**1.1 Have all key stakeholders been involved in the development and approval of the CCCP Plan?**		
	1.2 Have partners been mobilized and committed to cancer control implementation?		
	▪ Resolutions from SPIPA Tribes and SPIPA Board		
	▪ Tribal Health Clinic Support Letters		
Funding for activities obtained	▪ Partnership agreements/MOU's		
	▪ Meeting Attendance by partners		
	1.3 Has funding been found to support CCCP implementation activities?		
Evaluation and Surveillance: Appropriate data gathering tools are designed, implemented and analyzed to assess implementation progress through Plan implementation	▪ Overarching CCCP administration funded (coordination, surveillance, grants management, etc.)		
	▪ Prevention activities funded?		
	▪ Screening/Early Detection activities funded?		
	▪ Treatment activities funded?		
	▪ Survivorship activities funded?		
Baseline data , timelines, and measures of effectiveness are established, partners committed	**1.4 Are evaluation and surveillance measures designed, implemented, analyzed and assessed?**		
	▪ Are surveillance measures (screening surveillance, cancer registry access) in place for all SPIPA Tribes?		
	▪ Are systems in place for evaluation (periodic surveys, periodic review with advisory committee)?		
CCC Plan continues to address the needs of each SPIPA Tribe	**1.5 Are systems in place to communicate results to SPIPA Tribes, Tribal Clinics and other partners?**		
	▪ Periodic reporting, communications and meetings taking place?		

CCCP Implementation Plan Evaluation: Cancer prevention and awareness

Prevention/ Awareness activities in place

Awareness Raised

Healthy Behaviors Increase, Risk Factors Decrease

Cancer is prevented

Evaluation Question	Evidence Documented?	Needs Improvement?
2.1 Are prevention and awareness activities in place at each SPIPA Tribe?		
-Are general cancer awareness and education activities in place at each SPIPA Tribe?		
-Are tobacco use prevention activities in place?		
-Are quit smoking/chew programs in place?		
-Are activity and exercise programs in place?		
-Are nutrition awareness activities in place?		
-Are transmissible cancer risk factors prevention in place (Hep C, HPV)?		
2.2 Has awareness about risk factors for cancer and preventive measures for cancer been increased?		
-Are appropriate systems in place to measure changes in awareness risk factors and preventative measures?		
-Are the tools and activities used to raise awareness of the risk factors and cancer prevention sufficiently effective?		
2.3 Have healthy behaviors increased and risk factors decreased?		
-Are appropriate systems in place to measure changes in risk and behavioral factors?		
-Are the tools and activities used to increase healthy behaviors and decrease risk factors sufficiently effective?		
2.4 Has the incidence of specific cancers decreased significantly over time for the SPIPA Tribal communities?		
-Are systems in place to measure cancer incident rates for the SPIPA communities?		

CCCP Implementation Plan Evaluation: Cancer Screening and Early Detection

	Evaluation Question	Evidence Documented	Needs Improvement?
Screening services in place	*3.1 Are screening services in place at each SPIPA Tribe to include adoption of quality standards of screening and adequate follow up/diagnostic services?*		
	▪ Are breast cancer screenings and follow up services in place?		
	▪ Are cervical cancer screenings and follow up services in place?		
	▪ Are prostate cancer screenings and follow up services in place?		
	▪ Are colorectal cancer screenings and follow up services in place?		
Awareness of importance of screening raised	**3.2 Has cancer screening awareness been raised in the SPIPA communities?**		
	▪ Are appropriate systems in place to measure changes in awareness related to cancer screening?		
	▪ Are the tools and activities used to raise awareness of the importance of cancer screening sufficiently effective?		
Screening Rates increase	**3.3 Have cancer screening rates increased for the SPIPA tribes?**		
	▪ Is a surveillance system in place to measure screening rates?		
	▪ Are breast cancers screening rates increasing?		
	▪ Are cervical cancers screening rates increasing?		
	▪ Are prostate cancers screening rates increasing?		
	▪ Are colorectal cancers screening rates increasing?		
Cancer is detected at precancerous or earliest stage	**3.4 Has cancer been detected at the earliest stage possible?**		
	▪ Are systems in place and accessible to track and monitor the stage of cancer and related information upon diagnosis?		
	▪ Are cancers being diagnosed at the earliest stage possible?		

CCCP Implementation Plan Evaluation: Cancer Treatment

	Evaluation Question	Evidence Documented	Needs Improvement?
Timely, quality treatment	**4.1 Are those diagnosed with cancer receiving timely and quality treatment?**		
	▪ Are systems and indicators in place to measure the timeliness and quality of treatment?		
	▪ Is cancer treatment timely?		
	▪ Is cancer treatment for all SPIPA community members' diagnosis with cancer of sufficient quality?		
Support services, including financial assistance, available for assisting those going through treatment	**4.2 Are support services available for assisting those going through treatment for all SPIPA Tribal communities?**		
	▪ Are resources available to assist with covering the cost of treatment?		
	▪ Do SPIPA Tribal and community members diagnosed with cancer have access to the latest treatment options?		
	▪ Do SPIPA Tribal and community members diagnosed with cancer have access to traditional/spiritual treatment?		
Treatment is successful	**4.3 Are cancer treatments for those diagnosed with cancer sufficiently successful?**		
	▪ Are systems in place to track and monitor the success of cancer treatment, both objective and perceived?		
	▪ Are cancer treatments sufficiently successful and/or improved over time?		

CCCP Implementation Plan Evaluation: Cancer Survivor Support

	Evaluation Question	Evidence Documented	Needs Improvement?
Cancer Survivors and caregivers receive ongoing support	**5.1 Are cancer survivors and caregivers receiving ongoing support at each SPIPA Tribe?**		
	-Are family support and education activities in place?		
	-Have cancer survivor support groups been formed and are sustained?		
	-Are systems in place to provide financial assistance for ongoing cancer related needs?		
	-Are resources and systems in place for home care for cancer survivors?		
	-Are cancer related pain management resources in place?		
	-Are indicators and systems in place to measure the effectiveness of survivor and caregiver support activities		
	-Are cancer survivor and caregiver support activities sufficiently effective?		
Quality of life improved for cancer survivors	**5.2 Has the quality of life improved for cancer survivors?**		
	▪ Are appropriate systems (surveys, interviews, indicators, etc.) in place to measure changes in quality of life for cancer survivors?		
	▪ Are the tools and activities used to improve the quality of life for cancer survivors sufficiently effective?		
Survival rate increase	**5.3 Are survival rates for those diagnosed with cancer increasing?**		
	▪ Are systems in place to track and monitor the cancer survivorship information such as survival rates?		
End of life support in place	**5.4 Are end of life support systems in place?**		
	▪ Are resources, training and assistance in place for end of life support?		
	▪ Are end of life support systems culturally appropriate and measurably effective for the SPIPA Tribes?		
	▪ Are end of life support systems measurably effective?		

Implementation Plan Evaluation

The SPIPA Comprehensive Cancer Control Program is off to a great start with numerous successes. To maintain the level of quality work and to continue to meet goals and objectives in a timely manner the program will continue evaluating the program with a thorough, broad-based approach. The program will employ the following evaluation approaches:

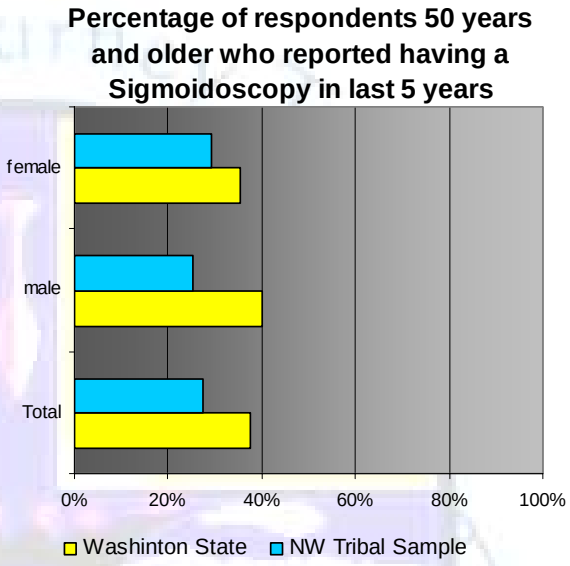
1. Professional Evaluator: The program will continue to be monitored by an outside evaluator (services provided in-kind by Dr. Alan Cheadle, University of Washington School of Public Health) who will measure the success and effectiveness of cancer control implementation based on the program's logic model as well as other benchmarks including the goals and objectives outlined in this plan.
2. Continuous Quality Improvement of Control Plan: The Program Coordinator will continually monitor the measures of effectiveness outlined in the Plan and will report the progress to the Advisory Committee. The SPIPA CCCP, in coordination with the Advisory Committee will assess the success, barriers and remaining gaps in completing the activities outlined in the plan. The plan will be adjusted to reflect changes in the environment as identified by the continuous review process.
3. Annual review by Cancer Advisory Committee, Partners and Stakeholders
   This plan will be reviewed by July 1st of each year.
   - Gaps in existing strategies to address the cancer burden will be assessed and identified.
   - Plan priorities and strategies will be updated and modified to enable continual identification of critical target areas for cancer prevention and control activities.
   - Plan priorities and strategies will be reviewed to make sure they are appropriate and sustainable in each of the Five Tribes.
   - Implementing agencies/organizations for emerging plan priorities will be identified.
   - Ongoing performance will be continually assessed and evaluated.
   - Training needs of partners will be assessed and addressed.
4. Data-based evaluation and decision making: Data gathered throughout the life of this project will be used, in a timely manner, to measure the effectiveness of cancer control implementation. Examples of data to be gathered to assist with evaluation include:
   - Cancer screening rates
   - Cancer cases: observed versus expected
   - Community cancer survey results
   - Number of activities completed based on measures of effectiveness

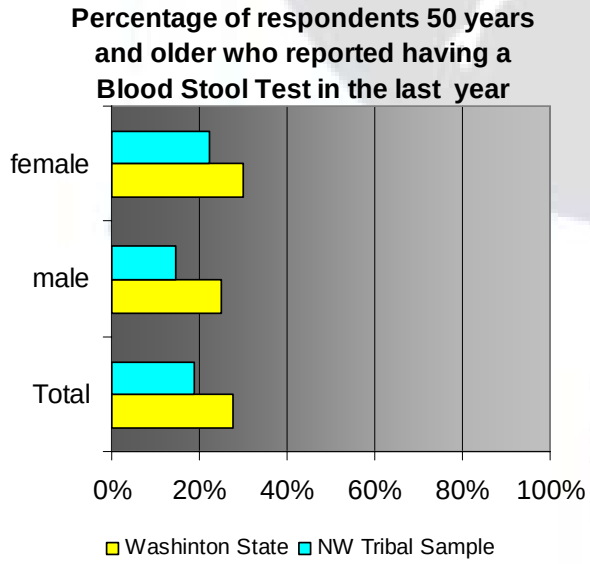
Action Plan for Colorectal Cancer

Background:

Colorectal cancer is the second leading cause of death from cancer in the United States. Risk factors for colorectal cancer include diet (red meat consumption), physical inactivity, alcohol consumption, obesity and smoking. Colon cancer is often linked to family history of colon cancer or polyps in the colon.

The US Preventive Services Task Force (USPSTF) strongly recommends that clinicians screen men and women 50 years of age or older for colorectal cancer. The USPSTF found good evidence that periodic fecal occult blood testing (FOBT) reduces mortality from colorectal cancer and fair evidence that Sigmoidoscopy alone or in combination with FOBT reduces mortality.[1]





Source for graphs: NW Tribal BRFSS, 2003

There are three screening tests for colorectal cancer:

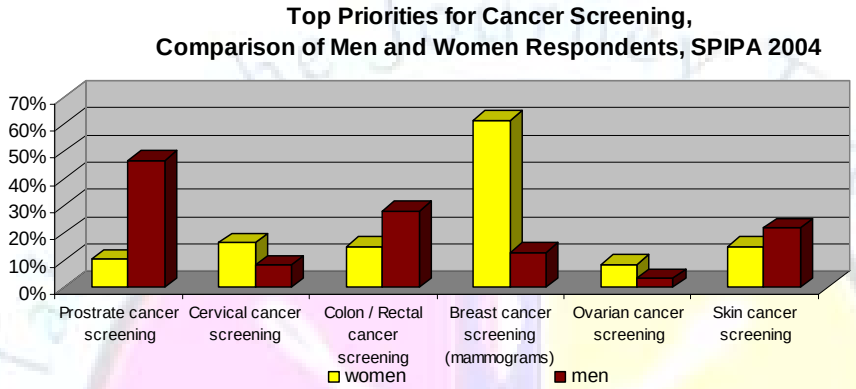
1. Sigmoidoscopy - a procedure to look inside the rectum and sigmoid (lower) colon for polyps, abnormal areas, or cancer.
2. Colonoscopy - procedure to look inside the rectum and colon for polyps, abnormal areas, or cancer.
3. Blood stool test - or fecal occult blood test (FOBT) checks stool (solid waste) for blood that can only be seen with a microscope. Small samples of stool are placed on special cards and returned to the doctor or laboratory for testing. Blood in the stool may be a sign of polyps or cancer.

Goal: Reduce morbidity and mortality from colorectal cancer to lower than expected rates for SPIPA communities[2] by 2012.

[1] US Preventive Services Task Force Recommendations for Colorectal Cancer Screening, 2004.
[2] "communities" include geographically defined census tract areas of SPIPA Tribal Communities.

Prevention objective: Increase awareness of risk factors and healthy lifestyle choices associated with prevention of colorectal cancer.

Action Item	Measures of Effectiveness	Time frame	Who is Responsible
10. Cancer prevention and screening workshops (youth, mid age, elders) at each of the 5 tribes. Collaboration with other organizations: ACS, ALA, NCI's CIS, NPAIHB/NTCCP (CCCP Plan 1.1.2)	Workshops completed	3-workshops per year	SPIPA w/TRIBES
11. Expand communication for colorectal cancer control and prevention issues and activities (i.e. newsletter, brochure, etc.) (CCCP Plan 1.1.3)	Increase distribution	Quarterly	SPIPA w/ Tribes and other health projects
12. Collaborative planning/sharing resources with all SPIPA and tribal health awareness and prevention programs (CCCP Plan 1.1.4).	Increase communication /regular meetings take place	Quarterly	SPIPA and tribal health directors
13. Create and enhance infrastructure of each tribe (i.e. hire and train community health outreach workers/educators) (CCCP Plan 1.1.6)	Dedicated FTE for cancer programs	Spring 2007	Tribal health departments



Screening

#4 SPIPA will work with the Tribal Clinics to screen at least 50% of the eligible population for colorectal cancer screening at the recommended time intervals.

Action Item	Measures of Effectiveness/ Data	Time frame	Who is Responsible
Surveillance 21. Develop a system for tracking colorectal cancer screening and follow up information for the Five Tribes.	Tracking system in place	Fall 2007	SPIPA and Tribal Health Clinics
22. Establish a baseline for colorectal cancer screening education, rates (Sigmoidoscopy, colonoscopy, FOBT) for the Five Tribes	Baseline established	Fall 2008	SPIPA and Tribal Health Clinics
23. Provide technical support to Tribal Clinics for tracking the rates of screening and follow up.	Technical assistance in place and tracked	Summer 2006	SPIPA and Tribal Health Clinics
24. Develop system to track colorectal cancer patient education provider education (work with RPMS, PCC form, etc).	Tracking system in place	Fall 2007	SPIPA and Tribal Health Clinics
25. Work with NPAIHB, Washington State Cancer Registry and Surveillance, Epidemiology and end Results to track prevalence of colorectal cancer for the Five Tribes.	Community cancer rates tracked and reported	Fall 2006	SPIPA and partners
Providers/Clinic			

#4 SPIPA will work with the Tribal Clinics to screen at least 50% of the eligible population for colorectal cancer screening at the recommended time intervals.

Action Item	Measures of Effectiveness/ Data	Time frame	Who is Responsible
26. Existing CCCP/NWWP Medical Advisory Committee adopts guidelines for colorectal cancer screening/education.	Guidelines developed and accepted	Fall 2006	SPIPA and Tribal Clinics
27. Assess provider knowledge of colorectal cancer; provide training (CMEs) to address gaps.	Trainings attended	Fall 2007	SPIPA, ACS and Tribal Clinics
28. Ensure providers receive strong support (clinic staff, referral specialists, patient education resources, etc.) for addressing colorectal cancer issues.	Provider survey results	ongoing	SPIPA and Tribal Clinics
29. Ensure adequate staffing at clinic (providers available)	Male provider at each clinic	ongoing	SPIPA and Tribal Clinics
30. Ensure provider visit time adequate to address/refer for colorectal cancer screening (FOBT in house, colonoscopy and Sigmoidoscopy referred out).	Patient and provider surveys	Spring 2009	SPIPA and Tribal Clinics
31. Utilize other “teachable moments” in the clinic, i.e.: posters in waiting rooms, restrooms, exam rooms, MA and clinic staff to provide patient education.	Teaching activities in place and tracked	Fall 2009	SPIPA, partners and Outreach workers
Patient			
32. Patient education on colorectal cancer issues. Outreach (video, health fairs, incentives, etc) for colorectal cancer.	Education activity completed	Winter 2008	SPIPA and Advisory Committee
33. Patient advocacy and education when referred out to specialist.	Patient navigator in place, patient survey	Spring 2008	SPIPA and Tribal Health Clinics
34. Address patient confidentiality issues (HIPAA education, refer to other clinic,)	Trainings and policies in place	Summer 2008	SPIPA and Tribal Clinics
35. Respect traditional beliefs, integrate traditional beliefs/ways into outreach – work with elders in order to	Community Wellness Survey	ongoing	SPIPA and Five Tribes

#4 SPIPA will work with the Tribal Clinics to screen at least 50% of the eligible population for colorectal cancer screening at the recommended time intervals.			
Action Item	**Measures of Effectiveness/ Data**	**Time frame**	**Who is Responsible**
understand best approach for outreach (work in a healing way).			
36. Ensure all patients are treated with respect and dignity – (education of clinic staff and referral clinics/providers).	Community Wellness Survey	ongoing	SPIPA and Tribal Health Clinics
Tribes/SPIPA			
37. Seek funding for incentives.	Funding in place	Spring 2007	SPIPA
38. Funding to hire an outreach worker – determine level of staffing needed.	Funding in place, staff hired	Fall 2008	SPIPA and Five Tribes
39. Seek funding (possibly fundraising, seek volunteers) to provide colorectal cancer screening and follow up for all community and tribal members (those not covered by other services).	Funding in place	Fall 2009	SPIPA and Tribal Clinics
40. Ensure all tribal and community members are receiving colorectal cancer screening, education and services.	Community survey results	Fall 2009	SPIPA and outreach workers

Treatment Objective:

Action Item	Measures of Effectiveness	Time frame	Who is Responsible
1. (Secure funding to hire) Case manager/patient navigator/patient advocacy for those going through treatment to address all the issues. (care, financial, etc.) 3.1.1	Staff in place, patient survey	Winter 2008	SPIPA and Tribal Clinics
2. Knowledge of the latest treatment options available, what to expect. Patient Driven, helped by advocate or SPIPA with resources such as www.cancer.gov, 1-800-4cancer, wikipedia, University affiliated hospital. 3.3.1	Research completed per patient	Ongoing, In place by Fall 2007	SPIPA, Tribal Health Clinic
3. Primary providers aware of quality specialists, support through continuing education and communication on latest treatment options 3.3.3	Communication in place for latest cancer info/options	Spring 2008	SPIPA and med. Advisory Committee

Survivorship Objective:

Action Item	Measures of Effectiveness	Time frame	Who is Responsible
1. Create a pamphlet of stages of what to expect after diagnosis including. 4.1.2	Pamphlet complete	Winter 2007	SPIPA, CIS, clinics and survivors
2. Create a handbook of stages of what to expect after diagnosis including coping, support, resources, etc. for cancer survivors created by survivors. (more detailed than pamphlet). 4.1.4	Handbook available	Spring 2008	SPIPA, SOE, Unbroken Circle, Survivors
3. Create a referral list linking newly diagnosed patients to talk with survivors. 4.2.11	List created	Fall 2006	SPIPA, Adv. Committee

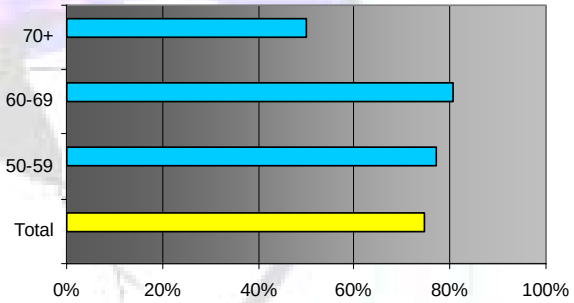
Action Plan for Prostate Cancer

Background:

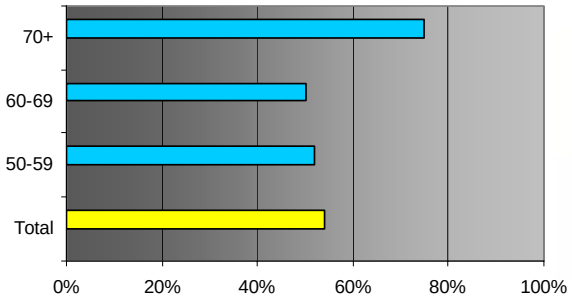
Risk factors for prostate cancer include a high fat diet, smoking and alcohol use, and a first degree relative with prostate cancer. Prostate cancer for American Indian men has been on the increase in the southwest and northern plains of the United States.[3] Prostate cancer survival among American Indians in western Washington is poorer than that among Whites in the same region[4]. Factors contributing to this include barriers to screening[5], stage at diagnosis and access to cancer treatment.

The U.S. Preventive Services Task Force (USPSTF) concludes that the evidence is insufficient to recommend for or against routine screening for prostate cancer using prostate specific antigen (PSA) testing or digital rectal examination (DRE). 50% of men between 50 and 69 report having a prostate-specific antigen (PSA) test in 2003. Over 75% of men in that age group do report ever having a digital rectal exam. Both the (PSA) blood test and digital rectal examination (DRE) should be offered annually, beginning at age 50 to all men.

Percentage of NW Native Male respondents 50 years and older who reported ever having a Digital Rectal Exam



Percentage of NW NativeMale respondents 50 years and older who reported having a Prostate-Specific Antigen (PSA) test in the last year



The DRE is less effective than the PSA blood test in finding prostate cancer, but it can sometimes find cancers in men with normal PSA levels. For this reason, The American Cancer Society recommends that both the DRE and the PSA be used for finding prostate cancer early. PSA screening is associated with important harms, including frequent false-positive results and unnecessary anxiety, biopsies, and potential complications of treatment. For this reason it is recommended that the health care provider discuss the benefits and potential harms of the PSA test with their patients.

Prostate Cancer Goal: Reduce morbidity and mortality from prostate cancer to lower than expected rates for SPIPA communities[6] by 2012.

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[3] Gilliland, et. al. Prostate cancer in American Indians, New Mexico, 1969 to 1994

[4] Sugarman, et. al. Cancer survival among American Indians in western Washington State (United States)

[5] Hoffman, et. al. Differences between men with screening-detected versus clinically diagnosed prostate cancers in the USA

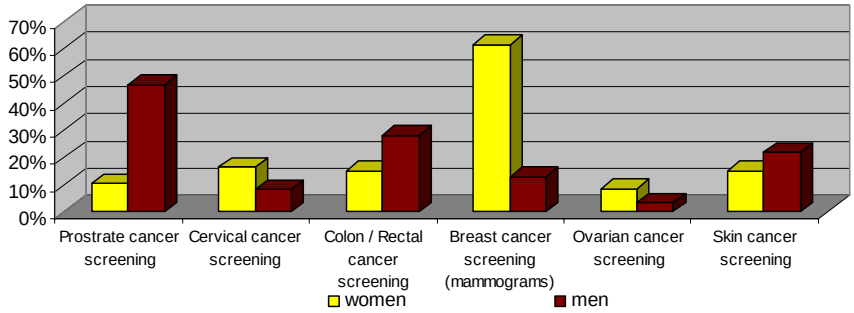
[6] "communities" include geographically defined census tract areas of SPIPA Tribal Communities.

Prevention objective: Increase awareness of risk factors and healthy lifestyle choices associated with prevention of prostate cancer.

Prevention objective: Increase awareness of risk factors and healthy lifestyle choices associated with prevention of colorectal cancer.

Action Item	Measures of Effectiveness	Time frame	Who is Responsible
14. Cancer prevention and screening workshops (youth, mid age, elders) at each of the 5 tribes. Collaboration with other organizations: ACS, ALA, NCI's CIS, NPAIHB/NTCCP (CCCP Plan 1.1.2)	Workshops completed	3-workshops per year	SPIPA w/TRIBES
15. Expand communication for prostate cancer control and prevention issues and activities (i.e. newsletter, brochure, etc.) (CCCP Plan 1.1.3)	Increase distribution	Quarterly	SPIPA w/ Tribes and other health projects
16. Collaborative planning/sharing resources with all SPIPA and tribal health awareness and prevention programs (CCCP Plan 1.1.4).	Increase communication /regular meetings take place	Quarterly	SPIPA and tribal health directors
17. Create and enhance infrastructure of each tribe (i.e. hire and train community health outreach workers/educators) (CCCP Plan 1.1.6)	Dedicated FTE for cancer programs	Spring 2007	Tribal health departments

Top Priorities for Cancer Screening,
Comparison of Men and Women Respondents, SPIPA 2004



Screening Objective: SPIPA CCCP will coordinate with the Tribal Clinics and other Tribal services annually to screen at least 50% of the eligible population for prostate cancer by 2009. (coincides with Comprehensive Cancer Control Plan Objective 2.2)

Action Item	Measures of Effectiveness	Time frame	Who is Responsible
Surveillance			
22. Develop a system for tracking prostate cancer screening and follow up information for the Five Tribes.	Tracking system in place	Fall 2007	SPIPA and Tribal Clinics
23. Establish a baseline for prostate cancer screening education, rates (PSA, DRE) for the Five Tribes.	Baseline established	Fall 2008	SPIPA and Tribal Clinics
24. Provide technical support to Tribal Clinics for tracking the rates of screening and follow up.	Technical assistance in place	Summer 2006	SPIPA and Tribal Clinics
25. Develop system to track prostate cancer patient education, provider education (work with RPMS, PCC form, etc).	System in place	Fall 2006	SPIPA and Tribal Clinics
26. Work with NPAIHB, Washington State Cancer Registry and Surveillance, Epidemiology and end Results to track prevalence of prostate cancer for the Five Tribes.	Community cancer rates tracked and reported	Spring 2006, annually	SPIPA and partners
Providers/Clinic			
27. Existing CCCP/NWWP Medical Advisory Committee adopts guidelines for prostate cancer screening/education	Guidelines developed and accepted	Summer 2007	SPIPA and Tribal Clinics
28. Assess provider knowledge of prostate cancer; provide training (CMEs) to address gaps.	Trainings attended	Winter 2007, ongoing	SPIPA and Tribal Clinics
29. Ensure providers receive strong support (clinic staff, referral specialists, patient education resources, etc.) for addressing prostate cancer issues.	Provider survey results	ongoing	SPIPA and Tribal Clinics
30. Ensure adequate staffing at clinic (male providers available).	Male provider at each clinic	ongoing	SPIPA and Tribal Clinics
31. Ensure provider visit time adequate for prostate cancer screening.	Patient and provider surveys	Spring 2007	SPIPA and Tribal Clinics

Screening Objective: SPIPA CCCP will coordinate with the Tribal Clinics and other Tribal services annually to screen at least 50% of the eligible population for prostate cancer by 2009. (coincides with Comprehensive Cancer Control Plan Objective 2.2)

Action Item	Measures of Effectiveness	Time frame	Who is Responsible
32. Utilize other "teachable moments" in the clinic, i.e.: posters in waiting rooms, restrooms, exam rooms, MA and clinic staff to provide patient education.	Teaching activities in place and tracked	Fall 2009	SPIPA and Outreach workers
Patient Focus			
33. Patient education on prostate cancer issues. Outreach (video, etc) for prostate cancer.	Education activity completed	Winter 2007	SPIPA and Advisory Committee
34. Patient advocacy and education in place when referred out to specialist.	Patient navigator in place, patient survey	Spring 2008	SPIPA and Tribal Health Clinics
35. Men's wellness clinic at least twice each year with great incentives.	Men's clinic participant lists	Winter 2008	SPIPA and Tribal Clinics
36. Address patient confidentiality issues (HIPAA education, refer to other clinic,)	Trainings and policies in place	Summer 2008	SPIPA and Tribal Clinics
37. Respect traditional beliefs, integrate traditional beliefs/ways into outreach – work with elders in order to understand best approach for outreach (work in a healing way).	Community Survey	ongoing	SPIPA and Five Tribes, Advisory Committee
38. Ensure all patients are treated with respect and dignity through education of clinic staff and referral clinics/providers.	Community Survey	ongoing	SPIPA and Tribal Clinics
Tribes/SPIPA Focus			
39. Seek funding for incentives for men.	Funding in place	Spring 2006	SPIPA
40. Funding to hire a men's outreach worker – determine level of staffing needed.	Funding in place, staff hired	Spring 2007	SPIPA and Five Tribes
41. Seek funding (possibly fundraising, seek volunteers) to provide prostate cancer screening and follow up for all community and tribal members (those not covered by other services).	Funding in place	Fall 2009	SPIPA and Tribal Clinics
42. Ensure all tribal and community members are receiving prostate cancer screening education and services.	Community survey results	Winter 2009	SPIPA and outreach workers

Treatment Objective:

Action Item	Measures of Effectiveness	Time frame	Who is Responsible
4. (Secure funding to hire) Case manager/patient navigator/patient advocacy for those going through treatment to address all the issues. (care, financial, etc.) 3.1.1	Staff in place, patient survey	Winter 2008	SPIPA and Tribal Clinics
5. Knowledge of the latest treatment options available, what to expect. Patient Driven, helped by advocate or SPIPA with resources such as www.cancer.gov, 1-800-4cancer, wikipedia, University affiliated hospital. 3.3.1	Research completed per patient	Ongoing, In place by Fall 2007	SPIPA, Tribal Health Clinic
6. Primary providers aware of quality specialists, support through continuing education and communication on latest treatment options 3.3.3	Communication in place for latest cancer info/options	Spring 2008	SPIPA and med. Advisory Committee

Survivorship Objective:

Action Item	Measures of Effectiveness	Time frame	Who is Responsible
4. Create a pamphlet of stages of what to expect after diagnosis including. 4.1.2	Pamphlet complete	Winter 2007	SPIPA, CIS, clinics and survivors
5. Create a handbook of stages of what to expect after diagnosis including coping, support, resources, etc. for cancer survivors created by survivors. (more detailed than pamphlet). 4.1.4	Handbook available	Spring 2008	SPIPA, SOE, Unbroken Circle, Survivors
6. Create a referral list linking newly diagnosed patients to talk with survivors. 4.2.11	List created	Fall 2006	SPIPA, Adv. Committee

Appendix

Time Line for SPIPA Comprehensive Cancer Control Plan Implementation: 2006-2011

Ongoing or annual efforts not included in timeline:

Prevention:

- Cancer prevention and screening workshops at each tribe (youth, mid age, elders) at each of the SPIPA Tribes – three per year during length of funded comprehensive cancer control program, in collaboration with other organizations (ACS, ALA, CIS, NPAIHB, etc.)
- Expand communication for cancer control issues and activities (i.e. newsletter)
- Collaborative planning/sharing resources with all SPIPA and Tribal Health programs
- Utilize (and spread the word) about NCI's Cancer Information Service 1-800-4-CANCER, ACS's 1-800-ACS-2345
- Train CHR's and outreach workers at each tribe to be certified to teach on Cancer 101 issues in the community

Screening

- Use state BCCEDP to serve those community members that are not currently eligible to receive mammograms through NWWP
- Ensure health care providers receive strong support (clinic staff, referral specialists, patient education resources, etc.) for addressing all cancer issues
- Ensure adequate staffing at clinics (male for prostate, female for breast and cervical, appropriate gender for skin cancer screenings)

Treatment

- Determine the level of quality rating for each treatment specialist, have information available.
- SPIPA and Tribal Clinics respect those who seek traditional/spiritual and western approaches to healing for cancer.
- Learn from each other about traditional/spiritual healing opportunities within the Five Tribes

Survivor Support

- Support group at all SPIPA Tribes with transportation and resources provided
- Separate activities for 1) survivors and 2) loved ones/care givers
- Include resources for the casino to provide (funding, refreshments, entertainment)
- Accept individual gifts

Time Line for SPIPA Comprehensive Cancer Control Plan Implementation: 2006-2011

Year	Goal▼	Time Frame for Activity			
		Winter	**Spring**	**Summer**	**Fall**
2006	Prevention	▪ TATU training at all 5 Tribes	▪ Work w/ diabetes staff at each tribe on exercise and nutrition	▪ Encourage traditional foods through publications, at events	▪ Challenge Tribal casinos & smoke shops to donate funds
	Screening	▪	▪ Work with partners (WSCR, NPAIHB, etc) to track cancer incidence and prevalence rates – annually ▪ Funding in place for incentives for men	▪ Provide technical assistance to tribes to track rates of cancer screening and follow up	▪ Medical Advisory Committee in place ▪ Develop system to track patient cancer education (on PCC, in RPMS)
	Treatment	▪ Participate in teleconferences, etc. on latest treatment options; SPIPA to alert community and clinics of events	▪ Support and advocate enrolling community and tribal members in WA Basic Health Plan	▪ Raise awareness of option for clinical trails as resources for covering the cost of treatment	▪
	Support	▪	▪ Checklist for survivor to identify needs in home	▪ Resource list of existing education and awareness for survivorship ▪ Partner with established pain management resources	▪ Include health clinics, CHR's, survivors, outreach workers on survivorship activities ▪ Home visits for homebound patients ▪ Referral list for newly diagnosed patients to talk to survivors

Time Line for SPIPA Comprehensive Cancer Control Plan Implementation: 2006-2011

Year	Goal▼	Time Frame for Activity			
		Winter	**Spring**	**Summer**	**Fall**
2007	Prevention	▪ Create a video/DVD with Cancer Survivors ▪ Food/nutrition article in each tribal paper at least annually	▪ Funding in place to Hire/train 0.6 FTE outreach worker at each tribe ▪ Sun screen available to all community and tribal members	▪ Youth participate in "Hutch High" ▪ Collaborate with fitness organizations to develop policies	▪ Teen/Adult tobacco survey (questions included in community health survey) ▪ Promote smoking quit lines ▪ Coordinate w/ Diabetes program to create healthy foods list
	Screening	▪ Coordinate all NWWP and CCCP activities ▪ Assess provider knowledge on cancer issues, provide training to address gaps ▪ Outreach activity for prostate cancer screening awareness (video, etc.)	▪ Seek funding/ fundraising for breast cancer screening for those not covered by NWWP ▪ Ensure provider visit time adequate for cancer screening and education ▪ Funding in place for prostate cancer screening and follow up for all tribal and community members ▪ Provide education on skin cancer prevention, screening and awareness	▪ Medical Advisory Committee reviews and adopts guidelines for prostate, skin and colorectal cancer screening ▪ Skin Cancer self exam (ABCDs) available at all Tribal Clinics	▪ Develop tracking system for prostate, skin and colorectal cancer screening, patient education and follow up
	Treatment	▪ Needs assessment with cancer survivors, existing barriers and areas to improve including timeliness	▪ Meet with Contract Health Services staff to gain their perspective on how to improve this system (payment for treatment) ▪ List serve and communication system for community and providers on latest research, events, notices	▪ Connect with hospital social workers, list of contacts & resources available	▪ Create Resource book for patient and family during treatment – update ongoing
	Support	▪ Create pamphlet of stages of diagnosis, what to expect ▪ Create awareness and referral to in-home services (COPES) ▪ Resources for pain management	▪ Counseling support for children ▪ Find and develop resources based on needs survey ▪ Time of passing – list of things to do	▪ Complimentary and alternative medicine for survivors ▪ Look for additional funding ▪ Transportation resources ▪ Coordination among health care team opportunities for them to meet with family	▪ Craft groups ▪ Housing resources during cancer treatment and follow up ▪ Partner/coordinate care with local hospice organizations

Time Line for SPIPA Comprehensive Cancer Control Plan Implementation: 2006-2011

Year	Goal▼	Time Frame for Activity			
		Winter	**Spring**	**Summer**	**Fall**
2008	Prevention	▪ Implement smoking cessation program ▪ Nicotine Replacement Therapy programs/resources	▪ NWWP & CCCP report to community collectively ▪ Certified exercise staff and activities at each tribe	▪ Chewing tobacco prevention activity ▪ Field trips to grocery store for label reading	▪ Clean Air policies in place at all 5 Tribes ▪ Video of Elders speaking on traditional use of tobacco
	Screening	▪ Men's Wellness Clinics planned for each tribe (2x/year) – with great incentives ▪ Patient education and outreach activity for colorectal cancer awareness, screening (video, etc.)	▪ Patient Navigator in place to help when patient is referred out for follow up ▪ Coordinate with NWWP to secure funding to provide cervical cancer screening and follow up for all uninsured an underinsured community and tribal members	▪ Patient confidentiality training/issues addressed	▪ Establish baseline of prostate, colorectal and cancer screening, patient education and follow up
	Treatment	▪ Funding in place to hire case manager/patient navigator	▪ TANF workers trained/certified as medical eligibility determiners at all Five Tribes or at SPIPA ▪ Primary providers aware of quality specialists, support through continuing education and communication on latest treatment options	▪	▪
	Support	▪ Coping, support, resources, etc. created by survivors ▪ Errand/Daily life support available for survivors ▪ Legal assistance ▪ Spiritual care in hospital setting	▪ Create handbook – what to expect, stages, coping, support, etc. ▪ Internet chat room ▪ Provide for hospice services in home ▪ Education and grief/loss counseling for family members	▪ Create a humor program ▪ Assistance with filling out forms ▪ Transportation & travel assistance for families to visit patients	▪ Retreat for cancer survivors ▪ Caregiver support activities, retreat, resources available ▪ Peer to peer support resources (age/gender specific)

Time Line for SPIPA Comprehensive Cancer Control Plan Implementation: 2006-2011

Year	Goal	Time Frame for Activity			
		Winter	**Spring**	**Summer**	**Fall**
2009	Prevention	▪ Promote participation and conditioning for events like Race for the Cure	▪ Start/enhance Tribal Community Gardens	▪ Support groups/activities for quitting tobacco	▪ Second hand smoke prevention activity
	Screening	▪ Annual skin cancer screening clinic at each tribe	▪ Education/awareness (BSE) for male breast cancer	▪ Secure funding to provide colorectal cancer screening and follow up for all uninsured and under insured community and tribal members	▪ Utilize other "teaching moments" in clinics (posters, waiting room, etc.) ▪ Ensure all tribal and community members are receiving colorectal cancer screening and follow up services
	Treatment	▪ Fund raising or funds secured for cancer treatment and misc. needs related to cancer treatment	▪ Increase local resources for cancer treatment (specialists available locally)	▪ Assist tribal clinics in finding alternative financial resources and updating patient information for DSHS	▪ Staff to assist patient with applying for financial resources to get into treatment
	Support	▪ In-home care services available (cooking/ cleaning/babysitting) ▪ Create system to determine eligibility and distribution of resources ▪ Assist with end of life costs and arrangements	▪ Funds available for equipment and supplies not covered by insurance or CHS ▪ Resources from casinos available (hotel, food, free pass to nightly show)	▪ Medical costs covered (create booklet listing financial services/ assistance) ▪ Legal assistance (workshop for power of attorney, living will)	▪ Annual cancer survivor day ▪ Counseling for patients ▪ Assistance with grieving process for loved ones

Time Line for SPIPA Comprehensive Cancer Control Plan Implementation: 2006-2011

Year	Goal	Time Frame for Activity			
		Winter	**Spring**	**Summer**	**Fall**
2010	Prevention	▪ Expand Healthy eating program (Squaxin Island model)	▪ Support and organize traditional activities	▪ Exercise arcade for youth at each tribe	▪ Nutritional and traditional eating and cooking classes
	Screening				▪ Outreach for breast and cervical cancer to those not reached by NWWP
	Treatment				
	Support	▪ Personal financial helper	▪ Pet care available	▪ Emergency funds for living expenses (rent, util., food)	▪ Skilled nursing services
2011	Prevention				
	Screening				
	Treatment				
	Support				

Resources

Acronyms

Acronyms - Administrative

ABMS – American Board of Medical Specialists
ACOS- American College of Surgeons
ACS- American Cancer Society
ALA –American Lung Association
ARC NW –Alliance for Reducing Cancer, Northwest
CCCP – Comprehensive Cancer Control Program
CCOP- Community Clinical Oncology Program
CDC- Centers for Disease Control and Prevention
CIS- Cancer Information Service
CISCS- Cancer Information Service Central Support
CNP – Community Network Program
CSSC- Clinical Studies Support Center
FHCRC- Fred Hutchinson Cancer Research Center
NCCAM- National Center for Complementary and Alternative Medicine
NCCN- National Comprehensive Cancer Network
NCI- National Cancer Institute
NIH- National Institutes of Health
NPAIHB – Northwest Portland Area Indian Health Board
NTCCP- Northwest Tribal Comprehensive Cancer Control Program
NWWP – Native Women's Wellness Program
RPMS –Resource and Patient Management System
SCCA- Seattle Cancer Care Alliance
SDPI –Special Diabetes Programs for Indians
SEER – Surveillance Epidemiology End Results
SOE –Spirit of the E.A.G.L.E.S
SPIPA – South Puget Intertribal Planning Agency
UBC – The Unbroken Circle
WDOH –Washington Department of Health
WSCR –Washington State Cancer Registry

Acronyms – Medical

ALL – Acute lymphocyte leukemia
AML – Acute myeloid leukemia
BMT- Bone marrow transplantation
BPH – Benign prostates hyperplasia
BRCA- Breast cancer
CA- Cancer
CAM – Complementary and alternative medicine
CBC – Complete blood count
CIN- Cervical intraepithelial lesion
CLL – Chronic lymphocyte leukemia
CML – Chronic myeloid leukemia
CNS – Central nervous system
CT- Clinical trial
CT/CAT – Computer aided tomography
D & C – Dilation and curettage
DCBE – Double contrast barium enema
DCIS- Ductal carcinoma in situ
DES- Diethylstilbestrol
DRE – Digital rectal exam
DX- Diagnosis
ERT- Estrogen replacement therapy
5-FU - Fluorouracil
FOBT – Fecal occult blood test
GERD – gastro esophageal reflux disease
GVHD – Graft-versus-host disease
HER2 – Human epidermal growth receptor 2
HIV – Human immunodeficiency virus
HPV- Human Papiloma virus
HRT- Hormone replacement therapy
HSIL – High-grade intraepithelial lesion
I-131 – Radioactive iodine
IORT – Intraoperative radiation therapy
IV – Intravenous
IVP – Intravenous pyelogram
LCIS – Lobular carcinoma in situ
LEEP – LOOP electrosurgical excision procedure
LSIL – Low-grade squamous intraepithelial lesion
MRI – Magnetic resonance imaging
NRT- Nicotine replacement therapy
PBSCT- Peripheral blood stem cell transplant
PDT- Photodynamic therapy
PSA – Prostate-specific antigen
RBC – Red blood cells
RT- Radiation therapy
SIL- Squamous intraepithelial lesion
SPF – Sun protection factor
TSH – Thyroid stimulating hormone
TURP – Transurethral resection of the prostate
TX- Treatment
UV – Ultraviolet
WBC - White blood cells

Glossary of Terms and Definitions

Access -The ability of people to reach or use health services. Barriers to access may be influenced by: (1) a person's locality, income or knowledge of services available; (2) the availability or acceptability of existing services.

Aden carcinoma (*AD-in-o-kar-sin-O-ma*) -Cancer that begins in cells that line the inside of organs. These organs make substances like hormones or milk. Most breast cancers are of this type. They begin in cells that make milk or in the cells that drain the breast milk.

Adrenal glands -The adrenal glands are two small glands that sit on top of the kidneys. They make hormones that help control heart rate, blood pressure and the way the body uses food.

Advanced Care Directives -These are written documents meant to communicate the conditions under which individuals wish to receive or refuse certain treatment or stop life-support treatment, in the event that they are no longer legally competent to make their own decisions.

Alkyl ting chemotherapy drugs -Alkyl ting chemotherapy drugs kill cancer cells by stopping them from dividing. Commonly used alkyl ting chemotherapy drugs include cyclophosphamide, busulphan, melphalan, mytomycin-C, and the platinum-based (cis-platinum, carboplatin) drugs. These drugs are used to treat slow-growing cancers.

Americans with Disabilities Act (ADA) -The ADA is a federal law that prohibits employers from discriminating against qualified individuals with disabilities in the job application process, hiring, firing, advancement, compensation, job training, and other privileges provided in the workplace.

Anatomic pathology -The study and diagnosis of disease based on structural changes in cells, tissues and organs.

Aromatase inhibitors -These medicines stop the body from producing the hormone estrogen. Aromatase inhibitors are used to treat most women with breast cancer, because estrogen makes the tumor grow. Aromatase inhibitors can also be used to treat infertility.

Aspiration -Taking out fluid or cells from a lump with a hollow needle and a syringe. This may be done to see if the lump is just a fluid-filled cyst. It can also remove cells to see if they are normal cells or cancer cells.

asymptomatic (*AY-simp-tuh-MAT-ik*) -Having no signs or symptoms of disease. For example, an asymptomatic lump has no associated pain, swelling, or bleeding.

Atrophy -A decrease in size or wasting away of cells, tissue, organs or muscle.

Autonomic nervous system -The autonomic nervous system is a branch of the peripheral nervous system that controls most body functions that happen automatically. Examples include: blood pressure, heart rate, sweating, bowel and bladder function.

Axilla -The axilla is commonly known as the armpit. The lymph nodes that filter lymph fluid for the upper part of your body are located in the axilla. For the lower limbs, the filtering lymph nodes are located in the groin.

Axillary -This refers to the underarm area, including the lymph nodes in that area.

Axillary lymph nodes -Lymph nodes found in the armpit area. They filter the lymph fluid that drains from the breast through the lymph vessels and goes back to the heart.

Axon -The long, hair like extension of a nerve cell that carries impulses from the cell body to another nerve cell.

Behavioral Therapy -A psychological technique used to help individuals change negative behavior.

Benign -Has no signs of cancer. The growth of the cells in the tumor, cyst, lump, tissue, or cells is under control. There is no spread to nearby tissue or to other parts of the body.

Benign -Generally applied to a tumor or neoplasm that is not malignant. Benign tumors don't spread to other organs, which is their main distinction from malignant tumors (cancer).

Bilateral mastectomy -Surgery that removes all of both breasts.

Bilateral (*by-LAT-uh-rul*) -Affecting both the right and left sides of body.

Biopsy -A biopsy is a procedure where cells or tissues are removed from the body so they can be examined under a microscope to look for unhealthy cells. During a biopsy, a doctor can remove an entire lump or remove a sample of tissue. A doctor can also use a needle to remove fluid or a small tissue sample. This procedure is called a needle biopsy.

Bisphosphonates -Bisphosphonates are medicines that can be used to treat osteoporosis. These drugs prevent cells that cause bone decay from being absorbed into the bones.

Bladder -The organ that stores urine produced by the kidneys.

Bowel -The bowel is part of the digestive system and includes the small and large intestine. The small intestine is where most food is digested and absorbed into the body. The large intestine absorbs water into the body and prepares feces to leave the body.
brachytherapy [also called implant radiation, internal radiation,or interstitial radiation]-
A procedure in which radioactive material is placed directly into or near the cancer. The radiation is sealed in needles, seeds, wires, or catheters.
BRCA1-A gene that maintains normal cell growth. If the gene becomes abnormal, then cell growth can become abnormal. The cells can grow out of control, forming a cancer. A woman who inherits an abnormal version of BRCA1 has a higher risk of getting breast and ovarian cancer.
BRCA2 -A gene that normally helps to prevent cell growth, especially the growth of abnormal or defective cells. A person who inherits an abnormal version of BRCA2 has a higher risk of getting breast, ovarian, or prostate cancer.
breakthrough pain -Pain that shows up in between doses of regular pain control medicine. It can happen for no reason that we know of. It can come from activity. Or it can happen because the dose of regular medicine is not strong enough.
breast reconstruction -Surgery to rebuild the breast's shape after a mastectomy.
breast-conserving surgery -An operation that completely removes the breast cancer along with a rim of normal breast tissue around it. Most of the normal breast is saved. There are 3 main ways this surgery is done: lumpectomy, quadrantectomy, and segmental mastectomy.
CA-125 -A protein that can be made by abnormal ovary cells. It can be a tumor marker. If it is present in high levels in the blood or in other body fluids or tissues, it may be a sign of ovarian cancer.
Calcification -Calcium that builds up in the tissues of the breast. It looks like grains of salt and can be seen on a mammogram. It cannot be found by touch.
Calcifications -Calcifications are tiny flecks of calcium—like grains of salt—in the soft tissue of the breast that can sometimes indicate the presence of an early breast cancer. Calcifications usually can't be felt, but they appear on a mammogram. Depending on how they're clustered and their shape, size, and number, your doctor may want to do further tests. Big calcifications— "macro calcifications"—are usually not associated with cancer. Groups of small calcifications huddled together, called "clusters of micro calcifications," are associated with extra breast cell activity. Most of the time this is non-cancerous extra cell growth, but sometimes clusters of micro calcifications can occur in areas of early cancer.
Cancer -Cancer is a group of diseases in which cells divide without control. Cancer cells can spread through the bloodstream and lymphatic system to other parts of the body.
Cancer -A malignant tumor or neoplasm. Malignant tumors have the propensity to spread either locally or through the lymphatic system or bloodstream, to other organs. Cancers are usually defined by the name of the organ from which they arise, e.g., breast cancer, but sometimes by the type of cells comprising the cancer (e.g. leukemia, arising from primitive blood cells).
Cancer continuum -The spectrum of cancer-related experience, including prevention, early detection, diagnosis, treatment, living with cancer, and end of life.
Cancer control -The totality of measures taken to reduce the impact of cancer, including prevention, early detection and screening, treatment, rehabilitation, and palliative care.
Cancer treatment -Specific treatment measures taken to cure cancer, or ameliorate its major effects. Cancer treatment includes surgery, radiation therapy, chemotherapy, hormone therapy, and pain relief measures.
Carcinogen -A chemical, infectious or physical agent that can cause cancer.
Carcinoma -A cancer that arises from epithelial tissue (the lining of an internal organ or skin).
Caregiver -A voluntary caregiver is a person, usually a family or community member, who looks after a person with a disability or health problem, and who is unpaid.
Cervix -The cervix is the part of the uterus which extends into the vagina. It is the passageway between the uterus and vagina. The cervix serves as a boundary between outside of the body and the inside of the body, keeping substances like sperm out of the uterus.
Chemotherapy -Treatment with anticancer drugs that destroy cancer cells.
Chemotherapy -The use of a chemical or chemotherapeutic agent to treat cancer or to limit its further progress.
Chromosomes -Tiny rod-shaped pieces in the nucleus of a cell that hold the DNA code needed to build a human. Most human cells have 46 chromosomes including 22 pairs of autosomes and the X and Y sex chromosomes. Sperm cells have 23 chromosomes.

Chronic -Refers to diseases and symptoms that continue or occur again and again for a long time without change.
Clinical breast examination (CBE) -The process of examining the breasts by a carefully trained health professional in order to detect early signs of breast cancer, when potentially still curable.
Clinical trial -A research activity used to evaluate the efficacy and safety of promising approaches to disease prevention and control. Interventional trials determine whether experimental treatments or new ways of using known therapies are safe and effective under controlled environments. Observational trials address health issues in large groups of people or populations in natural settings.
Colostomy -A colostomy is a surgical incision into the colon to make an opening to the outside of the abdomen. This opening serves as a substitute anus, allowing the intestines to get rid of bodily waste until the colon can heal. Waste falls into a collection pouch outside of the body.
Community -A collective of people identified by their common values and mutual concern for the development and wellbeing of their group or geographical area.
Complementary and alternative medicine [also called CAM] -Forms of treatment that are used in addition to, or instead of, standard treatments. Their purpose is to strengthen your whole mind and body to maximize your health, energy, and well-being. These practices are not considered "standard" medical approaches. They include dietary supplements, vitamins, herbal preparations, special teas, massage therapy, acupuncture, spiritual healing, visualization, and meditation.
Complementary and alternative medicine -Complementary and alternative medicine refers to a broad range of therapies used both to treat and prevent disease that are not considered to be part of conventional medicine.
Complete remission -When a cancer survivor shows no signs or symptoms of cancer.
Conventional treatment [also called conventional therapy)-An accepted and widely used treatment for a certain type of disease. This is based on the results of past research and experience. This term is often used as a contrast to alternative, or complementary, treatment. You usually get conventional treatment from doctors and nurses in a hospital or clinic.
Counseling -Counseling is a general term that refers to a range of services provided by a professional that are designed to reduce emotional distress. The counseling process involves identifying the causes of distress and using specific techniques to relieve and manage distress.
Coverage -The proportion of all eligible people screened by a program, calculated as the total number screened divided by the number of those who are eligible.
Crude (death) rate -The portion of a defined population that died during a specified period. The word “crude” is used to distinguish this measure from a rate that has been adjusted for differences in the age structure of populations (i.e. an age standardized rate.)
Cryosurgery-Treatment performed with an instrument that freezes and destroys tissue. It can be used to treat cancer. This is a form of cry therapy.
Cyst-A sac or capsule filled with fluid.
Cysts -Unlike cancerous tumors which are solid, cysts are fluid-filled masses in the breast. Cysts are very common, and are rarely associated with cancer. Ultrasound is the best way to tell a cyst from a cancer, because sound waves pass right through a liquid-filled cyst. Solid lumps, on the other hand, bounce the waves right back to the film.
D&C [also called dilation and curettage] -A procedure that removes the inside lining of the uterus. First the cervix is opened (or dilated) so that a small spoon-shaped instrument (called a curette) can be put into the uterus. Then the curette is used to take out the uterine lining.
DCIS [also called ductal carcinoma in situ or intraductal carcinoma]-Abnormal breast cells that involve only the lining of a milk duct. These cells have not spread outside the duct into the normal surrounding breast tissue.
diagnostic procedure -A method used to see if a disease is present or not. It is also used to figure out what kind of disease is present.
Denial -Denial is a psychological term that describes an unconscious defense mechanism characterized by the refusal to acknowledge painful realities, thoughts or feelings.
Deoxyribonucleic Acid (DNA) -The material that spells out the code for each gene on a chromosome.
Diagnosis -The identification of a disease or health condition, or the name of the disease or condition.
Dialysis -A way to clean the blood when the kidneys are not working properly. (Cleaning the blood is usually the kidneys' job.) The blood passes through a special machine that removes chemicals, waste products, and toxins.

differentiation -This term describes how mature the breast cancer cells are compared to normal breast cells. Well-differentiated tumor cells that are mature look a lot like normal breast cells and tend to grow slowly. Undifferentiated, or poorly differentiated, tumor cells do not look or work like normal cells. They grow quickly and have a tendency to spread.
disease-specific survival-The percentage of people in a study who have survived a particular disease since diagnosis or treatment. Only deaths from the disease are counted. Subjects who died from some other cause are not counted.
DNA (deoxyribonucleic acid) -The biochemical carrier of genetic information; the constituent material of all genes.
Duct -A tiny part of the body shaped like a tube or pipe. Body fluids pass through it—for example, tear ducts, bile ducts, and milk ducts.
Ductal carcinoma in situ [also called DCIS or intraductal carcinoma] -Abnormal breast cells that involve only the lining of a milk duct. These cells have not spread outside the duct into the normal surrounding breast tissue.
Durable power of attorney -This document is also called a health care proxy. A durable power of attorney is a form of advance notice that allows an individual to give another individual legal authority to make decisions on his or her behalf. This document is used in situations where a person is not capable of making his or her own decisions.
Dysplasia -Cells that do not look normal under a microscope but are not cancer.
Early detection -The detection of cancer prior to the development of symptoms, or as soon as practicable after the development of symptoms.
Effectiveness -The extent to which a specific intervention, procedure, regimen or service, when implemented, does what it is intended to do for a defined population.
Emotional numbness -Emotional numbness is a symptom of emotional trauma, where an individual becomes detached from others, is unable to react appropriately emotionally or suppresses emotions.
Encapsulated -Contained in a specific, localized area and surrounded by a thin layer of tissue.
Endocrinologist -A doctor who specializes in treating problems involving the body's hormone system.
Endometrial -Having to do with the endometrium -- the layer of tissue that lines the inside of the uterus.
Endometrial biopsy-A test that takes a sample of tissue from the lining of the uterus. Then the tissue is looked at under a microscope to see if it is normal or abnormal.
endometrial cancer -Cancer of the inner lining of the uterus.
endometriosis -A condition in which tissue that is like the lining of the uterus grows in abnormal places outside the uterus. This can happen in the pelvis or in the abdomen. This is not a cancer. But it can result in cysts, pain, infertility problems, and other symptoms.
Endoscopy -The use of a thin, lighted tube (called an endoscope) to examine the inside of the body.
Endothelial cell -The main type of cell found on the inside lining of blood vessels, lymph vessels, and the heart.
Epidemiology -The study of the distribution and determinants of health-related states or events in specific populations.
Equal Employment Opportunity Commission -The EEOC is the federal agency that enforces laws to protect employees from employment discrimination. It also oversees Alternative Dispute Resolution.
Equity (in health) -Fairness.
Estrogen -Estrogen is a hormone made by the ovaries in women. This hormone helps control a woman's menstrual cycles (periods).
Estrogen receptor [also called ER] -This is a special type of protein found on some cancer cells. Estrogen attaches to it, and this can cause the cancer cells to grow.
Etiology -The cause or origin of disease.
Excisional biopsy -Surgery that takes out an entire lump or suspicious area to be checked under a microscope.
Fallopian tube -The Fallopian tube is the tube that connects each ovary to the uterus. This tube is the path that an egg must travel to get from the ovary to the uterus.
Evaluation -Assessment of a service or program against a standard. Evaluations can be: (1) formative (informs the development and improvement of a programme); (2) an assessment of the process (describes the program and helps to explain why it produces the results it does); (3) an outcome evaluation (an assessment of the ultimate effects of a program).
Evidence-based medicine -Clinical decision-making based on a systematic review of the scientific

evidence of the risks, benefits and costs of alternative forms of diagnosis or treatment.
Evidence-based practice -Practice that is based on scientific evidence that demonstrates effectiveness.
Familial cancer risk assessment -The investigation of (1) a reported family history of cancer; (2) an individual who develops cancer at a young age (usually under 50 years) with no family history to assess cancer risk for individuals and/or members of their family.
Family and Medical Leave Act -A federal law that provides job-protected unpaid medical leave for employees who qualify under this law.
Fecal -Wastes from the digestive tract; feces.
Fibroadenomas -Fibroadenomas are movable, solid, rounded lumps made up of normal breast cells. While not cancerous, these lumps may grow. And any solid lump that's getting bigger is usually removed to make sure that it's not a cancer. Fibroadenomas are the most common kind of breast mass, especially in young women.
Fibrocystic breast disease -Breast gland tissue build-up or cysts. They can become swollen and painful. They are not cancerous. But some types of fibrocystic changes are associated with an increased risk of breast cancer in the future.
Fibroid [also called leiomyoma] -A type of benign (non-cancerous) tumor. It is usually found in the wall of the uterus or digestive system.
Fine-needle aspiration [also called needle biopsy] -This is a test that uses a hollow needle to remove tissue or fluid. Then the material is looked at under a microscope to see if it is normal or abnormal.
Free radicals -These are the chemicals released in a process called oxidation. Oxidation is when molecules in cells split and become unstable. This unstable activity causes a chain reaction in the surrounding molecules. The resulting free radicals can harm important molecules in the cells, including genes. Free radicals can work both for us and against us: Increased free radical activity might combine with other factors to cause some cancers. On the other hand, radiation therapy works in part by creating free radicals.
Gene therapy -Treatment that tries to fix a gene that's causing a cancer or making the cancer grow. It may also help the body's ability to fight the cancer. It may help make cancer cells easier to attack with new treatments.
Genetic testing -Checking a person's genes to see if there are changes that could lead to an increased risk for getting a specific disease.
Gastrointestinal system -The gastrointestinal system is, essentially, a long tube running through the body that works to digest food and then remove it from the body. This system includes the esophagus, stomach, pancreas, small intestine and large intestine.
Genes -The functional unit of heredity, genes are composed of DNA sequences. They are located within the chromosomes, and determine particular characteristics of an individual.
Genetic mutation -An error in the gene caused by damage. This may result in a faulty or altered protein, or no protein being produced.
Genetic testing -Analyzing an individual's genetic material to diagnose a genetic disease or condition, or to determine a predisposition to a particular health condition.
Genetics -The study of heredity and the variability of inherited traits.
Genome -The genetic material of an individual.
Goal- A high-level strategic action.
Graft vs. host disease -Graft vs. host disease is a disease that may happen after you receive a bone marrow transplant. When someone going through treatment for cancer receives bone marrow from a donor, it is possible that the donor's white cells will attack parts of the receiver's body. The parts of the body commonly affected by GVHD are the skin, stomach and liver.
Gray -A gray is a unit of measure for the dose of radiation therapy given to a particular part of the body.
Guidelines -A formal statement directing a defined task or function. Examples include clinical practice guidelines and guidelines for the ethical conduct of medical research.
Gynecologic oncologist -A doctor who specializes in treating cancers of the female reproductive organs. These organs include the vulva, vagina, uterus, fallopian tubes, and ovaries.
Gynecologist -A doctor who specializes in taking care of women. This kind of doctor focuses on preventing and treating illnesses of the female reproductive organs.
Gynecologist -A doctor who specializes in treating problems in a woman's reproductive system.
Gynocologic oncologists -Physicians who treat cancers of the female reproductive organs (i.e. cervix, uterus, ovaries).
Health care proxy -Also referred to as durable power of attorney, a health care proxy is a form of

advance notice that assigns an individual to make decisions for a person who is not capable of making his or her own decisions.

Health care team -A health care team includes any doctors, nurses, social workers, psychologists, nutritionists or other health care providers you depend on for medical service, help and information.

Health inequality -Differences in health that are unnecessary, avoidable and unjust.

Health promotion -The process of enabling people to increase control over and improve their health.

Health status A description and/or measurement of the health of an individual or population.

HIPAA -The Health Insurance Portability and Accountability Act of 1996 (HIPAA) was signed into law on August 21, 1996. This law includes important new protections for millions of working Americans and their families who have preexisting medical conditions or might suffer discrimination in health coverage based on their health.

Histopathological diagnosis -The determination of the nature of a disease by the microscopic examination of cells and tissues.

Hormonal therapy [also called hormone therapy or endocrine therapy] -Cancer treatment that removes, blocks, or adds hormones.

Hormone -A hormone is a chemical substance carried throughout the body in the blood where it stimulates or suppresses cell and tissue activity.

Hormone replacement therapy [also called HRT] -Hormones (estrogen, progesterone, or both) given to women after menopause. They are used to ease symptoms of menopause.

Hormones -Chemicals made by glands in the body. They circulate in the blood and control the actions of certain cells or organs. For example, estrogen is made in the ovary, travels in the blood to the breast, and can stimulate the growth of breast cells.

Hospice -Hospice refers to programs that focus on quality of life for dying persons. Most hospice care is provided in the patient's own home. Bereavement follow-up services are offered to family members in the year after the death of their loved one.

Human genome project -An international project designed to identify the totality of the sequences of human genes.

Hyperthyroidism -Hyperthyroidism is a condition that can happen when your body produces too much thyroid hormone. Some of the symptoms are cramps, diarrhea, chest pain, weight loss and nervousness.

Hypothalamus -The hypothalamus is an area deep in the brain that is part of the limbic system. The hypothalamus controls sex hormones, sperm production, blood pressure, body temperature and more, by making and sending hormones through the bloodstream as messengers to the pituitary gland.

Hypothyroidism -Hypothyroidism is a condition that can happen when your body doesn't produce enough thyroid hormone. Some of the symptoms are weakness, hair loss, constipation and feeling tired all the time.

Hysterectomy -An operation that removes the uterus.

Ileostomy -An ileostomy is a surgical procedure that involves cutting the small intestine and connecting it to an opening on the outside of the abdomen. This procedure allows feces to leave the body through the opening instead of through the anus.

Imaging -Methods of producing pictures of areas inside the body. Examples of these are X-rays, mammogram, and ultrasound.

Immunosuppression -This is a way to make the body's immune system weak so it is less able to fight infection or disease. It also makes the body less likely to reject a transplant. Sometimes, if you've had a transplant, your doctor may use special drugs to weaken your immune system. At other times, it's harmful to have a weak immune system. This could happen as a side effect of treatment (like from chemotherapy). Or it can be a part of a disease, like AIDS.

In situ cancer -Early cancer that has not spread into nearby tissue.

In vitro -A process that takes place in the laboratory -- outside the body. (This is the opposite of "in vivo," which means in the body.)

In vitro fertilization (IVF) -A woman takes hormones to ripen multiple eggs in her ovaries, which are then taken out with a needle placed through the top of the vagina. In a laboratory, the eggs and sperm are combined to create embryos. These embryos will then be transferred back into the woman’s uterus.

In vivo -A process that takes place in the body. (This is the opposite of "in vitro," which means outside the body, or in the laboratory.)

Incidence rate -The rate at which new cases of cancer occur.

Incidence -The frequency of occurrence of any event or condition in a defined population over a defined

period of time.
Incisional biopsy -Surgery in which a part of a lump or suspicious area is taken out of the body. It is then looked at under a microscope to see if it's normal or abnormal.
Inflammatory breast cancer -A fairly rare type of breast cancer. The breast looks red and swollen and feels warm. The skin of the breast may look like the skin of an orange. Sometimes a lump is also found in the breast.
Intervention -A program or series of programs to address a need or concern.
Invasive lobular carcinoma [also called ILC] -Cancer that starts in the milk glands. It grows into the normal surrounding tissues. Between 10% and 15% of all breast cancers are of this type.
Irradiation -The use of high-energy radiation—from x-rays, neutrons, and other sources—to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy) or from materials called radioisotopes. Radioisotopes produce radiation and can be placed in or near the cancer or in the area near cancer cells. This type of radiation treatment is called internal radiation therapy, implant radiation, interstitial radiation, or brachytherapy. Systemic radiation therapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that circulates throughout the body. Irradiation is also called radiation therapy, radiotherapy, and x-ray therapy.
Irrigation -Irrigation is adding water to flush an area such as the bowel. This stimulates a bowel movement, similar to an enema.
Killer cells -White blood cells that attack cancer cells and body cells that have been invaded by foreign substances.
Laparoscope -A thin, lighted tube used to look at tissues and organs inside the abdomen. Also used to remove part or all of the colon through small incisions made in the wall of the abdomen.
Lesion -An area of abnormal tissue change. For example, a lump, wound, or area of injury.
Limbic system -The limbic system involves various structures of the brain that control emotions, hormonal secretions, mood, motivation, and pain and pleasure sensations.
Living will -This is a form of advance notice that specifies in writing what kind of medical care a person wants or does not want in the event of terminal illness or incapacity.
Lobe -A portion of an organ such as the liver, lung, breast, or brain.
Lobular carcinoma in situ [also called LCIS] -An overgrowth of cells in the lobules of the breast. These cells are not likely to turn into an invasive cancer. But having them means a higher risk of getting breast cancer in either breast.
local cancer -An invasive malignant cancer confined entirely to the organ where the cancer began.
Localized -Keeping to the site of origin, without any sign of spread to other areas.
Lumpectomy -A lumpectomy is surgery to remove a tumor and possibly some surrounding healthy tissue. The tissue is examined to determine if cancer cells have spread beyond the tumor.
Lumpectomy -Surgery to remove the cancer and a small amount of normal tissue around it.
lymphedema -A condition in which too much lymph fluid collects in tissue. This causes swelling. It can happen in the arm after lymph nodes in the underarm are removed. It can also happen if there is radiation to the lymph nodes or chemotherapy. It can get worse if the arm is hurt in any way.
Lung capacity -Lung capacity is the measure of the amount of air that the lungs may contain at various points in the respiratory cycle.
Lymph fluid -Lymph fluid is the clear fluid that travels through the lymphatic system and carries cells that help fight infections and other diseases. It can also be called lymph.
Lymph node dissection -Lymph node dissection is a surgery that removes lymph nodes so they can be examined to see whether they contain cancer. This surgery can also be called a lymphadenectomy.
Lymph node dissection [also called lymphadenectomy] -Surgery in which lymph nodes are removed and looked at to see if they have cancer in them.
Lymph node mapping -Lymph node mapping is a procedure to identify lymph nodes that contain tumor cells. Dyes and radioactive substances are usually injected into the area of the tumor to help the surgeon locate the lymph nodes. It can also be called sentinel lymph node mapping.
Lymph nodes -Lymph nodes are small, bean-shaped organs located along the vessels of the lymphatic system. Clusters of lymph nodes can be found in the neck, underarms, chest, abdomen, and groin. Lymph nodes store white blood cells that help fight infection. They also filter lymphatic fluid. Sometimes they are called lymph glands.
Lymph vessel -The lymph vessel is a thin tube that carries lymphatic fluid and white blood cells through the lymphatic system. It can also be called a lymphatic vessel.

Lymphatic system -The lymphatic system is a network of tissues, organs, vessels, and glands that produce, store, and carry cells that fight infection in the human body.
Magnetic resonance imaging [also called MRI] -This is a test that looks at areas inside your body. Detailed pictures are made by a magnet linked to a computer. These are read by a radiologist.
maintenance therapy -Treatment that is given to help a primary (original) treatment keep working. Maintenance therapy is often given to help keep cancer in remission.
Malignancy -An uncontrolled growth of cells. It can spread into nearby normal tissue. It can also travel to other parts of the body.
Malignant -Cancerous; a growth that tends to spread into nearby normal tissue and travel to other parts of the body.
Mammogram -An x-ray picture of the breast.
Mammography -The use of x-rays to create a picture of the breast (mammogram) to help diagnose and localize breast cancer.
Marker -A diagnostic indicator for where disease may develop.
Mastectomy -A mastectomy is surgery to remove a woman's breast. It is usually done to treat breast cancer. Sometimes women at high risk for breast cancer get mastectomies because they want to decrease their risk for breast cancer.
Mastectomy -Surgery that removes the whole breast.
Menopause -The time of life when a woman stops getting her period, or menstruating. This is sometimes called "change of life."
Menstrual cycle -The monthly cycle of hormonal changes in a woman's body before menopause. A cycle starts at the beginning of one menstrual period and ends at the beginning of the next.
Melanoma -Melanoma is a type of cancer that begins in the cells that are responsible for the color of your skin, hair and eyes. Melanoma usually shows up as a dark spot on your skin or begins as a mole. Melanoma can also develop in the eye. Advanced melanomas can spread to other parts of the body, like your lymph nodes, lungs or liver.
Menopause -Menopause is when menstrual periods stop because the ovaries are producing low levels of hormones or almost none at all. Menopause is sometimes called the "change of life."
Metastasis -The spread of cancer to another location in the body.
Metastatic cancer -Metastatic cancer is cancer that spreads to a different part of the body. For example, if lung cancer spreads to the bone, it is called metastatic lung cancer, not bone cancer.
Modified radical mastectomy -A modified radical mastectomy is a surgery for breast cancer in which the breast, the lining over the chest muscles, and some or all of the nearby lymph nodes are removed. Sometimes the surgeon also removes part of the chest wall muscles.
Monitoring -The performance and analysis of routine measurements aimed at detecting changes.
Morbidity -Illness.
Mortality -Death.
Mortality rate -The portion of a defined population that dies during a specific period.
Multiple myeloma -Multiple myeloma is cancer of the plasma cell. Plasma cells are found in lymphatic tissue and produce antibodies to help fight infection.
Objective -The expected results from an activity or program.
Occupational therapist -Occupational therapists will evaluate the impact of the cancer or its treatment on your activities at home or at work. They can help you learn to manage your daily activities and incorporate any physical changes caused by cancer into your home and work life.
Oncologist -A physician who treats cancer. A clinical oncologist or radiotherapist is a doctor who treats cancer with radiation. A medical oncologist treats cancer with drugs.
Oncologist -A specialist in the treatment of cancer.
Oncology -The study, diagnosis, treatment and management of cancerous tumours.
Optimal treatment -Treatment known to provide the best outcome based on current knowledge.
Organelles -Organelles are small, specialized organs inside a cell that perform specific functions such as metabolizing energy or manufacturing protein.
Osteoclasts -Cells in your body that break down bone.
Ostomy -Surgically-created opening to the outside of the body.
Outcomes -All the possible changes in health status that may result from exposure to a causal factor or from the handling of a health problem.
Outcomes -The anticipated overall effects of an Intervention or program, especially in relation to whether

the overall program goal has been achieved.
Overactive bladder -Overactive bladder is characterized by involuntary bladder contractions that occur as your bladder is filling with urine. A person will have a sudden, intense desire to urinate.
Palliative care -Palliative care refers to maintaining high quality of life for those living with a serious illness. This type of care is focused on comfort and provides relief from pain and other distressing symptoms. Palliative care also concerns end-of-life care, rather than curing a disease.
Palliative care(a) -'An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.' (WHO 2002).
Palliative care(b) -Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount, to achieve the best possible quality of life for patients and their families.
Pap smear -A screening test to help identify malignant or premalignant changes in the cervix. It is performed by obtaining cells from the exterior of the cervix uterus, staining them with a special technique derived by Papanicolau (hence the Pap test), and examining them under a microscope. (Alternative name: pap test).
Paraneoplastic syndrome -Paraneoplastic syndrome is a condition that develops as an effect of having a cancer, but is not caused directly by the tumor. It is often caused by the body's immune response against the cancer.
Parkinson's disease -Parkinson's disease is a chronic disease of the nervous system characterized by: a tremor of the hands, arms, legs, jaw, and face; stiffness of the limbs and trunk; and bladder problems. These symptoms will grow worse over time.
Partial response -Usually described as a 50% reduction in the size of a tumor after treatment.
Pathologist -A doctor who specializes in the examination of normal and diseased tissue.
Pelvic floor muscles -Pelvic floor muscles are the group of muscles surrounding the opening of the bladder and urethra that help with bladder support and closure.
Penectomy -A penectomy is a surgery that removes part or all of the penis. It is usually used to treat penile cancer.
Person-centred -Recognition of a person's total wellbeing, including their physical, emotional, spiritual, social and practical needs within the context of family and community. For SPIPA this means recognizing and responding appropriately to a culturally appropriate holistic view of health.
Phosphodiesterase-5 inhibitors (PDE-5 inhibitors) -PDE-5 inhibitors are medicines like Viagra, Levitra or Cialis that can help men get erections by increasing the levels of certain chemicals in the tissues inside the penis. They promote blood flow. In women, PDE-5 inhibitors might help with vaginal lubrication and swelling, especially for women who have low estrogen and do not want to take replacement hormones.
Physical therapist -A physical therapist can help you adjust to the physical changes in your body by teaching you exercises and physical activities that can help condition your muscles and restore strength and movement.
Pituitary gland -The pituitary gland is a small gland at the base of the brain. It is controlled by the hypothalamus, and in turn sends out messenger hormones that control sperm production in the testicles.
Population health -The health of a population, measured by health status. Populations may be defined by locality, biological criteria such as age or gender,
social criteria such as socioeconomic status, or cultural criteria. A population health approach aims to maintain and improve the overall health outcomes of entire populations and reduce inequalities in health between different groups.
Population-based -Pertaining to a defined population.
Potential years of life lost (PYLL) -PYLL is a measure of premature mortality that represents the number of years of life "lost" when a person dies prematurely from any cause. For example, if one assumes a life expectancy of 75 years, the PYLL for a person dying at age 25 would be 50.
Precursor -A condition or state preceding the overt, pathological onset of a disease. Precursor states may sometimes be detectable by screening, or may be used as a risk marker.
Predictive value -In screening and diagnostic tests, the probability that a person with a positive test is a true positive (i.e. does have the disease) is referred to as the "positive predictive value of the test." The predictive value of a negative test is the probability that a person with a negative test does not have the disease.

Premature menopause -Premature menopause is defined as menopause that happens in women before the age of 45. Some chemotherapy medicines, radiation to the ovaries, or surgery to remove both ovaries can put a young woman into sudden, early menopause. Premature menopause can be temporary or permanent. Women in premature menopause due to cancer treatment tend to have more severe hot flashes and vaginal dryness than women who experience a gradual, natural menopause.
Prevalence -The number of cases of disease in a population, at a defined point in time, irrespective of the time of diagnosis. It is usually expressed as the number of cases of disease per 100,000 individuals in the population. It is a measure of the total burden of disease in a population.
Prevention -Actions aimed at eliminating or minimizing the impact of disease and disability.
Primordial follicle -Immature follicles that make up your ovarian reserve.
Principle -A fundamental basis for action.
Prophylactic -Use of medical procedures or treatments to prevent or defend against a disease.
Proprioception -Proprioception is the ability to sense the location of one joint in relation to another, which is essential for balance and coordinated movement.
Prostate -The prostate is the gland that surrounds the neck of the bladder and urethra in men. It supplies seminal fluid, the milky liquid that contains sperm, for ejaculation.
Protocol -A defined program for treatment.
Psycho-oncology -The study, understanding and treatment of social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer as applied across the cancer control continuum.
Puberty -The stage of growth when adult sexual body parts mature and fertility becomes possible.
Public health services -Services offered on a population basis. These include all programs, interventions, policies and activities that improve and protect the health of individuals and the community. Public health services intervene at the population or group level, as distinct from individual personal health services.
Public health -The science and art of promoting health, preventing disease and prolonging life through organized efforts of society.
Qualified Individual -This is a legal term and means an individual can perform the essential functions of the job with or without a reasonable accommodation.
Quality of Life -Quality of life refers to the level of satisfaction that an individual experiences in life. Factors include: economic status, physical and mental health, relationships with others, personal development, and recreation.
Quality-of-life -A measure of the extent a patient is free from pain or disability caused by disease, and the extent he or she is able to perform the normal functions of life unaided.
Radiation Oncologist -A physician who treats cancer using radiation.
Radiation oncologist -A specialist in the treatment of cancer using X-ray techniques.
Radiation Therapy -Radiation therapy uses high-energy rays to kill or shrink cancer cells. External radiation is the use of a machine to aim high-energy rays at the cancer from outside the body. Internal radiation therapy is the placement of a radioactive substance, such as cesium, iridium, or iodine, inside the body as close as possible to the cancer.
Radical cystectomy -A radical cystectomy is a surgery to remove the bladder or nearby tissues and organs (such as the prostate gland, seminal vesicles and part or all of the urinary tube).
Radical hysterectomy -A radical hysterectomy is a surgery sometimes used to treat cervical cancer. It removes the cervix, the uterus and part of the vagina. A radical hysterectomy sometimes involves removing nearby lymph nodes, ovaries or the fallopian tubes.
Radical prostatectomy -A radical prostatectomy is a surgery to treat prostate cancer by removing the prostate gland and the two small glands behind it called the seminal vesicles. These three glands produce the liquid that makes up a man's semen.
Rate -A measure of the frequency of occurrence of a phenomenon. A rate is an expression of the frequency with which an event occurs in a defined population in a specified period of time.
Reasonable Accommodation -A reasonable accommodation is a change to allow an individual to perform the essential functions of his or her job and enjoy equal benefits and privileges that an employer provides. Changes may include modifying work schedules, installing new work equipment, and restructuring job responsibilities.
Rectal -Refers to the rectum.
Rectum -The lower part of the large intestine where feces are stored.
Relative survival -Relative survival is the ratio of the proportion of observed survivors in a cohort of cancer patients to the proportion of expected survivors in a comparable set of cancer-free individuals.

Rheumatoid arthritis -Rheumatoid arthritis is arthritis of the joints and other organs. It is usually inflammatory and causes pain, swelling, and stiffness.
Risk factor -Something that increases an individual's chance of developing a certain disease or condition.
Risk factors -An aspect of a person's condition, lifestyle or environment which increases the probability of occurrence of a disease.
Screening -Cancer screening is the early detection of cancer, or precursors of cancer, in individuals who do not have symptoms of cancer. These interventions are often directed to entire populations or to large and easily identifiable groups within the population. A screening test is not intended to be diagnostic; rather, a positive finding will have to be confirmed by special diagnostic procedures.
Screening mammogram -A screening mammogram is an x-ray of the breast used to detect breast changes in women who have no signs of breast cancer. It usually involves two x-rays of each breast.
Sequelae -A morbid condition(s) or symptom following a disease.
Sexual Dysfunction -Sexual dysfunction is the inability to react emotionally and/or physically to sexual stimulation in a way expected of the average healthy person or according to one's own standards. Sexual dysfunctions may affect various stages in the sexual response cycle - desire, excitement and orgasm. Dysfunction can be caused by a wide range of psychological, physiological, or combined reasons.
Sexual Health -The World Health Organization defines sexual health as "the integration of the physical, emotional, intellectual, and social aspects of sexual being in ways that are positively enriching, and that enhance personality, communication, and love. Every person has a right to receive sexual information and to consider sexual relationships for pleasure as well as for procreation."
Speech and language pathologist/therapist -A speech therapist can evaluate your speech, language, cognitive-communication, and swallowing skills. He or she can help survivors who have difficulty talking or swallowing after treatment for cancer.
Sperm cell -A sperm cell is a cell made in a man's testicles that contains 23 chromosomes (either an X or Y sex chromosome and 22 autosomes). The sperm cell has a tail, which helps it swim through the woman's reproductive system to meet an oocyte. The sperm has an oval head with a special "cap" that contains chemicals that can drill a hole in the oocyte, allowing the sperm to enter and fertilize the oocyte. Only one sperm can fertilize an egg.
Sperm count -Sperm count is the number of sperm present in a sample of semen. A normal sperm count is at least 20 million sperm in each milliliter of semen.
Spermatogonia -Spermatogonia are the cells in each testicle, which become active around puberty and start producing sperm cells. It takes about three months to produce a mature, human sperm.
Spiritual distress -Spiritual distress is when an individual is trying to find meaning in life or is questioning or feeling unsure about his or her spirituality. Spiritual distress can cause problems in that person's daily life.
Stage -A description of how widely a cancer has spread to adjacent lymph nodes and other parts of the body.
Staging (cancer) -Cancer staging systems describe how far cancer has spread and put patients with similar prognosis in the same group. In overall stage grouping, there are four stages. In general, stage I cancers are small localized cancers that are usually curable, while stage IV usually represents inoperable or metastatic cancer. Stage II and III cancers are usually locally advanced and/or with involvement of local lymph nodes.
Stakeholders -Organizations/groups with a direct interest and involvement in aspects of cancer control.
Statistics -The science of collecting, summarizing, and analyzing numerical data. The term is also applied to the data themselves.
Strategy -A course of action to achieve targets.
Stress incontinence -Stress incontinence is characterized by urine leaks when applying pressure to a full bladder in activities such as coughing, laughing and exercising.
Support and rehabilitation -At the broadest level, the provision of the essential services to meet the physical, emotional, nutritional, informational, psychological, spiritual and practical needs throughout a person's experience with cancer.
Surveillance -Systematic ongoing collection, collation, and analysis of data and the timely dissemination of information to those who need to know so that action can be taken.
Survivor -You are a survivor from the time you find out you have cancer, through your treatment and for the rest of your life.
Survivorship -Cancer survivorship describes the many experiences and emotions that are part of living life as a cancer survivor.

Systemic effects -Systemic effects are aftereffects of cancer and cancer treatment that can affect many body systems and organs rather than being contained in one area or organ.
Tamoxifen -Tamoxifen is a hormone medicine used to prevent or treat breast cancer. It protects breast cells from the hormone estrogen. However, tamoxifen also acts like a weak estrogen in the vagina and uterus. Tamoxifen does not interfere with women's desire for sex and may actually add some vaginal lubrication for women who are in menopause.
Taxanes -Taxanes are a group of chemotherapy drugs that includes paclitaxel (Taxol) and docetaxel (Taxotere). These drugs are used to prevent the growth of cancer cells.
Testosterone -Testosterone is a hormone made in men's testicles and in women's ovaries and adrenal glands. Testosterone is released into the bloodstream where it travels to many parts of the body. It helps men and women feel desire for sex. A woman's body naturally produces less testosterone than a man's body.
Thyroid -The thyroid is a gland located at the base of the neck. The thyroid produces hormones to regulate metabolism and calcium balance in the body.
Trend -The general direction (for example, rising falling or stable) of change over time
Tumor -A new and abnormal formation of tissue, as a lump or growth. Tumors may be benign (rarely life-threatening) or malignant.
Urethra -The tube that carries urine from the bladder to the outside of the body.
Urge incontinence -Characterized by the frequent and sudden need to urinate.
Urologist -A urologist is a physician specializing in treating problems involving male and female urinary functions or the male reproductive organs.
Urostomy -Surgically-created opening from the urinary system to the outside of the body.
Vaginectomy -A vaginectomy is a surgery to remove part or all of the vagina. Total vaginectomy is usually a treatment for vaginal cancer or advanced cancer of the cervix. Parts of the vagina may be removed as part of surgery to treat bladder or colorectal cancer. Vaginal reconstruction is often done at the same time.
Vinca alkaloids -Vinca alkaloids are anticancer drugs that slow down cancer cell growth by stopping cell division. They are made from the periwinkle plant.