Northwest Portland Area Indian Health Board
Northwest Tribal Cancer Control Project
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Working Toward Cancer-free Tribal Communities

Twenty-year Comprehensive Cancer Control Plan

Submitted to Delegates of the Northwest Portland Area Indian Health Board

June 14, 2003

Dedication

This is dedicated to all our community members who have ever been diagnosed with cancer and to their loved ones who have cared for them through the course of this disease. More and more often, people are living far beyond this diagnosis. However, far too often we have experienced the feelings of heartache and helplessness as we see cancer takes its toll in our communities. The efforts of many are helping to ease the cancer burden in our communities. This document represents the work of those who are daring to envision cancer-free tribal communities for many generations to come.

Acknowledgements

In July 1998, the delegates of the Northwest Portland Area Indian Health Board ratified the original Comprehensive Cancer Control Plan for the Northwest Tribal Cancer Control Project. At the same time, the delegates established the Northwest Tribal Cancer Coalition whose first members were named in January 1999. They expanded to become more broad-based in July 2000 and, at their next quarterly meeting, they committed to developing a twenty-year plan. In April 2001, the subsequent quarter, they gathered for a work session to envision our communities twenty years hence. They forecasted what barriers might stand in the way of fulfilling this vision and generated many solutions for surmounting these obstacles.

It is through the dedicated work of the members of the Northwest Tribal Cancer Coalition that this plan has emerged. Many dozens of people have attended approximately twenty meetings over the past four years of the Northwest Tribal Cancer Coalition.

In May 2003, the Steering Committee met for the first time. These are the individuals who faithfully attended Coalition meetings over the past four years.

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Preface

Background

Cultural Strengths as Protective Factors

A "strengths-based" approach (Nissen, 2001) focuses on building and enhancing strengths of a community, rather than focusing on reducing or mitigating problems. Culture is a resource that shapes how people see their world and structure their community and family life.

The cultural strengths of American Indians and Alaskan Natives can act as protective factors that buffer the effects of cancer and illness, as well as enrich daily life under less stressful conditions (Hungary Smith, 2001; R. Jensen, personal communication, June 14, 2000; Oxendine, 2000; Ross, 2000). "Community traditions, and spiritual or religious healing or beliefs, play a major role in maintaining health and returning people to balance" (Baseline Measures Workgroup, 1996, p. 3).

Among these cultural strengths are a strong sense of family and community. Family and extended family relationships have influence in many areas, including the support and respect for children and the elderly. Family can be especially helpful in sharing in the care of the sick and administering medicines. Family members can remind each other to get appropriate cancer screening tests, and provide encouragement to follow up on symptoms of disease by getting an appointment to see a healthcare practitioner.

Strong connections exist between tribes; some of these connections have been formalized, as with the Affiliated Tribes of Northwest Indians (ATNI). In general, tribal members are interested in sharing information, resources and knowledge about what's happening in the community. The wide dispersal of tribes outside urban areas means that some resources found at one location could be drawn in for use elsewhere.

Other values that draw together AI/AN people include a respect for tribal authority and other leaders, and a high value placed on preserving traditional ways. Ties to the land are important, as is the preservation of family and tribal histories. Traditional community events such as pow-wows, sports, and music also are cultural strengths that bring people together in community. A further sense of community can be found in the spiritual belief in a Creator or higher power that is held by many AI/AN.

Another cultural strength lies in the use of traditional foods. Many AI/AN have access to food sources, such as wild game and fowl, not available in grocery stores. The variety of foods available could help improve nutrition.

Many American Indians and Alaskan Natives take a holistic outlook on health, which may make a return to traditional ways of living, attractive and other healthy behaviors. Health may be viewed in relation to the Earth, and traditional medicines used. A preference for traditional medicines may make tribal healers a natural path for referring patients for cancer treatment. Healers can be strong advocates for their patients, explaining to other healthcare providers about cultural beliefs regarding health (for example, a focus on breast *health*, not breast *cancer*). Healers can be very helpful in advocating for improvement in health behaviors.

The existing network of health clinics, the availability of screening services and treatment for qualified AI/AN are additional protective factors available in communities. These facilities are a base to expand tribal awareness about cancer. The health education protocol of the Indian Health Service has encouraged policies regarding smoke-free tribal facilities, for example, and has supported the commitment of tribes toward cancer control in general.

Finally, a sense of humor is among the most important cultural strengths shared by American Indians and Alaskan Natives. The ability to laugh and joke when life is difficult is a rare gift.

Behavioral Change for Wellness

Although cancer cannot always be avoided, people can reduce their risk of getting cancer and other diseases by practicing healthy behaviors. If, however, a person already has cancer or some other condition that threatens her or his health, risk reduction is still a good strategy for returning to health and preventing further illness.

Primary prevention (risk reduction) includes changing behaviors, such as smoking cessation, and dietary and exercise changes.

Good behavioral targets are 1) related to health outcomes, 2) a good fit with community priorities (cultural factors), and 3) amenable to change (Bowen, 2001). You must change the context or setting in order to change behavior. In the example of tobacco use, change behaviors through changing cues (e.g. avoiding other people who smoke), changing supports (e.g., family-based and community-based interventions), offering “good” choices (e.g., public no-smoking areas), and changing awareness, knowledge, skills, and resources (e.g., through education and smoking cessation programs).

The socio-ecological approach to individual behavior change and maintenance argues that you can't separate the individual from his or her environment when contemplating and promoting individual behavior change. Healthy communities help support healthy behaviors by making it easier for people to practice them. They can set priorities that have an impact on multiple issues, rather than just one. “Data-based” activities (i.e., those backed by research) are the most reliable for changing behaviors (e.g., tobacco-use reduction).

Leading Health Indicators

Six of the Leading Health Indicators listed in *Healthy People 2010* (2000) are cancer-related. These are increasing physical activity, decreasing obesity, decreasing tobacco use, practicing responsible sexual behavior, improving environmental quality, and assuring access to health care. The bulleted guidelines suggest goals for increasing healthy behaviors (and decreasing unhealthy behaviors).

1) Physical Activity

- Increase the proportion of adolescents who engage in vigorous physical activity that promotes cardio respiratory fitness three or more days per week for twenty or more minutes per occasion.
- Increase the proportion of adults who engage regularly, preferably daily, in moderate physical activity for at least thirty minutes per day.

2) Obesity

- Reduce the proportion of children and adolescents who are obese.
- Reduce the proportion of adults who are obese.

3) Tobacco Use

- Reduce cigarette smoking by adolescents and adults.

4) Sexual Behavior

- Responsible sexual behavior
- Increase the proportion of adolescents who abstain from sexual intercourse or use condoms if currently sexually active.

5) Environmental quality

- Reduce the proportion of persons exposed to air that does not meet the U.S. Environmental Protection Agency's health-based standards for ozone.
- Reduce the proportion of nonsmokers exposed to environmental tobacco smoke.

6) Access to health care

- Increase the proportion of persons with health insurance.
- Increase the proportion of persons who have a specific source of ongoing care.

Introduction

Background

About the Northwest Portland Area Indian Health Board

About the Northwest Tribal Cancer Control Project

Northwest Tribal Cancer Coalition

About the Twenty-year Plan

Planning for the next twenty years of comprehensive cancer control is a daunting task. Many changes in science, medicine, technology, and society will occur over that period, and it is unlikely that any plan would survive without changes. The Twenty-year Plan, Working Toward Cancer-free Tribal Communities, presented here, has incorporated a number of mechanisms that will allow flexibility concerning that which the future brings. Strategies in the plan will lead to assessment and re-evaluation, and then adjustments to keep the plan on track, as needed.

The main characteristic of the Twenty-year Plan is its integrated and coordinated approach towards preventing and controlling cancer in tribal communities. A systems focus using a wider, non-linear way of dealing with data builds on, but is much different from, previous methodologies. In A Beginning Case for Comprehensive Cancer Control (no date), the Centers for Disease Control and the American Cancer Society note that the "experiences and knowledge gained from [categorical cancer programs] provide a solid basis on which cancer prevention and control can take the next quantum leap forward: the movement towards 'comprehensive' programs that link categorical efforts in such a way as to assure that the resulting impact on the cancer burden is greater than individual programs would have by themselves" (p. 1).

Reducing the cancer burden is an urgent task for American Indian and Alaskan Natives. According to *Healthy People 2010* (2000), the rate of cancer death is around 129 per 100,000 for American Indians and Alaska Natives, compared to 202 per 100,000 for all US residents. Although this rate is apparently lower than the overall mortality rate, AI/AN have the worst overall cancer survival rate in comparison with all other racial and ethnic groups (CDC, 2001). Among the reasons for this discrepancy may be the underreporting of cases, the effect of co-morbidities, or lack of access to treatment facilities.

Preventing cancer is of the utmost importance. Various cancer types can be viewed as preventable or non-preventable, depending on known risk factors, but it is vital that we not blame not victim for not preventing his or her own cancer or recognizing signs of a "preventable" cancer in others.

So this Twenty-year plan is intended as a resource as well as a guide for action to prevent and reduce cancer in tribal communities. Who will read and use the Twenty-year plan? Some potential "stakeholders" are:

- General community members
- Cancer survivors
- Family caregivers
- Policy-makers (tribal and non-tribal)
- Tribal councils
- Administrators
- Teachers, as a school curriculum teaching tool
- Researchers, AI/AN and others
- Community Health representatives
- Tribal cancer contacts
- Tribal clinics: providers/clinicians
- Clinical directors/medical directors

Overview of the Twenty-year Plan

The Twenty-year plan, Working Toward Cancer-free Tribal Communities, is based on **theoretical assumptions** that include:

- Cancer prevention and control efforts are best addressed through a comprehensive approach, rather than one that is based solely on specific cancer sites in the body
- Cancer control is a community issue
- The tribes participating in the Northwest Cancer Control Program will form coalitions between themselves and outside partners to address the issue of preventing and controlling cancer
- Tribal communities have the ability to influence public policy and effect change
- Cancer control must be addressed at multiple levels of care
- Data, research, and evaluation are essential tools for making decisions about cancer prevention and control

The **goal** of the Northwest Tribal Cancer Control Project's Comprehensive Cancer Control Twenty-year Plan is to reduce cancer incidence, mortality, and morbidity among American Indians and Alaskan Natives (AI/AN) in Northwest tribal communities.

Objectives are statements about what needs to be accomplished in order to meet the goal of the Twenty-year plan. They have a single aim or purpose, are measurable, and have a specified time for completion. In general, they express the intention to

- decrease the incidence of cancer
- decrease mortality from cancer
- increase the use of screening guidelines by healthcare practitioners
- increase patient awareness of the importance of screening
- increase the rate of age-appropriate screening
- increase the number of cancers detected at an early stage
- increase access to appropriate treatment
- increase funding to pay for screening and treatment

The objectives are listed in Tables 1 – 5.

Strategies are the interventions or actions that will be taken to reduce the cancer burden for American Indians and Alaskan Natives. A "strategy is a means to accomplish an objective, which in turn is a means of achieving a goal. A strategy may be a health intervention on an individual or population level, but can also refer to such things as a systems change initiative (e.g., education or legislation) or further data collection." (Hare et al., 1999)

Evaluation is the tactic for knowing whether change has occurred as the result of a strategy. First, baseline data will be collected to establish a starting point against which progress can be measured. Additional data collections will take place at intervals to see whether change is occurring, and whether it is in the desired direction. Some of these data will be used to measure the effectiveness of program operations (process evaluation), so that programs can be altered if they are not working as expected. For example, if data showed no change as the result of a media program to increase awareness of a tobacco cessation service, then the media program could be changed or eliminated.

Data will also inform outcome evaluation, which measures change in knowledge, attitudes, behavior, and status of program participants. An example of outcome data would be an increase in the number of tribal members who receive screening for colorectal cancer. The Twenty-year plan will use three time points at which the effects of activities to reduce the cancer burden in AI/AN will be measured: *short term* (1 to 5 years), *medium term* (5 to 15 years), and *long term* (15 to 20 years). An example of a short term evaluation would be counting the number of participants in a cancer prevention program, to see if this number increased as a result of some promotional activity. A medium term evaluation might involve surveying a group of cancer survivors about whether their risky behavior patterns had changed as a result of getting cancer. A

long-term evaluation would look at reduction in deaths as a result of a multiple-year effort to reduce cancer.

Accurately anticipating changes in comprehensive cancer control over the next 20 years is unlikely. Therefore, any workable long-term evaluation plan must use cycles of review to keep it up to date with changes that will surely occur. Problems and the solutions to them are usually not linear, and a structure will be needed to provide a means for making adjustments. The Centers for Disease Control recommend the **Framework for Comprehensive Cancer Prevention and Control** (Abed et al., 2000) to serve this purpose.

Section 1: The Plan

Introduction

Background

Cancer Burden among American Indians and Alaskan Natives in the Northwest

Cancer is the second leading cause of death among American Indians and Alaska Natives (AI/AN). Below are statistics which at least partially describe the cancer burden in Indian Country.

Cancer Incidence: During 1992-1998, the incidence rate for all cancer sites for AI/AN was 202.7 per 100,000 in comparison with 401.4 for Whites.[1] **Insert ACS footnote**. During that time, it was 227.7 for AI/AN males (vs. 470.4 for White males) and 186.3 for AI/AN females (vs. 354.4 for White females).[i] AI/AN region-specific cancer incidence rates are not available through national databases such as the National Center for Health Statistics or American Cancer Society; this is because calculations are not done with small cell sizes. The most recent (1996-1997) overall, age-adjusted cancer incidence rates in the Portland area are 269.4 for AI/AN males (vs. 475.4 for White males) and 250.2 for AI/AN females (vs. 350.1 for White females). (See Appendix XX for rates for specific cancer sites.)

Cancer Mortality: During 1994-1998, the age-adjusted, overall cancer mortality rate in the Portland Area was 106.9 for AI/AN males compared with 206 for U.S males and 91.9 for AI/AN females compared with 138.6 for U.S. females. (Footnote this citation). During 1992-1998, the mortality rate for AI/AN for all cancer sites was 105.4 (vs. 164.5 for Whites).

Estimated New Cases: The American Cancer Society estimates that in 2002 there will have been 5,200 new cancer cases in Idaho, 16,800 in Oregon, and 25,600 in Washington.[2]

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[1] American Cancer Society

[2]

Five-Year Survival: The relative five-year survival rate is worse among AI/AN when compared to all other races in the US and this disparity in survival is increasing over time. (Insert footnote: Gilliland et al, 1998) Five-year relative survival rates for AI/AN living in the northwest have never been calculated. However, they are available for Alaska Natives living in Alaska. Because of some similarities in cancer risk factors among AI/AN in the Portland Area and in Alaska, the five-year relative survival rates for AKN are presented as estimates of the Northwest survival rates. According to Lanier et al, five-year relative survival rates between 1984 and 1994 were 40.3 for AKN males vs. 54.9 for U.S. White males and 51.5 for AKN females vs. 61.5 for U.S. White females. The overall rate for AKN was 45.4 vs. 56.7 for all U.S. Whites. (See Appendix XX).

Racial Misclassification: The above rates need to be interpreted with caution. Due to racial misclassification on medical records, the American Cancer Society recommends discretion in interpreting comparisons between racial groups. (Insert ACS footnote). Racial misclassification has been well recognized as a significant problem by tumor registries. The Puget Sound SEER cancer registry in western Washington conservatively estimates a 40% misclassification of American Indians and Alaska Natives in their registry. (Footnote: Frost, F., Taylor, V, Fries, E. Racial misclassification of Native Americans in a surveillance, epidemiology, and end results cancer registry. JNCI 1992:84:12: 957).

The objectives in these five tables are measurable aims that together will lead to the accomplishment of the goal of approaching cancer-free tribal communities. To the right of each objective is a set of strategies to help reach the objective, and to the right of each set of strategies is a set of evaluations, to test whether the strategies were effective. Each objective has a percentage sub goal that is the *short term* (1 to 5 years), *medium term* (5 to 15 years), or *long term* (15 to 20 years) expectation to be reached.

Table 1. Objectives for Breast Cancer

No.	Objective	Strategy	Evaluation
1.	Increase the percentage of primary care providers (PCPs) who practice ACS screening guidelines for mammography. Goal: 80%, 90%, 100%	• Educate PCPs to counsel their patients about mammograms in an age-appropriate and culturally-sensitive manner • Mail letters to all PCPs asking them to document in patient chart • Provide a standardized form for recording on patient chart • Promote idea within professional organizations • Give feedback to PCPs	• Count number of PCPs who receive information on how to counsel Survey PCPs to obtain baseline data • Survey PCPs to obtain baseline data • Yearly chart audit to see if rate changes
2.	Increase awareness of the risk factors for breast cancer. Goal: 70%, 80%, 90%	• Implement a community education campaign (mentoring, media, tribal leaders)	• Count number of people who received information on risk factors • Measure knowledge of risk factors • Survey community for change in level of awareness of risk factors
3.	Increase the awareness of women aged 40 and older about the importance of annual mammograms. Goal: 70%, 80%, 90%	• Develop a community awareness campaign • Plan a “women’s health day” to distribute information about breast health • Plan an activity in connection with Breast Cancer Awareness Month (October)	• Record activities of awareness campaign • Record number of persons served at community health day • Measure awareness of importance of screening • Survey community for change in level of awareness of importance of screening
4.	Increase percentage of women age 40 and over that receive a yearly mammogram.	• Acquire a mammography unit for use in tribal communities • Provide transportation to clinic site	• Obtain baseline measures on percentage who receive screening • Record number who receive incentive to

No.	Objective	Strategy	Evaluation
	Goal: 60%, 70%, 80%	• Provide incentive to get exam • Provide childcare services.	get screening • Record change in the number of women who receive a mammogram
5.	Increase the number of women diagnosed with breast cancer who have access to appropriate treatment. Goal: 80%, 90%, 100%	• Educate PCPs to refer women for appropriate services (surgery, radiotherapy, chemotherapy) • Organize community members to provide transportation for women needing daily or weekly treatments	• Record number of PCPs receiving information • Count rides given to treatment facilities • Record change in number of persons receiving treatment
6.	Increase payment coverage of mammograms and treatment of breast cancer. Goal: 40%, 60%, 80%	• Educate policy-makers about the importance for government or insurance coverage of costs of mammograms and treatment of breast cancer	• Obtain baseline measure of how screening and treatment are paid • Record Educate policy-makers about the importance efforts • Survey PCPs for change in names of payers from private parties to insurance or public entities
7.	Increase available support to women being treated for and survivors of breast cancer. Goal: 50%, 70%, 90%	• Organize a breast cancer support group	• Obtain baseline measure of number of women eligible to attend support group • Survey for quality of life before support group begins • Record number of women attending the support group • Assess change in quality of life
8.	Increase available support to caregivers of women living with breast cancer. Goal: 50%, 70%, 90%	• Provide training to caregivers • Organize a caregivers' support group	• Obtain baseline measure of number of potential caregivers • Survey for knowledge of care giving and quality of life • Record the number of caregivers who receive training

No.	Objective	Strategy	Evaluation
			• Assess for change in knowledge of care giving • Record the number of caregivers who attend the support group • Assess for quality of life

Table 2. Objectives for Cervical Cancer

No.	Objective	Strategy	Evaluation
1.	Increase the percentage of primary care providers (PCPs) who practice ACS screening guidelines for PAP tests. Goal: 80%, 90%, 100%	• Educate PCPs to counsel their patients about PAP tests in an age-appropriate and culturally-sensitive manner • Mail letter to all PCPs asking them to document in patient chart • Provide a standardized form for recording on patient chart • Promote idea within professional organizations • Give feedback to PCPs	• Count number of PCPs who receive information on how to counsel • Survey PCPs to obtain baseline data • Yearly chart audit to see if rate changes
2.	Increase awareness of the risk factors for cervical cancer. Goal: 70%, 80%, 90%	• Implement a community education campaign (mentoring, media, tribal leaders)	• Count number of women who received information on risk factors • Measure knowledge of risk factors • Survey community for change in level of awareness of risk factors
3.	Increase awareness of the importance of having an annual PAP test for prevention and early detection of cervical cancer.	• Develop community awareness campaign • Plan a “women’s health day” to distribute information about cervical health	• Record activities of awareness campaign • Record number of persons served at community health day • Measure awareness of importance of

No.	Objective	Strategy	Evaluation
	Goal: 70%, 80%, 90%		screening • Survey community for change in level of awareness of importance of screening
4.	Increase the percentage of sexually active women (aged 18-70) who receive annual PAP tests. Goal: 85%, 95%, 100%	• Provide transportation to clinic site • Provide incentive to get exam • Provide child care services	• Obtain baseline measures on percentage who receive screening • Record number who receive incentive to get screening • Record change in the number of women who receive a PAP test
5.	Increase access to appropriate treatment for cervical cancer. Goal: 80%, 90%, 100%	• Educate PCPs to refer women for appropriate services (surgery, radiotherapy, chemotherapy) • Organize community members to provide transportation for women needing daily or weekly treatments	• Record number of PCPs receiving information • Count rides given to treatment facilities • Record change in number of persons receiving treatment
6.	Increase payment coverage of screening and treatment of cervical cancer. Goal: 40%, 60%, 80%	• Educate policy-makers about the importance for government or insurance coverage of costs of PAP tests and treatment of cervical cancer	• Obtain baseline measure of how screening and treatment are paid • Record Educate policy-makers about the importance efforts • Survey PCPs for change in names of payers from private parties to insurance or public entities
7.	Increase available support to women being treated for and survivors of cervical cancer. Goal: 50%, 70%, 90%	• Organize a women's cancer support group	• Obtain baseline measure of number of women eligible to attend support group • Survey for quality of life before support group begins • Record number of women attending the support group • Assess change in quality of life

No.	Objective	Strategy	Evaluation
8.	Increase available support to caregivers of women living with cervical cancer. Goal: 50%, 70%, 90%	• Provide training to caregivers • Organize a caregivers' support group	• Obtain baseline measure of number of potential caregivers • Survey for knowledge of care giving and quality of life • Record the number of caregivers who receive training • Assess for change in knowledge of care giving • Record the number of caregivers who attend the support group • Assess for quality of life

Table 3. Objectives for Colorectal Cancer

No.	Objective	Strategy	Evaluation
1.	Increase the percentage of primary care providers (PCPs) who practice ACS screening guidelines for colorectal cancer. Goal: 80%, 90%, 100%	• Educate PCPs to counsel their patients about testing for colorectal cancer in an age-appropriate and culturally-sensitive manner • Mail letters to all PCPs asking them to document in patient chart • Provide a standardized form for recording on patient chart • Promote idea within professional organizations • Give feedback to PCPs	• Survey PCPs to obtain baseline data • Count number of PCPs who receive information on how to counsel • Yearly chart audit to see if rate changes
2.	Increase the capacity for providing colorectal screening exams in tribal	• Provide support for training in performing colonoscopy to PCPs practicing in tribal clinics	• Survey PCPs to obtain baseline data • Count number of PCPs who receive

No.	Objective	Strategy	Evaluation
	clinics. Goal: 50%, 70%, 90%		training in performing colonoscopy
3.	Increase awareness of the risk factors for colorectal cancer. Goal: 70%, 80%, 90%	• Implement a community education campaign (mentoring, media, tribal leaders)	• Count number of people who received information on risk factors • Measure knowledge of risk factors • Survey community for change in level of awareness of risk factors
4.	Increase awareness of the importance of receiving screening for colorectal cancer after age 50. Goal: 70%, 80%, 90%	• Develop community awareness campaign • Plan a "community health day" to distribute information about colorectal cancer • Plan an activity in connection with Colorectal Cancer Awareness Month (March)	• Record activities of awareness campaign • Record number of persons served at community health day • Measure awareness of importance of screening • Survey community for change in level of awareness of importance of screening
5.	Increase the percentage of persons over age 50 who receive screening for colorectal cancer (FOBT, colonoscopy). Goal: 70%, 80%, 90%	• Provide incentive to get exam • Provide transportation to clinic site	• Obtain baseline measures on percentage who receive screening • Record number who receive incentive to get screening • Count rides given to screening facilities • Record change in the number of persons who receive diagnostic tests for colorectal cancer
6.	Increase access to appropriate treatment for colorectal cancer. Goal: 80%, 90%, 100%	• Educate PCPs to refer persons for appropriate services (surgery, radiotherapy, chemotherapy) • Provide transportation to treatment site	• Record number of PCPs receiving information • Count rides given to treatment facilities • Record change in number of persons receiving treatment
7.	Increase payment coverage of screening and treatment	• Educate policy-makers about the importance for government or insurance	• Obtain baseline measure of how screening and treatment are paid

No.	Objective	Strategy	Evaluation
	of colorectal cancer. Goal: 40%, 60%, 80%	coverage of costs of screening and treatment of colorectal cancer	• Record Educate policy-makers about the importance efforts • Survey PCPs for change in names of payers from private parties to insurance or public entities
8.	Increase available support to persons being treated for and survivors of colorectal cancer. Goal: 50%, 70%, 90%	• Organize a cancer support group	• Obtain baseline measure of number of persons eligible to attend support group • Survey for quality of life before support group begins • Record number of persons attending the support group • Assess change in quality of life
9.	Increase available support to caregivers of persons living with colorectal cancer. Goal: 50%, 70%, 90%	• Provide training to caregivers • Organize a caregivers' support group	• Obtain baseline measure of number of potential caregivers • Survey for knowledge of care giving and quality of life • Record the number of caregivers who receive training • Assess for change in knowledge of care giving • Record the number of caregivers who attend the support group • Assess for quality of life

Table 4. Objectives for Lung Cancer

No.	Objective	Strategy	Evaluation
1.	Increase percentage of	• Educate PCPs to counsel their patients	• Survey PCPs to obtain baseline data

No.	Objective	Strategy	Evaluation
	primary care providers (PCP) (including dentists) who ask patients 6 years and older about tobacco use at every visit (or at least once every 2 years). Goal: 80%, 90%, 100%	about lung cancer in a culturally-sensitive manner • Mail letters to all PCPs asking them to document in patient chart • Provide a standardized form for recording on patient chart • Promote idea within professional organizations • Give feedback to PCPs	• Count number of PCPs who receive information on how to counsel • Yearly chart audit to see if rate changes
2.	Increase awareness of the risk factors for lung cancer. Goal: 70%, 80%, 90%	• Implement a community education campaign (mentoring, media, tribal leaders)	• Count number of people who received information on risk factors • Measure knowledge of risk factors • Survey community for change in level of awareness of risk factors
3.	Reduce the percentage of adult current tobacco users. Goal: 20%, 15%, 10%	• Promote a ban on advertising of tobacco products • Implement a community education campaign (mentoring, media, tribal leaders) • Establish tribal anti-tobacco councils • Increase price/tax on tobacco products • Promote smoke-free environments in tribal communities	• Obtain baseline data on use from BRFSS/YTS • Obtain baseline data on media advertising efforts • Count number of people contacted in education campaign • Report of activities of tribal anti-tobacco councils • Report on price/tax on tobacco products • Survey media for changes in frequency of advertising • Survey users for change in percentage of adult current tobacco users and those who intend to quit within one year
4.	Reduce percentage of youth	• Develop addition to school curriculum	• Obtain baseline data on use from

No.	Objective	Strategy	Evaluation
	under 18 years who have ever tried tobacco products. Goal: 60%, 40%, 30%	• Train peer mentors • Form parent support group • Develop media information program • Educate youth about ritual use of tobacco	BRFSS/YTS • Record curriculum addition • Count parents who attend support group • Count media program contacts • Count number of youths educated about ritual use • Survey youth for change in percentage who have ever tried tobacco products
5.	Reduce smoking among pregnant women. Goal: 20%, 15%, 10%	• Develop community awareness campaign • Target WIC and First Steps users	• BRFSS/YTS for baseline data • Count number of pregnant women contacted about smoking • Survey pregnant women for changes in smoking patterns
6.	Increase availability of tobacco use cessation services. Goal: 50%, 90%, 100%	• Develop cessation protocol • Establish outreach program • Establish PCP referral protocol • Educate policy-makers about the importance for use of Tobacco Settlement money to fund cessation services • Obtain grant money to fund new services	• Obtain baseline data on existing cessation services • Obtain report of use and success rates • Count number of PCPs who agree to refer • Record successful attempts to obtain funding • Survey for changes in number of existing cessation services
7.	Increase awareness of tobacco use cessation services. Goal: 80%, 90%, 100%	• Develop media campaign to increase awareness • Develop and distribute a listing of tobacco cessation services	• Obtain baseline data from BRFSS/YTS • Count media campaign contacts • Survey for changes in awareness of cessation services
8.	Increase access to appropriate diagnosis and treatment of lung cancer.	• Educate PCPs to refer persons for appropriate services (diagnostic, surgery, radiotherapy, chemotherapy)	• Survey PCPs to obtain baseline data on referrals

No.	Objective	Strategy	Evaluation
	Goal: 80%, 90%, 100%	• Provide transportation to clinic or treatment site • Provide incentive to get diagnosis/treatment	• Count number of PCPs who receive information on how to refer • Count rides given to treatment facilities • Count number of persons receiving incentive • Yearly chart audit for change in number of persons receiving treatment
9.	Increase payment coverage of diagnosis and treatment of lung cancer. Goal: 80%, 90%, 100%	• Educate policy-makers about the importance for use of Tobacco Settlement money to fund diagnosis and treatment of lung cancer	• Obtain baseline data on who pays for diagnosis and treatment • Record successful attempts to obtain funding • Survey PCPs for change in names of payers from private parties to insurance or public entities
10.	Increase environmental tobacco smoke (ETS) free homes and daycare sites. Goal: 70%, 80%, 100%	• Implement a community education campaign (mentoring, media, tribal leaders)	• Obtain baseline data from BRFSS/YTS • Count number of persons receiving education on ETS • Count number of community areas with anti-ETS policies • Yearly site visits by CHRs to obtain data on change in rates of ETS in homes and daycare sites
11.	Increase environmental tobacco smoke (ETS) free tribal and private institutions. Goal: 70%, 80%, 100%	• Institute a weekly smoke-free day at casinos • Implement locally developed policies on clean indoor air in community areas • Showcase efforts of early adopters	• Obtain baseline data on ETS in community areas • Random visits by tribal leaders to ascertain compliance with request at casinos and community areas
12.	Increase enforcement of laws regulating sales of	• Inform all local sellers of tobacco products about increased enforcement effort	• Obtain baseline of state records of past violations

No.	Objective	Strategy	Evaluation
	tobacco products to minors. Goal: 80%, 90%, 100%	• Develop protocol for reporting illegal sales without revealing identify of informant	• Obtain community reports of violations • Observational survey to see change in compliance with law
13.	Increase tribal tobacco taxes to match state level. Goal: 20%, 40%, 50%	• Develop educational strategy to persuade tribal leaders to increase tobacco taxes (cost/benefit analysis, ethical considerations, etc.)	• Key informant interviews with tribal leaders to assess attitudes toward taxes/tax increase • Audit tribal records to see if taxes increased
14.	Increase available support to persons being treated for and survivors of lung cancer. Goal: 50%, 70%, 90%	• Organize a cancer support group	• Obtain baseline measure of number of persons eligible to attend support group • Survey for quality of life before support group begins • Record number of persons attending the support group • Assess change in quality of life
15.	Increase available support to caregivers of persons living with lung cancer. Goal: 50%, 70%, 90%	• Provide training to caregivers • Organize a caregivers' support group	• Obtain baseline measure of number of potential caregivers • Survey for knowledge of care giving and quality of life • Record the number of caregivers who receive training • Assess for change in knowledge of care giving • Record the number of caregivers who attend the support group • Assess for quality of life

Table 5. Objectives for Prostate Cancer

No.	Objective	Strategy	Evaluation
1.	Increase the percentage of primary care providers (PCPs) who practice ACS screening guidelines for prostate cancer. Goal: 80%, 90%, 100%	• Educate PCPs to counsel their patients about testing for prostate cancer in an age-appropriate and culturally-sensitive manner • Mail letter to all PCPs asking them to document in patient chart • Provide a standardized form for recording on patient chart • Promote idea within professional organizations • Give feedback to PCPs	• Count number of PCPs who receive information on how to counsel • Survey PCPs to obtain baseline data • Yearly chart audit to see if rate changes
2.	Increase awareness of risk factors for prostate cancer. Goal: 70%, 80%, 90%	• Implement a community education campaign (mentoring, media, tribal leaders)	• Count number of people who received information on risk factors • Measure knowledge of risk factors • Survey community for change in level of awareness of risk factors
3.	Increase awareness of the importance of making an informed decision about having a digital rectal exam and PSA blood test for early detection of prostate cancer. Goal: 70%, 80%, 90%	• Develop community awareness campaign • Plan a “men’s health day” to distribute information about prostate health • Plan an activity in connection with Prostate Cancer Awareness Month (September)	• Record activities of awareness campaign • Record number of persons served at men’s health day • Measure awareness of importance of screening • Survey community for change in level of awareness of importance of screening
4.	Increase percentage of men who receive age-appropriate education about screening for prostate cancer (DRE,	• Provide incentive to get exam • Provide transportation to clinic site	• Obtain baseline measures on percentage who receive screening • Record number who receive incentive to

No.	Objective	Strategy	Evaluation
	PSA tests). Goal: 60%, 70%, 80%		get screening • Count rides given to screening facilities • Record change in the number of persons who receive diagnostic tests for colorectal cancer
5.	Increase access to appropriate treatment for prostate cancer. Goal: 80%, 90%, 100%	• Educate PCPs to refer men for appropriate services (surgery, radiotherapy, chemotherapy) • Provide transportation to treatment site	• Record number of PCPs receiving information • Count rides given to treatment facilities • Record change in number of persons receiving treatment
6.	Increase payment coverage of diagnosis and treatment of prostate cancer. Goal: 40%, 60%, 80%	• Educate policy-makers about the importance for government or insurance coverage of costs of screening and treatment of prostate cancer	• Obtain baseline measure of how screening and treatment are paid • Record Educate policy-makers about the importance efforts • Survey PCPs for change in names of payers from private parties to insurance or public entities
7.	Increase available support to men being treated for and survivors of prostate cancer. Goal: 50%, 70%, 90%	• Organize a men's cancer support group	• Obtain baseline measure of number of persons eligible to attend support group • Survey for quality of life before support group begins • Record number of persons attending the support group • Assess change in quality of life
8.	Increase available support to caregivers of men living with prostate cancer. Goal: 50%, 70%, 90%	• Provide training to caregivers • Organize a caregivers' support group	• Obtain baseline measure of number of potential caregivers • Survey for knowledge of care giving and quality of life • Record the number of caregivers who

No.	Objective	Strategy	Evaluation
			receive training • Assess for change in knowledge of care giving • Record the number of caregivers who attend the support group • Assess for quality of life

Section 2: Addressing the Challenges of Comprehensive Cancer Control

Barriers to achieving comprehensive cancer control (CCC) exist at all levels of the system and must be acknowledged and addressed before work can proceed. Some potential barriers are concrete and relatively easy to address; others are more abstract, but may help to identify why the project may be proceeding slowly. Three clusters of barriers are listed below, including those on the tribal level, the state governmental level, and the theoretical level.

Tribal Level

Several groups and many individuals contributed to the effort to identify barriers to realizing cancer prevention and control, and their efforts are organized below as the first fourteen barriers. Each identified barrier is followed by observations and suggestions that may facilitate overcoming resistance.

1) Lack of information about the importance of cancer screening. Lack of education can lead to negative attitudes towards cancer screening, and to fear and denial about its value. Attitude change comes before behavioral change, so work on strategies that change attitudes. Be persistent – you may not know until later that you changed an attitude.

   Showcase screening "success stories," including survivor testimonies, and positive role modeling by survivors. Encourage community members and cancer survivors to tell their stories so others will get screened. Tribal leaders who have a positive attitude towards screening can be an asset in helping others overcome negative attitudes. Offer ongoing support groups and peer counseling.

   Provide information that is in "real life" terms (i.e., cancer strikes *x* of *y* people, instead of using less easy-to-understand statistics). Educate to dispel "fatalism" about cancer, and address specific fears. Promote prevention and early detection, and educate about the improved chance of surviving cancer if caught early. Frame the message about cancer from a wellness perspective. The approach should be positive, with no blame about preventable cancer issues. Give prevention/education priority in planning and funding at least 10% of the time. Determine protocols, and start with information regarding non-invasive methods.

   An educational effort might begin by conducting focus groups in communities to assess the appropriate starting point, or educational level, and to develop ideas for how the message about screening and risk reduction should be communicated. Be sure that appropriate translation is available for those not fluent in English.

Integrate information about cancer prevention and control into current tribal programs as appropriate – Head Start, youth programs, substance abuse programs, women's health and senior programs. Educate casino management to do preventive efforts. Begin new programs that can include cancer control information, such as wellness workshops. One acronym for teaching prevention and risk reduction is "AIMS": Awareness, Information, Motivation and Skills-building.

A media campaign, with posters, ads, and informational videos would be a good vehicle for disseminating information about risk reduction and prevention. Use visual aids and culturally relevant information for your population (e.g., youth, elders, men, women, etc.). Use youth advocates to open doors.

2) Lack of full participation from tribes. Invite new tribes to join existing coalitions; network with existing tribes. Get advocates from existing tribes to meet with new tribes and act as mentors. Determine which tribes are working toward Restoration. Incorporate prevention and early detection awareness into the new tribal self-identity (for example, use tobacco only for sacred rites).

3) Lack of outreach to urban populations. There are many possible sites for outreach to urban populations. Identify Indian organizations in the urban area. Identify community recreation centers, sports events (involve professional sports heroes), educational institutions (schools, college campuses), health fairs, and pow-wows. These sites all offer the opportunity to give out information on health promotion and disease prevention.

   Establish health advocacy groups. Identify non-traditional venues to reach urban groups about cancer control. Integrate or link with existing programs to maximize resources. It may be helpful to offer incentives for participation in order to expose people to the message about cancer control.

   Use media to get the message out to urban populations: radio, newspapers, and media commercials with Native teens. Information on the Internet is likely to be more available to Urban Indians than to Tribal people, through public access to computers at schools and libraries.

   Urban people have certain resources and tribal people have other resources; bring these assets together.

4) Economic incentives to use tobacco. Tribes get income from the sale of tobacco. Cigarettes are often sold singly, or packaged in small quantities that are affordable by youth. Tobacco may be placed in store displays so it can be easily stolen, following

the theory that losses now are more than recovered when the person becomes addicted to nicotine.

Ceremonial use and social use of tobacco may overlap, as when someone uses tobacco as an offering at a wake, then "has a last smoke" in honor of the deceased. Families may provide tobacco to youth.

5) Lack of tribal leadership support. Involve leaders in goal setting and planning from the outset. Recruit people to serve on the Council who will support health initiatives – change the culture of leadership. Make tribal support of health issues a voter issue.

Educate leadership about tribal needs around cancer, and the extent of the problem; the effort will need their ongoing support to be effective. Use the surveillance survey date to inform leadership of relevant cancer concerns. Include leaders at national conferences (such as NCAI, NIHB, NICOA, NIGA). A tribal leader may be a cancer survivor, too, and may be willing to be an advocate for cancer control.

Community leaders may face barriers that include a lack of understanding by tribal members, goals not clearly communicated, mistrust, and a lack of participation.

6) Lack of community role models (individuals and families). Identify the attributes of persons who could serve as role models. Hold focus groups in the communities to determine what represents an ideal role model. Recruit tribal leaders/elders to promote healthy choices and early screening efforts.

Identify both elders and youths in the community to serve as peer mentors and role models. Reach people at young ages through Head Start, and develop high school leadership role models for younger kids. Survivors who are willing to share their experience with cancer in a positive way (not using "scare tactics") would be good role models. Role models should be highly visible in the community, and should "walk their talk." They should not smoke or use illegal drugs.

Recognize and reward positive role models for all ages/groups; recognize individuals who are practicing healthy lifestyles, including families considered by their communities to be "healthy families." Staff and peer mentors should be trained, supported, encouraged, and possibly paid.

Begin a media campaign to attract and publicize role models. Create "role model" campaigns for families by role (fathers, mothers, elders, and older youth) that relate to positive family dynamics. Utilize Native American role models for health promotional media campaigns. Create videos that show Native leaders promoting healthy lifestyles. Community environments also should serve as examples.

7) Data issues. Collecting data (baseline and ongoing evaluation data) provides the basis for knowing what work needs to be done for cancer prevention control, and whether programs are having the desired effect of reducing cancer morbidity and mortality. Programs should be evaluated regularly, and the results used to make adjustments. Currently, there is insufficient use of cycles of planning and implementation (CQI).

   The importance of data collection should be promoted with tribal leaders. Data collection should be integrated into tribal cancer prevention protocols, and used in decision-making. Positive and/or negative incentives may be used to assure complete and accurate collection of data. In general, there is a need to increase the awareness of cancer as an issue.

   Non-scientists should also be involved in data issues. Disseminate data to the public to promote ownership. The terminology and findings should be clear and understandable to the layperson. Establish a tribal website for reporting information on the cancer control effort.

   Assess existing data sources. Perform literature reviews to see what is there already, and what is not. Existing periodic surveys (e.g., BRFSS/YRBS/YTS) should be examined with three-state cooperation to obtain a sample size adequate for drawing conclusions. Death certificates list race, so can be a source of information.

   Improve existing data collection systems. Information management will drive resources in the future. Modify data intake forms to include race and ethnicity (existing data systems do not always identify patients as AI/AN, leading to misclassification, under-reporting, and non-reporting). Improve and standardize reporting in health care facilities (clinics, hospitals). Provide training for accurate data entry.

8) Lack of AI/AN scientists and health professionals. Strengthen the skill level of current AI/AN health professionals and healthcare employees.

   There is an issue of respect for or agreement with the practice of research, and some disrespect for academics and researchers. What does this mean for the collection of data?

   Family support is essential to encourage kids to go to school. Strengthen the science curriculum in schools. Begin talking about careers in health at the Head Start level. Hold Career Days to increase awareness of opportunities to work in science and health careers.

   Give research experience early – starting in high school. Less intense exposure to research can begin as early as middle school. Coordinate outreach and recruitment

efforts with existing organizations. Establish opportunities for students to participate in internships and practical. Involve youth in existing community projects to introduce them to research activities.

Identify mentors and role models (including non-AI/AN individuals) to mentor youth/young adults into the academic and health care workforce. Develop a "Day with a (doctor, scientist...)" program to expose youth to one-on-one mentoring in a workplace situation. School counselors can identify partners to help with youth development in science.

Provide financial support for training. Scholarships = motivation. Offer financial aid and other incentives to complete training.

9) Lack of resources or poor coordination of resources. Need public information about similar comprehensive cancer control plans (State, NPAIHB, etc.) to identify gaps in resources. If indicated, create a position for a cancer-specific information specialist.

Identify existing coalitions; work together to build trust. Form coalitions and partnerships with other tribes and organizations (e.g., State Health Divisions, American Cancer Society, Cancer Information Service, cancer centers, schools). Create a lead organization to coordinate efforts. Meet regularly, and invite new members to attend. Consolidate WHPP/CCP/BCC.

Establish easy and frequent opportunities for people/organizations to share stories and experiences. Create a clearinghouse or web page to help communication between these partners. Develop a tribal website of links. Education and awareness will help in coordination of resources. Be sure that the coordination of resources benefits all stakeholders.

10) Lack of IHS money for treatment, CHS, pharmaceuticals. Increase public and government awareness about the level of funding needed; express to tribal leaders the importance of the issues. Include urban and newly federally recognized tribes in the funding stream. Tribes and health boards can act as advocates. Raise physician awareness of how to access low-cost medications (the drug assistance program on the Pharmaceutical Association website).

Change current allocations of funds. The current formulas are inequitable, especially for NW Treaty tribes. Support tribes with health centers equally. Change IHS policy regarding CHS. Identify strategies that stretch CHS dollars. Initiate one or two model projects offering comprehensive care prescription service.

Lobby Congress to make the IHS an entitlement program, and to increase funding for cancer treatment. Identify key partners who can help lobby for change (American

Cancer Society, State Health Departments). Write letters to Congressional committees.

Insurance issues: Use the insurance plan for billing; encourage IHS people to buy insurance.

11) Lack of money for the work of cancer control. Increase the cigarette tax to meet state levels. Redirect the additional money to health promotion activities (e.g., promoting smoke-free homes and cars, giving employee incentives to those who don't smoke, providing a smoking cessation program for those working with youth/health programs).

    Write grant proposals. Apply for funding from the federal government and its agencies (CDC, NIH, NCI, AHCQ, DoD). Apply for funding from private foundations and businesses, such as the Robert Wood Johnson Foundation, American Legacy Foundation, the Susan G. Komen Breast Cancer Foundation, and the American Cancer Society. Educate the community about these "hidden" funding resources (foundations).

    Raise funds through partnering with industry, approaching drug companies for support, organizing fund-raining activities (such as walks to promote cancer control activities), and casino-based fundraising or information days. Apply for grant funding specific to data collection in AI/AN communities.

    Work for legislative changes to increase funding. Educate leaders on the benefit of lobbying. Appropriate funds at the Congressional level for prevention and screening, as well as treatment.

    Reduce the need for money. Maximize existing resources by creating and maintaining linkages with related agencies. Emphasize prevention to reduce cases, and therefore, costs. Use hospital charity care policies (Hill-Burton Act).

12) Lack of age-specific educational and culturally-relevant materials on cancer control. Make use of existing materials. Check with the American Cancer Society at 1-800-227-2345 to ask what they already have. Look on the World Wide Web for resources, for example Native Circle (at Mayo Clinic).

    Advocate with agencies to produce appropriate materials. Make sure public health agencies that produce materials include Native American culturally relevant information AND that AI/AN have input into materials development. Be sure translation is available.

Develop our own materials, using native leaders and role models. Have AI/AN design, develop, illustrate, produce, and market educational materials to Native communities. Involve the community in the process, using focus groups to develop materials. Develop interactive, computerized health education materials with graphics.

Develop curricula on topics of interest in cancer control, for example, prevention and cessation for AI/AN youth and for the community.

13) Barriers encountered by patients seeking cancer screening or treatment. Health care providers may not perceive a need for all aspects of cancer control and prevention, and may neglect to tell patients about screening. A health care provider may not be willing to provide a full range of screening exams (e.g., PAP, PSA), or may not employ the appropriate screening exam for the patient's age and family history of cancer.

Poor provider communication skills (such as the ability to communicate at a level appropriate to the individual patient), a lack of time and/or resource information, and staff retention and training issues, may affect a provider's ability to give care. A provider may not be able to supply culturally appropriate care, and may lack materials and resources for use with tribal members.

The approach to cancer prevention and control is not uniform across the system; yet there is a need to allow for variation among tribal communities. A mitigating factor is the strength of the infrastructure of the IHS and tribal clinics.

Patients may face personal financial barriers related to the cost of screening and follow-up. They may lack access to transportation.

Clinics may be associated with illness; get them to also be associated with health.

14) Problems in meeting the needs of family caregivers. Establish resources for caregivers to family members with cancer. Develop ways to prevent caretaker "burn out." Provide resource books and videos for caregivers. Establish a support group. Develop a website for family caregivers, and an online information exchange, so they can share their insights and get support from others in similar situations. Provide funding for caregivers.

Offer ongoing training for all caregivers who are involved in giving supportive care to family members living with cancer. Health care professionals and staff should also receive training to raise their awareness of the issues facing family caregivers and the resources that are available.

Respite should be available for caregivers. Respite day care centers could be built on tribal lands. Other family members could be trained to provide respite for the primary caregiver. Assisted living facilities (ALF) and comprehensive care centers should be built to meet the ongoing needs of an aging population.

State Governmental Level

Abed et al. (2000) identified a further six potential barriers (numbers 15 – 20) to comprehensive cancer control at the state level.

15) Organizational upheaval. Comprehensive cancer control requires a stable communication and reporting system at the state level; even a minor reorganization in state government could cause a disruption.

16) Change in state government. Planning and implementation of comprehensive cancer control programs is hindered by potential changes that occur in state government around increased involvement by the legislature in decision-making about programs, by increasingly decentralized programming, and by a reduction in the government infrastructure.

17) Varying levels of development and resources. The changing and unequal resources available in different states makes the nationwide coordination of a comprehensive cancer control program difficult.

18) Brief funding cycles. Resources are available year to year and may only be available for a short time. This method of funding makes it difficult to do the long-range planning needed for comprehensive cancer control.

19) Hierarchical organization. Present organizational structure does not facilitate coordination of planning and programs between internal and external organizational units.

20) Categorical funding. The current program of categorical funding for cancer control may be a strong impediment to instituting comprehensive cancer control. Abed. Et al. (2000) also mention restrictions on the use of federal funding that may restrict the flexibility needed for states to institute CCC, the fear of losing categorical funding already in place, resistance to change, insularity of categorically-funded organizations that are self-sufficient, and a current focus on service delivery (of mammograms, PAP smears, etc.) that hinders the development of a comprehensive plan.

Theoretical Level

A third set of five barriers (numbers 21 – 25) were described by Rogers and Shoemaker (cited in Abed et al., 2000) as factors that influence the rate of innovation diffusion. Abed et al. suggest that the rate of adoption of comprehensive cancer control may be affected by these barriers.

21) Relative advantage of CCC over other approaches to cancer prevention and control. Comprehensive cancer control will be compared to the current "categorical" or programmatic approach that focuses on site-specific cancer programs; it may not be perceived immediately as being more advantageous.

22) Compatibility of CCC with existing values, experiences, and needs. The comprehensive cancer control approach is not necessarily compatible with the existing climate, which has supported categorical funding arrangements in the past.

23) Complexity of CCC. Comprehensive cancer control is more difficult to understand and use than its predecessor; it requires a range of stakeholders to cooperate to make fundamental and wide-ranging organizational changes.

24) "Trial ability" of CCC. Trial ability refers to the potential for doing a small-scale trial of a new idea; however, the scope and complexity of comprehensive cancer control reduce the feasibility of a limited trial.

25) Observability of CCC. Because CCC is an abstract concept, it is much more difficult than a material innovation for observers to see and understand.

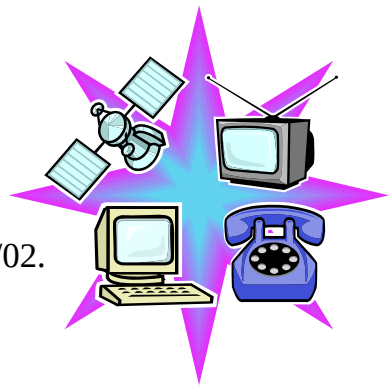
Appendix A: Highlights: Working Toward Cancer-free Tribal Communities

Great things are happening in Indian Country. Many people are working to fulfill their vision for a healthy community for themselves and their loved ones. For example, take a look below for examples of these efforts. Members of staff serving northwest tribal communities submitted highlights of their cancer control efforts, which are noted below in alphabetical order.

Highlights from Coeur d'Alene Tribe

Reported by Connie Nelson, RN

Who implemented the cancer control strategies and whom did you reach? Currently in progress…Discussing with persons as to what their needs are. Lanette and one of our patients started a cancer support group. Connie is working on a program to administer IV fluids during chemotherapy as the patients often become dehydrated. In the works is a plan to create a position for a computer specialist who would create web sites for cancer education. Connie & Lanette are to provide an in-service to seniors on the importance of screenings. Others are thinking about handouts for services in the area. Where to go for URG's scans, colostomy supplies, etc. other needs for free (hopefully).



Describe the strategy you implemented. See answer above.

Describe where the activity took place. Plummer and Worley, Coeur d'Alene Reservation

Provide dates and times. See above – support group #1 meeting on 12/11/02.

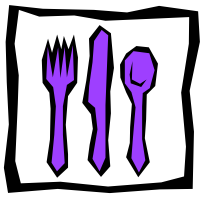
What were you aiming to accomplish? Looking at needs of community

To what extent did you achieve your goal? Our goal that was set for In-service for seniors on screening to be taken 1/1/03 – Connie still working on coverage.

Highlights from Cow Creek Band of Umpqua Indians

Reported by Noreen Thompson

Who implemented the cancer control strategies and whom did you reach? Linda Hartman and Andrea Davis (CHR)



Describe the strategy you implemented. Cancer Awareness Dinners/Displays, Cancer Tele-Health Education (Skin Cancer)

Describe where the activity took place. Medford, OR Rogue Regency Inn (Dinner), Bend, OR Travelodge (Dinner)

Provide dates and times. March 15, 2002 5-8 (Medford Dinner), April 25, 2002 7-8 (Skin Cancer), May 24, 2002 5-8 (Bend Dinner)

What were you aiming to accomplish? To educate Tribal members on Cancer and prevention of cancer by providing information through a "Health Fair" setting to educate tribal members on cancer in the comfort of their own homes and allow them to ask questions without embarrassment.

To what extent did you achieve your goal? Excellent information was provided by a Health Professional outside a clinic setting, allowing Tribal members to ask questions freely.

Highlights from Cow Creek Band of Umpqua Indians

Reported by Dr. Sharon Stanphill

Who implemented the cancer control strategies and whom did you reach? Wellness Center staff – Nurses, Doctor, CHR, DM Educator

- Reached Tribal Members from service area (Southern, Eastern, and Central Oregon)

Describe the strategy you implemented.

- Cancer Prevention Dinners and Educational displays and program speakers from various cancer centers
- Displays and programs – speakers from various cancer center projects
- TND staff – CEU
- Newsletter - educational

Provide dates and times. Fall 2001 & 2002 and Spring 2002

What were you aiming to accomplish?

1. Start Cancer center support amongst tribal members
2. Provide educational resources
3. Start cancer program with Wellness Center

To what extent did you achieve your goal? 100% all goals accomplished; we will now go to each Tribal Community annually for flu & health fairs

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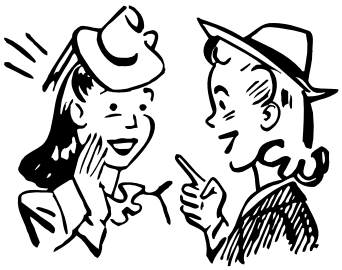
Highlights from Upper Skagit Tribe

Reported by Anne Hurd, ARNP

Who implemented the cancer control strategies and whom did you reach? Anne Hurd, Jean Wendell, April Kimman, Stella Cuthbert, U.S. Education Family staff and current team.

Describe the strategy you implemented. Smoking Cessation Program and supplies breast health. Model with lump, "Bead" to visualize lump poster and educational pamphlets.

Describe where the activity took place.
Upper Skagit Community lawn and
Community Center Clinic



Provide dates and times.
Cultural Awareness August and Highlighted
October Breast Health Month

What were you aiming to accomplish? Reduction of access to Tobacco materials and Anti-Smoking supplies to encourage quitting smoking. Breast and Health Awareness and mammogram appointments kept.

To what extent did you achieve your goal? Many more expressed without quit "for children's sake. More women willing to schedule and keep mammogram appointments to teach self breast exam. Women's Health focused exams. Review stats on lung cancer, heart disease, and smoking.

Highlights from Stillaguamish Tribe

Reported by Anne Hurd, AENP

Who implemented the cancer control strategies and whom did you reach? Anne Hurd ARNP – Clinic patients, community members, Ramon Rogers - CDC

Describe the strategy you implemented.

1. Smoking Cessation Classes

2. Tobacco focused exam
3. Postcards, fliers at fair booths
4. Free patches, pills and gum
5. October month – targeted for Breast Cancer reduction, exams and Cancer reduction beads
6. Identify smoker by questions

Describe where the activity took place.

1. Clinic – Exam room
2. Conference teaching room
3. Community gatherings
4. Festival of River - August

Provide dates and times. August 10th weekend Festival on the River and Clinic day-to-day and week-to-week

What were you aiming to accomplish?

1. Lung cancer and heart disease risk and reduction
2. Quit smoking
3. Breast exams and mammograms
4. Lump awareness

To what extent did you achieve your goal? People listened and participated. Kept mammograms appointments. Fewer complaints about being pancake flat on mammography and yes, this is data driven.

Highlights from Shoalwater Bay Tribe

Reported by Lisa Shipman

Who implemented the cancer control strategies and whom did you reach? Lisa Shipman and Charlene Nelson reached women and girls of the Shoalwater Bay Community and surrounding areas.

Describe the strategy you implemented.

1. Dinner meeting with special speaker
2. Being a speaker at different community functions
3. Fun gatherings and activities, information booths and food.

Describe where the activity took place. Most of our activities took place in our tribal center, but some were done in churches and community centers.

Provide dates and times. Year long, but the last one was December 19, 2002 4 p.m. to 7 p.m.

What were you aiming to accomplish? Get women and girls together to have a good time and learn about breast and cervical cancer.

To what extent did you achieve your goal? Activities:

1. Haircuts
2. Manicures
3. Massages
4. Drop Cloth painting
5. Clay Roses
6. Avon
7. Breast & Cervical Cancer Videos

We also spoke about cancer and had a nice catered meal. We gave out pink roses and had a raffle. We had over 40 people show up and take part.

Highlights for Nez Perce Tribe – Medical Department

Reported by Linda Busch, RN

Who implemented the cancer control strategies and whom did you reach? Nimiipuu Health medical providers have implemented the cancer control strategies as espoused by the CDC for breast, cervical, prostate and colon cancers.

Describe the strategy you implemented.

Screenings: Women-for breast cancer, mammograms every year age 40 and above. For cancers of the female tract, a pap smear starting at age 18 or when sexually active and every one to two years after that per provider's discretion, Men-for age 50 and above, routine PSA's and a rectal exam, for all people over 50-for bowel cancer, colonoscopy is ordered and quaiac cards

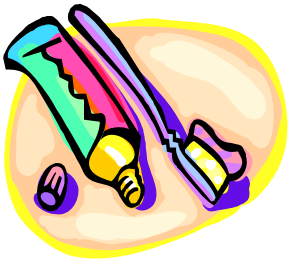
Describe where the activity took place. All these screenings were done here at our clinic except the colonoscopy, which is a contract health service.

Provide dates and times. For all people-inquiries into smoking habits and invitations to stop smoking in conjunction with pharmalogical treatments

What were you aiming to accomplish? Our case manager is currently keeping a log of the cancer patients and is working on implementing a cancer registry so that all providers will have information available for statistics as well as patient care.

To what extent did you achieve your goal? Providers go over the cancer list monthly at their peer review to update and add names as necessary.

Highlights for Nez Perce – Dental Department



Reported by Dental Department

Who implemented the cancer control strategies and whom did you reach? Head and neck examinations on all dental clinic patients. This strategy has been utilized since Nimiimpuu Health was taken over the Nez Perce Tribe.

Describe the strategy you implemented. A head and neck examination and screening for cancer through this methods is a recognized standard of practice. The clinical screening along with patient risk behaviors helps us to profile the patients for intervention on education and possible cessation programs.

Describe where the activity took place. This activity took place on a daily basis at the time of the Dental Examination.

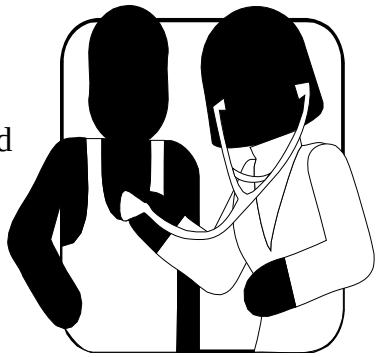
What were you aiming to accomplish? Through visual clinical assessment and palpating the tissue we can screen for oral pathology, oral cancers etc… If a suspicious area is detected, it is noted in the record, and the treatment reflects the next step in diagnosis. Many times the next step is a tissue biopsy. The dental clinic maintains its Histology log in the cases of biopsy. Secondly, taking the history on risk behaviors and discussing with the patient those behaviors may help to indicate if the patient is interested in cessation intervention programs. If the patient is not, and we are suspicious of possible tissue representation, we will monitor these patients on a frequent recall basis. Finally, in the case of the latter where the patient is not interested in cessation intervention, we may make recommendations, for example, as to placement of the smokeless tobacco in the mouth at differing sites rather than onsite all the time. Another example if the patient uses not filtered cigarettes we may suggest switching to filtered.

Highlights for Nez Perce Nation - Community Health/Wellness Department

Reported by Merrell Wilson-Simpson, RN, BSN

Who implemented the cancer control strategies and whom did you reach? As a department, we divide the responsibility of the strategies to available staff. Our Maternal Child Health Nurse with her Aide set up a booth during the month of October, which is Breast Cancer Awareness Month. Then during other activities, our PHN/CHR staff set up booths with the help of available CHWD staff. We presented our materials to the people of the Nez Perce reservation. If we could reach as many people as possible with our prevention message then we had a good day. We set our numbers to target at least 40 people at each screening.

Describe the strategy you implemented. Our usual strategy has to set up health booths with information for all types of cancer, diabetes, hypertension, exercise, etc. During October, we focused on breast cancer. Every health screening we did, we asked the client if they got yearly check ups and then encouraged them to do so with regard to cancer, diabetes, and heart health screening. We also had little gifts and handouts for our clients to remind them of the importance of staying healthy. We got a fair number of women who got their yearly PAP smears done and also had the provider do a breast exam as well. Our providers also referred each female patient 40 and over to get a mammogram done. We are also looking at establishing a cancer support group with a few very interested community members**.**



Describe where the activity took place. The community health & wellness department sets up various health screening booths at yearly community activities. Our booths this year were set up at the following activities:

1. General Council – May 2002 session
2. General council – September 2002 session
3. Women's Health expo – October 2002, Lewiston mall
4. Looking Glass Pow-wow – August 2002
5. Chief Joseph Warriors Pow-wow – June 2002
6. Matalayma Pow-wow – May 2002
7. Family Wellness Day – August 2002

These were the main activities we attended when we screened the public. Our 2003 department objectives include more of these types of activities with more public relations for the department, so that the people will contact our office first for any information regarding their health.

Provide dates and times. See Previous question.

What were you aiming to accomplish? As a health and wellness department, we try to educate the public about health promotion and disease prevention by providing related information and material to make them aware of the consequences of poor health. We provide different aspects of health, buy try to include those areas specific to the

individual patient. We deal manly with Diabetes because of the prevalence on this reservation, but also include for women materials for women's health, and also the same for the men. Our goal this year is to try to reach more men about the importance of staying healthy. In previous we found surveys that our men care about the importance of staying healthy. In previous we found surveys that our Nez Perce men do not seek medical help unless they are in very dire need of medical help. We are trying to promote health maintenance with the men at each screening booth.

To what extent did you achieve your goal? We have not yet surveyed the individuals or the population to see if the healthy population has increased its visits to the clinic for maintenance rather than illness. We are hoping to devise a short survey that will accomplish this task for us. We do notice, though, that more clients have approached the staff about certain health information, whether it is about diabetes, smoking, high blood pressure, or cancer.

Comments (Use additional paper, if needed.) Cancer is on the rise on the Nez Perce reservation. As the Community Health & Wellness Supervisor, I would like to see more of my staff increase our knowledge base for treatment, palliative care, and mostly, prevention.

Highlights for Nez Perce Tribe
Reported by Virginia Jesch, RN, BSN

Who implemented the cancer control strategies and whom did you reach? Providers Implemented – patients are reached

Describe the strategy you implemented.
Breast Cancer awareness week – breast cancer
Smoking Cessation – lung cancer
Use of Sunscreen – skin Cancer
High Fiber diet – colon cancer
Use of acid blocking – cancer of stomach & esophagus
Encourage low fat diet - breast cancer rates

Describe where the activity took place. Kamiah NiMiPuu Health Clinic and Lapwai NiMiPuu Health Clinic

Provide dates and times. Ongoing

What were you aiming to accomplish? Reduce cancer occurrence in Nez Perce Tribe and other Native Americans who use our clinics.

To what extent did you achieve your goal? Moderate success – it's tough to get people to stop smoking

Comment. Use additional paper, if needed. At present we have one person recovering from breast cancer, one recovering form thyroid cancer and one detoxing inoperable cancer of the esophagus.

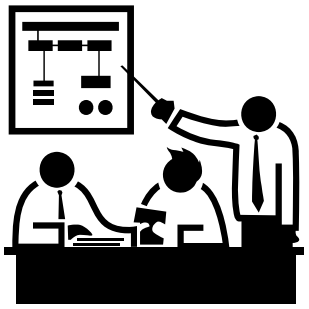
Highlights from Yakama Nation

Reported by Margaret Bolte

Who implemented the cancer control strategies and whom did you reach? Yakama Indian Health Center – Yakama Nation – Planning Committee involved several organizations in the community.

Describe the strategy you implemented. Community Outreach – Planning (Committee meetings) schedule 4-5 months before event – Involve community members in planning of event.

Describe where the activity took place.
Breast cancer awareness event – Toppenish WA
Yakama Nation Cultural Center



Provide dates and times.
October 3, 2002 – One day conference

What were you aiming to accomplish?
Promote awareness and education on breast cancer.

To what extent did you achieve your goal? Increased attendance to conference – A "Cancer Support Group" among Yakama Nation has been developed.

Highlights from Skokomish Tribe

Reported by Skokomish Health Nurse.

Who implemented the cancer control strategies and whom did you reach? Native Women's Wellness Program – SPIPA, Breast and Cervical Cancer Prevention Project, Outreach Project.

Describe the strategy you implemented. Provided Tribal Outreach workshops to reach women and inform, educate and encourage women's health screenings. Works closely with women's health provider.

Describe where the activity took place. Tribal Community, Tribal Clinic, tribal health fair, women & girls gatherings, luncheon's, etc…

Provide dates and times. Energy week – Monday, Wednesday and Thursday Women's Wellness provider – monthly mammograms.

What were you aiming to accomplish? Prevention through more screenings.

To what extent did you achieve your goal? In usual women's wellness screenings.

Highlights from Colville Tribes

Reported by Darlene Zacherle

Who implemented the cancer control strategies and whom did you reach? Darlene Zacherle/Tobacco Coordinator Colville Tribal Health Programs
The attendees to the "Baby Boomers 50,000 Mile Check-up.
Describe the strategy you implemented. Power Point presentation on "Cancer 101 Learning Module 5", along with printed materials to each member.
Describe where the activity took place. Nespelem Community Center.
Provide dates and times. November 20th, 2002 at 10 a.m. I gave the presentation. I will be giving another one December 19th, 2002 at the Inchelium "Baby Boomers 50,000 Mile Check-up."
What were you aiming to accomplish? Increase the number of Tribal Member's education on "Cancer Risk Factors and Risk Reduction."
To what extent did you achieve your goal? 17 members attended the presentation and I was asked to present again 12/19/02.
Comments Use additional paper, if needed. I really enjoy presenting the Module and will look forward to being able to present the revised one to the elders at our Senior Meal Sites.

Highlights from Colville Tribes

Reported by Darlene Zacherle

Who implemented the cancer control strategies and whom did you reach? Darlene Zacherle/Tobacco Coordinator Colville Tribal Health Programs. The classes were open to anyone who was willing to try stopping the use of commercial tobacco.
Describe the strategy you implemented. With this program, the Quit Day is not until the 3rd week of the sessions. The participants were able to learn coping strategies to help handle their stressors and withdrawal

symptoms.
Power Point presentations were given along with printed materials to each member. A cassette tape was also given with the program.
Describe where the activity took place. Freedom From Smoking Cessation Classes were offered at the four District locations on the Colville Reservation. Three from Nespelem, five from Omak, four from Keller, and three from Inchelium with a total of fifteen participants.
Provide dates and times. Nespelem, HRD Conference Room/ Monday's 12 p.m. 9/9/02, 9/16/02, 9/23/02, 9/30/02, 10/7/02, 10/14/02, 10/21/02, 10-28-02
Omak Tribal Health Office/ Monday's 6 p.m. 9/9/02, 9/16/02, 9/23/02, 9/30/02, 10/7/02, 10/14/02, 10/21/02, 10-28-02
Keller Tribal Health Office/Tuesday's 12 p.m. 9/10/02, 9/17/02, 9/24/02, 10/01/02, 10/8/02, 10/15/02, 10/22/02, 10-29-02
Inchelium Connections Office/Tuesday's 6 p.m. 9/10/02, 9/17/02, 9/24/02, 10/01/02, 10/8/02, 10/15/02, 10/22/02, 10-29-02
What were you aiming to accomplish? Decrease the number of Tribal Member who used commercial tobacco and educate those who were trying to quit.
To what extent did you achieve your goal? Six members attended every class and received an incentive. After six weeks, four participants were still successful. They will be sent an incentive.
Comments (Use additional paper, if needed.) I found this program and the participants very informing. I really wish that there were more funding sources available for Cessation Programs.

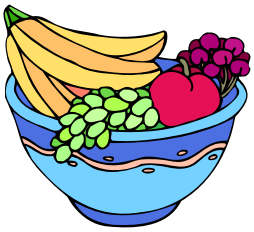
Highlights from Suquamish Tribe

Reported by Barabara Hoffman

Who implemented the cancer control strategies and whom did you reach? Barbara Hoffman, Community Health Nurse Tribal Elders, members and employees

Describe the strategy you implemented. Health Fair: Information on appropriate diet, exercise, healthy lifestyles, including: quitting smoking were provided to those who attended the health fair took which place in the tribal gym on September 28, 2002 and referrals were given to providers for individualized advice/intervention. Approximately 50 people attended the health fair.

Nutrition Bingo with the assistance of Kitsap Co. Extension office four monthly bingo games were at the Elders lunch November 14, December 12, and January and February TBA. The goal was to give information on:
Low Fat
High Fiber
Reducing sodium
Food safety to elders and tribal employees in a
Prizes are awarded such as bean soup mix (high fiber)
Walking program information



Comments use additional paper, if needed. The comments received have been very positive. The game was enjoyable and at least one concept could be recalled by participants.

Highlights from Warm Springs Tribes
Reported by Judith E. Charley

Who implemented the cancer control strategies and whom did you reach? A mini grant through Northwest Portland Area Indian Health Board and Oregon State Health Department in the amount of $4,400.00 was granted to the Community Health Education Team for six consecutive years. Responsibility for implementing this fell to Judith E. Charley, Community Health Information Specialist.

In 2000 a Women's Health Education Forum was formed and that in turn evolved into Women of Warm Springs (W.O.W.) this forum is for all community women, though our primary focus would be to women forty years of age and older.

Describe the strategy you implemented. The grant focus was primarily an education focus at increasing awareness, informing our women of the importance of regular annual personal women's health exams, screenings, and mammograms. Motivate the womenfolk to learn and offer opportunities to learn breast self examination (BSE) as a self-care skill, and skills of being an informed health consumer.

Describe where the activity took place. Our primary meeting place is in the Atrium room at the I.H.S. Health and Wellness Center.

Provide dates and times. On the first Wednesday of each month we have a planning meeting. On the second Thursday of each month we hold W.O.W. a Women's Health Education Forum.

What were you aiming to accomplish? W.O.W. was conceived to take a triple treat approach to health education. Each time we met a nutritious luncheon also served as a hands on teaching opportunity. Every month we had a new and different health education topic. We had a small craft that could be put together or made in less that a half-hour. All of this is planned to be accomplished during the noon hour for one hour every month. We wanted to avoid turning off the people we were trying to reach by the tiresome talking heads straight lecture approach.

To what extent did you achieve your goal? The fact that we have being awarded for six consecutive years by our grant agency speaks for itself. We took positive and healthy risks as a planning group, proved ourselves to be consistent and the rest speaks for itself.

Comments. Use additional paper, if needed. In closing, both Sharon John and Ruth Jensen and the respective projects they oversee have proven to be vital resources and more, I've actually had some hands-on technical training by the board on graphic design and layout.

Highlights from Northwest Band of Shoshoni Tribe

Reported by Robin Troxell

Comments: Our Cancer Projects will begins in 2003

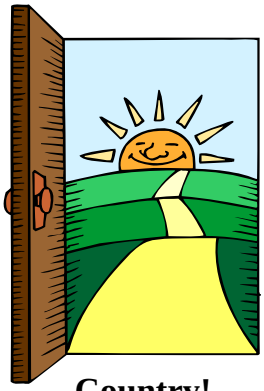
Highlights from Chemawa Indian Health Center
Reported by Dianna Goulsby RN/PHN

Who implemented the cancer control strategies and whom did you reach? Ongoing practices

Describe the strategy you implemented. Pap's – for cervical cancer, Stool – colon cancer, PSA Testing – prostrate, Mammograms – breast cancer and X-ray's as indicated, other labs as indicated.

Describe where the activity took place. Ongoing at Chemawa Clinic.

What were you aiming to accomplish? Regular routine screenings to identify problems early.



Congratulations to everyone for maker a brighter future for Indian Country!

Appendix B: Constructs for Twenty-year Comprehensive Cancer Control Plan

Framework for Comprehensive Cancer Control

In essence, the Framework presents a cyclical process with four phases. In the first phase, the question is, "what should be done?" and the answer is to set optimal objectives using data. In the second phase, the question is, "what could be done?" and the answer is based on determining what is possible to achieve. In the third phase, the question is, "what can be done?" and the answer is determined by capacity and what is feasible. In the fourth phase, the question is, "what is achieved?" (What was done?) And the answer is based on outcomes of the data collected earlier. At this point, the cycle is ready to begin again, with the question, "what should be done?" In this way, progress toward the goal of reducing cancer incidence, morbidity, and mortality among American Indians and Alaskan Natives is continually being reviewed. This review, using the Framework, assures the stakeholders in the Twenty-year plan that it will be able to adjust and remain viable over time.

Building Blocks Model

The **Building Blocks** are six objectives identified by the Centers for Disease Control in its "logic model" for comprehensive cancer prevention and control that should lead to a progressive reduction in the cancer burden. These objectives are a general guide that must be adapted to the needs of American Indians and Alaskan Natives. The Building Blocks are explained below:

A. Assessing and addressing the cancer burden involves assessing needs, available resources, and gaps that relate to cancer.

   In the planning phase, target areas for cancer prevention and control are selected and prioritized.

   In the implementation phase, the priority strategies are designed, implemented, and evaluated.

   As a result of addressing the cancer burden, morbidity and mortality rates fall, and disparities between groups are reduced.

B. Utilizing data/research/evaluation means that "evidence-based" strategies are developed to address the needs and disparities that have been identified. Strategies that have been implemented are evaluated for process and outcomes.

   In the planning phase, both planning data (for needs assessment) and research data (for strategy development) are reviewed and used as a basis for decision-making. Data and research gaps are identified.

   In the implementation phase, data that have been collected are used to support planning and setting priorities. Gaps that were identified in the planning stage begin to be addressed.

   Ultimately, a cyclical process is established to assess, strategize, prioritize, implement, and evaluate strategies.

C. Mobilizing support requires priority setting by a broad group of stakeholders. This group builds on the existing efforts and capacities of its partners to develop strategies and expand on them.

   In the planning phase, the group develops priorities for allocating existing resources, and identifies gaps in resources and level of support.

   In the implementation phase, existing resources are being well utilized, while the group develops new resources for cancer control and improves its ability to coordinate the use of these resources.

As a result of mobilizing support, ongoing support for cancer control (for example, from general revenue funds) is secured.

D. Building partnerships takes place between broad groups of stakeholders, which implements strategies jointly.

In the planning phase, the original members of the group remain committed as new members join. Coalition and subcommittee meetings are held regularly and are well attended.

In the implementation phase, members commit to being accountable for implementation. Coordination among programs and services improves, and the atmosphere grows more collaborative.

As a result of building partnerships, the partners advocate and act in a concerted manner, and adopt a comprehensive approach among them.

E. Enhancing the infrastructure includes mechanisms for coordination, communication, documentation, tracking, monitoring, problem solving, and capacity building for comprehensive cancer prevention and control.

In the planning phase, management and administrative structures and procedures are developed; planning products are produced, disseminated, and archived.

In the implementation phase, sound, yet flexible, structures are in place, including ongoing monitoring. Partnership members assume increasing responsibility.

In the final stage, the partnership becomes a new entity that is greater than the sum of its parts.

F. Institutionalizing the initiative means that there are efforts on multiple fronts to ensure that collaboration is ongoing and self-sustaining.

In the planning phase, the members represent a broad base, and all feel they are being heard and are benefiting from the association.

In the implementation phase, the partnership is a visible focal point for cancer policy and activities. Mechanisms are developed to ensure that the collaborative process is sustainable.

Finally, the comprehensive approach has become the way the business of cancer prevention and control is conducted.

Spectrum of Prevention

The **Spectrum of Prevention** (Cohen, 1993) is a tool for thinking about how individuals and groups influence each other. The Spectrum "identifies multiple levels of intervention and helps people move beyond the perception that prevention is merely education" (Prevention Institute). In the original model, the six levels are 1) strengthening individual knowledge and skills, 2) promoting community education, 3) educating providers, 4) fostering coalitions and networks, 5) changing organizational practices, and 6) influencing policy and legislation. For use in the Twenty-year plan, The Spectrum of Prevention suggests that there are **levels of influence** on which individuals and groups can affect the AI/AN cancer burden. The levels are:

Individuals

Tribal communities

Providers are teachers, health care practitioners, and parents – anyone who contributes toward cancer control.

Coalitions and networks consist of private and public groups that work together with AI/AN to reduce the cancer burden, such as the American Cancer Society (ACS), The Susan G. Komen Breast Cancer Foundation, the National Cancer Institutes (NCI), and the Cancer Information Service – Pacific Region.

Organizations are not focused on cancer reduction as their main business, but present opportunities for influencing cancer reduction; schools and workplaces are examples of such organizations.

Policy-makers and leaders represent a level of influence that can affect, for example, insurance coverage for cancer therapies, or smoke-free environments.

Levels of Care

The six **levels of care** are points on the continuum of cancer control that describe the actions that can be taken with respect to cancer. They include the following:

Risk reduction is a high priority for reducing the cancer burden for American Indians and Alaskan Natives. The Harvard Center for Cancer Prevention (1996) estimates that "Through lifestyle modification, we can decrease cancer mortality by 50 percent." Healthy behaviors to reduce the risk of cancer include maintaining a healthy weight; getting at least thirty minutes of moderate exercise daily; not smoking; eating less animal fat and more fiber, fruits, and vegetables; avoiding excess alcohol intake; avoiding sun

exposure; practicing responsible sexual behavior; and seeing your doctor regularly. While lifestyle modification can greatly reduce the risk of getting some types of cancer, other types, such as breast cancer and prostate cancer, have unmodifiable risk factors. For these types of cancer, early detection and treatment is the key. One section of the Twenty-year plan is dedicated to encouraging the practice of healthy behaviors through lifestyle modification.

Prevention is possible for cancers where there is a strong link between a precipitating factor and the occurrence of the cancer (for example, lung cancer can largely be prevented by not smoking tobacco and avoiding second-hand smoke), or where a diagnostic test exists that detects a pre-cancerous state that can be treated (for example, routine Pap tests can detect pre-cancerous changes in cervical cells which can be treated so that cancer never develops). As science uncovers additional connections between behaviors and the development of specific cancers, and more precise diagnostic tests are developed, the prospects for cancer prevention will expand.

Early detection of cancer is important, because cancer is more treatable in its earlier stages. Age-appropriate screening is an important tool in identifying breast cancer (mammograms, clinical breast exam, breast self-exam), cervical cancer (PAP test), colorectal cancer (fecal occult blood test, sigmoidoscopy, colonoscopy), and prostate cancer (PSA blood test, digital rectal exam). Lung cancer is diagnosed through x-ray and sputum testing, but these tests are not recommended as cancer screening exams for asymptomatic persons. When symptoms of possible cancer are present, diagnostic screening is done, using the same tests.

Treatments for cancer vary, but often include radiation and chemotherapy regimens, and hormonal treatments. Treatment at an early stage of the disease is more likely to lead to recovery. American Indians and Alaskan Natives may not receive prompt treatment for a cancer diagnosis for a variety of reasons. Potential barriers to receiving treatment are discussed in another section of the plan, along with suggestions for overcoming the barriers to treatment.

Rehabilitation occurs following treatment for cancer, with a focus on helping the patient and the patient’s family return to an optimal level of functioning in the community. Rehabilitation may consist of attending a support group composed of others who have undergone a similar experience with cancer, and who can offer suggestions and emotional sustenance. It may have a medical component in the case of persons who, for example, must learn to deal with an ostomy or prosthesis.

Palliative care: The World Health Organization's (2001) definition of 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. The goal of palliative care is achievement of the best quality of life for

patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment." Hospice is a good resource in the care of a late-stage cancer patient, where comfort care and control of pain are the primary issues.

Types of Cancer

The five cancer sites (**types of cancer**) that are addressed in the Twenty-year plan (breast, cervical, colorectal, lung, and prostate) are those which have high rates of incidence, morbidity, and mortality and/or those, which are highly preventable by screening (American Cancer Society, 2001). These sites were selected because reduction in these types of cancer will have the broadest impact in reducing premature death from cancer among American Indians and Alaskan Natives.

- Breast cancer
- Cervical cancer
- Colorectal cancer
- Lung cancer
- Prostate cancer

Logic Model for Comprehensive Cancer Control

The Key to the Logic Model is as follows:

BB = Building Blocks

BB1: Assess/address cancer burden
BB2: Utilize data/research/evaluation
BB3: Mobilize support
BB4: Build partnerships
BB5: Change organizational practice
BB6: Institutionalize initiatives

SP = Spectrum of Prevention

SP1: Strengthen individual knowledge and skills
SP2: Promote community education
SP3: Educate providers
SP4: Foster coalitions and networks
SP5: Change organizational practice
SP6: Influence policy and legislation

LC = Level of Care

LC1: Risk reduction
LC2: Prevention
LC3: Early detection
LC4: Treatment
LC5: Rehabilitation
LC6: Palliative care

The logic model for comprehensive cancer control (Figure 1) is intended to illustrate the "theory of change" (W. K. Kellogg Foundation, 2000) that has influenced the design and plan for the Twenty-year Plan for comprehensive cancer prevention and control in tribal communities. It gives a "big picture" view of the way the Plan is expected to work. The CCC logic model shows important connections between the Building Blocks (objectives), the Spectrum of Prevention (a model of behavioral influence), and the six Levels of Care that are addressed in the Twenty-year plan. The arrows in the logic model show movement in a generally left-to-right direction, indicating a sequence to the model.

Beginning at the left side of the model, the first steps in the Twenty-year plan are to assess and address the cancer burden (BB1) by collecting baseline data. These data, and other research and evaluation data about the cancer burden (BB2), have a reciprocal function in that information from data collected is used to determine what other data are needed. Data are also used to bring about system changes.

At the same time, support is mobilized (BB3) for the comprehensive cancer control project, and is used to build partnerships (BB4), which reciprocally mobilizes further support. This process fosters the formation of coalitions and networks (SP4), which leads to enhancing the infrastructure (BB5). An enhanced infrastructure leads to bolder system changes and individual behavioral changes.

Promoting community education about cancer control (SP2) leads to a strengthening of individual knowledge and skills (SP1) about cancer prevention and control. As individuals gain in knowledge and skills, they can effect individual behavioral changes that will help them deal with prevention and control issues. As more and more individuals change their behaviors, the system is affected; reciprocally, changes in the system feed back to help individuals change behaviors. Educating providers about cancer prevention and control (SP3) leads to changes in organizational practice (SP5), and changes in organizations lead to system changes.

The bracketed area of the logic model concerns the levels of care for cancer prevention and control as they are affected (and reciprocally affect) both individual behavioral changes and changes in the system. Risk reduction (LC1) and prevention (LC2) concern interventions that precede disease. Both involve primary prevention, which is an effort to

decrease the incidence of cancer and other disease conditions through behavioral changes such as smoking cessation and dietary and exercise changes. An additional benefit of risk reduction is to improve health, through an emphasis on wellness and healthy behaviors, and lower the risk of the onset of other diseases (e.g., diabetes, hypertension, and heart disease).

Early detection (LC3) through screening leads to an earlier stage at diagnosis, and to earlier treatment (LC4). The earlier treatment is received, the more likely a decrease in morbidity and mortality can be expected. Early detection and treatment are secondary prevention strategies, which lead to limiting the consequences of cancer. Screening includes mammography, colonoscopy, and PSA testing for prostate cancer, for example. In some cases, early detection and treatment of precancerous conditions can actually prevent cancer from occurring (e.g., PAP tests that uncover precancerous cells on the cervix).

Treatment (LC4) also leads to rehabilitation (LC5) and palliative care (LC6), depending on the stage of cancer. Both rehabilitation and palliation lead to an increased quality of life for the person who has been treated for cancer.

Finally, system and individual behavioral changes that affect the level of care (bracketed area) lead to the institutionalization of initiatives (BB6) that affect cancer prevention and control. As initiatives are institutionalized, they influence policy and legislation (SP6) about comprehensive cancer control.

Figure 1. Logic Model

Appendix C: Types of Cancer

Breast Cancer

An estimated 192,200 new invasive cases of breast cancer are expected to occur among women in the United States during 2001. Mammography is the best way to detect breast cancer in its earliest, most treatable stage-an average of 1.7 years before a woman can feel the lump. Mammography also locates cancers too small to be felt during a clinical breast examination. Source: http://www.cdc.gov/cancer/nbccedp/info-bc.htm

Cervical Cancer

Cervical cancer is nearly 100 percent preventable, yet according to the American Cancer Society, an estimated 12,900 new cases of invasive cervical cancer will be diagnosed in 2001 and about 4,400 women will die of the disease. The occurrence of deaths from cervical cancer has declined significantly. The good news is that cervical cancer is preventable and curable if it is detected early.

Cervical cancer rates are higher among older women; however, cervical intraepithelial neoplasia (or CIN), the precursor lesion to cervical cancer, most often occurs among younger women. Therefore, screening younger women is an important strategy that can actually prevent cervical cancer from developing almost 100 percent of the time. Furthermore, when cervical cancer is detected at its earliest stage, the five-year survival rate is more than 90 percent.

Studies that have identified risk factors associated with cervical cancer have shown that cervical cancer is closely linked to certain sexual behaviors:

- human papillomavirus (HPV) infection
- immunosuppressive disorders such as HIV/AIDS
- failure to receive regular Pap test screening.

Experts agree that infection with certain strains of the HPV is one of the strongest risk factors for cervical cancer. The sexual behaviors specifically associated with greater risk are intercourse at an early age, multiple male sexual partners, and sex with a male partner who has had multiple sexual partners. Experts also agree that one of the most important things women can do to reduce their risk of cervical cancer is to receive regular screening with a Pap test.

The American Cancer Society, National Cancer Institute, American College of Obstetricians and Gynecologists, American Medical Association, American Academy of

Family Physicians, and others recommend that annual Pap testing should begin at the onset of sexual activity or at age eighteen, and less frequently at the discretion of the doctor and patient after three or more annual tests have been normal.

Women who are past menopause (change of life) still need to have regular Pap tests. However, women who have undergone a hysterectomy in which the cervix was removed do not require Pap testing, unless the hysterectomy was performed because of cervical cancer or its precursors. Source: http://www.cdc.gov/cancer/nbccedp/info-cc.htm

Colorectal Cancer

Colorectal cancer, or cancer of the colon or rectum, is the second leading cause of cancer-related deaths in the United States. The American Cancer Society estimates 135,400 new cases will be diagnosed in 2001. Recent studies show that screening reduces mortality from colorectal cancer. Source: http://www.cdc.gov/cancer/colorctl/index.htm

Lung Cancer

Tobacco use remains the leading preventable cause of death in the United States, causing more than 400,000 deaths each year and resulting in an annual cost of more than $50 billion in direct medical costs. Each year, smoking kills more people than AIDS, alcohol, drug abuse, car crashes, murders, suicides, and fires — combined!

Nationally, smoking results in more than five million years of potential life lost each year.
Approximately 80% of adult smokers started smoking before the age of eighteen. Every day, nearly 3,000 young people under the age of 18 become regular smokers. More than five million children living today will die prematurely because of a decision they will make as adolescents — the decision to smoke cigarettes. Source: http://www.cdc.gov/tobacco/issue.htm

Prostate Cancer

After lung cancer, prostate cancer is the second leading cause of cancer death among men in the United States. It is also the most commonly diagnosed form of cancer, other than skin cancer in men. The American Cancer Society estimates that in 2001, nearly 198,100 men will be diagnosed with prostate cancer and an estimated 31,500 will die. Source: http://www.cdc.gov/cancer/prostate/index.htm

Appendix D: Matrices for Comprehensive Approach

Each of the five matrices is based on one of the five types or sites of cancer included in this plan: breast cancer (Table 1), cervical cancer (Table 2), colorectal cancer (Table 3), lung cancer (Table 4), and prostate cancer (Table 5). The first column of the matrix includes the numbered objectives from the corresponding Table, the level of care that that objective addresses (risk reduction, prevention, early detection, treatment, rehabilitation, and palliation), and the level - or levels - of influence in the community that the objective requires (individual, tribal community, provider, coalition or network, organization, and policymaker/advisor). Finally, the building blocks affected are indicated. These are assessing and addressing the cancer burden; utilizing data, research and evaluation; mobilizing support, building partnerships, enhancing the infrastructure, and institutionalizing initiatives.

Figure 2. Breast Cancer Matrix

Objective	Type of Cancer					Level of Care						Level of Influence						Building Blocks					
	Breast	Cervical	Colorectal	Lung	Prostate	Risk reduction	Prevention	Early detection	Treatment	Rehabilitation	Palliative care	Individual	Tribal community	Provider	Coalition/network	Organization	Policy-maker/leader	Assess/address cancer burden	Utilize data/research/eval	Mobilize support	Build partnerships	Enhance infrastructure	Institutionalize initiative
1.	X							X						X				X	X	X		X	X
2.	X					X						X	X					X	X	X	X		
3.	X							X				X	X		X			X	X	X	X		
4.	X							X				X	X		X			X	X	X	X	X	
5.	X								X			X	X	X				X	X	X	X	X	
6.	X							X	X			X		X		X	X	X	X				X
7.	X									X		X	X					X		X	X	X	X
8.	X								X	X	X	X	X	X				X		X	X	X	X

Figure 3. Cervical Cancer Matrix

Objective	Type of Cancer					Level of Care						Level of Influence							Building Blocks					
	Breast	**Cervical**	Colorectal	Lung	Prostate	Risk reduction	Prevention	Early detection	Treatment	Rehabilitation	Palliative care	Individual	Tribal community	Provider	Coalition/network	Organization	Policy-maker/leader		Assess/address cancer burden	Utilize data/research/eval	Mobilize support	Build partnerships	Enhance infrastructure	Institutionalize initiative
1.		X					X	X						X					X	X	X		X	X
2.		X				X						X	X						X	X	X	X		
3.		X					X	X				X	X		X				X	X	X	X		
4.		X					X	X				X	X						X	X	X	X	X	
5.		X							X			X	X	X					X	X	X	X	X	
6.		X					X	X	X			X		X		X	X		X	X				X
7.		X								X		X	X						X		X	X	X	X
8.		X							X	X	X	X	X	X					X		X	X	X	X

Figure 4. Colorectal Cancer Matrix

Objective	Type of Cancer					Level of Care						Level of Influence						Building Blocks					
	Breast	Cervical	**Colorectal**	Lung	Prostate	Risk reduction	Prevention	Early detection	Treatment	Rehabilitation	Palliative care	Individual	Tribal community	Provider	Coalition/network	Organization	Policy-maker/leader	Assess/address cancer	Utilize data/research/eval	Mobilize support	Build partnerships	Enhance infrastructure	Institutionalize initiative
1.			X					X						X				X	X	X		X	X
2.			X					X						X		X						X	X
3.			X			X						X	X					X	X	X	X		
4.			X					X				X	X		X			X	X	X	X		
5.			X					X				X	X	X				X	X	X	X	X	
6.			X						X			X	X	X				X	X	X	X	X	
7.			X					X	X			X		X		X	X	X	X				X
8.			X							X		X	X					X		X	X	X	X
9.			X						X	X	X	X	X	X				X		X	X	X	X

Figure 5. Lung Cancer Matrix

Objective	Type of Cancer					Level of Care						Level of Influence						Building Blocks					
	Breast	Cervical	Colorectal	**Lung**	Prostate	Risk reduction	Prevention	Early detection	Treatment	Rehabilitation	Palliative care	Individual	Tribal community	Provider	Coalition/network	Organization	Policy-maker/leader	Assess/address cancer burden	Utilize data/research/eval	Mobilize support	Build partnerships	Enhance infrastructure	Institutionalize initiative
1.				X				X						X				X	X	X		X	X
2.				X		X	X					X	X					X	X	X	X		
3.				X		X	X					X	X			X	X	X	X	X	X	X	X
4.				X		X	X					X	X	X	X	X		X	X	X	X	X	X
5.				X		X	X					X	X		X			X	X	X	X	X	X
6.				X		X	X						X	X	X	X	X		X	X	X	X	X
7.				X		X	X					X				X		X	X	X	X		
8.				X				X	X				X	X					X	X	X	X	

Figure 6. Prostate Cancer Matrix

Objective	Type of Cancer					Level of Care						Level of Influence						Building Blocks					
	Breast	Cervical	Colorectal	Lung	**Prostate**	Risk reduction	Prevention	Early detection	Treatment	Rehabilitation	Palliative care	Individual	Tribal community	Provider	Coalition/network	Organization	Policy-maker/leader	Assess/address cancer burden	Utilize data/research/eval	Mobilize support	Build partnerships	Enhance infrastructure	Institutionalize initiative
1.					X			X						X				X	X	X		X	X
2.					X	X						X	X					X	X	X	X		
3.					X			X				X	X		X			X	X	X	X		
4.					X			X				X	X		X			X	X	X	X	X	
5.					X				X			X	X	X				X	X	X	X	X	
6.					X			X	X			X		X		X	X	X	X				X
7.					X					X		X	X					X		X	X	X	X
8.					X				X	X	X	X	X	X				X		X	X	X	X

Appendix E: Glossary

Appendix F: References

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