



Northwest Tribal Colorectal Cancer Screening Toolkit

A publication of the Northwest Portland Area Indian Health Board





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a publication of the Northwest Portland Area
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Acknowledgments/Disclaimer

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The cover “*A New Day for Healing*,” and all other art in the toolkit, is by Amanda Wright, Modoc/Klamath. Maisie MacKinnon and Erik Kakuska (Zuni Pueblo), did the graphic design adaptation of the art and the layout for the publication.

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It is NPAIHB's sole intention that the Colorectal Cancer Screening Toolkit be used in whole or in part, for preparing and implementing a screening program for American Indian and Alaska Native (AI/AN) local communities. The publication is not a substitution for the medical treatment and professional advice of health care professionals.

The findings and conclusions in this toolkit are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.



Table of Contents

Part One: Introduction to Colorectal Cancer

| | |
|---|---------------|
| Chapter One: Introduction | 11 |
| Vision of the Colorectal Cancer Screening Toolkit (CRCST) | 11 |
| What is the Colorectal Cancer Screening Toolkit? | 12 |
| Toolkit Organization | 13 |
| Toolkit Components | 16 |
| Chapter Two: Background | 17 |
| What is Colorectal Cancer? | 17 |
| Risk Factors | 18 |
| Family History | 20 |
| Screening Options and Characteristics of Screening Tests | 25 |
| Screening Recommendations | 22 |
| Is CRC Screening Cost Effective? | 23 |
| Treatment for CRC | 23 |
| Treatment: Cost-Saving Due to Screening | 24 |
| CRC among Northwest AI/AN | 24 |
| Chapter Three: Risk Reduction and Prevention Information | 29 |
| Obesity and Diabetes Type II | 29 |
| Diet | 30 |
| Physical Activity | 31 |
| Habitual Tobacco Use | 33 |
| Alcohol Consumption | 34 |
| Aspirin | 34 |

Table of Contents - continued

Part Two: Community-based Programs

| | |
|--|-----------|
| Chapter Four: Community Readiness Assessment | 37 |
| Levels of Readiness..... | 37 |
| Understanding Levels of Readiness | 39 |
| Level One - Community Awareness | 39 |
| Level Two - Individual Awareness and Motivation | 40 |
| Level Three - Community and Administrative Capacity | 41 |
| Level Four - Clinic Practice and Systems | 42 |
| <hr/> | |
| Chapter Five: Planning for Community Programs | 45 |
| Engaging Stakeholders and Creating a Planning Team..... | 46 |
| Assigning Roles and Responsibilities | 46 |
| Program Planning: Defining Program Aims, Objectives, Strategies and Action Plans..... | 46 |
| Financial Considerations: Budgets and Grants | 50 |
| Evaluating your Program | 51 |
| Obtaining Tribal Council and Community Approval..... | 52 |
| <hr/> | |
| Chapter Six: Implementation for Community Programs..... | 55 |
| Level One - Community Awareness | 56 |
| Get to Know Your Clinic | 56 |
| Collaboration with Similar Programs..... | 57 |
| Media Campaigns..... | 58 |
| Community Education and Event Planning | 61 |
| Recruiting Participants | 62 |
| Level Two - Individual Awareness and Motivation | 64 |
| Individual Counseling | 64 |
| Motivational Interviewing..... | 65 |
| Examples of Existing Community Programs in Native Communities..... | 66 |

Part Three: Collaboration

| | |
|---|-----------|
| Chapter Seven: Collaboration Between Community and Clinical Programs | 73 |
|---|-----------|

Part Four: Clinic Programs

| | |
|---|-----------|
| Chapter Eight: Clinical Screening Programs | 83 |
| Northwest I/T/U Clinics..... | 0 |
| Client Reminders, Reduce Structural Barriers, Small Media | 0 |
| IPC | 0 |
| Examples of successful clinics | 0 |
| Cowlitz Tribal Clinic | 0 |
| Warm Springs Health and Wellness | 0 |
| Checklists and Flowcharts for Levels of Screening | 0 |
| *Chapter Summary | 0 |
| Tools: | |
| Patient Registration intake form with cancer screening | |
| Clinical Screening Algorithm | |
| CRC Screening Tests | |

| | |
|-------------------------|------------|
| References | 103 |
|-------------------------|------------|

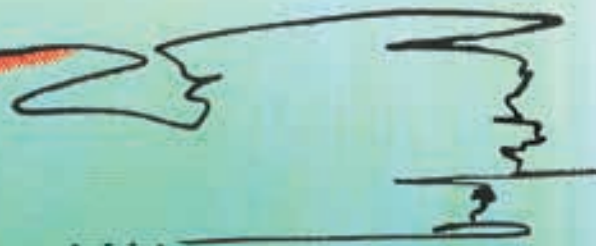
Table of Contents - continued



Northwest Portland Area Indian Health Board
Colorectal Cancer Program Toolkit

Part One:

Introduction to Colorectal Cancer





Chapter 1: Introduction

Introduction

¹Colorectal cancer, or cancer of the colon or rectum, (CRC) is the second leading cause of cancer-related deaths among both men and women in the United States. Colorectal cancer affects both men and women and is highly preventable through screening. ²Only 46.1% of American Indians and Alaska Natives (AI/AN) aged 51-80 met screening guidelines and requirements in 2012.

In Indian Country, ³CRC incidence rates are similar to non-Hispanic Whites, but AI/ANs have lower CRC screening rates and lower five-year survival rates for all cancers combined than any other ethnic group. ⁴Regional data from the Northwest also show poor cancer survival.

The Northwest Tribal Comprehensive Cancer Program, Office of Healthy Communities WA State Department of Health, Knight Cancer Center, Oregon Prevention Research Center, and community representatives from Northwest Portland Area Indian Health Board (NPAIHB) member tribes collaborated to develop the Northwest Colorectal Cancer Screening Toolkit. (CRCST) This toolkit is intended to increase screening rates and reduce incidence of CRC and CRC-related deaths among tribal communities. The CRCST reflects the most current CRC recommendations and practices. The CRCST is the first colorectal cancer prevention and screening resource guide developed specifically for northwest tribes; tools and information were gathered and/or developed for this community.

Vision

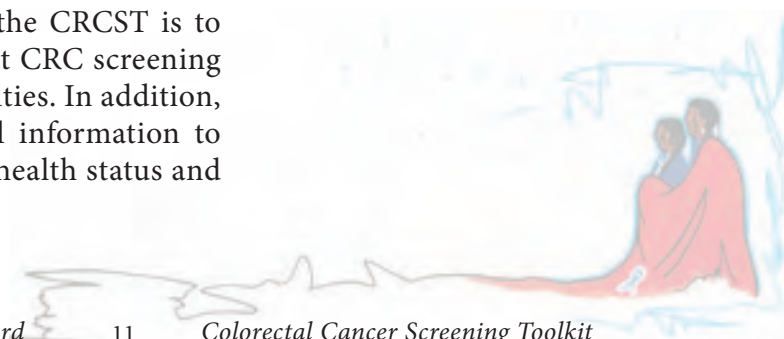
The vision of the NPAIHB in developing the CRCST is to assist the development of culturally relevant CRC screening and prevention services in AI/AN communities. In addition, the CRCST is intended to provide helpful information to tribal communities about CRC to improve health status and quality of life among AI/AN.



***“I called them out
and asked for a
show of hands for
those over 50 – and
those who have been
screened.”***

— Andy Joseph Jr.

**Confederated Tribes of the
Colville Reservation**



“⁸History illustrates that American Indians and Alaska Natives (AI/AN) were healthy and physically fit. Native men and women lived off the fruits of the land and shared physically challenging responsibilities as a part of their survival.”

Anyone can develop colorectal cancer. CRC develops from polyps- or abnormal growths on the colon or rectal wall. Screenings can detect the presence of polyps before they turn into cancer, so they can be removed. Screening is the number one way to prevent CRC. ⁵AI/ANs are diagnosed with CRC at later stages compared to non-Hispanic Whites. Low colorectal cancer screening rates help explain late-stage diagnoses and low survival rates. As with other screenable cancers, early diagnosis is critical in reducing the disparity in cancer survival.

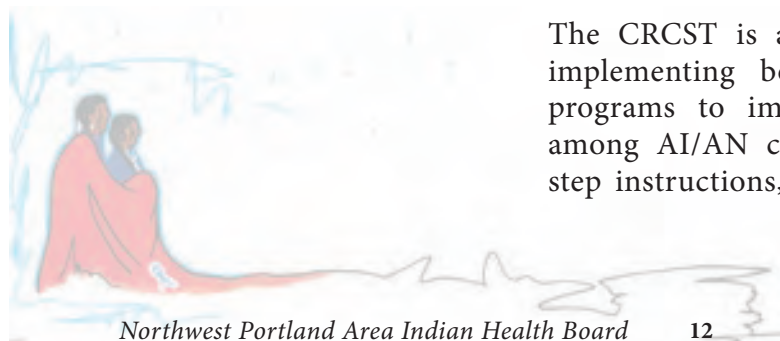
Although anyone can develop CRC, increased risk is associated with many lifestyle factors. CRC, like many chronic diseases, is associated with tobacco use, lack of physical activity and unhealthy eating habits. Sedentary lifestyles have increased through the years, but that lifestyle also increases our risk of chronic diseases. In addition to our increasingly sedentary lifestyles, unhealthy, processed foods are more accessible and often times less expensive than nutritious whole foods. ^{6,7} Lifestyle changes and low screening rates may explain why CRC has emerged as the second leading cause of cancer deaths among AI/AN populations.

Risk reduction and prevention-based initiatives have proven successful in promoting CRC screening and reducing CRC incidence and risk factors. Although promotion of overall health reduces the risk of CRC, the number one prevention method is screening. Among NPAIHB member tribes, a lack of education about the importance of CRC screening and limited access to screening services appear to be among the strongest factors that predict low screening rates. This toolkit aims to assist tribal communities in developing and implementing programs that address both screening and reducing the risk of CRC through overall health promotion.

It is our hope that tribes will use the materials presented here to support the health of their communities. Some tribes may use the whole toolkit while others may choose a few components that work well for them.

What is the Colorectal Cancer Screening Toolkit?

The CRCST is an informative manual for creating and implementing both community and clinic-based CRC programs to improve screening rates and reduce risk among AI/AN communities. Recommendations, step-by-step instructions, and tools are included to support tribal



communities in implementing their own CRC screening and prevention programs. The CRCST is based on current research, best-practices, community input, and medical standards of care.

Toolkit Organization

The CRCST has four distinct parts: (1) introduction and background information, (2) community-based screening promotion and risk reduction, (3) community-clinical collaboration, and (4) clinic-based screening promotion. Ideally, every community will have clinicians and community health promotion professionals who work collaboratively and can utilize this toolkit in its entirety. Some communities will not have an established community-clinical collaboration when they decide to implement a CRC prevention program. This toolkit was designed with this in mind; community-based programming is intended to assist community health representatives or other health promotion professionals and the clinic-based section is intended for doctors and other clinical providers. Collaboration is centered on building relationships and capacity between community and clinical screening programs.

The CRCST consists of nine chapters. Each chapter has tools that can be modified to fit your community's specific needs.

Part One: Introduction to Colorectal Cancer

Chapter One: Introduction

This chapter explains why this toolkit was created and includes explanations on toolkit organization and format.

Chapter Two: Background

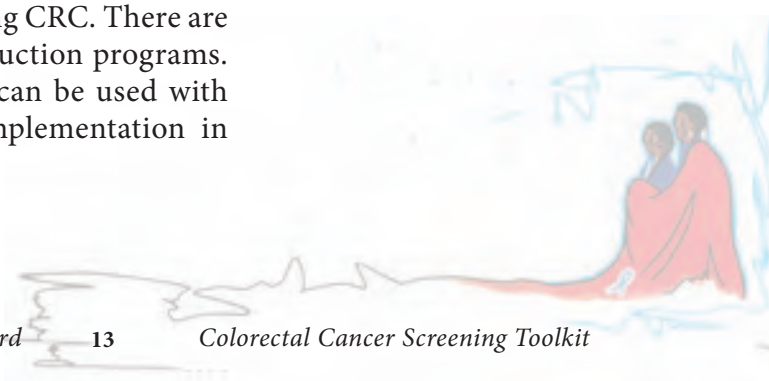
This chapter describes colorectal cancer, how it develops, and its impact on Northwest AI/AN communities. The chapter also explains different screening and treatment options for CRC.

Chapter Three: Risk Reduction and Prevention Information

This chapter describes modifiable factors that may increase an individual's risk for developing CRC. There are also community-based ideas for risk reduction programs. Topics and information in this chapter can be used with methods for program planning and implementation in chapters four through six.

Did You know?

In the Portland Area- CRC is the third leading form of cancer among AI/AN males and females living in the Northwest Portland Area (OR, ID, WA), representing 13.4% and 8.9% of all types of cancer respectively.



Part Two: Community

Chapter Four: Community Readiness Assessment

The readiness assessment provides information and resources to determine if your community is prepared for program implementation and, if so, what type of program will best meet the needs of your community. This chapter outlines different kinds of prevention programs and is the foundation for program planning and implementation.

Chapter Five: Planning for Community Programs

This chapter builds from the readiness assessment and describes a comprehensive program planning process. The step-by-step guide facilitates thorough program preparedness and evaluation methods.

Chapter Six: Implementation of Community Programs

Community program implementation provides ideas, materials, and instructions on implementing individual and group screening promotion programs. Examples of other successful CRC prevention programs in Indian Country are described in this chapter.

Part Three: Collaboration

Chapter Seven: Collaboration Between Community and Clinical Programs

This chapter provides tips to collaborate in building capacity and establish working relationships between community and clinical prevention efforts

Part Four: Clinic

Chapter Eight: Clinical Screening Program Preparation

This chapter gives a brief overview of successful strategies and resources for increasing screening rates in Northwest Tribal Clinics.

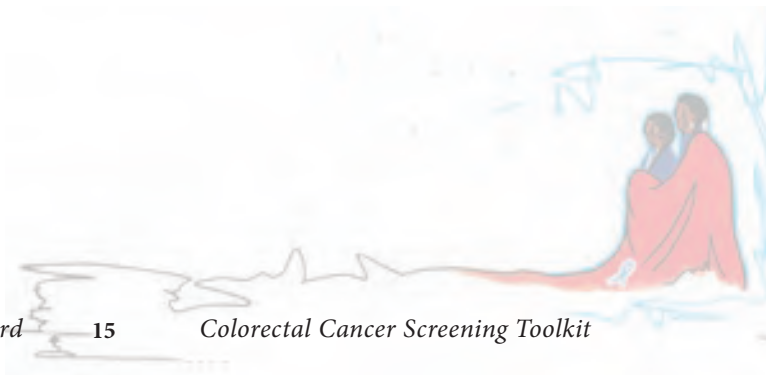


Toolkit Components

- Each chapter has an introduction and summary that briefly describe that chapter.
- Each chapter includes useful tools. Ready-made tools (e.g., flyers and templates) are found in the toolkit pocket at the end of each chapter.
- Each chapter has tool box descriptions with reference numbers that explain tools referenced in the main body of that chapter.
- Side-bar boxes throughout the DST alert you to tools, present interesting facts, and point you to additional resources.
- The Oregon Healthy Authority (in contract with Metropolitan Group) and NPAIHB's The Cancer You Can Prevent Media Guide is an example of a large-scale CRC prevention media campaign. Tribes in Oregon can work with the Oregon Health Authority to develop similar media materials. (*available upon request) Tribes outside of Oregon can use this toolkit as a reference guide for what has worked in Oregon.
- The CD located in the back pocket of the CRCST binder contains all the tools as well as other information referenced throughout the toolkit

Introduction Chapter Summary

American Indians and Alaska Natives are at increased risk for late-stage diagnosis of CRC and death due to CRC. In recent decades, there has not been significant improvement in AI/AN screening rates compared to other races or ethnicities. This toolkit addresses the need for culturally relevant CRC screening and prevention programs and will help you develop and implement a program that is right for your community. This chapter introduces the contents and organization of the CRCST.





Chapter 2: Background

Background

What is Colorectal Cancer?

Colorectal cancer (CRC) refers to any cancer that develops in any part of the large intestine (colon or bowel), or the rectum. There are several types of CRC but the majority are adenocarcinomas. CRC develops from tumors called adenomatous polyps or adenomas. A polyp is an abnormal growth and adenomas are tumors. Polyps can develop because of a variety of conditions. For example, people whose diets include large amounts of red meat or preserved or processed meats are more likely to develop polyps. People can also be born with a genetic tendency to develop polyps.

It is important to remember that polyps and adenomas are not cancer. Less than 5% of all adenomas become cancer; some polyps can become cancer if left undetected and/or untreated. It can take five years for a polyp to develop into cancer. The larger the polyp, the more likely and more quickly it will develop into cancer. If a polyp is removed and found not to have cancer, it is called benign. Once a polyp is removed it will not develop into cancer. However, those who have a history of polyps have an increased risk of developing new polyps.

Colorectal cancer, like other cancers, is diagnosed in stages. Stages are used to categorize how much a cancer has spread in the body. There are four CRC stages (I-IV). Stages I and II categorize CRC that has spread throughout different parts of the colon or rectum. Stages III and IV categorize CRC that has spread beyond the colon and rectum to lymph nodes or other organs in the body.

Without treatment, CRC can be fatal. Depending on tumor size, location and likelihood of spread, treatment may include removing the tumor by colonoscopy or removing the portion of the colon affected (by colon resection or colectomy). If the disease is known or likely to spread, additional treatment with radiation or chemotherapy may be recommended.



“Our traditional lifestyle includes healthy low-fat diets, active lifestyles, spiritual priorities, and tobacco used for sacred and not recreational purposes. This can still work for us today to prevent heart disease, diabetes, and cancer.”

— Stella Washines, 2011

Yakama Nation

Courtesy: 2002 President's Cancer

Panel

Because patients of advanced age (75 and older) may have other serious medical problems, sometimes treatment is not recommended; the aggressive treatment of cancer may be too hard on them. In these situations, patients and their families decide whether to treat the cancer.

It is important to know that polyps, adenomas, and CRC can develop without any symptoms. Screening is the number one way to prevent colorectal cancer.

Finding benign polyps and removing them is much easier than treating them after they have become cancer. This is why early testing and detection are important. Everything else about screening revolves around the best and most cost-effective way to find and remove polyps before they become cancer. The importance of starting a CRC screening and prevention program in your community is urgent when you consider that polyps and CRC can develop without symptoms and that screening is the most effective way to prevent CRC. For more information, look at tool 2.1 Colorectal Cancer Screening: Basic Fact Sheet.

Risk Factors

Although anyone can develop CRC, some people more likely to develop CRC due to a number of risk factors. There are modifiable and non-modifiable risk factors for developing CRC. Modifiable risk factors are those that have to do with lifestyle choices, including smoking, food choice, and exercise. Individuals can change modifiable risk factors by changing their everyday behaviors. Non-modifiable risk factors cannot be changed by an individual and include age, sex (biologically determined male or female), and genetics. Genetics are often assessed by reviewing family history or through special genetic testing. Both types of risk factors contribute to the likelihood that an individual may develop CRC. Following is a description of both types of risk factors:

Modifiable Factors for Colorectal Cancer

- ¹Tobacco use- Smoking tobacco is associated with an increased risk of colorectal cancer.
- Physical activity- Exercise is shown to be a protective factor, meaning that the more an individual exercises, the lower his/her risk is for developing CRC. ²While high levels of exercise may potentially decrease this risk by as much as 50%, even moderate physical activity can lower risk.



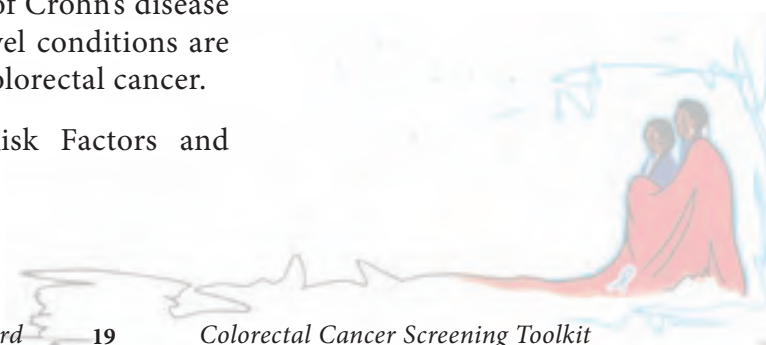
Nutrition- The American Cancer Society advocates for an overall healthy diet and has dietary recommendations that include limiting consumption of red and processed meats and eating a wide variety of fruits, vegetables and whole grains.

- **Obesity-** Individuals who are overweight or obese are at an increased risk for developing CRC. ^{3,4} Studies show that obesity (depending on where fat is stored in the body, sex and age) may double CRC risk
- **Diabetes-** ⁵Type 2 Diabetes is related to obesity, but mounting evidence shows that untreated or unregulated diabetes (due to unstable insulin levels) may increase the risk of CRC. ^{6,7} Type 1 and 2 diabetes are associated with an increased risk of CRC.
- **Alcohol consumption-** Even moderate alcohol use (e.g., 2-4 drinks per day as a lifetime average) is linked to an increased risk of colorectal cancer.

Non-modifiable Factors for Colorectal Cancer

- **Age (50+)** - Over 90% of colorectal cancer cases are diagnosed in people ages 50 and over.
- **Sex-** Sex (male or female) risk overall is equal, but women have a higher risk for colon cancer, while men are more likely to develop rectal cancer.
- **Personal history of CRC or adenomatous polyps-** Individuals with a previous history of either colorectal cancer or adenomatous polyps are at increased risk for developing new cancers in other areas of the colon and rectum.
- **Personal history of CRC or adenomatous polyps-** Individuals with a previous history of either colorectal cancer or adenomatous polyps are at increased risk for developing new cancers in other areas of the colon and rectum.
- **Personal history of chronic inflammatory bowel disease-** Individuals with a history of Crohn's disease or other chronic inflammatory bowel conditions are at an increased risk of developing colorectal cancer.

For more information, see tool 2.2: Risk Factors and Symptoms.



Family History

As identified above, having a family history of CRC or adenomatous polyps is a non-modifiable risk factor. Therefore, obtaining family history from individuals is vital to determining individual risk. Based on family history, an individual may be found to have average, increased, or high risk for CRC. This will factor into determining the type of screening that should be performed, the age at which screening should begin, and how often the individual should be screened. For another look at risks associated with CRC, see tool 2.3, Individual Risk Based on Family History of CRC.

Screening Options & Characteristics of Screening Tests

There are three options for CRC screening that are fully recommended by guideline consensus groups: Fecal Occult Blood Test (FOBT), flexible sigmoidoscopy, and colonoscopy. Family history of CRC and personal risk factors determine individual level of risk and the appropriate test for an individual. Below is a description of each of the three risk levels and the recommended screening tests.

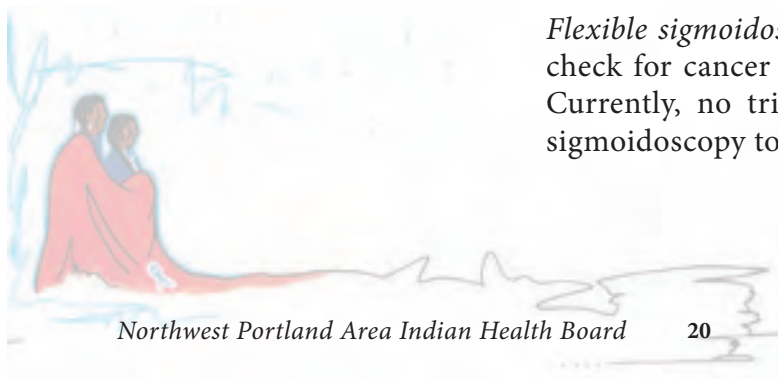
Risk Levels:

- Average: no risk factors, no symptoms
- Increased: CRC or adenomatous polyp in a first degree relative
- High: 8personal history of more than eight years of Crohn's Disease or Ulcerative Colitis or a hereditary (from family) polyp syndrome

Screening Tests:

Fecal Occult Blood Test (FOBT) - An FOBT is a test used to find blood in the stool. Three small stool samples are scraped from three separate bowel movements with a stick and then wiped on closable cards. Those cards are sent to a laboratory for testing. There are two kinds of FOBT tests, the guaiac-FOBT and the immunochemical FOBT (iFOBT or FIT).

Flexible sigmoidoscopy- A flexible sigmoidoscopy is used to check for cancer or polyps in the lower third of the colon. Currently, no tribal clinics in the Northwest use flexible sigmoidoscopy to test for CRC.



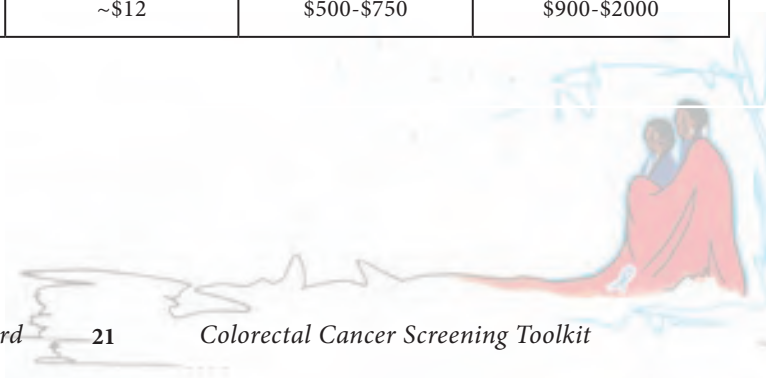
Colonoscopy- A colonoscopy is used to check for cancer or polyps in the entire colon. A colonoscope is a flexible, 30 inch long, ½ inch diameter tube with a light on one end and a lens for viewing on the other end. It is inserted into the rectum. The colonoscope passes through the entire length of the colon. Polyps and other tissue can be removed during the examination to test for the presence of cancer. During a colonoscopy, strong sedatives are given intravenously to allow the patient to sleep through the procedure.

The table below briefly outlines the different screening tests, what they involve, and how much they cost. Tool 2.4, Screening Tests at a Glance, is a detailed description of the characteristics and preparation required for each test, as well as other tests used for screening, and can be found in the toolkit pocket of this chapter. Physician and patient test choice depends on preparation required, test location, the information obtained, cost, availability and risk level.

Screening Recommendations from ACS, USPSTF, IHS

The American Cancer Society (ACS) and the U.S. Preventative Services Task Force, both recommend CRC screening for individuals with average risk of developing CRC. Not all of these tests listed were described above.

| | Guiac FOBT | Immunochemical | Sigmoidoscopy | Colonoscopy |
|---|--|-----------------------|---|------------------------------------|
| Administered | Home | Home | Clinic or Hospital | Clinic or Hospital |
| Restrictions | Yes, Food with Red Meat or Citrus (Orange, lemon, etc.) Medications Aspirin, ibuprofen, Vitamin C | None | Yes, no food 24 hours before Only checks 50% of colon | Yes, no food 24 hours before |
| How specific to finding CRC | 95.2% ⁹ | 95.4% ¹⁰ | 100% ¹¹ | 100% ¹² |
| How sensitive to detecting CRC or adenomas if they exist | 33% ¹³ | 53%-73% ¹⁴ | 94% ¹⁵ | 94% ¹⁶ |
| Cost (before insurance) | \$1.50 | ~\$12 | \$500-\$750 | \$900-\$2000 |



Did you know?

The presence of polyps is not necessarily bad. Polyps are not cancer. Some polyps may turn into cancer with time. That is why it is important to have them removed.

Specifically, the ACS recommends that at age 50, individuals follow a course of screening that places them in one of two groups, these groups are as follows:

Group A: Tests that detect polyps and/or cancer

- a flexible sigmoidoscopy every 5 years, or;
- a double contrast barium enema every 5 years, or;
- a CR colonography (also known as a virtual colonoscopy) every 5 years, or;
- a colonoscopy every 10 years

Group B: Tests that primarily find cancer

- a Fecal Occult Blood Test (gFOBT) every year, or;
- a yearly Fecal Immunochemical Test (FIT) every year, or;
- a Stool DNA test (sDNA)

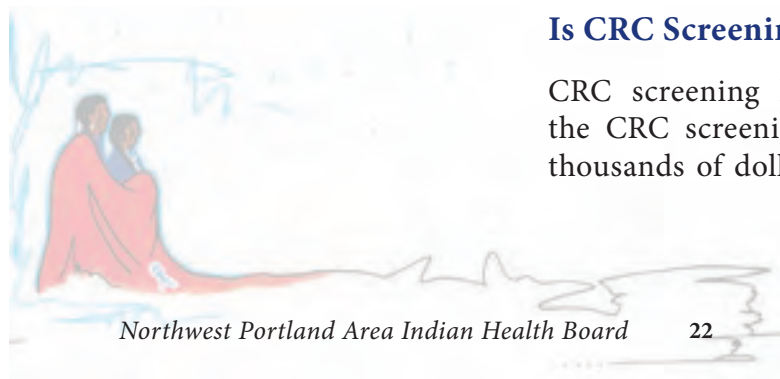
Like the American Cancer Society, the U.S. Preventive Services Task Force (USPSTF) also recommends screening for CRC at certain ages and intervals. The USPSTF recommends screening adults for CRC using FOBT, sigmoidoscopy, or colonoscopy beginning at age 50 and continuing until age 75. According to the USPSTF, screening people in this age group using any one of the three regimens will be about equally effective in preventing CRC. These regimens are as follows:

- annual screening using high-sensitivity FOBT, or;
- screening every five years using sigmoidoscopy, combined with high-sensitivity FOBT, or;
- screening every 10 years using colonoscopy

In the ¹⁷“Strategic Plan to Increase Colorectal Cancer Screening among American Indians and Alaska Natives Executive Summary,” IHS promotes routine screening in general, but not specific CRC screening tests. Thus, in instances where endoscopy access is limited, clinics should focus on the FOBT or FIT screening tests.

Is CRC Screening Cost Effective?

CRC screening has clear cost-saving benefits. ¹⁸Any of the CRC screening methods can save individual patients thousands of dollars. Screening is far less expensive than



cancer treatment. Programs that promote CRC screening are also cost-effective. Programs featuring patient mailings have been found to be the most cost-effective strategy in improving screening rates. For example, one program implemented two patient mailings including an annual stool blood test card;¹⁹ they significantly increased CRC screening rates at a cost of \$42 per patient.

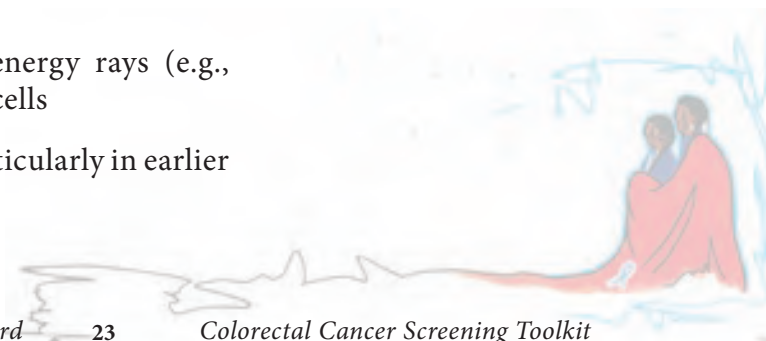
There are many types of screening programs— those based on annual FOBT followed by colonoscopy if positive; those based on flexible sigmoidoscopy every five years with annual FOBT in between; and those based only on initial screening colonoscopy with repeat tests based on findings. Other factors such as ²⁰“patient acceptability, screening compliance, cost, availability of colonoscopy and human resources required should all be considered in deciding which CRC screening program is most appropriate, as well as in providing specifics for cost-effectiveness.” Health care budget considerations may be the bottom-line that dictates which screening test is most likely and fitting possible for clinics or patients.. Although colonoscopies are considered to be the gold standard for CRC screening, screening programs based solely on colonoscopy might not be the strategy of choice for programs with fixed or minimal budgets. ²¹Programs based on annual FOBT may result in more overall benefit, both financially and in patient health, compared with colonoscopy-based programs because of screening feasibility. As one physician said, ²²“the best screening test is the test that gets done.”

Treatment for CRC

Once colorectal cancer is diagnosed, there are four main types of treatment:

- Surgery - surgical removal of abnormal cells/cancerous growth
- Chemotherapy - the use of oral or intravenous drugs to fight cancer
- Biologically targeted therapies - the use of drugs (often man-made proteins called monoclonal antibodies) to attack the cancerous parts of cells
- Radiation therapy - the use of high-energy rays (e.g., x-rays) to shrink tumors or kill cancer cells

Surgery is the most common treatment, particularly in earlier



stages. It is also common to have additional treatments either after surgery or at the same time. The main goal of surgery is to remove the cancerous tumor while chemotherapy and radiation help to prevent the spread or return of cancer. Targeted therapy may be less severe than chemotherapy and is most often used either in conjunction with chemotherapy or by itself if chemotherapy is not effective.

Treatment: Cost-Savings Due to Screening

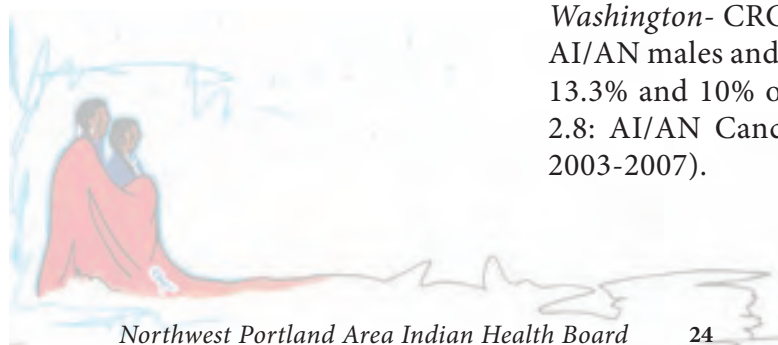
Colorectal cancer treatment can be quite expensive. ²³Even when detected early, the treatment cost for colorectal cancer is around \$30,000 per patient. Late stage CRC treatment is even more expensive at about \$120,000 per patient. The treatment savings of screening go beyond financial considerations; ²⁴colorectal cancer found at an early stage through screening has about an 85-95% cure rate. The later cancer is diagnosed, the lower the survival rate. ²⁵Even cancer diagnosed in stage I has a lower survival rate than screening and prevention.

CRC among Northwest AI/AN

Overall, risk for developing CRC is higher for AI/AN than the rest of the population nationally. However, these rates vary by region and state. True CRC rates in AI/AN communities can be difficult to calculate because of inaccurate race classification and low levels of screening and diagnosis. Inaccurate race classification is when AI/AN are misclassified as another race in public data sources. To correct this, the Northwest Tribal Registry works to improve classification of races and Northwest AI/AN cancer estimates. This corrected data is published and used for educational fact sheets, including tools 2.5- 2.9 in the toolkit pocket of this chapter. Based on this work, a summary of CRC in the Northwest by state is shown below.

Oregon- CRC is the third leading form of cancer among AI/AN males and females in living in Oregon, representing 13.6% and 6.7% of all types of cancer respectively. (See tool 2.7: American Indian and Alaskan Native Cancer Incidence and Screening: Oregon, 2003-2007).

Washington- CRC is the third leading form of cancer among AI/AN males and females living in Washington, representing 13.3% and 10% of all types of cancer respectively. (See tool 2.8: AI/AN Cancer Incidence and Screening: Washington, 2003-2007).

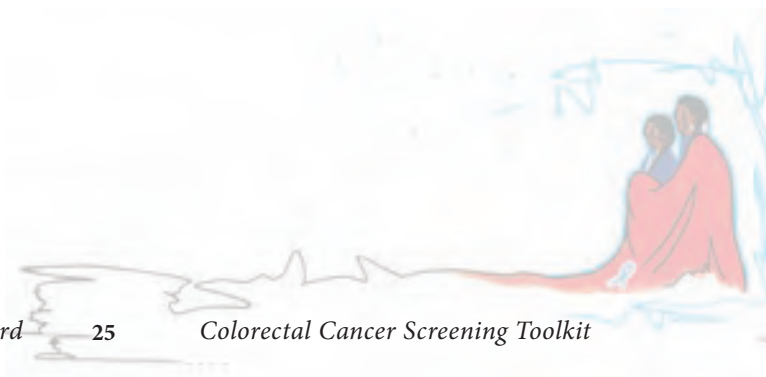


Idaho- CRC is the fourth leading form of cancer among AI/AN males and females living in Idaho, representing 10.9% and 7.8% of all types of cancer respectively. (See tool 2.9: AI/AN Cancer Incidence and Screening: Washington, 2003-2007).

Portland Area- CRC is the third leading form of cancer among AI/AN males and females living in the Northwest Portland Area (OR, ID, WA), representing 13.4% and 8.9% of all types of cancer, respectively. In the 2008 reporting year, only 35 % of AI/AN patients aged 51-80 had CRC screening within the previous year. ²⁶While this is higher than the national IHS average of 29%, it still falls below both the IHS screening goal of 50% and the current U.S. screening rate for non-Hispanic whites (NHW) of 61.6%.

Background Chapter Summary

This chapter described the basics of colorectal cancer, including risk factors for developing it, the main screening tests that detect it, screening recommendations, and treatment for patients diagnosed with CRC. It should be noted that while there is a high incidence of CRC among AI/AN in the Northwest, prevention and early detection through screening could significantly decrease both CRC incidence and mortality.



Tool Box Description

2.1 Colorectal Cancer Screening: Basic Fact Sheet

- The double-sided basic fact sheet describes CRC, risk factors, the importance of screening and types of screening tests. It also shows a simple graphic of the gastrointestinal system.

2.2 Risk Factors and Symptoms

- The Risk Factors and Symptoms sheet lists factors that make an individual at an increased individual's risk to develop of CRC. There is also a description of possible symptoms.

2.3 Individual Risk Based on Family History of CRC

- The Individual Risk chart shows the increased risk based on different family settings.

2.4 Screening Tests at a Glance

- This chart is a detailed description of available tests for CRC screening, associated preparation, how they work, and how frequently they need to be taken.

2.5 AI/AN Cancer Incidence and Screening Idaho, Oregon, and Washington, 2003-2007

- The double-sided Cancer Incidence and Screening sheet shows rates for all cancer prevalence and mortality among AI/AN in the Northwest.

2.6 AI/AN Cancer Incidence and Screening: Oregon, 2003-2007

2.7 AI/AN Cancer Incidence and Screening: Washington, 2003-2007

2.8 AI/AN Cancer Incidence and Screening: Idaho, 2003-2007

- The Cancer Incidence and Screening sheets for specific states has cancer prevalence and mortality rates.
- You can use any of these tools as an education piece to show the prevalence of cancers in your community.







Chapter 3: Risk Reduction and Prevention Information

Risk Reduction and Prevention Information

Introduction

Chapter two described colorectal cancer risk factors, screening options, and treatment of the disease. This chapter expands on information in chapter two by giving further detail on how to reduce individual risk of CRC. Although screening is the number one way to prevent CRC, focusing on promoting health and risk reduction can reduce the number of people who develop CRC as well as reduce impact of CRC for those who are diagnosed. Efforts to reduce CRC risk should focus on modifiable risk factors—those that can be controlled—such as diet, physical activity, alcohol consumption and tobacco use.

This chapter provides background information on modifiable risk factors and simple program ideas to promote health in your community. If risk reduction is a component of your overall program, consider coordinating with existing fitness, nutrition, and tobacco cessation programs. In addition, use information and ideas in this chapter with the next three chapters to develop a strong and comprehensive program. Information in this chapter can be used in any type of community-based program (e.g., media campaign, individual or community education).

The Importance of Prevention

Promoting healthy lifestyle choices is incredibly important for improving quality of life and reducing the risk of a number of chronic diseases. In Indian country, too many people are diagnosed with preventable chronic diseases. Our life expectancy is shorter than the general population and our risk of both developing chronic diseases and of dying due to those diseases is much higher. We can prevent these outcomes in our communities through promoting and living healthy lives.



“The only statistic I was given to bring here is out of the last 40 deaths in Warm Springs, 15 of them [37.5%] were due to cancer...we are catching them too late...our people need to understand that. The way to help them to understand that is to increase awareness....”

— Judy Charlie,

Warm Springs Tribe

Courtesy: 2002 President's Cancer
Panel

Check out:

**For more on
nutrition and
eating well.**

**[http://www.
choosemyplate.
gov/](http://www.choosemyplate.gov/)**

**Indian Health
Services nutrition
information at :**

**[http://www.
ihs.gov/
MedicalPrograms/
Diabetes/index.cf
m?module=resou
rcesInstantDownl
oads](http://www.ihs.gov/MedicalPrograms/Diabetes/index.cfm?module=resourcesInstantDownloads)**

Obesity and Type 2 Diabetes

Obesity and diabetes are highly related to developing CRC. Patients with type 2 diabetes are at even higher risk for developing CRC if they do not regulate insulin levels through medication or diet. It is important to collaborate with your diabetes coordinator to ensure community members are frequently screened for diabetes. Both type 2 diabetes and obesity can be addressed through overall health and wellness efforts listed below.

Diet

Eating well can improve overall health including reducing risk of CRC, type 2 diabetes and other chronic and preventable diseases. The Centers for Disease Control and Prevention recommends maintaining a healthy weight to reduce CRC risk.

Below are specific dietary recommendations that may lower CRC risk:

- Limit foods high in saturated (animal) fat (e.g., butter, bacon, cheese).
- Eat five or more servings of fruits and vegetables every day.
- Choose whole grains (e.g., whole oats, brown rice, whole wheat, etc.) over refined or processed grains, (e.g., white flour, white rice, refined pastas, etc.)
- Eliminate or at least limit red or processed (e.g. bologna) meats.
- Eliminate or put strict limits on sugary foods, such as candy, cookies, etc.
- Eliminate or put strict limits on sugary beverages, such as soda, Gatorade, etc.
- Increase water intake to eight glasses per day.

Traditional native diets offer healthy whole foods that promote health. Traditional foods include: salmon, berries, lean game meat, roots, and nuts. There are 17 Traditional Food Projects in Indian Country funded by five-year grants from the CDC. In the Northwest, Nooksack and the Confederated Tribes of Siletz Indians have received Traditional Food Project grant funds to promote traditional healthy eating.



- Overall, eat or drink (anything besides water) in moderation to maintain a healthy weight.

For more information see tools 3.1 and 3.2, My Native Plate.

As part of your comprehensive CRC prevention program, consider including diet-focused workshops and activities. You can encourage others by showing them that learning about new food is easy, fun and that other people in the community enjoy healthy food

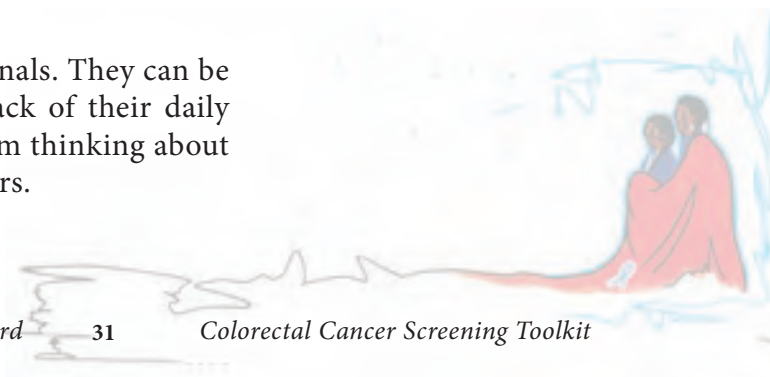
Below are community activities that focus on improving participant's diets:

- Create and publish a weekly/monthly traditional or healthy foods newsletter that spotlights new and healthy recipes. Share healthy eating tips and personal stories of people in the community who are working to maintain a healthy diet.
- Host community cooking classes or workshops where people can see how easy healthy cooking can be. There are multiple resources online for recipes and teaching others how to cook.
- Promote and celebrate traditional foods in your community.
- Host a community potluck (maybe connected with another event) and have a healthy food theme or spotlight ingredient (e.g., kale or broccoli).
- Start a community garden plot and encourage families to grow edible plants.
- Start a group that discusses new recipes, challenges of eating well and supports members to learn how to eat well.
- Start an eating competition. For example, see who can eat the most vegetables in one week. Give prizes to all who participate and to the winners.
- Start an online or in-person forum for sharing healthy and easy recipes.
- Encourage people to keep food journals. They can be private, but having people keep track of their daily food intake is a good way to get them thinking about changing their food-related behaviors.

Check out:

The New Native American Cuisine: Five-Star Recipes from the Chefs of Arizona's Kai Restaurant by Marian Betancourt.

This cookbook, and many others, include modern recipes with traditional native ingredients.



Physical Activity

Physical activity is another controllable risk factor. Regular physical activity greatly reduces the risk of a large number of chronic diseases and is essential to maintaining a healthy weight. Regardless of weight or BMI, physical regular physical activity can decrease CRC risk. ¹Research shows that regular physical activity is associated with a 24% risk reduction as compared with no physical activity among both men and women. ²There is also evidence that higher energy expenditures (high- intensity physical activity) lead to even greater CRC risk reduction. That means, the more active an individual is, the lower his or her individual risk.

High-intensity or vigorous physical activity is anything that gets a person's heart going and includes running, jumping jacks, or other aerobic activities. Moderate exercise includes brisk walking, water aerobics, or using a push lawn mower. The American Cancer Society and the National Cancer Institute suggest physical activity ranging from 30-60 minutes of moderate to vigorous intensity at least five days per week.

Coordinating physical activity workshops or events can be relatively simple to integrate into your community. Remember to consider working with the diabetes coordinator, tribal fitness coordinator or any other community partner who might be interested in encouraging people to get moving. Below are simple ideas for including exercise-focused workshops in your program:

- Start a community walking group. Invite others to go for walks once or twice a week. Pick different walking routes and try to keep it welcoming and comfortable for people of all abilities and ages.
- Facilitate community exercise groups. You can work with someone in the community who is familiar with teaching exercises or you can learn some techniques to get others moving. NPAIHB offers fitness training every year at Nike Native Fitness. Contact wtdp@npaihb.org for more information.
- Start a long-term community fitness challenge. For example, start a pedometer walking challenge. Ask people to wear a pedometer (to keep track of the number of steps they take) and try to increase the number of steps they take in a day. For more



information visit: www.thewalkingsite.com

- Encourage people to find exercise partners. Your program can help people find their partners and help them set fitness goals.
- Host a community athletic event such as a softball or basketball game, a dance or a hike. Community athletic events could be regular (e.g., annual basketball games) and could be combined with a healthy potluck.
- Promote or teach new sports and physical activities. You can promote new exercises with media and education tools. For example, each month spotlight a new physical activity that people can try (either something they can do on their own or a class that is held nearby).
- Promote family-based exercise. You can use a media campaign or a series of workshops to encourage people to increase the amount of time they spend being active or outside with kids, grandkids, pets or friends.

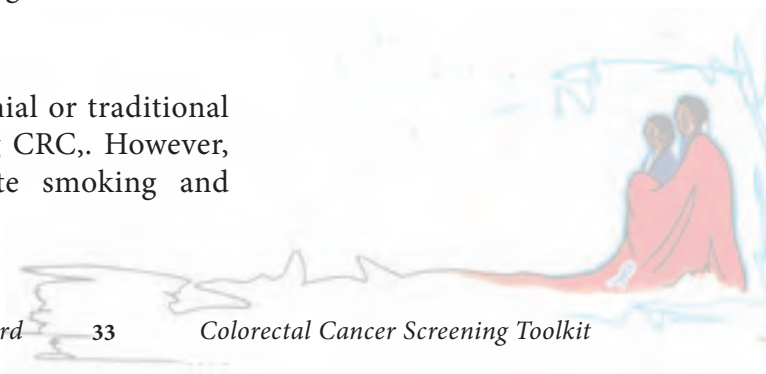
For more ideas and information on physical activity in Indian Country including Physical Activity Kits for all ages go to

www.letsmove.gov/indiancountry

Integrating overall wellness through physical activity and diet promotion is important in any chronic disease prevention program. There are also a number of other risk factors that can be controlled, but may be outside of the scope of a CRC prevention coordinator. Chapter seven outlines building partnerships with other programs to support risk reduction. Below is background information and recommendations for tobacco, alcohol and other specific lifestyle guidelines.

Habitual Tobacco Use

Infrequent participation or use of ceremonial or traditional tobacco is not a risk factor for developing CRC,. However, habitual tobacco use, including cigarette smoking and



“I’ve gone back to a lot of native food... I try to include that in my diet, the roots, and fish and deer meat.”

- Tribal Focus Group, 2011

chewing tobacco, is associated with a long list of negative health impacts. ³Besides heart disease and lung cancer, long-term tobacco use is associated with an increased risk of CRC. Prior to program implementation, you can work with the tobacco coordinator to decide on a referral process for patients. Refer to Chapter Six: Program Implementation for more information on collaborating with similar programs. Current smokers should be referred to tobacco cessation resources or the tobacco cessation coordinator. If you decide to facilitate tobacco cessation as part of your program, there are numerous materials and resources available. For example, consider attending a Second Wind Tobacco Cessation Training offered by NPAIHB and the Northern California Indian Development Council. For more information, please contact Lou Moerner with Northern California Development Council at: lou@ncidc.org.

Alcohol Consumption

⁴Excessive alcohol consumption is linked to an increase in CRC risk. Limit alcoholic beverages to no more than two drinks per day for men and one drink per day for women. If patients who have chronic alcohol or other substance use issues and would like to limit or quit using, refer them to a substance abuse counselor or rehab center. Limiting alcohol consumption can also help maintain a healthy weight by lowering the number of calories consumed.

Aspirin

⁵There is increasing evidence that taking a regular dose (daily or three to five times per week) of aspirin may reduce the risk of CRC. However, the relationship between CRC and aspirin is still being studied. We suggest any CRC program coordinator conduct further research before suggesting aspirin as a preventative measure for patients. All patients should consult a physician before taking regular doses of aspirin.

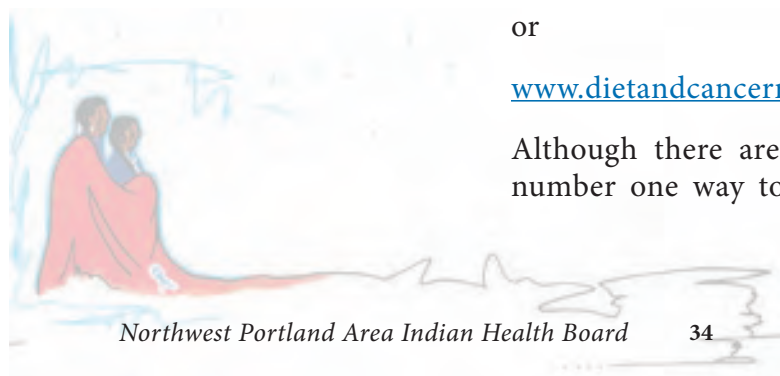
For more information on risk reduction and CRC prevention go to:

www.cancer.org/Cancer/ColonandRectumCancer/DetailedGuide/colorectal-cancer-prevention

or

www.dietandcancerreport.org

Although there are many factors associated with CRC, the number one way to prevent it is to be screened. Promotion



and education of the benefits of CRC screenings should be an emphasis of every CRC prevention program. However, programs that do not have access to clinical services can also focus on promoting protective health behaviors.

Risk Reduction Chapter Summary

The risk reduction and prevention supplement provided useful information on preventing CRC. Protective factors such as healthy diet maintenance, regular physical activity, and moderate use of alcoholic beverages, are explained and described. Program activities and suggestions for diet and exercise are included.

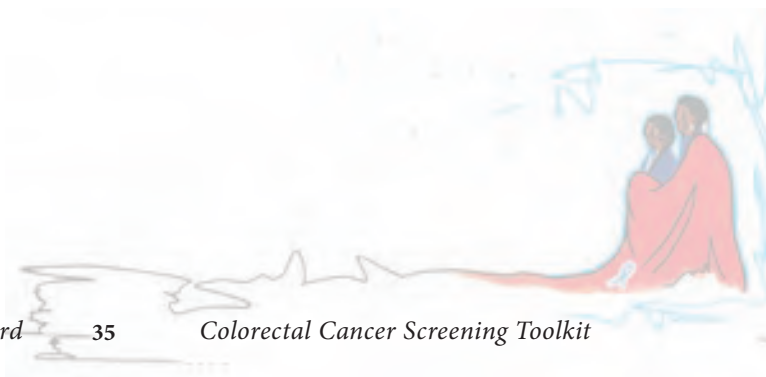
Tool Box Description

3.1 My Native Plate: An Easy Way to Help your Family Know How Much to Eat

This resource was developed by IHS and is a native adaptation of Choose My Plate. The full size placemat can be used to understand portion sizes.

3.2 More My Native Plates for your Family

This poster includes native plates for youth and alternative examples of well-rounded meals.







Northwest Portland Area Indian Health Board
Colorectal Cancer Program Toolkit

Part Two:

Community-based Programs







Chapter 4: Community Readiness Assessment

Community Readiness Assessment

Now that you have background information on CRC, you are prepared to conduct a readiness assessment. A readiness assessment determines what kind of program you can efficiently and effectively provide. It assesses what is being done in your community so you can build from existing efforts. If your community is not yet ready to implement a screening program, this chapter can identify how to prepare your community to increase CRC awareness and screening. Programs may vary from general community education to improving methods of colorectal cancer screening at clinics. In addition, the readiness assessment can be used as an evaluation tool after implementation.

A community readiness assessment is important to developing a successful program or plan. The assessment tool provided can be utilized with limited resources. If your community has the capacity to expand on the assessment tools offered, it is highly suggested you do so. This toolkit has a brief assessment (Tool 4.1) that can be found in the pocket at the end of this chapter.

Levels of Readiness

This chapter defines four levels of readiness. Each level builds off the previous level.

You can use questions to evaluate necessary resources and/or potential barriers to address before moving on to the next level. The provided assessment is in the form of a short survey. Responses will be “yes” or “no” to all questions. The survey should take about ten minutes to complete and can be found in the toolkit pocket of this chapter (Tool 4.1: Levels of Readiness Assessment).

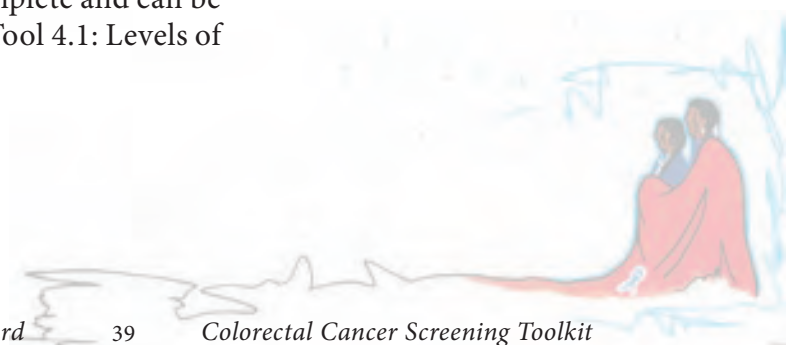


“Coming through these doors is a very, very big step for a lot of our people. This is not really within our cultural realm to talk about things like this.”

— Stella Washines

**Tribal Council,
Yakama Nation, Washington**

Courtesy: 2002 President's Cancer
Panel



**For more
thorough
readiness
assessment
materials, see:**

**[www.
TriEthnicCenter.
ColoState.edu](http://www.TriEthnicCenter.ColoState.edu) and
<http://ctb.ku.edu>**

Questions are categorized into the following four levels:

1. Community awareness
2. Individual awareness and motivation
3. Community and administrative capacity
4. Clinical practice and systems of care

Successful screening and awareness programs will move through the levels in order. For example, communities shouldn't focus on individual awareness and motivation until overall community awareness of CRC screening and prevention is in place. Levels are outlined in detail below and can be used as a roadmap for program development.

Program readiness can be simply and quickly assessed. ¹Listed below is a step by step process to conducting a brief assessment in your community.

1. Define your target population. For most communities, this will be all residents aged 50 to 75. Some communities may want to have an education portion that is targeted to a larger section of the community. If so, think about where your program will take place and who it will impact?
2. Identify a representative sample of community members to complete the assessment survey. This assessment is intended to be completed by at least one person involved in the development and implementation of the program. Your community's level of readiness will be more accurate if it is completed by multiple people. Ideally community members who complete the assessment will be representative of a diverse range of program stakeholders, including clinicians, CHRs, PHNs, community leaders, or patients.
3. Take the assessment survey yourself and administer the assessment survey to community members.
 - a. ** If you have more time and/or resources available, consider conducting a group discussion among key informants or individual key informant interviews. Adapt questions from the survey so they are open-ended. Responses can highlight specific strengths of existing prevention or screening efforts and may provide strategies or ideas for developing program focus area and materials.



4. Analyze the results of the surveys according to level descriptions detailed below. If participants answer “yes” to every question in a level, program components in that level are already being addressed. Any “no” responses indicate an opportunity to work within that level.

Understanding Levels of Readiness

Each level indicates a different kind of community-based program. Assessment responses will be fundamental in identifying program objectives, strategies and actions. The assessment may also point out potential barriers in your community. Communities may have barriers that will slow or even prevent screening. Some potential barriers have been outlined below, however, it is important that you discuss and brainstorm other potential barriers in your community.

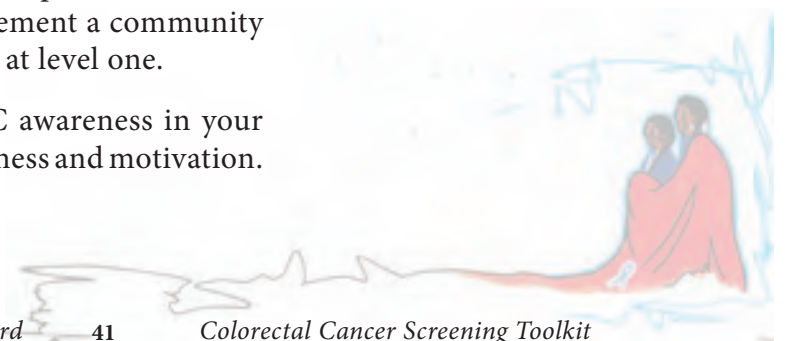
Level One- Community Awareness

Community awareness is a fundamental component of your colorectal cancer prevention and screening program. Responses in level one determine preventative and awareness efforts that exist within your community and indicate areas your program should address. Additionally, any “no” answers may indicate potential barriers in the development and implementation of your program. Some barriers related to level one include but are not limited to:

- a. Limited knowledge of CRC
- b. Limited knowledge on CRC risk factors and risk reduction
- c. Limited knowledge on CRC screening methods
- d. Community resistance
- e. Socio-cultural barriers (e.g., sensitivity to discussing CRC or methods for screening)

Program resources and activities that address potential program areas and barriers within the community are discussed in Chapter six, Program Implementation. Chapter three has risk reduction and prevention information and chapters five and six have specific methods to develop and implement a community screening education and outreach program at level one.

Now that you understand the level of CRC awareness in your community, you can assess individual awareness and motivation.



Level Two- Individual Awareness and Motivation

General community knowledge and marketing of colorectal cancer screening is not enough to make a significant impact on increasing screening rates. Although screening and prevention media exists in the community, individual members may not necessarily be exposed to it. This level ensures individuals in the community are aware of CRC, screening and prevention methods, and how or where to access screening. This level also focuses on increasing participation rates of individual community members who decide to be screened for CRC. Individual motivation is crucial to the success of your screening program. Responses to questions in Level two determine individual motivations and behaviors and indicate possible barriers among individuals. Some barriers related to Level two include:

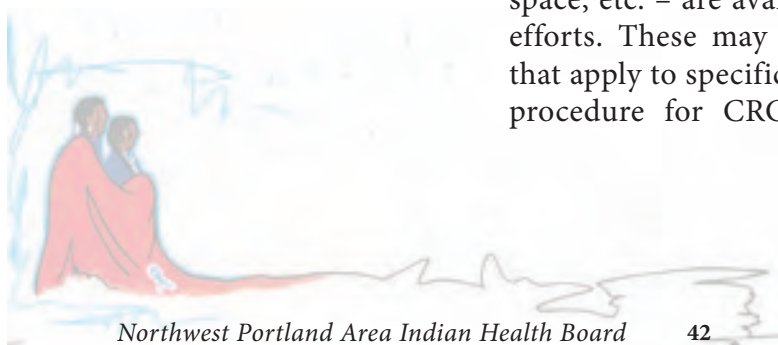
- a. Embarrassment of being screened
- b. Limited exposure to CRC media campaigns
- c. Financial concerns related to cost of screening
- d. Financial concerns related to cost of treatment
- e. Individual Education level
- f. Language barriers
- g. Socio-cultural barriers

The training activities and processes necessary for individual capacity building at level two are addressed in chapter six, Program Implementation and chapter seven, Communication and Collaboration between Community and Clinical Programs.

With both community and individual awareness established, how will administrative policies and the community support a CRC screening and prevention program?

Level Three- Community and administrative capacity

Community and administrative capacity is the community's ability to ensure that local resources – people, time, money, space, etc. – are available to support prevention and screening efforts. These may include administrative and local policies that apply to specific populations or that designate a particular procedure for CRC screening. Policies should be tailored

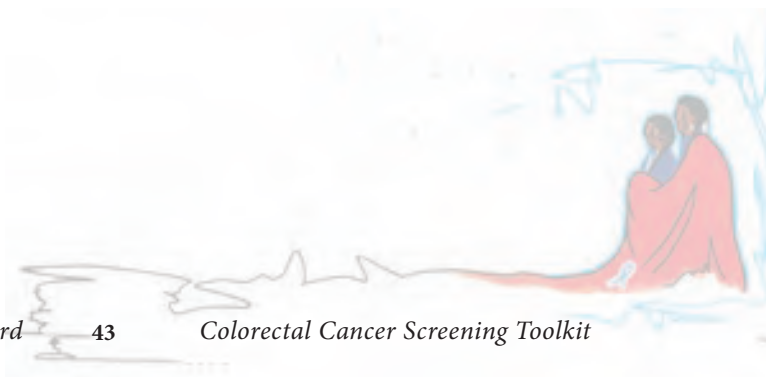


to your community's needs and have Tribal Council, health board, administration, and clinical/nursing team support. This level describes whether the community is equipped for a screening program, and if not, helps determine capacity building opportunities. Potential barriers in community and administrative capacity include:

- a. Lack of Tribal Council support
- b. Institutional barriers
- c. Lack of staff time allocated for CRC education or collaboration with health care providers
- d. Minimal investment from important stakeholders (e.g., potential funders or community leaders)
- e. Leaders of change are not aware of or do not support CRC screening
- f. Not enough resources (e.g., funding) for a CRC prevention program
- g. Community members do not have easy access to a screening site
- h. Clinic or healthcare providers are not aware of CRC screening and prevention efforts
- i. Community health workers and health care providers do not collaborate on prevention efforts

Program planning and implementation resources for building community capacity are addressed in Chapter five and six. Methods for engaging community leaders, key stake holders and addressing issues of access or lack of resources are also addressed in chapter five. Materials and resources regarding collaboration between community education and outreach efforts and clinical screening programs are provided in chapter seven. Specific clinic and health care provider activities and information are included in chapter eight.

Once community, individual, and administrative support are assessed, you can examine the local clinical practices and systems of care for CRC screening.



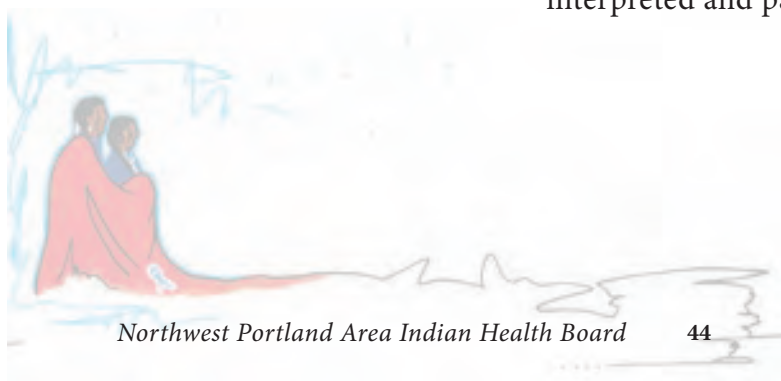
Level Four- Clinic Practice and Systems

Clinical practice and systems preparedness is a clinics' ability to actually screen or refer patients to appropriate screening facilities. Once this component is in place, office policies should be set up to address ongoing support—such as patient follow-ups and patient reminders—to ensure that patients are screened at the appropriate times and receive appropriate referrals and follow-up care. Responses to questions in level four identify existing strategies and protocols to recruit and retain eligible patients for screening. Responses will elucidate areas of improvement and barriers to conducting an effective clinical screening program. Some barriers include:

- a. Outdated knowledge
- b. Inconsistent or no guidelines
- c. Overestimation of screening rates
- d. Cost and reimbursement for screening tests
- e. Inadequate resources
- f. Lack of health care providers
- g. No outreach protocol to recruit or remind patients to be screened
- h. Lack of follow-up protocol
- i. Lack of connection with referral clinic for colonoscopies

Developing, implementing, and conducting clinical screenings for your community at level four is detailed in chapter eight.

The assessment results will prepare you to think about the context of your CRC prevention and screening program. Different communities will have different programs. The results will point to whether your program should take place in the community, in the clinics, or in a combination of the two. Results of the readiness assessments will need to be interpreted and part of program planning.



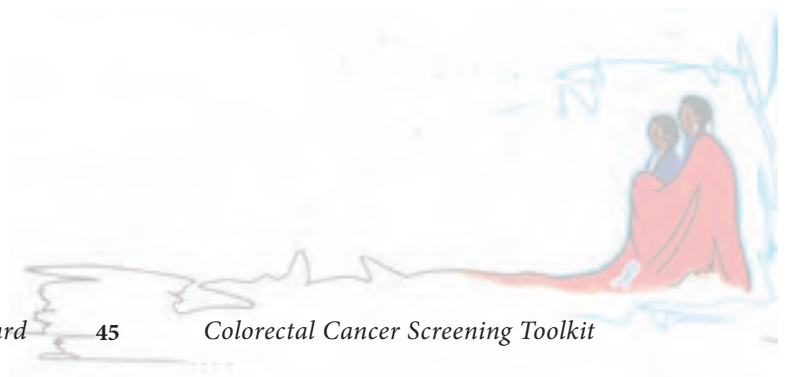
Readiness Assessment Chapter Summary:

This chapter discussed how to conduct a readiness assessment for CRC screening programs. Levels of readiness were introduced and explained. Levels included: (1) community awareness, (2) individual awareness and motivation, (3) community and administrative capacity, and (4) clinical practice and systems. This chapter also identified later chapters that will help you create relevant program activities depending on your community's level of readiness. Planning a program according to your community's level of readiness will contribute to the overall success of the program. Successful programs will increase the number of individuals who are screened for colorectal cancer and ultimately decrease mortality from colorectal cancer.

Tool Box Description

4.1 Readiness Assessment Survey

- This Readiness Assessment Survey is a detailed list of questions that you and other stakeholders can take to determine the kind of program is appropriate for your community.
- Give this survey to as many people who may be connected with CRC screening or program planning as possible.





Planning for Community Programs

Planning for Community Programs

Once you have determined the needs of your community, you can begin to plan a CRC prevention and screening program. Utilizing the results of the readiness assessment, consider where the program will take place and what issues should be addressed. You will need to refer back to the results throughout the planning process. Tool 5.1, Connecting Levels of Readiness to Program Mission and Context, can give you a sense of the context and example program platform that is appropriate for your community's level of readiness.

The first step to creating a CRC screening program is to develop a plan that outlines overall aims, objectives, strategies and specific actions. This chapter details the steps to program planning and how to develop a specific plan for your community. The success of any program is dependent on thorough planning. Although planning uses time and resources, it ultimately builds a strong foundation. The program will be more comprehensive, and subsequently, foster greater change in your community. It is crucial that program planning is completed prior to implementation.

Program planning uses your community readiness assessment to effectively build from what exists in your community. This chapter includes toolkit materials to engage potential stakeholders, create a detailed action plan, develop a basic program budget, and design an evaluation. While this chapter presents a combination of program planning models that will be useful in developing your program, there are many alternative, in-depth resources available.



"I think that the next time the decision makers...decide they are going to go to their doctor, I think we should put them all on a deferred or on a waiting list for 90 days and let them sit at home and worry about it. Let them feel that lump for 90 days....Maybe you want to go into town for a regular routine physical. Put yourself on a six month waiting list...The next time you want to go to the dentist, wait a year."

-Bob Brisbois

Spokane Tribe of Indians

Courtesy: 2002 President's Cancer

Panel

Engaging Stakeholders and Creating a Planning Team

Your screening program is likely to be more successful if the community is involved and supports your effort. In chapter four, Readiness Assessment, you identified key stakeholders. These and other stakeholders should be engaged in the program planning process to increase capacity and efficacy of your program. Reaching out to potential stakeholders is a preliminary way to educate your community about CRC prevention and screening. Beyond engaging community members in the assessment, an inclusive planning process and community collaboration will improve the program overall. Tool 5.2 is a worksheet for determining and engaging stakeholders.

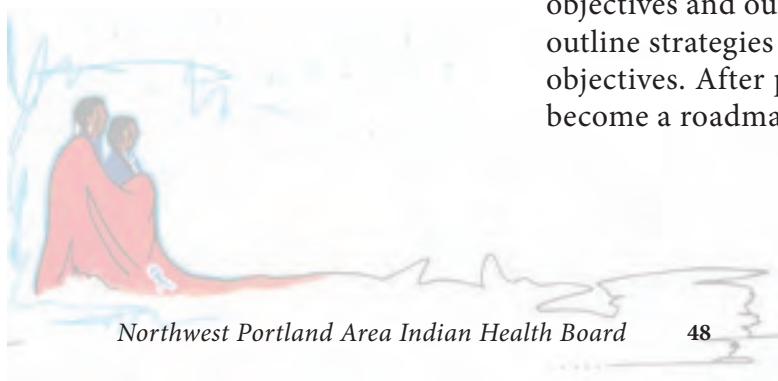
Engaged community members who are willing to be involved will be the core of the program and should participate in the entire planning process. Although more community members may have participated in the readiness assessment, a planning group should not exceed 15 members. The planning group should reflect the people who will be impacted by the CRC screening or prevention program. The group should also include some members who have a long-term commitment to the program. Lastly, the group should include representatives from multiple sectors, including advocacy groups, concerned residents, health care providers and potential program recipients.

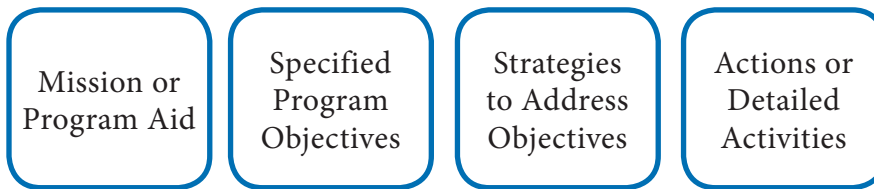
Assigning Roles and Responsibilities

During the planning process the team must consider individual roles and responsibilities. Prior to further program planning, the team must honestly and realistically evaluate how much responsibility each person can take. This is especially important if members are volunteers.

Program Planning: Defining Program Aims, Objectives, Strategies and Actions Plans

Action planning is a guide to defining the overall goals of your CRC prevention and screening program. It will encourage the planning group to think of specific and achievable objectives and outcomes. Action planning also allows you to outline strategies and interim indicators to address program objectives. After program implementation, action plans will become a roadmap for program evaluation.





The figure above illustrates the steps to developing a community action plan. Moving through each step will help you create a detailed outline for program implementation.

Program Aims: The big picture

The first step is defining your overall program mission or program aim. Program aims are broad, overarching goals your program will be designed to accomplish.

- Why are you planning a CRC prevention and screening program?
- What kind of program will it be?
- The program aim should be brief and outcome-oriented.
- What do you want to achieve?
- The program aim should include what will be done to address the issue, but not be too limiting in what strategies will be considered.

Program aims for CRC prevention or screening will depend on your community's readiness level. Some example program aims include:

"To increase community awareness of colorectal cancer and screening in my community through community events, media, community education, and advocacy"

"To increase the screening rate of CRC through access to screening services, patient follow-up, and community education"

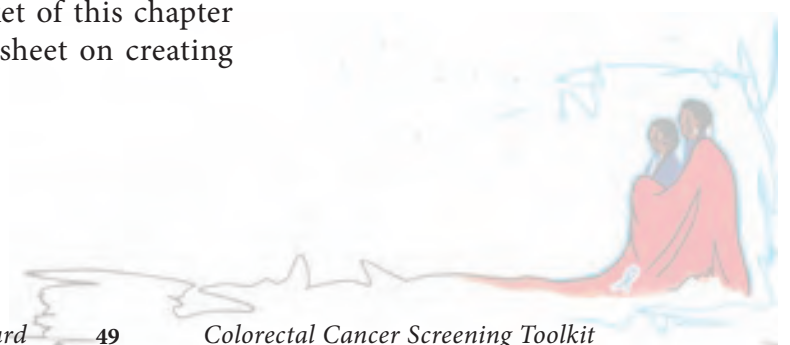
Please refer to tool 5.3 in the toolkit pocket of this chapter for a more detailed explanation and worksheet on creating program aims.

Resource:

For more in-depth planning descriptions, tools and checklists go to the University of Kansas' Community

Toolbox online:

<http://ctb.ku.edu>



Consider this:

Objectives must be measurable. In order to measure the impact of your program, you will need to collect baseline measurements prior to implementation.

Objectives

Objectives are measurable results that address how program aims will be achieved. Creating objectives will allow you to break down program aims and examine measurable milestones. In addition, forming objectives will organize and prioritize feasible methods to reach overall program aims.

Objectives answer the question how much of what will be accomplished by when. Different objectives can be directed at particular groups within your community. Strong objectives clearly define what needs to be measured and when it should be accomplished.

Objectives are SMART:

- **Specific-** What will be achieved?
- **Measurable-** How much change will be achieved and can you measure it?
- **Achievable-** Is it potentially achievable?
- **Realistic-** Is it realistic considering available resources?
- **Timed-** When will this objective be achieved?

The format for developing objectives is:

By [date], increase/decrease by [quantified amount, % or number] of [who] will [what].

Example objectives include:

- “By January 2014, all community buildings will have CRC screening brochures available.”
- “By the year 2014, all community members will agree with the statement, ‘Colorectal Cancer screening is critical for adults over the age of 50 or with a family history of Colorectal Cancer.’ ”
- “By January 2016, increase by 50% the percentage of community members over 50 who have annual FOBT.”
- “By the end of the year 2018, all clinics will have a CRC screening outreach protocol in place for patients over the age of 50. “

Please refer to tool 5.4 in the toolkit pocket of this chapter for a more detailed explanation and worksheet on creating program objectives.



Strategies

Objectives define what success looks like for a particular program whereas strategies specify how your program will realize those objectives. Strategies allow you to focus your efforts and consider how each objective will be accomplished. Strategies are the link between what the program is intended to accomplish and what actions will be taken to achieve program success. Strategies point out a path and are inclusive of multiple potential methods; they do not name specific people and their tasks.

Strategies will be developed for each objective. Multiple strategies can apply to one objective. They should include obstacles and resources and be diverse in how they apply to each objective. Strong strategies include the following characteristics:

- Highlight relevant approaches without limiting action to specific skills or tasks
- Consider and utilize resources and assets
- Address current obstacles
- Reach the target population and advance the overall program aims

There is no explicit format for writing strategies, but some sample strategies include:

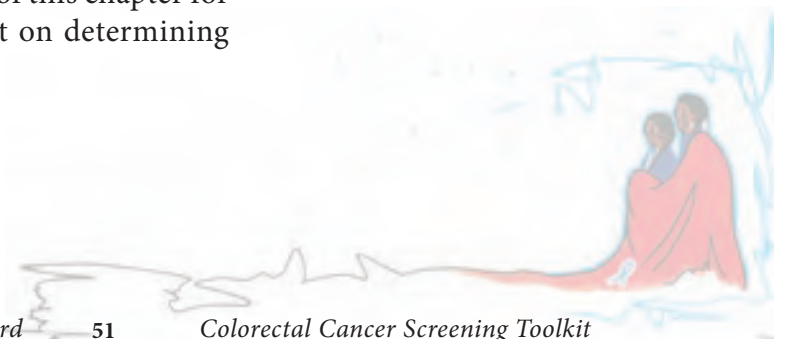
- “Build a community partnership with all relevant organizations in order to promote colorectal cancer awareness and screening”
- “Use media advocacy to promote public awareness of colorectal cancer and screening.”
- “Promote coordination between community health representatives and clinics or health practitioners.”
- “Modify policies or local laws governing colorectal cancer screening outreach.”

Please refer to tool 5.5 in the toolkit pocket of this chapter for a more detailed explanation and worksheet on determining strategies.

Resource:

For ideas on objectives consider the *Healthy People 2020 Cancer Objectives*. These can be found at:

<http://healthypeople.gov>



Action Planning

Action planning is the final element of the planning process. An action plan describes how strategies will be implemented by breaking down strategies into detailed tasks. This is the opportunity to describe in detail how strategies will be put into action to achieve the program's objectives. Developing an action plan will assist you to not overlook any details in creating your program and will help you increase overall efficiency. Action plans need to be revised and adapted regularly as the program grows and tasks are completed. A complete set of action plans are very thorough and increase efficiency. Action plans ensure multiple perspectives and methods are being considered to reach program aims.

Action plans are comprised of multiple elements to outline different tasks in detail. Each task should include the following:

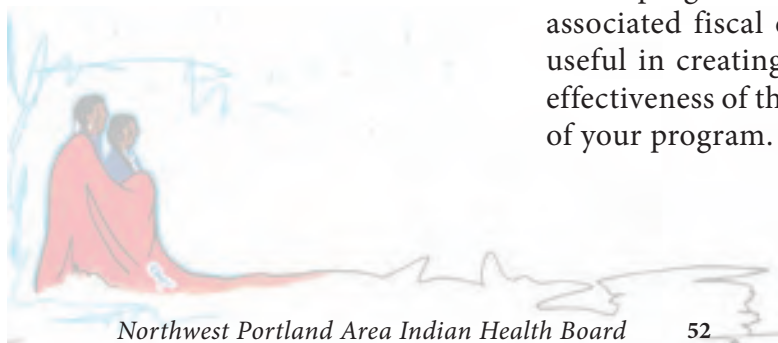
- What needs to happen? Describe the task.
- Who is responsible for the task?
- When should this task be completed?
- What resources are needed to carry out the task?
- Who else needs to know about the planned task or change? Who needs to be involved?

Each task needs to be clear, complete and up to date.

When planning an event it's important to look at the calendar to check if other events are going to conflict. Tool 5.6 is a checklist of potential tribal and community events to consider when planning. Please refer to tool 5.7, Drafting an Action Plan, in the toolkit pocket of this chapter for an in-depth description of action plans. Tool 5.8 is a template for creating action plans.

Financial Considerations: Budgets and Grants

Depending on the size of your program, the planning team may need to develop a program budget. If nothing else, it is important to brainstorm and understand anticipated costs of the program. Costs include any resources, staff time, or associated fiscal expenses. Budget and expense records are useful in creating grant applications, evaluating the overall effectiveness of the program, and understanding the capacity of your program.



Tribes may also seek grant opportunities for funding. Several relevant grant opportunities exist, including grants specific to AI/AN communities. Below is a short list of initiatives and grant resources for cancer prevention efforts:

Spirit of EAGLES Initiative: Each year the Spirit of EAGLES grant helps fund community-based projects to increase awareness and understanding of cancer. Further information on the Spirit of EAGLES initiative and a downloadable application:

www.nativeamericanprograms.net/

NPAIHB Local Tribal Community Cancer Implementation Funding: These funds support NPAIHB member tribes to implement tribal cancer control plans. Many different activities are funded every year. For more information visit: www.npaihb.org

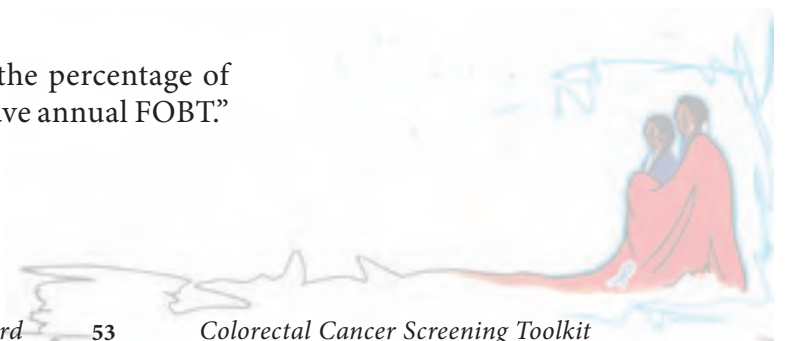
Northwest Health Foundation: The Northwest Health Foundation focuses on initiatives that support the health of people in Oregon and Southwest Washington. They fund many grants every year. For more information visit: nwhf.org

Evaluating your Program

Evaluation is critical to understanding the effectiveness of your program. Evaluations can determine whether the CRC program is achieving its goals. Evaluations can be conducted throughout the program implementation process. Programs are often evaluated at the conclusion of a program or the end of grant funding. However, process and midterm evaluations are highly useful and give insight to current program needs or processes that were not initially considered. Evaluations serve as opportunities to revise program plans and objectives and identify areas of improvement.

It is important that plans for evaluation are considered in the program planning phase so questions are not augmented altered because they may to misrepresent the true program impact. In order to truly measure program impact, your CRC program will need to collect baseline measurements for each objective that will be evaluated after implementation. An example objective might say:

- “By January 2016, increase by 50% the percentage of community members over 50 who have annual FOBT.”



Consider this:

Consider including/gathering baseline data on objectives while developing the action plan.

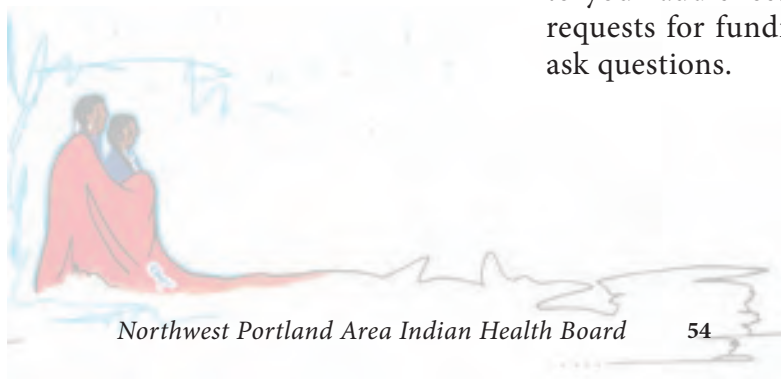
To determine if the CRC program has achieved a 50% increase, the CRC program must have already obtained the number of community members over 50 who have annual FOBT prior to CRC program implementation.

Evaluations can be informal or highly in-depth; consider how in-depth your evaluation can be with your given resources. Although comprehensive evaluations offer more detailed information, even informal evaluations can be useful. The program planning team can utilize the community readiness assessment and program objectives as evaluation tools. For a basic evaluation of program impact, you can ask community readiness assessment participants to re-take the assessment at a predetermined period of time after program implementation (e.g., after one year). For a more in-depth evaluation, you or another team member can measure program outcomes against all of your action planning objectives. It is important to be realistic about the level of evaluation your program can provide. If conducting a thorough evaluation is possible, consider doing further research on how to conduct program evaluations.

Obtaining Tribal Council and Community Approval

Tribal council and health board or health committee support is important to community acceptance of your CRC screening and prevention program. You can present your proposed program and share sample program materials. Presenting your program provides an opportunity to communicate with leaders in your community about the importance of CRC screening and prevention as well as gain support from the tribal council and health board for future projects. Consider obtaining tribal council's support with a presentation.

The presentation can demonstrate the benefits of CRC screening and the need for a prevention program (For talking points see, Oregon Health Authority Appendix B, pgs. 1-2). Present enough information so that the council can make an informed decision, but do not overwhelm them with documents. As with any presentation, avoid using medical jargon and technical terms that are not familiar to your audience. Be prepared to justify expenses and any requests for funding. Allow enough time for the council to ask questions.



Chapter Summary

Community program planning is fundamental to the success of any health program. Program planning guides you to consider thoroughly outline and utilize resources, barriers, and objectives related to your program. Program planning is the opportunity to decide what you want to achieve (Program Aims/Mission) and the steps needed to achieve it (Objectives, Strategies, Action Plan). This chapter described how to plan and evaluate a new community-based program.

Tool Box Description

5.1 Connecting Levels of Readiness to Program Mission and Context

- Connecting levels of readiness helps you understand your community's level of readiness and how it can become a base for program planning.

5.2 Determining and Engaging Stakeholders

- Determining and Engaging Stakeholders guides you to think about who you can contact in your community to be involved.
- It also has some ideas on how to connect with the people you have identified as potential stakeholders.

5.3 Developing Program Aims

- This is a simple worksheet to help the planning team determine CRC program aims.

5.4 Creating Program Objectives

- This worksheet builds off the program aims worksheet and guides the planning team to create SMART objectives.

5.5 Creating Strategies

- The Creating Strategies tool builds off the previous two worksheets. It has suggestions on how to create strong strategies.

5.6 Considerations for Event Scheduling

5.7 Drafting an Action Plan

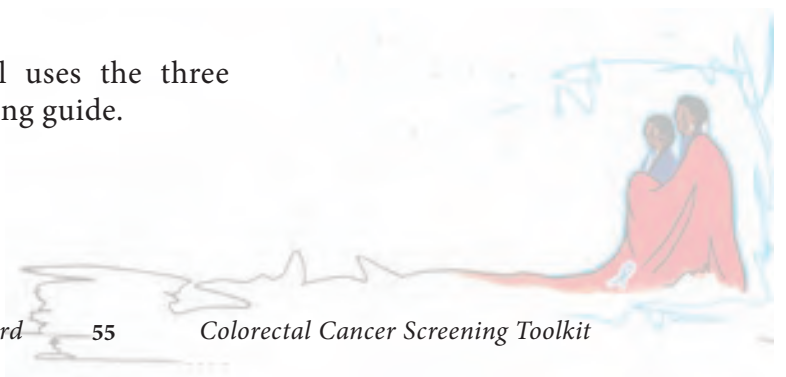
- The Drafting an Action Plan tool uses the three previous tools and has a brainstorming guide.

Consider this:

Check out the Northwest Health Foundation's free evaluation Handbook for a more in-depth guide on conducting evaluations.

Find it at:

<http://nwhf.org/sources#handbook>



5.8 Action Plan Template

- The Action Plan Template can be used to list specific tasks, assign people who are responsible, and estimate costs for each task.

Pgs. 1-2 CRC Talking Points (Oregon Health Authority, Native American Media Guide) (*available upon request)

- The CRC Talking Points from the Native American media Guide are useful for proposing or describing your new CRC program. They are also useful talking points for a community education- based CRC program.



Implementation for Community Programs

Implementation for Community Programs

This chapter contains the tools and details to help you implement your well-planned CRC screening and prevention program. Program implementation is when you put your ideas, planning and hard work into action. This chapter is divided into two sections based on the readiness assessment levels that are relevant to implementing community-based programs. That is, the tools and information in this chapter are intended for programs that are not based in or work closely with a clinic or CRC screening provider. You may use all the tools in either section based on your program's level of readiness or you may pull a tool from any section that best fits your program.

This chapter includes methods and tools for working with community partners, planning events, launching a public awareness campaign, and conducting individual-level counseling for patients. Read through the entire chapter to get an idea of different types of programs. Use the results from your readiness assessment to determine which program components are appropriate and useful. For example, if the results of the readiness assessment show that increasing public awareness of CRC is still needed then level one program methods and activities will help you reach your program objectives.

The methods and tools in this chapter are intended to be used to promote prevention, risk reduction and screening information described in chapters two and three. Ideally, programs will focus on both increasing screening and reducing risk factors among community members. If your community does not yet have access to a clinic or your program is unable to work with a clinic, risk reduction and prevention may be the center of your program.



“They said, ‘No, they don’t need that. They don’t need that prevention and education. What they need is research.’ Yes, we do, but we also need this other track alongside of it to help us.”

-Julia Davis-Wheeler,

**Tribal Council,
Nez Perce Tribe**

Courtesy: 2002 President's Cancer
Panel

Level One- Community Awareness

Increasing community awareness is a good place to start if your program is not yet working with health care providers or clinics. Although working with clinics will make a well-rounded program, community-based efforts alone can impact CRC awareness. Level one implementation components include materials and ideas for community education, modifiable risk reduction, media campaigns, and event planning.

Get to Know Your Clinic

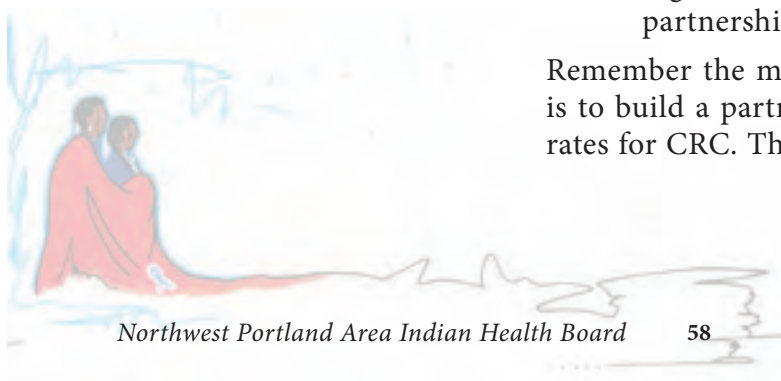
One of the first steps to implementing your CRC screening and prevention program is connecting with the clinic. It is important to understand what screening services they offer and what they are already doing to address CRC. If you do not already work with (or for) the clinic you should set up a preliminary meeting. This meeting can be the first step in establishing a partnership and will give you an idea of what screening services are available. Below is a list of questions to ask in the initial meeting:

- What CRC screening services and tests do you offer?

If you do not offer colonoscopies, where do you refer patients for colonoscopies?

- When are services available (e.g., clinic hours)?
- What are the GPRA screening rates in our community?
- Do you talk to patients about CRC screening? If so, what do you say to them?
- Do you reach out to tribal members over the age of 50 and remind them to be screened? If so, what are you doing now to remind them?
- We are building a CRC screening and prevention education program. Do you have any suggestions?
- Can we continue to work together to increase screening rates?
- What are the best ways for us to continue to work together? What are our next steps in building this partnership?

Remember the main purpose of connecting with the clinic is to build a partnership to increase screening and survival rates for CRC. The more you can work with your clinic, the



more effective the community portion of the program can be because patients are more likely to follow through with screening if they know exactly where to go and what to expect.

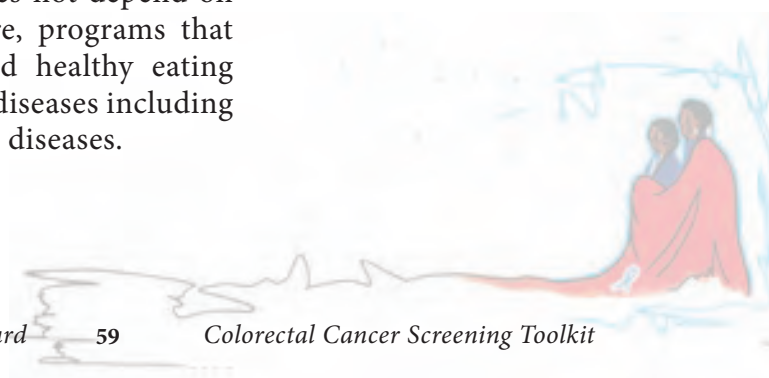
Collaboration with Similar Programs

The next step to establish an effective program is to partner with similar programs in your community. If you do not know or do not work with the tobacco coordinator, diabetes coordinator, or any other healthy lifestyle leader, you should set up a meeting. Building partnerships with other coordinators may give you access to their program participants, health events, and other health promotion tools. If your program focuses on modifiable risk reduction (described in chapter two), you can team up with other coordinators to have a more efficient approach.

The larger you can build your partnership network, the more awareness and acceptance there will be for your CRC prevention program. Below is a list of potential people to reach out to and how they can support your program:

| Who | How they support your program |
|---|--|
| Traditional healers (e.g., Medicine man or woman) | Access or encourage clients who may be uncertain of Western or conventional medicine |
| Community groups (e.g., cancer survivors group, elders group, or diabetes groups) | Access more clients and community support, community groups can also refer clients to your program. |
| Tobacco, diabetes, or other health program coordinators | Support and coordinate risk reduction programming (e.g., exercise and nutrition classes) and refer clients to your program |
| Cancer coalition, health board members, health committee members | Support community acceptance of your program by spreading the word and help coordinate community events. |

Once you've built partnerships in the community, program implementation can begin. Many community-based programs focus on risk reduction (as described in chapter two) because risk reduction education does not depend on coordination with the clinic. Furthermore, programs that focus on increasing physical activity and healthy eating habits reduce the risk for multiple chronic diseases including CRC, type two diabetes and cardiovascular diseases.



Below are methods for increasing CRC awareness and community education ideas.

Media Campaigns

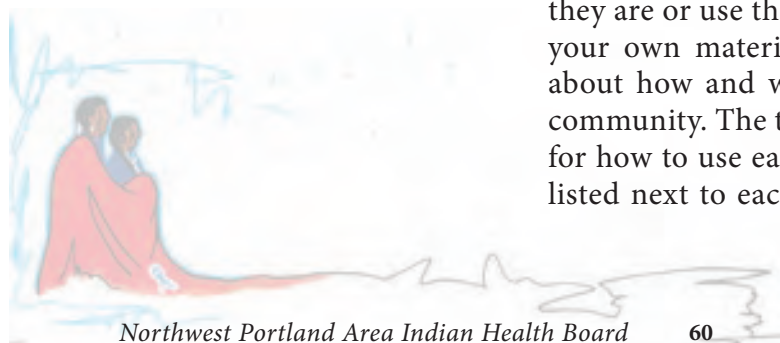
Media campaigns are one of the most common methods used to promote community health. Community relevant campaigns are a non-invasive way for information to reach a large number of people. Media includes brochures, TV commercials, posters, tribal newsletters, posters at clinics,

| Who | How they support your program |
|--|---|
| Counselors | Your program can refer clients to counselors or spiritual leaders for emotional support, including helping patients overcome fear of screening or dealing with cancer diagnosis. |
| Spiritual Leaders | |
| Financial assistance programs | It is important to know of any program that may be able to help patients with the financial burden of screenings. |
| Transportation organizations (if the clinic is not nearby) | You may need to help clients get to screening or treatment services. Connecting with a transportation service (e.g., bus company) may help clients follow through with screening and treatment. |

or any other form of communication. ¹Media campaigns, especially when combined with individual reminders, can lead to an increase in cancer screening behavior. ²In the Pacific Northwest, the Oregon Health Authority (in contract with Metropolitan Group) and NPAIHB's The Cancer You Can Prevent campaign improved CRC screening rates in Clatsop County, OR.

The Oregon Health Authority (in contract with Metropolitan Group) and NPAIHB's complete Cancer You Can Prevent media toolkit is included as Appendix B. Your program can use any of the tools and materials in the Media Toolkit.

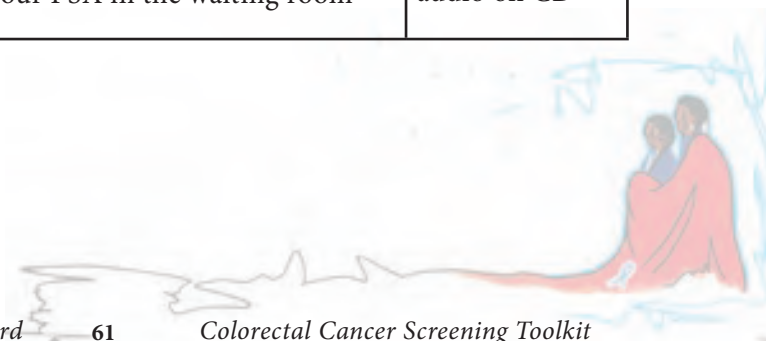
This toolkit includes a number of media materials and examples. Your program may use the provided materials as they are or use the ideas and messages present here to create your own materials. Beyond the suggestions below, think about how and where messages best reach people in your community. The table below is a list of media tools and ideas for how to use each one. Examples and modifiable tools are listed next to each component and are found in the toolkit



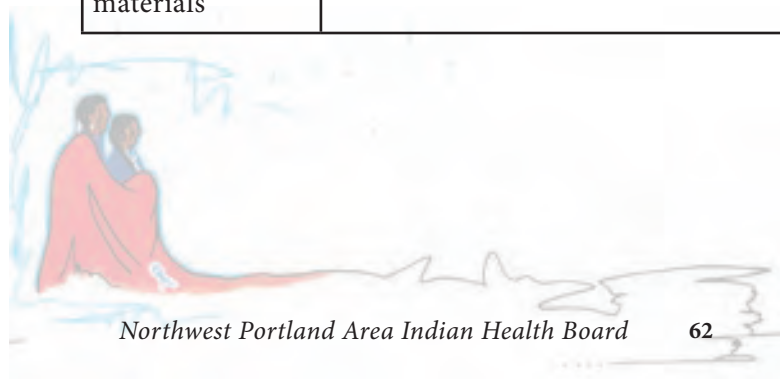
pocket of this chapter.

Media campaigns can be a simple way to increase public awareness. In addition to ongoing media campaigns (e.g., posters, PSA, and brochures), media can be used to promote community events.

| Media Component | Ideas for how or where to use Tribal media tools | Tool reference number |
|--|---|---|
| Brochures | <ul style="list-style-type: none"> Have available at events and community sites | 6.1.1 -6.1.4 |
| Fact Sheets | <ul style="list-style-type: none"> Make sure they are relevant to your communities | 2.1-2.9; 6.1.5-6.1.7 |
| Flyers | <ul style="list-style-type: none"> Have available at events and community sites. Post in community sites (e.g., message boards or clinics) Give out to community members. Give to workplaces to share with employees. Publicize community events (e.g., health fair or other events people can learn about CRC). | 6.1.8- 6.1.11; 6.2.4 (Event planning) |
| Posters | <ul style="list-style-type: none"> Post in community sites, workplaces, or clinics Publicize community events | 6.1.8- 6.1.11 |
| Press release | <ul style="list-style-type: none"> Send to Tribal newspaper for publication Event program publications | Appendix B, pgs. 9-11 |
| Newspaper article or advertisement | <ul style="list-style-type: none"> Submit to your local magazine, newsletter, or newspaper Give to local businesses to send out to employees in workplace newsletters or emails | Appendix B, pgs. 12-13; 6.1.12 & 6.1.13 |
| Mail outs (e.g., postcards, cards) | <ul style="list-style-type: none"> Send out to all community members who are 50 or older | 6.1.14- 6.1.17 |
| Emails | <ul style="list-style-type: none"> Give sample emails to community leaders, workplace supervisors, health care providers and others to send out to their contacts Email your contacts about CRC, possible events, and talking points for CRC | 6.1.18 - 6.1.21 |
| Radio or TV Public Service Announcements (PSA) | <ul style="list-style-type: none"> Contact your local radio station to see if they will read your PSA script Ask the clinic to play your PSA in the waiting room | Appendix B, pgs. 14-15, PSA audio on CD |



| Media Component | Ideas for how or where to use Tribal media tools | Tool reference number |
|---|--|------------------------|
| Speakers at presentations or community events with talking points | <ul style="list-style-type: none"> Identify spokespeople Ask them to speak at a community event (e.g., health fair, powwow or CRC education event) | Appendix B, pgs. 3-6 |
| Spokesperson (e.g., a cancer survivor) Stories | <ul style="list-style-type: none"> Use stories or quotes for newsletters, posters or other materials Ask people to share their stories with others in the community either at events or on their own | Appendix B, pgs. 3-6 |
| CRC Readers' Theater Script (a play or stage reading script) ³ | <ul style="list-style-type: none"> Use "What's the big deal?" theater script or create your own community play or readers' theater Make a stage production with the CRC Readers theater script Invite community members to participate in a group reading event Read the script aloud on a radio show | Appendix C |
| Websites or social media (e.g., Facebook or Twitter) | <ul style="list-style-type: none"> Consider developing a website with CRC screening information including screening locations, options, and costs Share event information or overall CRC prevention tips online Create a video with a spokesperson who will tell their CRC story and post it on Youtube or Facebook Create a safe place for people to have online discussion about CRC, screening, diagnosis, and treatment Use a readers' theater script to create a short movie to post online Promote community health events | 6.1.22 |
| Talking points for health talks | <ul style="list-style-type: none"> Present to a group of elders, potential partners (e.g., radio broadcaster) or to a community group Talk to people you know about CRC prevention basics Share information with Tribal council or health board to gain support of your program | Appendix B, pgs. 1-2 |
| Presentation Slides | <ul style="list-style-type: none"> Use with talking points to introduce CRC to your community Present at community events | (made available on CD) |
| Games or interactive presentation materials | <ul style="list-style-type: none"> Use after any presentation to engage and quiz the community on CRC facts | 6.1.23, 6.1.24 |



Community Education and Event Planning

Community education can vary from one-time events to ongoing health talks or a series of risk reduction workshops (see chapter three). When planning educational event(s) be sure to consider costs, materials, location, and what is possible in your community.

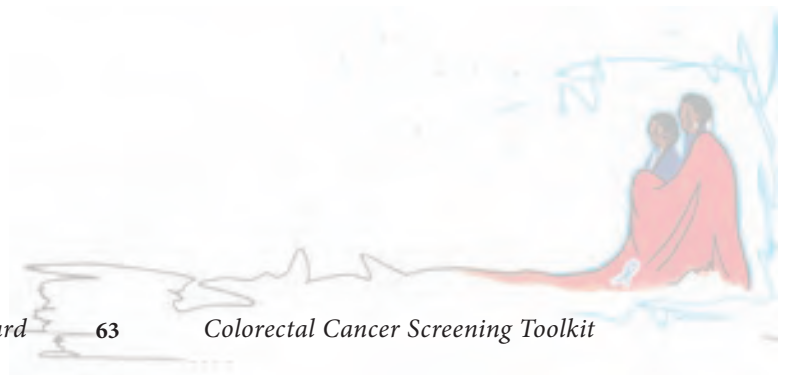
With the tools provided, consider community education options listed below to increase public awareness of CRC:

- Host an informational table at a highly visible location
- Host a table at a health fair
- Plan a CRC screening and prevention informational session
- Plan a series of workshops on CRC education and awareness
- Work with the Diabetes coordinator or other health, nutrition, or fitness people to coordinate health classes or events (e.g., group walking days, cooking classes, or fitness classes)
- Host a small community informational meeting with people you know to help you spread the word
- Give a presentation at a tribal council or health board meeting
- Ask a CRC survivor, family member of CRC patient, or someone who has been screened to share his or her story
- Host a large CRC event day with multiple tables and resources including:
 - o Health care providers
 - o Risk reduction education
 - o Screening information
 - o Kiki (a giant inflatable colon available for events)
 - o Storytellers
 - o Healthy lifestyle presentation

**For examples go to
youtube:**

**[http://www.
youtube.com/user/
ANTHCepicenter/
videos](http://www.youtube.com/user/ANTHCepicenter/videos)**

**Consider hosting
an educational
CRC event during
CRC awareness
month: March**



It is important that events are well planned and evaluated for further improvement. There are multiple event planning resources located in the toolkit pocket of this chapter.

Event planning tools included:

- 6.2.1 Considerations for planning your event
- 6.2.2 Day of event checklist
- 6.2.3 Post Event Checklist
- 6.2.4 Presenter checklist
- 6.2.5 Event flyer templates
- 6.2.6 Sign-in sheet for events
- 6.2.7 Event Evaluation Instructions
- 6.2.8 Participant Evaluation Form
- 6.2.9 Summary evaluation Spreadsheet
- 6.2.10 Event Comments Summary Form
- 6.2.11 Post-Event Program Team Evaluation

Recruiting Participants

Once you decide what type of education events your program will coordinate, you will need to consider how to encourage community members to attend events and activities. Media and advertising campaigns are one way to spread the word, but you should also consider promoting events through people. Identify appropriate places and times to talk to community members. Events (e.g., powwows or health fairs) and community sites are good times to connect with people.

Beyond talking to people at community events, it is effective to have high profile tribal members (people who many community members know and look up to) advocate for CRC prevention. Identify community leaders or people who many others look to for guidance. Ask them to be champions for your program by spreading the word. This may mean they tell their friends why CRC screening is important or that they speak on behalf of CRC screening at a local event. Below is a list of locations to recruit individuals:

- Community centers
- Fitness center
- Workplaces
- Health clinics
- Health fairs
- Homes of target population
- Powwow
- Sweat lodges
- Tribal Treaty and Restoration Events
- Long houses



Kiki the Colon

Contact Eric Vinson
at NPAIHB for
more information.
evinson@npaihb.org



While planning events, make your workshops and activities engaging and interesting. Try using games or story telling instead of traditional presentations. Don't make every presentation exactly the same; try new and exciting styles to keep people interested. Also, ask people what kind of activities or presentations interest them most. You can ask people before an event what they are interested in or you can ask them after to learn what they enjoyed most. At the end of an event ask your participants to spread the word. For example, if ten people come to your first workshop and they really like it, ask them to each bring one friend to the next prevention workshop to double participant rates.

Be sure to consider accessibility and convenience for your target population. Can people get there easily or will you need to provide transportation? Frequent and short (less than 60 minutes) workshops have been shown to attract and retain more participants than longer workshops⁴. Other ways to increase attendance at your event or workshop include providing incentives and making sure your events are accessible. Incentives (e.g., prizes, small gifts, or food) do not have to be expensive. There are differing opinions on the use of incentives, so maybe just use them for the first couple of events. Be creative and think what would help you attend a community event.

Level one tools will help you increase community awareness about CRC prevention and screening. Tools in this level include materials for developing a media campaign and coordinating events.

Level Two- Individual Awareness and Motivation

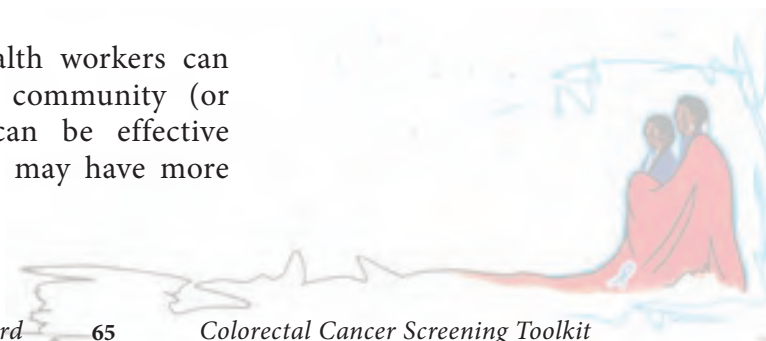
Media campaigns and events are useful community-wide methods of increasing CRC awareness. Unfortunately, media messages may not reach every individual in the target population and individuals may not be immediately willing to participate in health events or workshops. Individual counseling can build on community awareness efforts. Level two describes strategies for increasing individual motivation. Below are ideas for individual education and counseling.

Individual Counseling

Health care providers or community health workers can conduct patient counseling. Sometimes community (or non-health care provider) counseling can be effective because CHRs or other program workers may have more

“We advertised that we had local speakers who were gonna tell their experience of cancer survivorship. They came to listen to that.”

- Tribal Focus Group, 2011



time to spend with patients. One-on-one counseling and health messaging may be more fitting for some individuals because each conversation can be tailored. In some cervical cancer programs, people were more receptive to individual counseling because they felt that someone was more invested in their health and wellbeing⁵.

Any kind of individual health counseling can be used to make the patient feel more comfortable with the disease, screening process and treatment. Simple and clear messaging will help the patient make informed and educated decisions about his or her health. Some cervical cancer programs have shown that giving patients detailed and complete information increases the likelihood that a patient will follow through with screening and on-going prevention efforts⁶.

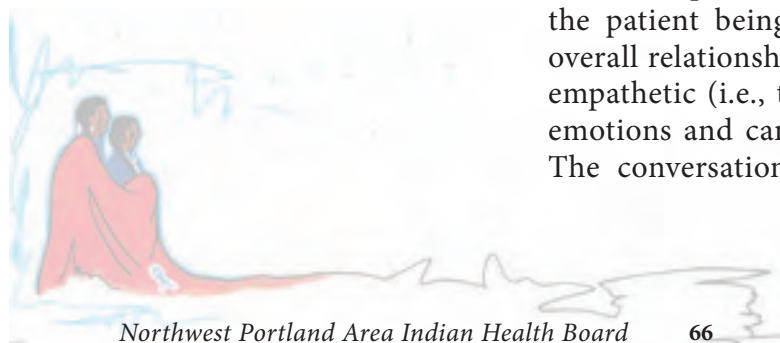
Although there are many types of counseling, this toolkit focuses on motivational interviewing because it respects AI/AN cultural values and is a promising tool for promoting CRC screening⁷.

Motivational Interviewing

Motivational interviewing (MI) ⁸is a counseling technique used to help way of communicating with individuals to increase their inner desire for and commitment and to change. MI was developed for substance abuse related health behaviors and addictions, but can also be applied to improving individual motivation for other health behaviors. Many communities use MI to promote patient behavior changes related to physical health, including overcoming barriers to receiving CRC screening. The MI method involves building trust with individual clients to guide them to find their own inner strength to change a behavior. MI is a powerful tool to help people make changes because it targets people's own motivation and ability to create solutions for themselves.

How Does Motivational Interviewing Work?

The basic components of MI are collaboration, drawing out ideas patients already have, and not forcing change on patients⁹. Motivational interviewing works by focusing on relationship building. MI focuses on the interviewer and the patient being equal in the conversation and in their overall relationship. The interviewer is non-judgmental and empathetic (i.e., the interviewer is sensitive to the patient's emotions and can see the world through the client's eyes). The conversation is centered on increasing the patient's



awareness of the behavior and its consequences, risks, or other issues. The purpose of the interview is to explore the patient's own thoughts on a behavior and encourage his or her inner motivation. Throughout the process, the interviewer supports change and helps the patient identify current resources to make healthier choices for him or herself.

Native Communities and MI

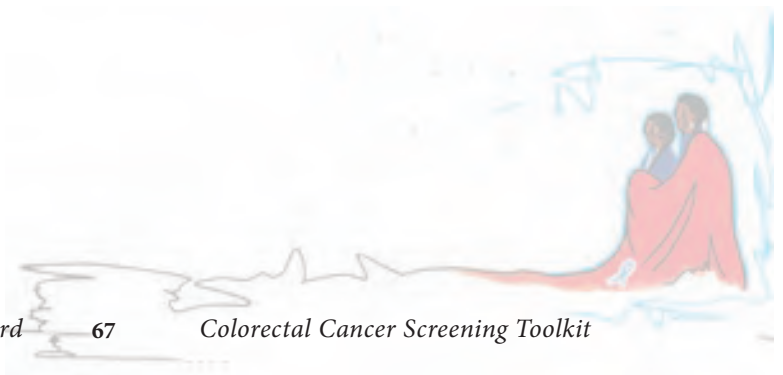
MI works well for many AI/AN communities for multiple reasons:

- MI promotes working with communities and not telling them what to do
- MI values a holistic and balance-oriented view of change and behavior
- MI relies on non-confrontational interaction
- MI engages people in solving their own problems
- MI respects the person's right to his or her own opinions
- MI supports self-efficacy (i.e., a person's willingness and ability to change) by supporting current strengths and resiliency
- MI fosters patients' belief in the possibility of change

Motivational interviewing focuses on encouraging people to gain control over their lives and supports the idea that communities have their own resources to bring about health and wellness. A respectful attitude, awareness of how problem behaviors affect the community, and teaching through doing are important cultural values that may help to facilitate change among AI/AN communities.

For a brief outline on how to conduct MI, refer to tool 6.3 in the toolkit pocket of this chapter.

Level two builds from level one by focusing on individual needs. Level two includes tools and information for working with people who may be reluctant to be screened.



Examples of Existing Community Programs in Native Communities

There are successful programs that focus on CRC risk reduction and prevention among tribal communities. CRC screening and prevention programs are often integrated with other public health programs to promote preventive screening and overall health. Below are some successful CRC programs in tribal communities:

South Puget Intertribal Planning Agency (SPIPA) Colon Health Program

The SPIPA Colon Health Program is rooted in community participation and serves seven southwest Washington tribes. The Colon Health Program reaches out to the tribal communities by connecting with patients at tribal health fairs and using community health representatives known as Patient Navigators. Patient Navigators promote screening and encourage tribal members to sign up for screenings at community events. As an added incentive for those who sign up for screening, the program does quarterly drawings for prizes. SPIPA also uses iPads to show colorectal health information in an interactive and entertaining way.

CRC Programs in Alaska

There are three CRC screening and awareness programs for Alaska Natives: the Southcentral Foundation's Medical Services Screening and Prevention "Colorectal Screening Program;" the Arctic Slope Native Association "Screening for Life Program;" and the Alaska Native Tribal Health Consortium (ANTHC) "Colorectal Cancer Program." Like SPIPA's Colon Health Program, ANTHC's Colorectal Cancer Program takes advantage of Patient Navigators to spread awareness and encourage community members to be screened. ANTHC also takes a culturally targeted approach in their cancer education program by utilizing tools such as a Healing Drum to symbolize tribal collaboration.

For more information on ANTHC's program visit their website at www.anthctoday.org/epicenter/colon/



Cherokee Nation

In Oklahoma, the Cherokee Nation Comprehensive Cancer Control Program (CNCCCP) has taken a slightly different approach. The CNCCCP obtained a giant replica of the a human colon to raise community awareness at a Cherokee National Holiday celebration to emphasize the importance of screening and prevention. Visitors can walk through a “Super Colon” that displays the various stages of CRC. They combined the larger than life visual with important CRC facts and pre- and post-quizzes. To encourage visitor participation, door prizes were raffled-off to people who completed the post-quizzes.

5-2-1-0 Let’s Go! Program

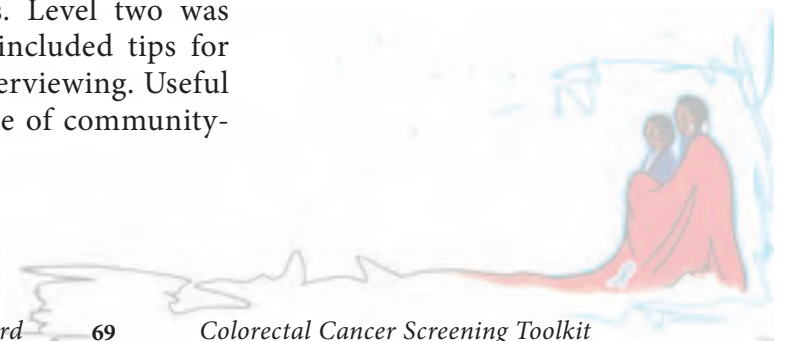
The 5-2-1-0 program doesn’t target CRC specifically, but is a simple approach for overall healthy living.

- 5 – Eat 5 fruits and vegetables every day.
- 2 – Limit screen time (TV, computer, video games) to 2 hours or less each day.
- 1 – Strive for 1 hour of physical activity a day.
- 0 – Limit the consumption of sugar sweetened beverages.

The number design is an easy way for people to remember small ways to improve their health. Patients pick a number and work on adding that number and its related behavior to their daily routine. They gradually work on adding all of the numbers and behaviors. This program shows that individuals can make small changes in their lifestyle to lower their CRC and other chronic disease risk. For more information, visit the Let’s Go Program website: www.lets-go.org

Implementation for Community-Based Programs Summary

This chapter described two levels of community-based CRC screening and prevention program implementation. Level one focused on increasing community awareness through media campaigns and educational events. Level two was centered on individual level change and included tips for individual counseling and motivational interviewing. Useful tools and guides are included for each type of community-based programming.



Tool Box Description

6.1

- Community awareness media tools begin with 6.1. These tools and templates can be used for community education and mass media campaigns.
- Many of these tools are successful examples of CRC campaigns and small media materials.

- 6.1.1 CDC CRCS Brochure
- 6.1.2 CRC Mini Brochure Native American
- 6.1.3 CRC screening brochure 10.07 Forest county Potawatomi AI & AN
- 6.1.4 Simple Colon
- 6.1.5 ACS CRCS Fact Sheet
- 6.1.6 CDC CRCS Fast Facts
- 6.1.7 Urban Indian CARES-fact-sheet AI & AN
- 6.1.8 CRC Poster Native American
- 6.1.9 Medicine Wheel Poster Michigan
- 6.1.10 PosterMichigan AI & AN
- 6.1.11 Urban Indian CARES poster AI & AN
- 6.1.12 Colon Native Final
- 6.1.13 CRC Daily Astorian fullpage v.6
- 6.1.14-17 Mailout Cards
- 6.1.18 UCAN Advertorial full page employee v.10
- 6.1.19 Sample Email Blasts
- 6.1.20 Basics for Starting a Social Media Campaign



6.2

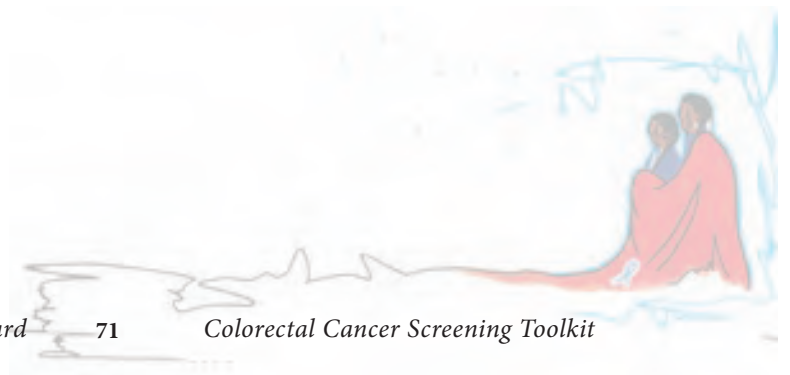
- Event planning tools begin with 6.2. These tools and worksheets will help ensure any community event is well planned and evaluated.

- 6.2.1 Considerations for event planning
- 6.2.2 Day of Event Checklist
- 6.2.3 Post Event Checklist
- 6.2.4 Presenter Checklist
- 6.2.5 Event Flyer template
- 6.2.6 Sign in sheet for events
- 6.2.7 Event Evaluation Instructions
- 6.2.8 Participant Evaluation Form
- 6.2.9 Summary Evaluation Spreadsheet
- 6.2.10 Event Comments Summary for Participant Evaluation
- 6.2.11 Post-Event Program Team Evaluation

6.3

- This tool is intended to instruct someone who does not yet have a background in MI and is unable to attend training. The basic tips should allow anyone to utilize some MI techniques in one-on-one patient interactions.

- 6.3.1 Basic Tips for Motivational Interviewing







Northwest Portland Area Indian Health Board
Colorectal Cancer Program Toolkit

Part Three:
Collaboration





Collaboration Between Community and Clinical Programs

Collaboration between Community and Clinical Programs

The most effective CRC programs have fluid and integrated community and clinic programs. Although complete collaboration is optimal, it can often be challenging for community-based health programs and clinics to work completely collaboratively. Sometimes, clinics and/or community-based programs perceive that their efforts are seen and understood by their clinic or community counterparts, when in reality they are not.

For example, in one Northwest tribal focus group CRC screening rates were relatively high, but community focus group participants felt that the clinic was not effectively reaching out to the community. In contrast, according to clinical key informant interviews, the clinic promoted CRC screening in the community and increased screening rates. The focus group participants (most of who were in the target age group to get screened) said they had not had any contact with the clinic about being screened. This example shows why clinic and community collaboration is important, challenging and hard to measure.

This chapter is designed to help facilitate working partnerships between community-based programs and clinical services. Program and clinical services collaboration is important in comprehensive health care. When clinical services and community-based health programs work together, patients have improved understanding, access, and health outcomes. The information in this chapter is intended for both clinics (and other CRC screening providers) and community-based programs



“Access to health care and the cancer centers is a barrier. The system for getting there is complicated and cumbersome.”

— Andy Joseph Jr.

**Confederated Tribes of the
Colville Reservation**

"Our Contract Health Case Manager, keeps track of who is having CRC screening tests. There is an opportunity for free/open communication to discuss things like CRC on the elders bus"

-Tribal Key Informant
Interview - 2011

Although this chapter offers many ideas, there are numerous situations that may occur in different communities. This chapter will encourage a framework that guides clinics and programs towards collaboration. Some specific collaboration issues are addressed including reaching out to the community (for clinical services), relationship building, and aligning health promotion messaging.

An individual's decision to be screened for CRC is influenced by numerous factors. The most effective interventions address environment, attitudes, knowledge, policy, social beliefs (are my friends getting screened?), costs, transportation, childcare, community support, etc. To effectively address all of these and truly have the greatest impact on CRC prevention and screening rates in your community, clinics and community-based programs must collaborate

Comprehensive CRC Screening and Prevention

First of all, it may be helpful to think about how an ideal program functions. It is important to keep this framework in mind as a goal. The most effective secondary prevention method (i.e., a colonoscopy) can be complicated because it is invasive, expensive, sometimes scary, and patients cannot go to their primary tribal clinic for this procedure. This demonstrates a need for resources from multiple sectors. Meaning, primary care providers are not necessarily the only people who will serve a person who needs to be screened for CRC. Depending on your tribal community, collaboration for a successful program may involve CHRs or Patient Navigators, primary care providers, health educators, benefit and transport coordinators. If your community clinic can offer screening services and a community-based program, then strong collaboration will include all of the following elements:

1. Community partners and clinicians meet regularly to discuss program details, timelines, challenges and success to screening and prevention in both clinics and community. Together they determine how to address any issues or challenges while sharing successes.
2. CHRs know about the CRC services at the clinic. They know hours, capacity, and challenges the clinicians are dealing with.



3. Clinicians know challenges in the community and work to address community barriers with CHRs (and other health promotion program coordinators).
4. Program objectives are mutually agreed upon and data is shared mutually (e.g., CHRs are aware of GPRA numbers and indicators). CHRs know if CRC screening rates have improved.
5. Program evaluation is conducted jointly.
6. Messaging and services are aligned. CHRs can tell patients what to expect at the clinic. Streamlined language is used regarding screening processes.
7. Clinicians and community partners identify and apply for program funding for their CRC program jointly.
8. If the clinic is part of the Improving Patient Care (IPC) program, then there should be an active IPC community liaison who clinicians know and work with.

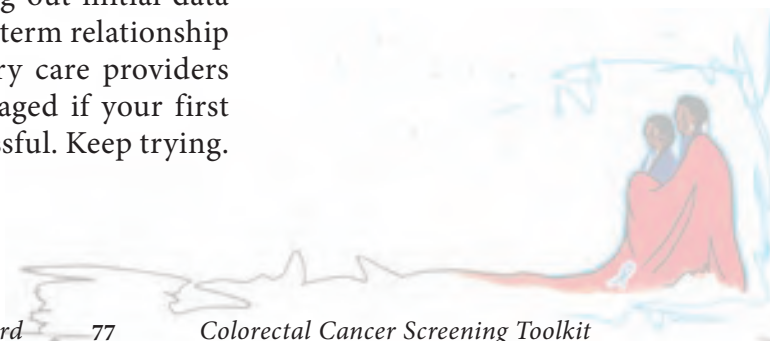
An ideal collaborative CRC prevention and screening program will have all of the above components and potentially more. Based on focus groups and research among Northwest tribes, collaboration is still a challenge for many communities. The following sections of this chapter identify some strategies for community-based programs to reach out to clinics, and clinic-based programs to reach out to community health. **It is always important to remember that the health of your community is a common goal that clinical and community-based health programs share.**

Community-based Program Outreach to Clinics

This section is for community-based programs that are looking to connect with their clinic about CRC prevention and screening. It is a more in-depth version of chapter six's "Get to Know Your Clinic" section. That section focuses on setting up a preliminary meeting with the clinic to get an understanding of CRC screening services and screening rates. It is important to go beyond finding out initial data and clinic services and instead build a long-term relationship with the clinic. Keep in mind that primary care providers are incredibly busy. Try not to be discouraged if your first attempts to reach out to them are not successful. Keep trying.

"By gentle persuasion; telling them the CRC statistics, giving them the education and letting them make up their mind, we created 'Cancer champions'. We found this to be helpful, encouraging others to get screened by sharing their story."

- Tribal Key Informant Interviews, 2011



When you are establishing your program and looking for program partners, it is important that you build trust, a quality program, and increase visibility. You want potential partners to take your program seriously. You can build program credibility by including any potential partners in the community needs assessment and program planning process (as seen in chapters four and five). To maintain contact and continue building your relationship, consider having a list of contacts who are interested in your program and send them monthly updates of your program. If program staff is more than one person, make sure there are consistent messages and goals.

Program visibility is also important to realizing the partnership potential of your new program. You want to make sure your program is known and visible in the community. One way is to participate in committees or coalitions. For example, if you are a participant of the Northwest Tribal Cancer Coalition, other coalition members will know you and your program and may be able to offer their help or advice. If your tribe has a health committee, this would also be a great place to be involved. If your program is housed in a clinic, make sure you are an active and visible employee at the clinic. Get to know others at the clinic and let them know what your program offers.

The key to any successful partnership is a strong relationship. See Tool 7.1 for tips on building new professional relationships.

Once you have a formal meeting set up with the clinic, go over information you think you will need from them. Remember, a partnership is beneficial to both partners. Think about how your program can help the clinic and emphasize that your goal (decreasing the impact of CRC) is the same. Tool 7.2 is a list of questions to ask the clinic. These questions are in addition to the, "Get to know your clinic" questions presented in chapter six.

Clinic-based Program Outreach to Community Partners

This section will be useful if your clinic is looking to partner with an existing CRC program or another health promotion program in the community. Many communities may not have a CRC prevention or screening program. If your clinic is looking to develop a new community program, please



see chapters two through six. The first step for clinics is to identify community program partners to approach (e.g., CRC prevention coordinator, tobacco coordinator, CHR, CHN, PHN, and/or tribal wellness coordinator). Tool 7.3 will help assess clinic workers knowledge of community-based programs and identify potential partners. Once you have set up a meeting, use tool 7.1 for useful tips on building new professional relationships. If you were unable to identify potential partners, consider making your cause known in the community. In other words, make your CRC program visible. If there are people interested in helping, they may step forward. For example, give community presentations frequently and ask for volunteers from the community.

Patient Navigators

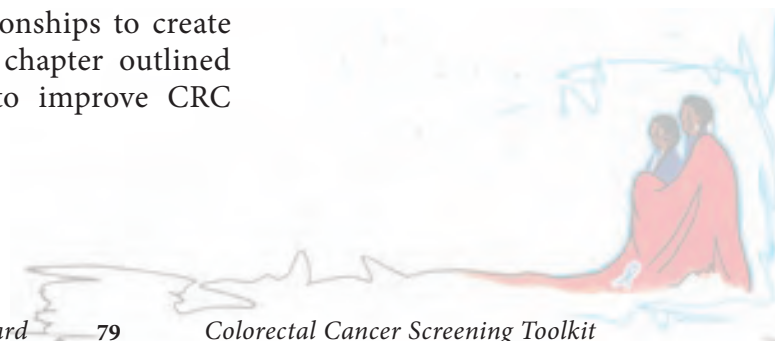
Some tribal health programs have patient navigators at their clinics to coordinate patients' cancer care and help patients overcome barriers to appropriate diagnosis and treatment of cancer. Navigators are in a position to be a strong partner for your CRC screening program. In many tribal communities they are involved in outreach and education in addition to case management.

Community-based Program Outreach without a clinic

There are some tribal health programs that don't have clinical services. There are also tribes that have satellite offices with limited resources. These can be challenging situations, but the community program can still reach out to community members and connect them to nearby clinical services. Without a clinic, consider building capacity to improve transportation services to your closest clinic.

Community Chapter Summary

The most effective CRC screening programs are collaborative efforts between the clinic and the community. Comprehensive programs will focus on community-level prevention and education as well as clinical processes to increase screening rates. Collaboration can be challenging, but can work if both groups take time to build trust and relationships to create a sustainable program partnership. This chapter outlined partnership building recommendations to improve CRC screening.



Tool Box Description

7.1 Tips for building Professional Relationships

7.2 Questions to ask Your Clinic

- For community-based health program

7.3 Community program Assesment for Clinic Based Program

- This list is a good place to start for a quick self-assessment of how well clinicians know what preventative and screening promotion efforts already exist in the community. This tool can be used in addition to questions in tool 4.1 Community Readiness Assessment.





Northwest Portland Area Indian Health Board
Colorectal Cancer Program Toolkit

Part Four:
Clinic Programs







Chapter 8:

Clinical Screening Program Preparation

Clinical Screening Program Preparation

Introduction

Previous chapters of this toolkit focus on promoting colorectal cancer screening and prevention in tribal communities. This chapter is about Northwest tribal clinics, existing cancer and screening rates, and potential improvement areas for clinics and community health workers, as identified in our focus group and key informant interviews. This chapter includes a brief overview of Indian Health Services' Improving Patient Care (IPC) model, as well as resources for improving CRC screening- and other services- through team-based approaches for patient care, building clinic capacity for prevention, screening and increasing patient tracking. Lastly, examples from two regional clinics that have successfully improved their screening rates will be described in detail.

Northwest Tribal Clinics

There are 43 federally recognized tribes in the Northwest Portland Area Indian Health Board service area of Washington, Oregon and Idaho. There are 39 tribal clinics in this service area. Each clinic is different and there is a wide range of clinic capacity. Some are large, well-staffed clinics with over 10 full primary care providers (including both doctors and nurse practitioners). Other tribal clinics are extremely small, rural and have primary care providers on a rotating schedule. In Indian country, there is a wide variety in clinic capacity so there is no one, single method for increasing CRC screening. There are many resources, including utilizing the IPC model, that are outlined below, however example success stories may be more effective in guiding your community's clinic in increasing screening rates.

What are the keys to your clinic's success in colorectal screening ?

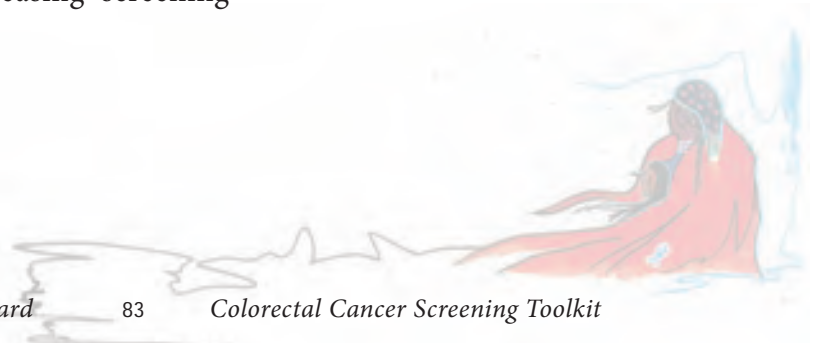
The Electronic Health Record reminder, puts CRC screening in the face of provider and nursing staff;

IFOBT vs. old cards has also become easier for patients because it is only one test;

Brightly colored envelopes are used for kits so that they stand-out at home;

Having GPRA and IPC objectives help to improve screening;

And, also receiving individual feedback regarding the GPRA scores help



Overview of Recommended Screening Tests

Fecal Immunochemical Test (FIT): This is a recent improvement over the traditional, guaiac-based FOBT. It uses a different immunochemical process to detect fecal occult blood that is more sensitive than the guaiac-based FOBT. It only requires one sample instead of three, includes a small plastic vial filled with liquid in which the stool sample is placed and does not have the dietary restrictions of the FOBT. Because of these characteristics, the FIT test is preferred over the FOBT for those clinics that offer stool testing for CRC screening. The FIT test is more expensive than traditional FOBT, but improves completion rates by patients. Despite better test performance characteristics, FIT tests have not been shown to be any more cost effective than guaiac-based FOBT¹.

Regardless of which type of stool-based test is used—the traditional FOBT or the newer FIT—it is important to keep in mind that these tests must be repeated annually in order to sufficiently screen patients and that any positive test result must have a complete colonoscopy performed. Pitfalls in stool-based screening include: failure to re-screen annually, failure to adequately educate the patient to collect the sample, failure of patients to return all samples properly or to follow dietary restrictions and failure of clinicians to follow-up on a positive test. For these reasons, and the fact that stool-based screening is not specific for CRC, endoscopic screening for CRC is preferred where cost is not a barrier for average risk patients.

Flexible sigmoidoscopy (FS): This screening method requires a trained endoscopist using a 30cm sigmoidoscope. The patient must undergo a bowel preparation that includes a low residue diet, laxatives and enemas. FS can be performed in an office or clinic setting and requires no anesthesia. The test can visualize adenomatous polyps in the first 30 cm of the rectum and descending colon, where approximately 2/3 of colorectal cancers occur. Adequate screening with this method requires that it be repeated every five years and that any positive examination is followed by a complete colonoscopy. Disadvantages of FS over stool-based tests are the increased need for patients to be educated and motivated to undergo a test that requires bowel preparation and



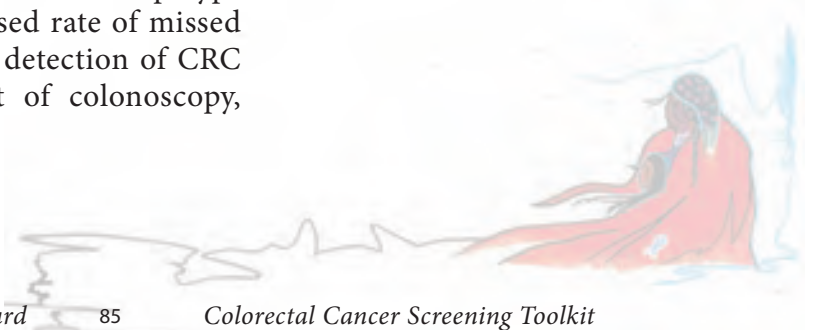
acceptance of a screening test that is invasive.

Colonoscopy: This screening method is the gold standard against which all other CRC screening tests are measured. Colonoscopy utilizes a 60 cm endoscope that fully visualizes the entire colon and rectum. Colonoscopy also allows for removal of adenomatous polyps, the pre-cursors to cancer, and allows for biopsy of suspicious areas. Unlike flexible sigmoidoscopy, colonoscopy does require anesthesia and must be performed in a clinical setting with adequate anesthesia and recovery services such as an ambulatory surgery suite or hospital. CRC screening with colonoscopy must be repeated every 10 years if no suspicious lesions are found. Screening by endoscopy (FS or colonoscopy) is approximately three times more likely to detect advanced CRC compared with fecal tests².

Other available tests: There are other available tests that may be helpful in screening for CRC but at present none of these tests have been recommended by the US Preventive Services Task Force (USPSTF) to screen for or prevent CRC.

Stool DNA Test: This test uses a stool sample to screen for cancerous cells. These tests along with tests that detect RNA and certain proteins associated with CRC show promising advantages over the FOBT or FIT tests in that they have increased sensitivity and specificity for detecting malignant cells and in some cases, cells from adenomatous polyps. However, a recent review did not find that these tests were cost-effective compared to currently available screening methods¹. Further evidence is needed from large clinical trials before these tests can be fully recommended.

CT Colonography (CTC): CTC can be a useful option for certain patients who are unable to undergo colonoscopy because of prior surgery or other reasons, but who still meet criteria for screening. CTC produces high-quality, three dimensional images of the entire colon. The preparation required is the same as that for colonoscopy, however there is no requirement for anesthesia. Advantages of CTC include higher patient acceptance of CTC compared to colonoscopy or double contrast barium enema (DCBE) in some studies, increased ability to detect advanced polyps (>10mm) compared to DCBE and decreased rate of missed cancers compared to DCBE. The rate for detection of CRC and advanced polyps is similar to that of colonoscopy,



however colonoscopy is superior in the detection of smaller (< 6 mm) adenomatous polyps and flat lesions (< 3mm in vertical height). The primary disadvantage of CTC is the necessity to undergo a second procedure, colonoscopy, in the event of a positive CTC. The inadvertent findings of extra-colonic pathology, which leads to additional diagnostic tests or procedures, is perceived as both an advantage and a disadvantage. In the case of identification of asymptomatic aortic aneurysm, there could be an advantage in decreased mortality and enhanced cost-effectiveness; while in the case of the identification of other conditions, including other cancers, the cost-effectiveness may be negated by the additional diagnostic and treatment procedures that patients undergo, which may or may not decrease mortality³.

Double Contrast Barium Enema (DCBE): DCBE is another radiologic method for viewing the colon and is still endorsed as a primary screening option by the American Cancer Society, US Multi-Society Task Force on Colorectal Cancer and the American College of Radiology. Because of superior performance of CTC compared with DCBE, The UK Department of Health no longer includes DCBE in its CRC screening program. DCBE requires colonic preparation as do CTC and endoscopy, offering no patient comfort advantages. Another factor affecting DCBE as an acceptable alternative is the relative lack of experience in performing and interpreting DCBE among radiologists in practice today.

The table below summarizes the recommendations for screening by two consensus guideline groups: 1) the joint statement of the American Cancer Society, US Multi-Society Task Force on Colorectal Cancer; and 2) the American College of Radiology (ACS/USMSTF/ACR) and the US Preventive Services Task Force (USPSTF).

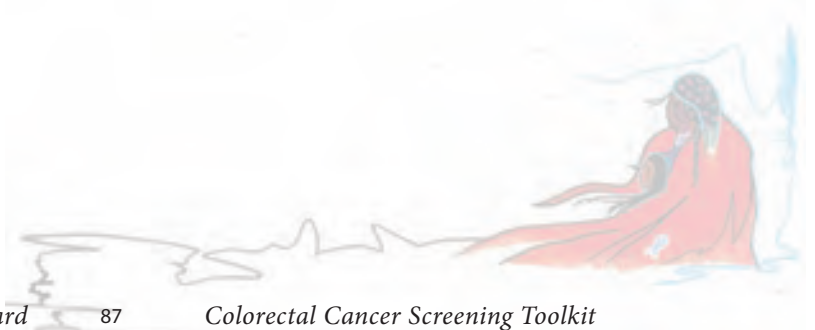
From:

<http://www.cancer.org/Healthy/InformationforHealthCareProfessionals/ColonMDCliniciansInformationSource/ColorectalCancerScreeningandSurveillanceGuidelines/comparison-of-colorectal-screening-guidelines>



Age to Begin and End Screening, and Test Prioritization

| Recommendation | ACS/USMSTF/ACR ⁴ | USPSTF ⁵ |
|---|--|---|
| Age to begin and end screening in average risk adults | Begin at age 50 and end screening at a point where curative therapy would not be offered due to life-limiting co-morbidity | Begin screening at age 50. Routine screening between ages 76-85 is not recommended. Screening after age 85 is not recommended. |
| Screening in high risk adults | Detailed recommendations based on personal risk and family history | No specific recommendations for age to begin testing or type of testing |
| Prioritization of tests | Tests are grouped into those that (1) primarily are effective at detecting cancer, and (2) those that are effective at detecting cancer and adenomatous polyps. Group 2 is preferred over group 1 due to the greater potential for prevention. | No specific prioritization of tests, though recommendations acknowledge that direct visualization techniques offer substantial benefit over fecal tests |
| Stool Testing, Guaiac based FOBT (gFOBT) | Annual screening with high sensitivity guaiac based tests | Annual screening with high sensitivity guaiac based tests |
| Stool Testing, Immunochemical-based FOBT (FIT) | Annual screening | Annual screening |
| Stool Testing, Stool DNA (sDNA) | sDNA is an acceptable option | Insufficient evidence to recommend for or against sDNA |
| Flexible Sigmoidoscopy | Screening every 5 years. Screening every 5 years, with annual gFOBT or FIT is an option | Screening every 5 years, with gFOBT every 3 years |
| Colonoscopy | Screening every 10 years | Screening every 10 years |
| CT Colonography | Screening every 5 years | Insufficient evidence to recommend for or against CT colonography |
| Double Contrast Barium Enema (DCBE) | Screening every 5 years | Not addressed |



Determining Levels of Screening

Recommendations for CRC screening are based on the natural history of disease and the relative health of the patient. Some patients may have conditions that place them at higher risk to develop CRC or could cause CRC to occur at a younger age. In developing a clinical practice, it is recommended to focus on a stratified CRC screening approach that identifies three risk levels: those at average risk, those at increased risk and those at high risk for CRC. Finally, some patients may be severely ill from co-morbid conditions and may not be candidates for CRC screening. Screening algorithms should be flexible enough to account for this patient group, as well.

Level 1: Average-risk

Men and women aged 50—80: Patients in this age group have no first-degree relatives with a history of CRC or adenomatous polyps.

Level 2: Increased Risk

Patients at increased risk either have a personal history or a family history of adenomatous polyps or CRC. These patients should NOT be screened with FOBT/FIT or FS tests but should be screened directly with colonoscopy. Because the incidence of adenomatous polyps increases with age, the proportion of individuals who fall into this category also increases with age, from around 20 to 25% at age 50 to 50% by age 75.

Level 3: High Risk

Patients at high-risk for CRC have one of three recognized hereditary syndromes that are associated with early onset and high probability of developing CRC. These syndromes include: hereditary nonpolyposis colorectal cancer (HNPCC), familial adenomatous polyposis (FAP), and attenuated FAP (AFAP). Patients with one of these three syndromes should be referred to specialty care for early and more intensive surveillance for CRC. ⁶Identifying these patients in the primary care setting can be challenging and requires careful elicitation of family history for any relative with the following:

- CRC or adenomas diagnosed prior to age 50
- Endometrial cancer diagnosed prior to age 50



- Two or more HNPCC-related tumors in a family or in an individual*
- Multiple colorectal adenomas (usually 10 or more) diagnosed over one or more exams

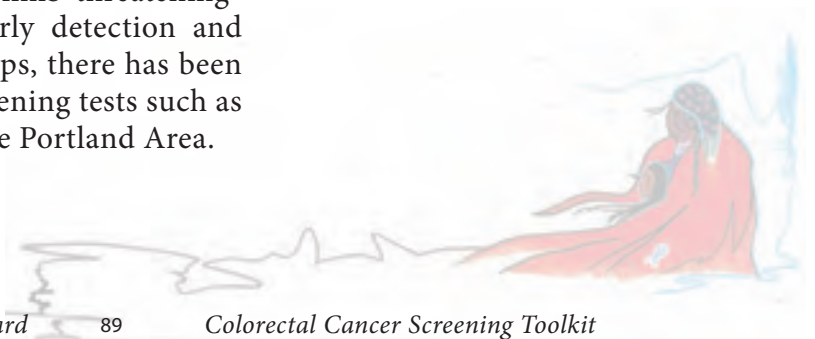
* HNPCC-related tumors include colorectal, endometrial, stomach, ovarian, pancreas, ureter and renal pelvis, biliary tract, brain (most often glioblastoma), small bowel, pancreatic, sebaceous gland adenomas and keratoacanthomas.

Building An Effective Office-Based CRC Screening Program

To build an effective office-based CRC screening program, it is important to identify what resources are available to support screening (i.e. availability of colonoscopy, financial resources), to clearly delineate who is responsible to initiate screening, to assign responsibility for follow-up of incomplete and positive screening tests and to determine how screening will be forecast and tracked for your patient population. Clear office policies for each of these areas will help achieve success in meeting CRC screening goals.

Identifying Resources

In the Indian Health system, which includes IHS, Tribal and Urban Indian Health Clinics (I/T/U), colonoscopy is generally not available except through referral to outside providers. Some areas, for example Alaska Area, have a network of trained mid-level providers who can perform flexible sigmoidoscopy. In the Northwest, the I/T/U clinics only provide outpatient services at free-standing ambulatory care clinics. Payment of referral care services is arranged through Contract Health Services (CHS), through other public sources (Medicare, Medicaid) or through private insurance. Because CHS funds can only be used to pay for the care of Tribal members living within the Contract Health Service Delivery Area (CHSDA) of a specific clinic, many AI/AN living in the Northwest may not be covered under this system. It is also a system that is severely underfunded leading to prioritization of care based on the severity of the condition. Under the current prioritization system, most clinics allocate almost their entire CHS budget to patients with Priority I, defined as “life or limb-threatening” conditions. Given the importance of early detection and treatment of CRC and pre-cancerous polyps, there has been interest in considering designation of screening tests such as colonoscopy as Priority I procedures in the Portland Area.



For those patients who are not eligible for CHS funded services, public or private insurance resources can be utilized to pay for CRC screening services. Patients over the age of 65 or who are disabled qualify for Medicare, which does pay for CRC screening (see table below).

Approved Medicare Colorectal Cancer Screening Tests

| Screening Test | Frequency | Recommended Population | Payment |
|--------------------------------|-----------------------|--|--|
| Fecal Occult Blood Test (FOBT) | Once every 12 months | Average risk | Patient pays nothing for the test, but you generally have to pay 20% of the Medicare-approved amount for the doctor visit |
| Flexible Sigmoidoscopy | Once every 48 months | Average risk or 120 months after a previous screening colonoscopy if remain average risk | Patient pays 20% of the Medicare-approved amount with no Part B deductible. If the test is done in a hospital, outpatient department, or an ambulatory surgical center, you pay 25% of the Medicare-approved amount |
| Screening Colonoscopy | once every 120 months | Average risk or 48 months after a previous flexible sigmoidoscopy | Patient pays 20% of the Medicare-approved amount with no Part B deductible. If the test is done in a hospital, outpatient department, or an ambulatory surgical center, you pay 25% of the Medicare-approved amount |
| | once every 24 months | High risk | |
| Barium Enema | every 48 months | Average risk | Patient pays 20% of the Medicare-approved amount with no Part B deductible. If the test is done in a hospital, outpatient department, or an ambulatory surgical center, you pay 25% of the Medicare-approved amount. |
| | every 24 months | High risk | |

Adapted from information available at: <http://www.medicare.gov/navigation/manage-your-health/preventive-services/colon-cancer-screening.aspx?AspxAutoDetectCookieSupport=1>



For those eligible for Medicaid, covered procedures may vary from state to state⁷. States participating in Medicaid are not required to provide CRC screening services. Clear disclosure of specific coverage of which CRC screening tests from each state was not readily available in an on-line search. For example, in ID, the Medicaid program provides payment for screening examinations currently recommended by the USPSTF^{8,9,10}. In Oregon, state law requires coverage of ACS recommended screening tests; in Washington, the law requires coverage for USPSTF or CDC recommended screenings⁹. It is recommended that providers and patients contact the Medicaid program in their states to be sure that screening costs will be covered. For those who are not eligible for any of the above and are uninsured, additional resources may be available¹⁰.

The conversation about paying for preventive services, like CRC screening, is changing rapidly with the passage of the Affordable Care Act (ACA). This legislation will ensure that CRC screening and other preventive services are provided by all plans participating in the health insurance exchanges *without charging co-pays*. At the time of this publication, State-based health insurance exchanges are not yet available for enrollment. Information about ACA covered preventive services can be found at:

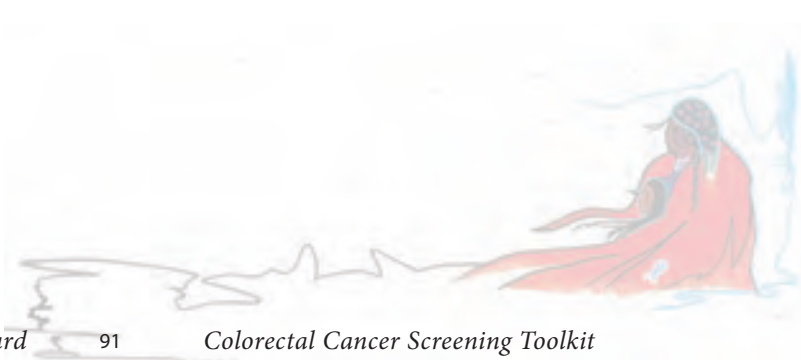
<https://www.healthcare.gov/what-are-my-preventive-care-benefits/>

For state-specific information, check the following websites for details:

Idaho: <http://www.yourhealthidaho.org/>

Oregon: <http://www.coveroregon.com/>

Washington: <http://www.wahealthplanfinder.org/>



Clinic Staff Roles and Responsibilities

The majority of Northwest I/T/U clinics use RPMS to collect patient information, including information about CRC screening, risk factors and related diagnoses. Although some clinics use commercially available systems, expertise on the capabilities of these systems is not widely available and there is no specific support for any other clinical data system other than RPMS at this time. For I/T/U clinics utilizing the RPMS Electronic Health Record (EHR) and for many other EHR systems, the use of clinical reminders is an effective tool for knowing when to recommend CRC screening. Forecasting logic in the RPMS system considers patient age, prior screening, prior diagnoses and family history if this information has been entered into the patient's medical record. For example, an average-risk patient who is 50 years old with no prior screening history will be forecast to receive some form of CRC screening. If the patient successfully completes an FOBT, he will be forecast for screening again in 12 months. However, if he undergoes colonoscopy and the result is negative, he will not be forecast to be screened again for 120 months (10 years).

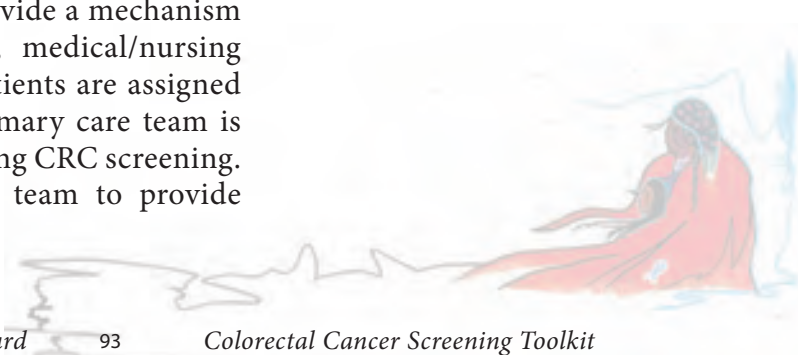
For an office with EHR, the following roles and responsibilities should be considered: (see table on next page)



| Role | Responsibility |
|---|--|
| Maintenance of Information Technology Infrastructure: computer systems, current version of RPMS/EHR | Information Technology Site Manager |
| Display of Clinical Reminders | Clinical Applications Coordinator (CAC) |
| Training in use of EHR, including clinical reminders | CAC |
| Review of CRC Clinical Reminders at every visit | RN/LPN or MA/NA interacting with patient during clinic visit |
| Initial offer of CRC screening | RN/LPN or MA/NA interacting with patient during clinic visit |
| Follow-up of CRC Screening offered | RN or LPN case manager |
| Follow-up of refusals | Primary Care Provider |
| Discussion of positive results, referral for specialty care or further testing as needed | Primary Care Provider in collaboration with RN/LPN case manager |
| Patient Education | Entire care team has a responsibility to educate the patient according to the patient's readiness to learn |
| Pre-test | RN/LPN or MA/NA interacting with patient during clinic visit |
| Post-test | Primary Care Provider in collaboration with RN/LPN case manager |

Even without EHR, clinics using RPMS can readily assign and perform these same roles and responsibilities if they make use of the Health Summary at each visit. The Health Summary is a feature within RPMS that can be customized to display the latest information on a variety of clinical conditions, including recommended screenings. In the absence of a full EHR with clinical reminders, a fully optimized health summary for each patient with up to date clinical information can be quickly reviewed at the start of every clinic visit to determine the need for CRC screening.

Ideally, care teams are established that provide a mechanism for good collaboration between nurses, medical/nursing assistants and primary care providers. Patients are assigned to these teams making it clear which primary care team is responsible for routine screenings, including CRC screening. Methods can be optimized within each team to provide



appropriate education, testing, referral and follow-up. The key to effective care teams is open communication in addition to each team member understanding his or her roles and responsibilities. Data can provide opportunities to discuss completeness and adequacy of screening, identify areas where improvement is needed and motivate all team members to do their best to provide optimal preventive care.

Overcoming Barriers

Patients will often identify barriers to screening if asked during the clinic visit. Common barriers include: misunderstanding of how to collect samples (FOBT/FIT), embarrassment regarding handling of stool samples (FOBT/FIT), discomfort related to bowel preparations (flexible sigmoidoscopy, colonoscopy, barium enema, CT colonography), fear or discomfort related to the test itself (flexible sigmoidoscopy, colonoscopy) fear of the test result (all forms of screening).

To overcome these barriers, the care team members must first develop a relationship of trust with the patient. Once rapport is established, education and materials can be provided. For some, the best form of education is through the use of models or other demonstrations. For others, brochures, drawings or other materials work best. Multimedia resources that show AI/AN people talking about their experience and the importance of screening have been used successfully in many communities. A questionnaire to help identify a patient's stage of readiness to accept CRC screening is available in the tool box, 8.1.4

Developing Screening Program Measures and Goals

Goals for CRC screening may be developed according to local needs but may also be dictated by external mandates such as GPRA or Meaningful Use. Examples of local measures that could be tracked include:

- Number of patients eligible for screening seen in one month (by any test or by a specific test)
- Percent of eligible patients screened in one month (by any test or by a specific test)
- Number/percent of refusals
- Number/percent of FOBT/FIT test kits not returned in one month



- Percent of patients referred for colonoscopy who complete the exam within 30 days

Local measures such as these can help track progress on important steps in the process of CRC screening.

The primary external measures for CRC screening developed through GPRA are displayed in the Appendix at the end of this chapter. These measures are reported for all IHS sites and many Tribal sites and can be found aggregated by area on the IHS Quality of Care website at:

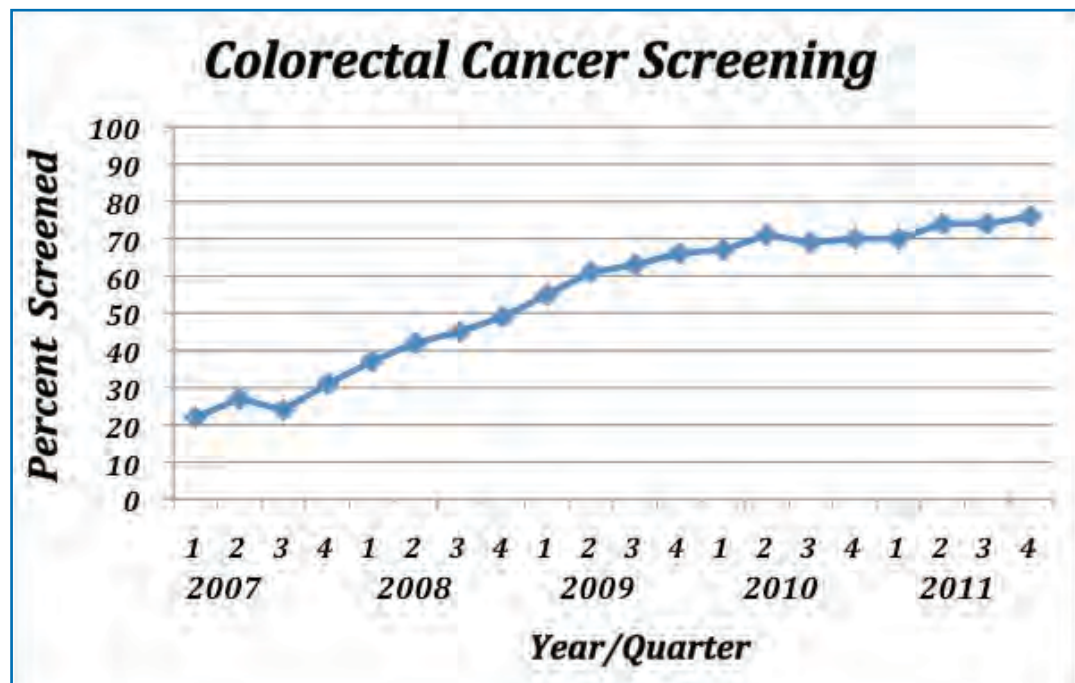
<http://www.ihs.gov/qualityofcare/index.cfm>



Tools for Improvement

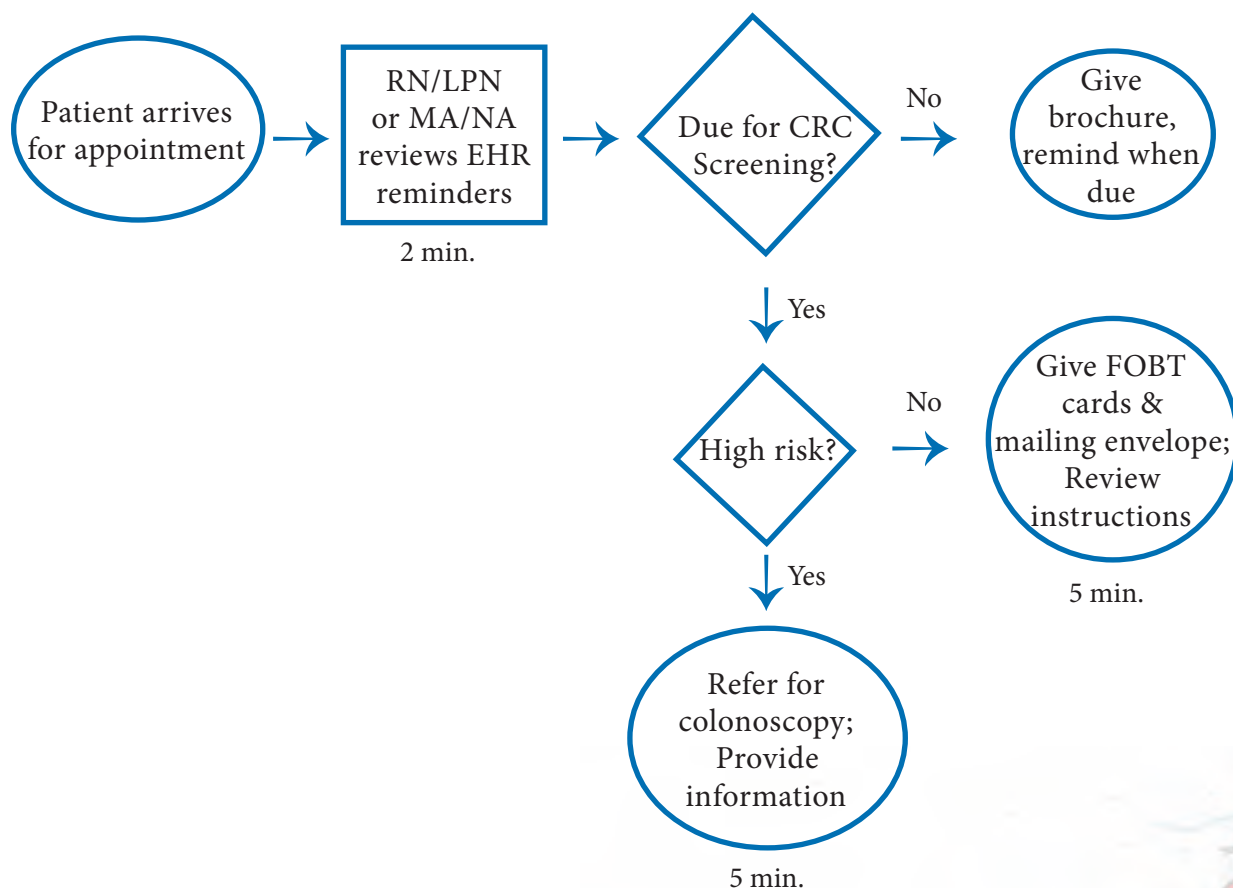
Data: The RPMS application, iCare, was developed to facilitate the management of patients assigned to a care team or to manage groups of patients with the same disease conditions such as diabetes, hypertension, rheumatoid arthritis, asthma and many more. Clinics with established primary care teams have successfully used iCare to identify patients in their panels who are in need of a variety of screenings, diagnostic tests or treatment regimens. By reviewing these patient panels with iCare, those patients who have not been in the clinic recently but who are due for CRC screening can be identified. Letters or phone calls can then be used to encourage them to be screened.

Data generated from iCare or from custom RPMS queries using QMAN can be exported to programs like Microsoft Excel to create graphs showing screening rates over time by provider or care team. These graphs can be used to provide valuable information for teams to improve their performance.



Process Mapping: Process mapping is a technique in which a clinical process such as patient registration, immunization services or screening is mapped out showing each individual step that must occur to complete the process. Once a process is mapped, the care team can evaluate the complexity of the process and look for opportunities to streamline. One way to start mapping a process is to walk through a typical clinic visit as a patient, either by shadowing a patient or giving a patient a form to fill in the steps and times for each step. Once the initial data is obtained, a visual map is created showing each step in the process and the amount of time taken. Tool 8.2.1 is a worksheet for process mapping.

Sample of Process Map

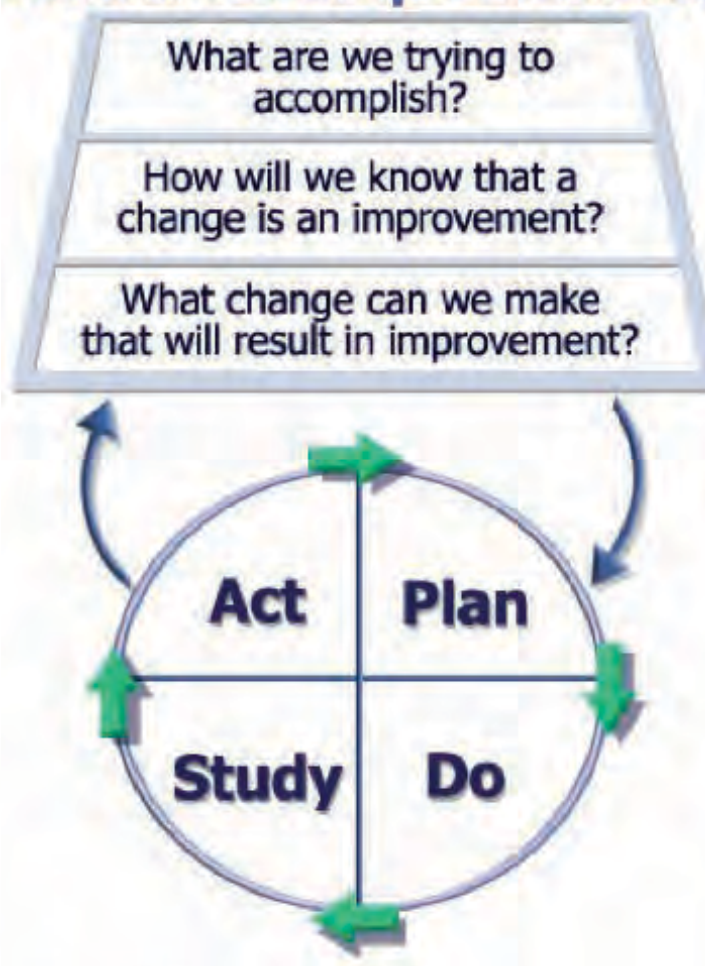


Model for Improvement: The Model for Improvement asks three fundamental questions of any improvement effort:

1. What are we trying to accomplish?
2. How will we know that a change is an improvement?
3. What change can we make that will result in an improvement?

A key strategy in quality improvement is to make small changes, sequentially, on small numbers of patients until a process is refined and ready to be implemented. This can be done through the Plan-Do-Study-Act cycle. Tool 8.2.2 is a worksheet for planning and documenting PDSA cycles. Key points for using the Model for Improvement are to be very specific, focus on small tests with just a few patients over just 1 or 2 days. It is vitally important to include a prediction

Model for Improvement



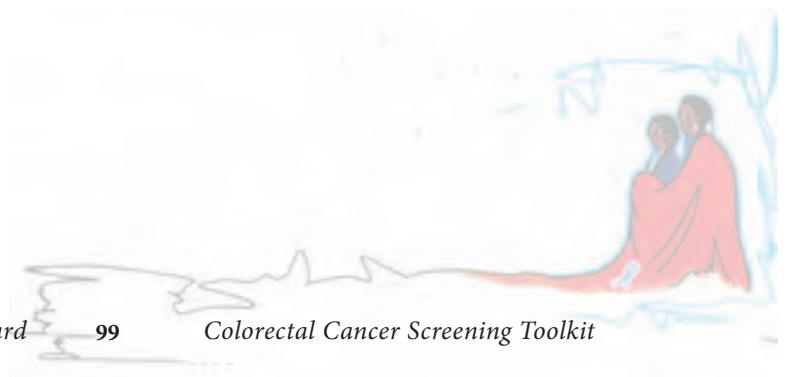
of what will happen before performing the test cycle and to include measureable data that can be readily collected and easily analyzed¹¹.

Section Summary

This section provides the rationale and descriptions of recommended methods for CRC Screening from a clinical perspective. To build a successful CRC screening program, it is important to identify resources to pay for screening, assign team roles and responsibilities, overcome barriers and develop measures for tracking progress. Helpful tools for developing a CRC screening program, specifically, as well as general quality improvement steps were included.

Additional Resources

1. Colorectal Cancer Screening Algorithm. Harvard University. Available at: <https://www.rmhf.harvard.edu/Clinician-Resources/Guidelines-Algorithms/2010/Colorectal-Cancer-Screening-Algorithm>
2. How to Increase Colorectal Cancer Screening Rates in Practice: A Primary Care Clinician's* Evidence-Based Toolbox and Guide 2008. American Cancer Society. Available at: <http://www.cancer.org/healthy/informationforhealthcareprofessionals/colonmdcliniciansinformationsource/cancerscreeningactionplan/index>
3. National Conference of State Legislatures: Colorectal Cancer Screening: What are States Doing? Updated: August 2011. Available at: <http://www.ncsl.org/default.aspx?tabid=14328>



Tool Box Description

8.1 _____

Colorectal Cancer Screening Tools

These tools include screening checklist and algorithms that can be given to providers or posted in exam rooms

8.1.1 Colorectal Cancer Screening Checklist

8.1.2 Risk-based Colorectal Cancer Screening Algorithm

8.1.3 Algorithm for FOBT/FIT-Based Colorectal Cancer Screening

8.1.4 Brief Questionnaire Identify Decision Stage- this tool can help determine a patient's readiness to make a decision about CRC screening. Also available at

<http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-028273.pdf>

8.2 _____

Quality Improvement Tools

These tools can be used to help improve any clinical process and may be especially helpful for identifying and guiding quality improvement initiatives to improve Colorectal Cancer Screening.

8.2.1 Process Mapping Worksheet

8.2.2 Plan-Do-Study-Act (PDSA) Worksheet

8.2.3 Clinical Reporting System measures for CRC screening, Version 13. Full documentation available at:

http://www.ihs.gov/RPMS/PackageDocs/BGP/bgp_1300.01u_logicselected.pdf





Northwest Portland Area Indian Health Board
Colorectal Cancer Program Toolkit

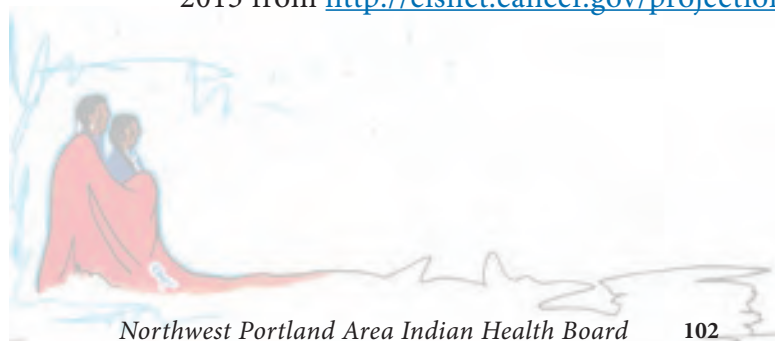
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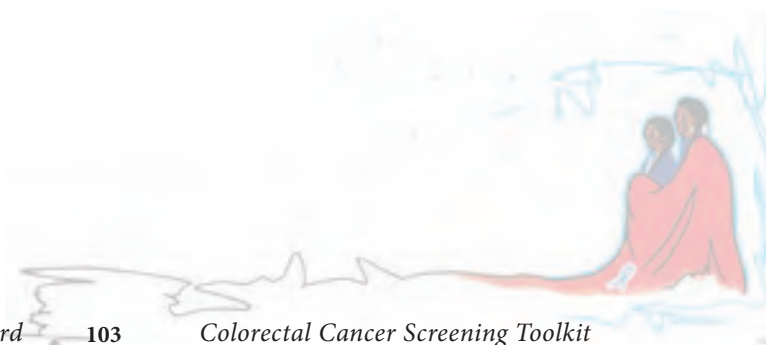
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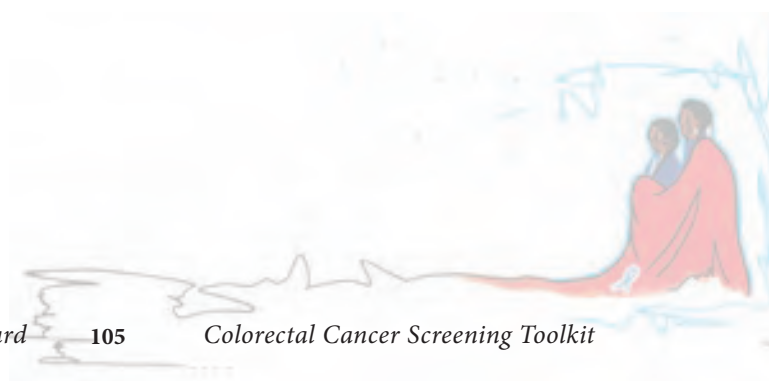
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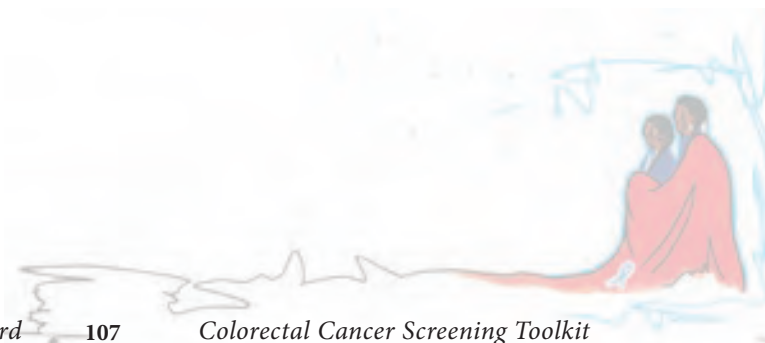
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**Northwest Tribal
Colorectal Cancer Screening
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