CANCER 101

A Cancer Education and Training Program for American Indians and Alaska Natives

Version 2 - October 2011

With updates and expanded content written by:
Katherine Josa Briant, MPH, CHES in collaboration with
Teresa Garrett Hill, DNP, MN, RN

In consultation with:
Northwest Portland Area Indian Health Board’s
Northwest Tribal Comprehensive Cancer Project

The original version of Cancer 101, completed in 2002 and updated in 2004, was written by Teresa Garrett Hill, DNP, MN, RN, of the Spirit of EAGLES in consultation with member tribes of the Northwest Portland Area Indian Health Board and the National Cancer Institute’s Cancer Information Service.
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CANCER 101

A Cancer Education and Training Program for American Indians and Alaska Natives

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Note: The original creation of the curriculum (completed in 2002) was supported by Centers for Disease Control & Prevention Cooperative Agreement #U55/CCU016012 (Northwest Portland Area Indian Health Board’s Northwest Tribal Comprehensive Cancer Project) and NIH grant #U01 CA 86098-01 (Spirit of EAGLES).

The contents of this document are solely the responsibility of the author and do not necessarily represent the official views of the CDC, NCI or the NIH.

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Acknowledgements

Many individuals have made this curriculum possible including tribal representatives who attended Cancer 101 trainings and reviewers from research institutions as well as reviewers serving Indian health programs in the Northwest. Together, they have provided invaluable recommendations in the update and expansion of this curriculum.

Contributors also include staff of the National Cancer Institute’s Cancer Information Service and of the Northwest Portland Area Indian Health Board.

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<table>
<thead>
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<th>Michelle Harrison, MSW</th>
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<td><strong>Former Information Specialist</strong></td>
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<th>Elizabeth Isaacson, BA</th>
<th>Laura Rankin, BA</th>
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<tr>
<th>Anna Ungar, MA</th>
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<th>Luella Azule (Umatilla/Yakima)</th>
<th>Janine Dankovchik</th>
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<td><strong>Former Project Specialist</strong></td>
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<td>Northwest Tribal Cancer Control Project</td>
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<th>Peggy Biery (Grand Ronde)</th>
<th>Megan Hoopes</th>
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<td><strong>Former Project Specialist</strong></td>
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<th>Ruth Jensen (Tlingit)</th>
<th>Eric Vinson (Cherokee)</th>
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<tr>
<td><strong>Former Director</strong></td>
<td><strong>Cancer Caregiver/Project Coordinator</strong></td>
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<th>Barbara Watson (Siletz)</th>
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The Cancer 101 cover photo is provided courtesy of:

**Larry Workman** (Quinault Indian Nation)

A special appreciation to:

**Beti Thompson, PhD**, Principal Investigator of the NCI-funded Center for Community Health Promotion Community Networks Program Center at Fred Hutchinson Cancer Research Center, for believing in the importance of empowering communities through education and supporting this endeavor.

**Stella Washines**, Chair of the Northwest Tribal Cancer Coalition, NPAIHB board member, and Yakama Tribal Council Woman, for ten years of leadership and commitment to cancer issues in Indian country.
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Marie T. Orines, of Fred Hutchinson Cancer Research Center for explaining how biospecimens are stored and providing a tour of the biorepository at FHCRC.

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**Member Tribes of the Northwest Portland Area Indian Health Board**

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<th>Burns Paiute Tribe</th>
<th>Makah Indian Nation</th>
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<td>Muckleshoot Indian Tribe</td>
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<td>Nez Perce Tribe</td>
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<td>Nisqually Tribe</td>
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<td>Nooksack Tribe</td>
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<td>Northwest Band of Shoshone Indians</td>
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<td>Port Gamble S’Klallam Tribe</td>
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<td>Cow Creek Band of Umpqua Tribe of Indians</td>
<td>Samish Indian Tribe</td>
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<td>Lower Elwha Klallam Tribe</td>
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<td>Upper Skagit Tribe</td>
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Collaborators extend their gratitude to the distinguished panel of reviewers whose experience and expertise have contributed to the value of these modules.

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<thead>
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<th>Title</th>
<th>Organization</th>
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<tr>
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<td>Public Health Nurse</td>
<td>Quinalt Indian Nation</td>
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<td>Noreen Thompson, RN</td>
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<td>Cow Creek Band of Umpqua Indians</td>
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<td>Shoshone Bannock Tribal Health</td>
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* denotes reviewers for the three new modules added to the curriculum
Preface

The Cancer 101 curriculum has come a long way! It began in the late 90’s as a collaboration between tribes and organizations dedicated to addressing health disparities among Native people. The vision was the creation of a tool that would be culturally relevant, increase knowledge and understanding about cancer, and empower tribal communities in the Pacific Northwest to address cancer issues. In 2002, the vision became a reality, and since then, Cancer 101 has been used across the country with Native populations as well as other ethnic and cultural groups.

Over time, we’ve learned from personal experience, as well as from other users, that the curriculum was easy to use and that it was an effective tool to increase knowledge and awareness about cancer. In an effort to document evidence about Cancer 101’s effectiveness, we continued to work with the Northwest Tribal Cancer Coalition to evaluate the curriculum as a community-based intervention, which was completed in 2009. The results established Cancer 101 as an evidence-based curriculum for AI/AN that has been research tested and found to be effective. Cancer 101 is found to increase knowledge about cancer and cancer control, change attitudes towards cancer risk and risk reduction, change the way people think about cancer issues and concerns in the communities, and empower training participants to access resources to act on cancer control issues in their communities.

In working with tribal community members to evaluate the curriculum, and the Northwest Tribal Cancer Coalition Chair, we learned that there a need to address additional topics. Those additional topics were briefly touched upon but not included in Version 1 of the Cancer 101 curriculum. Cancer 101 (Version 2) adds this additional content.

Cancer 101, Version 2 includes the seven modules from Version 1. Version 1 content was updated to reflect the most current information available on cancer data, screening guidelines, and risk factors. Cancer 101, Version 2 features three new modules: Role of Genes in Cancer, Biospecimens and Biobanking, and Chronic Conditions and Cancer. To improve the flow of the curriculum content, these three new modules have been placed in between the original modules in the original version of Cancer 101.

The process to update and expand the curriculum included interviews, presentations and volunteer readers. Past Cancer 101 trainees were interviewed to learn how the curriculum could be improved. We presented the three new module topics at a Northwest Tribal Cancer Coalition meeting in May 2011 and five reviewers volunteered to read the content and provide feedback and suggested edits. The Confederated Tribes of Warm Springs offered to host a pilot session for the three new modules. We are grateful to all the individuals who took the time to talk with us, review materials, and participate in training. Their input has been invaluable in this process.

We are dedicated to continuing to work together with tribes in their efforts to reduce the burden of cancer. We hope that Cancer 101, Version 2 will be a useful tool in your community. We look forward to hearing from you as you use it. Your feedback will help us continue to refine and improve the curriculum.

Kerri Lopez     Kathy Briant     Teresa Garrett Hill
Each learning module is designed for presentation as a 30- to 40- minute education session; or the entire curriculum may be presented as a two-day workshop on cancer education. Learning modules include stated goals and objectives for each topic, pre and post self-assessment, PowerPoint presentation, glossary, references, and resource materials as appropriate.

### Learning Module 1

**“Cancer among American Indians and Alaska Natives”**

...provides information about the growing health concern of cancer among American Indians and Alaska Natives including contributing factors, interpretation of current data, and survival statistics.

<table>
<thead>
<tr>
<th>Module 1: Cancer Among American Indians and Alaska Natives</th>
<th>M1-1</th>
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<tbody>
<tr>
<td>Pre/Post Self-Assessment</td>
<td>M1-2</td>
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<tr>
<td>Pre/Post Self-Assessment Answer Key</td>
<td>M1-3</td>
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<tr>
<td>Section 1: Cancer Background</td>
<td>M1-4</td>
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<tr>
<td>Section 2: What’s Known and not Known About Cancer among American Indians and Alaska Natives</td>
<td>M1-6</td>
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<tr>
<td>Section 3: Cancer Survival among American Indians and Alaska Natives</td>
<td>M1-8</td>
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<td>Glossary of Terms</td>
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<td>Resources for Learning More</td>
<td>M1-11</td>
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<td>References</td>
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### Learning Module 2

**“What Is Cancer?”**

...describes how cancer develops and discusses the five main groups of cancer.

<table>
<thead>
<tr>
<th>Module 2: What is Cancer?</th>
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<tr>
<td>Pre/Post Self-Assessment</td>
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<td>Section 1: What is Cancer?</td>
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<tr>
<td>Section 2: Benign Versus Malignant Tumors</td>
<td>M2-6</td>
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<tr>
<td>Section 3: Types of Cancer</td>
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<td>Glossary of Terms</td>
<td>M2-8</td>
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<td>References</td>
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Learning Module 3
“Cancer Risk Factors and Risk Reduction”
...focuses on understanding cancer risk factors and learning how to reduce risks associated with cancer.

Module 3: Cancer Risk Factors and Risk Reduction............................................................ M3-1
Pre/Post Self-Assessment ..................................................................................................... M3-2
Pre/Post Self-Assessment Answer Key ............................................................................... M3-3
Section 1: What is a Risk Factor? ..................................................................................... M3-4
Section 2: Risk Reduction ................................................................................................. M3-6
Glossary of Terms ............................................................................................................. M3-9
Resources for Learning More ......................................................................................... M3-11
References ....................................................................................................................... M3-13

Learning Module 4
“Role of Genes in Cancer”
...describes genes, their role in the body, how changes in their function may lead to cancer, and discusses genetic testing.

Module 4: Role of Genes in Cancer.................................................................................... M4-1
Pre/Post Self-Assessment .................................................................................................. M4-2
Pre/Post Self-Assessment Answer Key ............................................................................. M4-3
Section 1: What Are Genes? .......................................................................................... M4-4
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Learning Module 5
“Cancer Screening and Early Detection”
...discusses the components of early detection and barriers associated with practicing early detection, and describes common symptoms associated with cancer.

Module 5: Cancer Screening and Early Detection .............................................................. M5-1
Pre/Post Self-Assessment .................................................................................................. M5-2
Pre/Post Self-Assessment Answer Key ............................................................................. M5-3
Section 1: Cancer Screening & Early Detection ................................................................. M5-4
Section 2: Barriers to Cancer Screening & Early Detection ............................................. M5-12
Section 3: Possible Symptoms of Cancer ........................................................................... M5-14
Cancer Sites Reference Worksheet ................................................................................... M5-16
Glossary of Terms .............................................................................................................. M5-21
Resources for Learning More .......................................................................................... M5-24
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Learning Module 6
“Cancer Diagnosis and Staging”
...discusses how cancer is diagnosed and how cancer stage is determined.

Module 6: Cancer Diagnosis and Staging ......................................................................... M6-1
Pre/Post Self-Assessment .................................................................................................. M6-2
Pre/Post Self-Assessment Answer Key ............................................................................. M6-2
Section 1: Cancer Diagnosis and Staging ........................................................................ M6-4
Section 2: Staging of Cancer ............................................................................................. M6-7
Glossary of Terms ............................................................................................................. M6-9
Resources for Learning More .......................................................................................... M6-11
References ......................................................................................................................... M6-12
Learning Module 9
“Chronic Conditions and Cancer”
...defines chronic disease and describes common types, their risk factors, signs and symptoms, contributing factors, and the growing concern about the increase in numbers of persons affected.

Module 9: Chronic Conditions and Cancer ................................................................. M9-1
Pre/Post Self-Assessment ......................................................................................... M9-2
Pre/Post Self-Assessment Answer Key ................................................................. M9-3
Section 1: What is a Chronic Disease? ................................................................. M9-4
Section 2: Common Chronic Conditions ............................................................. M9-7
Section 3: Concerns About Chronic Conditions ................................................. M9-14
Section 4: Preventing Chronic Conditions ......................................................... M9-19
Glossary of Terms ............................................................................................... M9-21
Resources for Learning More .............................................................................. M9-25
References .......................................................................................................... M9-26

Learning Module 10
“Support for Patients and Caregivers”
...addresses some of the psychological and social issues that affect cancer patients and their caregivers and discusses ways to be supportive.

Module 10: Support for Patients and Caregivers ...................................................... M10-1
Pre/Post Self-Assessment ..................................................................................... M10-2
Pre/Post Self-Assessment Answer Key ............................................................... M10-3
Section 1: Coping with the Cancer Diagnosis—How to be Supportive ............. M10-4
Section 2: Life after Cancer Treatment—On the Path to Recovery ................. M10-7
Section 3: Life after Cancer Treatment—Survivorship ..................................... M10-8
Glossary of Terms ............................................................................................... M10-10
Resources for Learning More .............................................................................. M10-11
References .......................................................................................................... M10-14
**Trainer Section**

…consists of the *Cancer 101* adaptation guidelines and training tips.

*Cancer 101 Adaptation Guidelines* ................................................................. T-1
*Training Tips* ........................................................................................................ T-10
*Trainer Activity Report* ......................................................................................... T-13

**Evaluation**

…consists of two documents: *Healthy Changes Checklist*, which can be distributed to participants, and a template for an overall training/workshop evaluation.

*Healthy Changes Checklist - Next Steps After Training!* ...................................... E-1
*Workshop Evaluation* .............................................................................................. E-3

**Resources**

…contains a list of national organizations involved in cancer control. You may choose to add resources from your community. There is also a list of resource materials that you may want to provide at a training, with ordering information.

*Organizational Resources* ....................................................................................... R-1
*Brochures and Pamphlets* ......................................................................................... R-5
Module 1: Cancer among American Indians and Alaska Natives

Goals
In this session, participants will gain an understanding of the growing health concern of cancer among American Indians and Alaska Natives (AI/AN).

Objectives
At the completion of Learning Module 1, participants will be able to demonstrate the following:

Section 1
Give two reasons why cancer is a growing health concern in today’s AI/AN communities.

Section 2
Discuss two facts regarding how data contributes to our understanding about the cancer health concern for AI/AN.

Section 3
Discuss two facts that contribute to poor survival for AI/AN diagnosed with cancer. Describe two factors that are likely to improve cancer survival rates for AI/AN.

Measures of Objective Accomplishment
The presenter will administer a pre self-assessment and a post self-assessment to measure participants’ knowledge of the module’s objectives. The pre self-assessment measures existing knowledge and the post self-assessment measures what was gained through the learning module.

NOTE
Each major learning point is clearly identified by boldface type throughout the guide and emphasized in the PowerPoint presentation.
See the glossary (at the end of the module) for words that are in bold blue italics throughout the module.
# Pre/Post Self-Assessment

## Cancer among American Indians and Alaska Natives

Do you agree (A), disagree (D), with these statements, or are you not sure (NS)?

*Circle your choice - A, D, or NS.*

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# Pre/Post Self-Assessment

## Answer Key

### Cancer among American Indians and Alaska Natives

The correct answer to each question, agree (A) or disagree (D), is underlined and in red.

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<tbody>
<tr>
<td>1.</td>
<td>A</td>
<td>D</td>
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|   |   | Increased life expectancy and lifestyles are two factors that may be associated with the increase of cancer among American Indians and Alaska Natives.  

**Note:** In addition to increased life expectancy and lifestyle, heredity, environmental exposures, viruses and bacteria are other factors that may also be associated with an increase in cancer among American Indians and Alaska Natives. |

| 2. | A | D |
|   |   | Cancer is the leading cause of death for Alaska Natives. |

| 3. | A | D |
|   |   | Current data for American Indians and Alaska Natives provides an accurate picture of the cancer problem in Indian country.  

**Note:** What we do not know about cancer relates to the “limitations” of existing cancer data among Al/A. Data show that Al/A throughout the U.S. have very different cancer mortality patterns. To understand more about these cancer patterns and develop effective risk reduction and control programs, accurate data on the health status of Al/A must be documented. |

| 4. | A | D |
|   |   | Cancer survival can be improved by participating in screening and early detection.  

**Note:** Early diagnosis of cancer improves the chances that treatment will be more effective and survival will be lengthened. This is particularly true for cancer of the cervix, colon and rectum, and breast. |

| 5. | A | D |
|   |   | Access to health care that is culturally appropriate will reduce barriers to care.  

**Note:** Providing access to health care that is culturally appropriate is critical to improving outcomes. Understanding how belief and value systems influence Al/A perceptions of health and illness is an important aspect of the health care process. |
Section 1
Cancer Background

For many years, cancer was not common among American Indians and Alaska Natives (AI/AN). It was thought perhaps that AI/AN had a natural immunity to this disease. Over time, however, researchers have discovered evidence that suggests that cancer did exist among AI/AN as far back as the late 1800’s. Today, cancer has become more common among AI/AN and is now a growing concern. Many of the factors that contribute to the development of cancer in AI/AN people have yet to be determined, however, changes in life expectancy and lifestyle are thought to play a significant role.

Increased life expectancy places American Indians and Alaska Natives at greater risk for cancer.

Life expectancy for AI/AN has increased dramatically over the last several decades from less than 50 years in the mid-1940’s, to 72.3 years in 2009. Much of this increase can be credited to advances in the treatment of infectious diseases and a decline in infant and maternal mortality. These reductions in mortality are largely due to improvements in public health measures such as immunization programs, improvements in sanitation, drinking water and access to primary medical care. Consequently, many individuals who would have died at an earlier age are now living to be much older. Given that most cancers occur in individuals over 45 years of age, the increase in life expectancy in AI/AN places them at increased risk for cancer.
As AI/AN live longer, the type of lifestyle they lead may influence their risk for developing cancer. In the past, traditional lifestyles included many practices that are thought to reduce one's risk for developing cancer. These included daily exercise, a diet rich in fruits, vegetables, and other natural foods, and reserving tobacco for ceremonial use rather than habitual use. In today’s world, lifestyles for many AI/AN have been made more convenient by advances in technology. Although many of these advances have led to improvements in the ease of performance of day-to-day activities, they have also led to a decrease in energy expenditures. Thus, today’s lifestyles have become more sedentary. Highly processed and convenience food items have replaced a diet once rich in natural foods. An increase in personal use of tobacco that is chewed or smoked has led to increased rates of cancer in AI/AN.\textsuperscript{4,5} Research is ongoing and early findings suggest lifestyles that include attention to proper diet (rich in natural foods), limited alcohol use, daily exercise, and the avoidance of known carcinogens may reduce one’s risk for developing cancer.

Although researchers have identified increased life expectancy and changing lifestyles as two factors that have influenced the rise in cancer rates among AI/AN, there are other contributing factors to consider. These factors include heredity, environmental exposures, viruses and bacteria. They will be discussed in more detail in Learning Module 3: Cancer Risk Factors and Risk Reduction.
Section 2

What is known and not known about cancer among American Indians and Alaska Natives

In general, much work still needs to be done in order to understand the issue of cancer among AI/AN. Because there is no single database that accurately depicts cancer-related data for AI/AN, multiple databases must be used to gather and assess this information.

Statistical data from the two major U.S. cancer registry systems (the National Program of Cancer Registries and the Surveillance, Epidemiology, and End Results (SEER) program), enhanced with record linkages to Indian Health Service and geographical data to correct for racial misclassification show the following:

- Cancer was the leading cause of death for American Indians between the ages of 45 to 64 between 2002 and 2004.6
- In Alaska, cancer is the leading cause of death for Alaska Natives.7
- While cancer incidence rates among AI/AN are lower than rates among non-Hispanic whites, there are differences by IHS region.8
- AI/AN are less likely than non-Hispanic whites to be diagnosed with cancers of the breast, colon and rectum, prostate, and cervix at localized stages when compared to non-Hispanic whites.9

We also know that patterns for certain types of cancers vary among American Indians and Alaska Natives. For example, American Indians have an increased incidence of cancers of the kidney, liver, stomach and gallbladder, and Alaska Natives have excess incidence rates for colon and rectum, stomach, kidney, lung and bronchus, liver, pancreas, esophagus, gall bladder, and cervix uteri when compared to non-Hispanic whites.10 Data also show that American Indians have increased mortality from cancers of the stomach, liver, gallbladder, cervix and kidney and Alaska Natives have excess mortality rates for stomach, colon and rectum, liver, gallbladder and kidney cancers when compared to the U.S. population.11
The top ten most common types of cancer occurring among American Indian and Alaska Natives include the following: lung & bronchus, prostate (men), colon & rectum, breast (female), kidney, Non-Hodgkin Lymphoma, bladder, stomach, pancreas and liver.\(^{12}\)

What we do not know about cancer relates to the “limitations” of existing cancer data among American Indians and Alaska Natives.

The term “limitations” refers to how the accuracy of the current data may be influenced by any of the following points:

- Racial misclassification
- Undercounting (due in large part to racial misclassification)
- Coding errors (which affects all data and is not specific to AI/AN)
- Inclusion of insufficient numbers of the racial group to formulate conclusions
- Data collection in selected geographic regions cannot be generalized to Peoples of other areas.

Findings show that AI/AN throughout the U.S. have very different cancer mortality patterns.\(^ {13}\) To understand more about these cancer patterns and develop effective risk reduction and control programs, accurate data on the health status of AI/AN must be documented.\(^ {14}\)
Section 3

Cancer Survival among
American Indians and Alaska Natives

As we become more familiar with the health concern of cancer among American Indians and Alaska Natives, the issue of survivability grows in importance. The data tells us that, overall, AI/AN have the lowest five-year relative survival rate for all cancer sites combined of any racial group in the United States.\(^{15}\) Factors that contribute to the low survival of AI/AN are not well understood. Although more investigation needs to be done, the following factors have been identified as potentially influencing survival:

- Late detection of cancer
- Genetic risk factors
- Poor compliance with recommended treatment
- Presence of other disease conditions
- Lack of timely access to state-of-the-art diagnostic or treatment methods
- Barriers to care such as lack of materials and programs about cancer risk and risk reduction that are culturally relevant, lack of AI/AN health providers, lack of accessible educational and training opportunities, English as a second language, poverty, transportation, and cultural beliefs surrounding cancer.\(^{16}\)

We know that cancer survival can be improved by increasing participation in screening and early detection services. Early diagnosis of cancer improves the chances that treatment will be more effective and survival will be lengthened. This is particularly true for cancer of the cervix, colon and rectum, and breast. For other types of cancer such as those cancers that affect the lung, no reliable screening test currently exists, and prevention is the key. The critical role of prevention in lung cancer must be emphasized. The majority of lung cancers are preventable by simply not smoking.
Reducing barriers to care is also likely to improve survival rates by increasing the number of individuals participating in screening and early detection activities. Providing access to health care that is culturally appropriate is critical to improving outcomes. Understanding how belief and value systems influence AI/AN perceptions of health and illness is an important aspect of the health care process. For example, understanding the importance of honoring modesty during screening exams may increase the likelihood that individuals, particularly elders, will continue to participate in these programs. Although more research is needed to improve survival rates for AI/AN diagnosed with cancer, encouraging participation in screening and early detection, and reducing barriers to care may have a positive influence on outcomes.

For more detailed information about cancer or the glossary terms, please refer to the Dictionary of Cancer Terms at http://www.cancer.gov/ or call the National Cancer Institute’s Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).
### Glossary of Terms

| **bacteria** | These are one-celled organisms visible only through a microscope. There are many varieties, only some of which cause disease in animals and humans. Most are non-disease causing; and many are useful. |
| **carcinogen** | This is any type of cancer causing agent. |
| **genetic** | Inherited; having to do with information that is passed from parents to offspring through genes in sperm and egg cells. |
| **genetic risk factors** | Those risk factors that are transmitted at birth through genes (the basic units of heredity). |
| **heredity** | The transmission of traits from parents to offspring. |
| **immunity** | The resistance of the body to the effects of a harmful agent. |
| **incidence** | The number of newly diagnosed cases during a specific time period. |
| **mortality** | The number of deaths during a specific time period. |
| **relative survival rate** | Compares the observed survival for a set of cancer patients to that observed for a group of normal persons of a similar age, race, and sex distribution. It is important to note that relative survival does not provide an estimate of the percent of the cancer population alive five years after diagnosis. |
| **risk factor** | Something that increases the chance of developing a disease. Some examples of risk factors for cancer are age, a family history of certain cancers, use of tobacco products, being exposed to certain chemicals, infection with certain viruses or bacteria, and certain genetic changes. |
| **statistical data** | The calculation of figures that provides information about the numbers, patterns, similarities and differences among things/individuals. |
| **virus** | An infectious agent that requires a susceptible place to grow and reproduce. |
Resources for Learning More

**American Cancer Society (ACS) – Cancer Facts & Figures:** These books provide data on the number of cancer cases, cancer deaths, and cancer survivorship.
http://www.cancer.org/Research/CancerFactsFigures/index

**Centers for Disease Control & Prevention (CDC) – Cancer FastStats:** This webpage provides links to cancer data (such as number of cancer cases and cancer deaths) as well as data about cancer care (ambulatory care, hospital inpatient care, home health care, hospice care, and nursing home care.)
http://www.cdc.gov/nchs/fastats/cancer.htm

**CDC – Cancer and Women:** This link provides information for women on reducing cancer risk and getting the right cancer screening tests at every stage of their lives.
http://www.cdc.gov/features/WomenAndCancer/

**CDC – Cancer and Men:** This link provides information for men on reducing cancer risk and getting the right cancer screening tests at every stage of their lives.
http://www.cdc.gov/features/CancerAndMen/

**CDC – Top 10 Cancers Among Men:** This link provides information on the 10 most commonly diagnosed cancer among men in the U.S.
http://www.cdc.gov/features/dsMenTop10Cancers/

**Institute of Medicine – The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Minorities and the Underserved (1999):** This link provides the Executive Summary for this report. The report explains that people who are poor, lack health insurance, or do not have access to high-quality cancer care, are more likely to be diagnosed with and die from cancer.
http://books.nap.edu/openbook.php?record_id=6377&page=1

**National Cancer Institute – The Human and Economic Burden of Cancer:** This link contains information on understanding cancer statistics.

**The Office on Women’s Health – Health Disparities Profiles:** This link provides information on key health indicators for different racial and ethnic populations in the U.S.

**U.S. National Library of Medicine – Information by Population Groups:** This link provides information on health topics relevant to different population groups.
References


Module 2: What is Cancer?

Goals
In this session, participants will gain an understanding of the following:
- The meaning of the word “cancer”
- The difference between benign and malignant tumors
- The process by which cancer spreads
- Types of cancer

Objectives
At the completion of Learning Module 2, participants will be able to demonstrate the following:

Section 1
Define cancer by describing the process through which normal cells become cancerous.

Section 2
Describe the difference between benign and malignant tumors.

Section 3
Describe two types of cancers and where they occur in the body.

Measures of Objective Accomplishment
The presenter will administer a pre self-assessment and a post self-assessment to measure participants’ knowledge of the module’s objectives. The pre self-assessment measures existing knowledge and the post self-assessment measures what was gained through the learning module.

NOTE
- Each major learning point is clearly identified by boldface type throughout the guide and emphasized in the PowerPoint presentation.
- See the glossary (at the end of the module) for words that are in bold blue italics throughout the module.

Target Audience
- Community members
- Staff of Indian health programs, including Community Health Representatives

Contents of Learning Module
- Instructor’s Guide with Pre/Post Self-Assessment and Self-Assessment Answer Key
- PowerPoint presentation
- Glossary
- Resources for Learning More
- References

Length
- Introduction of session/module overview (:05)
- Pre self-assessment (:07)
- Presentation of module (:30)
- Optional video: “Cancer in the Great Land” (:17)
- Post self-assessment (:05)
- Closing (:03)
### Pre/Post Self-Assessment

#### What is Cancer?

*Do you agree (A), disagree (D), with these statements, or are you not sure (NS)?

*Circle your choice - A, D, or NS.*

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>D</th>
<th>NS</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>Cancer is a disease that occurs when cells grow, or divide, in an orderly fashion.</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td>Malignant tumors do not spread to other parts of the body.</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td>A tumor is always cancerous.</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td>Treatment decisions are based on the type of cancer involved.</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td>The site where cancer begins in the body is called the “primary site”.</td>
</tr>
</tbody>
</table>
## Pre/Post Self-Assessment

### Answer Key

**What is Cancer?**

*The correct answer to each question, agree (A) or disagree (D), is underlined and in red.*

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>A</td>
<td>D</td>
</tr>
</tbody>
</table>
|    | Cancer is a disease that occurs when cells grow, or divide, in an orderly fashion.  
    *Note:* Cancer is a disease that develops when cells grow, or divide, and form more cells **without** control or order. |
| 2. | A | D |
|    | Malignant tumors do not spread to other parts of the body.  
    *Note:* Malignant tumors are cancer. Cancer cells can invade and damage nearby tissue and organs by breaking away from a malignant tumor and entering the bloodstream or the lymphatic system. This process is called metastasis. |
| 3. | A | D |
|    | A tumor is always cancerous.  
    *Note:* Tumors can either be benign (non-cancerous) or malignant (cancer). |
| 4. | A | D |
|    | Treatment decisions are based on the type of cancer involved.  
    *Note:* To plan the best treatment for cancer, the doctor needs to know the type of cancer and the stage of the disease. |
| 5. | A | D |
|    | The site where cancer begins in the body is called the “primary site”. |
Section 1

What is Cancer?

The term “cancer” refers to a group of more than 100 different diseases that begin in cells, the body’s basic unit of life. Cells are the structural and functional units of all living organisms. They are so small, that they can only be seen through a microscope. Some organisms, such as bacteria, are unicellular, consisting of a single cell. Other organisms, such as humans, are multi-cellular, or have many cells. We have billions of cells in our bodies.

Although there is no word for cancer in many tribal dialects, many American Indians and Alaska Natives (AI/AN) are aware of its existence. AI/AN have witnessed the devastating effects of this disease either through their own personal experience or that of a family member or friend. For this reason, mention of the word cancer often generates feelings of fear, sadness and isolation among AI/AN affected by this disease. In addition, some AI/AN view cancer as a form of punishment. There is a critical need to educate AI/AN about cancer in order to move beyond myths toward understanding and knowledge. Education about cancer will assist AI/AN in developing focused interventions that will reduce the risk of developing cancer and ultimately lead to a cancer free existence.

Cancer is a disease that develops when cells grow (divide) and form more cells without control or order. All organs of the body are made up of cells. Cells have many parts, each with its own function. For example, each cell can take in nutrients, convert them into energy, carry out special functions, and grow or divide, as necessary. Each cell has a nucleus, which serves as the cell’s brain, sending directions to the cell to grow, mature, divide, or die. Under normal circumstances, new cell growth and old cell death are kept in balance. In cancer, this balance is disrupted. This disruption can result from uncontrolled cell growth or loss of a cell’s ability to self-destruct. This process may be easily understood by first considering “normal cell growth”.

M2 - 4
Normal cell growth: The process of making new body cells is called cell division or mitosis. Take, for example, the skin. The outer layer of normal skin, called the epidermis is roughly a dozen cells thick. Cells in the bottom row of this layer, called the basal layer, divide just fast enough to replenish cells that are continually being shed from the surface of the skin. Each time one of these basal cells divides, it produces two cells. One remains in the basal layer and retains its capacity to divide. The other travels out of the basal layer and loses the capacity to divide. The number of dividing cells in the basal layer therefore stays the same.

Abnormal cell growth - the beginning of cancerous growth: During the development of skin cancer, the normal balance between cell division and cell death, or apoptosis, is disrupted. Apoptosis protects the body by removing genetically damaged cells that could lead to cancer. The basal cells now divide faster than is needed to replenish the cells being shed from the surface of the skin. Each time one of these basal cells divides, the two newly formed cells will often retain the capacity to divide, thereby leading to an increase in the total number of dividing cells.

This gradual increase in the number of dividing cells creates a growing mass of tissue called a “tumor”. If the rate of cell division is relatively rapid, and no “self-destruct” signals are in place to trigger the cell to die, the tumor will grow quickly in size. If the cells divide more slowly, tumor growth will be slower. But regardless of the growth rate, tumors ultimately increase in size because new cells are being produced in greater numbers than needed. As more and more of these dividing cells accumulate, the normal organization of the tissue gradually becomes disrupted. Tumors can either be benign (non-cancerous) or malignant (cancer).
Section 2

Benign Versus Malignant Tumors

Benign tumors are not cancer. They do not spread to other parts of the body and are usually not a threat to life. Benign tumors are often removed because their size may cause a problem or for cosmetic reasons.

Malignant tumors are cancer. Cancerous cells in these tumors are abnormal and divide without control or order due to oncogenes. Oncogenes are normal genes that have been changed, or mutated and therefore have affected a cell’s ability to control functions such as cell replication and cell death. When the cell cycle (cell division and cell death) proceeds without control, cells can divide without order and accumulate genetic defects that can lead to a cancerous tumor.

Cancer cells can invade and damage nearby tissue and organs by breaking away from a malignant tumor and entering the bloodstream or the lymphatic system. This is how cancer spreads from what is called the original or primary site to form new tumors in other parts of the body. The process by which cancer spreads from its original or primary site to another part of the body is referred to as metastasis.

When cancer spreads or metastasizes, the new tumor has the same kind of abnormal cells as the primary (original) tumor and is referred to by the same name as the primary tumor. For example, if colon cancer metastasizes (spreads) to the liver, the cancer cells in the liver are colon cancer cells. The disease is called metastatic colon cancer (not liver cancer).
As discussed in Section 1, there are over 100 different types of cancer and they can originate almost anywhere in the body. **Treatment decisions are based on knowing the type of cancer involved.** In addition to the primary organ site, cancers are described by the types of cells that become malignant. **Knowledge of the terms used to describe the various types of cancers helps us to better understand information about the cancer diagnosis.**

Cancers are divided into five main groups:

- **Carcinomas** are cancers that begin in the *epithelium*, the body’s skin or in tissues that line or cover the internal organs such as the lung, breast, and colon. Eighty to ninety percent of all cancers are carcinomas.

- **Sarcomas** are cancers that start to grow in bones, cartilage, fat, muscle, blood vessels, or other *connective tissues* such as nerves, joints, or deep skin tissues.

- **Lymphomas** are cancers that arise in the *lymph nodes* and *lymphoid tissues* (tissues of the body’s immune system.)

- **Leukemias** are cancers that start in the tissue that forms blood such as the *bone marrow*. In a person with leukemia, the bone marrow makes abnormal *white blood cells*.

- **Myelomas** are cancers that start in plasma cells, which are a type of white blood cell.

Scientists use a variety of technical names to distinguish among the many different types of cancers. **In general, these names are created by using different prefixes that stand for the name of the cell type involved.** For example, the prefix “osteo” means bone, so a cancer arising in bone is called osteosarcoma. Similarly, the prefix “adeno” means gland, so a cancer of gland cells is called adenocarcinoma - for example, a breast adenocarcinoma.
# Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>apoptosis</td>
<td>A type of cell death in which a series of molecular steps in a cell leads to its death. This is the body’s normal way of getting rid of unneeded or abnormal cells. The process of apoptosis may be blocked in cancer cells. Also called programmed cell death.</td>
</tr>
<tr>
<td>benign</td>
<td>A tumor that is not cancerous. Benign tumors may grow larger, but do not spread to other parts of the body. Also called nonmalignant.</td>
</tr>
<tr>
<td>bone marrow</td>
<td>A soft sponge-like material found in the center of most bones. Its principle function is to produce red blood cells (cells that carry oxygen to all parts of the body), white blood cells (cells that help the body fight infections and other diseases), and platelets (cells that help the blood clot to prevent bleeding; also called a thrombocyte).</td>
</tr>
<tr>
<td>cancer</td>
<td>A term for diseases in which abnormal cells divide without control or order and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems. There are more than 100 different types of cancer. Also called malignancy.</td>
</tr>
<tr>
<td>cells</td>
<td>Cells are the basic unit in the organization of living substance. Although cells may be widely differentiated and highly specialized in their function, they have the same basic structure; that is they have an outer covering called the membrane, a main substance called the cytoplasm and a control center called a nucleus.</td>
</tr>
<tr>
<td>connective tissue</td>
<td>Supporting tissue that surrounds other tissues and organs. Specialized connective tissue includes bone, cartilage, blood and fat.</td>
</tr>
<tr>
<td>epidermis</td>
<td>This is the outer most layer of skin.</td>
</tr>
<tr>
<td>epithelium</td>
<td>A thin layer of tissue that covers organs, glands, and other structures within the body.</td>
</tr>
<tr>
<td>lymphatic system</td>
<td>The tissues and organs that produce, store, and carry white blood cells that fight infections and other diseases. This system includes the bone marrow, spleen, thymus, lymph nodes, and lymphatic vessels (a network of thin tubes that carry lymph and white blood cells). Lymphatic vessels branch, like blood vessels, into all the tissues of the body.</td>
</tr>
<tr>
<td>lymph node</td>
<td>A rounded mass of lymphatic tissue that is surrounded by a capsule of connective tissue. Lymph nodes filter lymph (lymphatic fluid), and they store lymphocytes (white blood cells). They are located along lymphatic vessels. Also called a lymph gland.</td>
</tr>
<tr>
<td><strong>lymphoid tissue</strong></td>
<td>Referring to lymphocytes, a type of white blood cell. Also refers to tissue in which lymphocytes develop.</td>
</tr>
<tr>
<td>-------------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>malignant</strong></td>
<td>Tumors which are cancerous; they grow wildly and have the potential to spread.</td>
</tr>
<tr>
<td><strong>metastasis</strong></td>
<td>The spread of cancer from one part of the body to another. Cells in the metastatic (secondary) tumor are like those in the original (primary) cancer.</td>
</tr>
<tr>
<td><strong>oncogene</strong></td>
<td>A gene that is a mutated (changed) form of a gene involved in normal cell growth. Oncogenes may cause the growth of cancer cells. Mutations in genes that become oncogenes can be inherited or caused by being exposed to substances in the environment that cause cancer.</td>
</tr>
<tr>
<td><strong>primary site</strong></td>
<td>The place in the body where cancer originates.</td>
</tr>
<tr>
<td><strong>tumor</strong></td>
<td>An abnormal swelling or enlargement of cells or tissues; tumors may be benign or malignant.</td>
</tr>
<tr>
<td><strong>white blood cells</strong></td>
<td>These are cells that protect the body against infection.</td>
</tr>
</tbody>
</table>

For more detailed information about cancer or the glossary terms, please refer to the Dictionary of Cancer Terms at [http://www.cancer.gov/](http://www.cancer.gov/) or call the National Cancer Institute’s Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).
Resources for Learning More

Inside Cancer – Multimedia Guide to Cancer Biology: This self-paced multimedia tutorial provides information the hallmarks of cancer, causes and prevention, diagnosis and treatment. [http://www.insidecancer.org/index.html](http://www.insidecancer.org/index.html)


NCI - Understanding Cancer Series: Cancer: This self-paced graphic-rich tutorial can be used for educational use by teachers, medical professionals, and the interested public. Can be downloaded in PDF and PowerPoint format. [http://www.cancer.gov/cancertopics/understandingcancer/cancer](http://www.cancer.gov/cancertopics/understandingcancer/cancer)

NCI – What is cancer?: Introductory information with a definition of cancer, a brief explanation of the origins of cancer in cells, basic cancer statistics, and links to other NCI cancer-related resources. [http://www.cancer.gov/cancertopics/cancerlibrary/what-is-cancer](http://www.cancer.gov/cancertopics/cancerlibrary/what-is-cancer)

NCI – What You Need To Know About™ Cancer: This booklet is part of a series on many types of cancer. The booklet explains possible risks, symptoms, diagnosis, and treatment and includes a list of questions to ask the doctor. [http://www.cancer.gov/cancertopics/wyntk/cancer](http://www.cancer.gov/cancertopics/wyntk/cancer)


References

Module 3: Cancer Risk Factors and Risk Reduction

Goals
In this session, participants will gain an understanding of cancer risk factors and how to reduce risks associated with cancer.

Objectives
At the completion of Learning Module 3, participants will be able to demonstrate the following:

Section 1
a) Describe the meaning of “risk factor”.
b) Describe two risk factors that influence the development of cancer.

Section 2
Describe two ways to take personal action to reduce risk for cancer.

Measures of Objective Accomplishment
The presenter will administer a pre self-assessment and a post self-assessment to measure participants’ knowledge of the module’s objectives. The pre self-assessment measures existing knowledge and the post self-assessment measures what was gained through the learning module.

NOTE
- Each major learning point is clearly identified by boldface type throughout the guide and emphasized in the PowerPoint presentation.
- See the glossary (at the end of the module) for words that are in bold blue italics throughout the module.
### Pre/Post Self-Assessment

#### Cancer Risk Factors and Risk Reduction

*Do you agree (A), disagree (D), with these statements, or are you not sure (NS)?*  
*Circle your choice - A, D, or NS.*

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>D</th>
<th>NS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td>Everyone is at risk for developing cancer in his or her lifetime.</td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td>Risk factors that increase our chance for developing cancer include the type of lifestyle we lead and the environment we live in.</td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
<td>There is little we can do personally to reduce our risk for cancer.</td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
<td>Environmental exposures account for most of the cancer diagnosed in American Indian and Alaska Native communities.</td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
<td>Eating a high fat, low fiber diet will help prevent cancer.</td>
</tr>
</tbody>
</table>
## Pre/Post Self-Assessment
### Answer Key

### Cancer Risk Factors and Risk Reduction

*The correct answer to each question, agree (A) or disagree (D), is underlined and in red.*

<p>| | | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1.</td>
<td>A</td>
<td>D</td>
</tr>
</tbody>
</table>
|   |   | Everyone is at risk for developing cancer in his or her lifetime.  
   **Note:** The most important risk factor for cancer is growing older. Most cancers occur in people over the age of 65. But people of all ages, including children, can get cancer too. |
| 2. | A | D |
|   |   | Risk factors that increase our chance for developing cancer include the type of lifestyle we lead and the environment we live in.  
   **Note:** Risk factors are conditions that increase the chance that cancer might occur. Risk factors that influence the development of cancer are related to lifestyle, environment, viral agents, and heredity. |
| 3. | A | D |
|   |   | There is little we can do personally to reduce our risk for cancer.  
   **Note:** Although some cancers are unavoidable such as those linked to heredity, the burden of many cancers can be reduced through education, taking personal action to reduce cancer risk, and participating in routine screening for early detection. |
| 4. | A | D |
|   |   | Environmental exposures account for most of the cancer diagnosed in American Indian and Alaska Native communities.  
   **Note:** Even though the environment has undergone many changes considered to be unhealthy, some researchers suggest that environmental exposure (which may account for only 1 to 5%) is not the major source of cancer in the AI/AN population. |
| 5. | A | D |
|   |   | Eating a high fat, low fiber diet will help prevent cancer.  
   **Note:** Lifestyle factors that contribute to increased risk for cancer include not eating enough fruits and vegetables, eating too many foods high in saturated fats (fried foods, full-fat dairy products, fatty cuts of meat) and not getting enough exercise. |
Section 1

What is a Risk Factor?

Doctors often cannot explain why one person develops cancer and another does not. But research shows that certain risk factors increase the chance that a person will develop cancer.

Risk factors are conditions that increase the chance that cancer might occur. The conditions that influence the development of cancer are related to lifestyle, environment, viral agents, and heredity. Although research is ongoing, there is a lack of specific data for cancer risk factors among American Indians and Alaska Natives (AI/AN). A century ago, cancer was thought to be a rare disease among AI/AN. However, changes in lifestyle and environment have placed many AI/AN at increased risk for cancer.

The most important risk factor for cancer is growing older. Most cancers occur in people over the age of 65. But people of all ages, including children, can get cancer too. (For a list of risk factors for specific cancer sites, please refer to the “Cancer Sites Worksheet” at the end of Module 5.)

Lifestyle: Some types of cancer are related to lifestyle (how we live and the choices we make). What we eat and drink, how much we exercise, and whether or not we smoke influences our risk for developing cancer. For many AI/AN, the shift from a traditional way of living to a more Western lifestyle (more processed foods, less exercise) has had a dramatic effect on health. In the past, AI/AN lifestyles included many of the practices thought to reduce cancer risk such as a diet rich in natural foods and daily exercise. A shift from ceremonial use of tobacco to commercial use has had a devastating effect on the health of many AI/AN. Smoking rates among the Northern Plains Indians and Alaska Natives have increased dramatically over the last few decades along with a rising incidence of lung cancer.¹

Environment: Some types of cancer are related to where we work and live. For example, exposure to carcinogens (cancer-causing agents) such as asbestos, uranium, nickel, radon, cadmium, vinyl chloride and benzene in the workplace may increase a person’s risk for developing cancer. Carcinogens have also been identified in the air, water and soil.
For example, pesticides that are known carcinogens have been found in sources of food and drinking water. Although several pesticides have been shown to cause cancer in animals, the relationship with human exposure remains under study. Even though the environment has undergone many changes considered to be unhealthy, some researchers suggest that environmental exposure (which may account for only 1 to 5%) is not the major source of cancer in the AI/AN population.¹

**Viral agents:** In addition to chemicals and radiation, a few viruses can trigger the development of cancer. In general, viruses are small infectious agents that cannot reproduce on their own, but instead enter into living cells and cause the infected cell to produce more copies of the virus. In the case of cancer viruses, some of their genetic information is inserted into the chromosomes of the infected cells, and this causes the cell to become malignant.

Only a few viruses that infect human cells actually cause cancer. Examples include human papilloma virus (HPV) associated with cervical cancer and Hepatitis B virus associated with liver cancer.

**Hereditary:** This refers to genes that control cell growth and death that are passed from parent to child. Some types of cancer (including melanoma and cancer of the breast, colon, ovary, and prostate) tend to occur more often in some families than in the rest of the population. This may be due to an alteration in the genes that increases a person’s chance to develop cancer. It is often unclear whether a pattern of cancer in a family is primarily due to heredity, factors in the family’s environment or lifestyle, or just a matter of chance. *(See Module 4 for in-depth information on the Role of Genes in Cancer.)*

**Certain forms of cancer disproportionately affect AI/AN when compared to the whole U.S. population.** For example, American Indians have an increased incidence of cancers of the kidney, liver, stomach and gallbladder, and Alaska Natives have excess incidence rates for colon and rectum, stomach, kidney, lung and bronchus, liver, pancreas, esophagus, gall bladder, and cervix uteri when compared to non-Hispanic whites.² Data also show that American Indians have increased mortality from cancers of the stomach, liver, gallbladder, cervix and kidney and Alaska Natives have excess mortality rates for stomach, colon and rectum, liver, gallbladder and kidney cancers when compared to the U.S. population.³ Although more research needs to be done to determine the cause of the excess incidence and mortality associated with these cancers, some researchers believe that heredity, viral agents, environment, lifestyle and infection may play a role.
Many risk factors can be avoided. According to scientific evidence, about two-thirds of all cancer deaths expected to occur in 2011 are expected to be related to preventable factors including tobacco, overweight or obesity, physical inactivity, and poor nutrition.4

The lifestyle we lead today has an influence on our health as we age. It takes many years for a single cancer cell to develop into a cancer that is detectable and requires treatment. So when an individual is diagnosed with cancer at age 50, the stimulus for that cancer may have occurred many years before. Although some cancers are unavoidable such as those linked to heredity, the burden of many cancers can be reduced through education, taking personal action to reduce cancer risk, and participating in routine screening for early detection.

Reducing Cancer Risk5, 6, 7, 8

By practicing healthy habits and teaching them to your family members, you can help reduce your family’s risk for cancer. Start making an effort to reduce your risk now by following these suggestions:

- **Don’t use tobacco.** One of the worst things you can do for your body is use tobacco. Not only is smoking a leading cause of cancer and death from cancer, it harms nearly every organ in the body and reduces your overall health. Tobacco use (smoking, chewing tobacco and snuff) causes cancers of the lung, esophagus, larynx (voice box), mouth, throat, kidney, bladder, pancreas, stomach and cervix in addition to other smoking related health problems such as heart disease, stroke and emphysema.9 Reject tobacco, and if you smoke, consider seeking help to quit (Call 1-800-QUIT-NOW, or 1-800-784-8669, to get smoking cessation assistance). If you don’t smoke, avoid exposure to secondhand smoke. Being around others who smoke may increase your risk for lung cancer.
Maintain a healthy weight. Being overweight or obese (weighing 20% or more than recommended for normal range) may increase the risk for certain forms of cancer (breast, colon, esophagus, kidney, stomach and uterus). Balancing the amount of food we eat with daily exercise will help us maintain a healthy weight and reduce our risk of cancer. Maintaining a healthy weight also reduces risk for other chronic diseases such as diabetes and heart disease. Lifestyle factors that contribute to increased risk for these diseases include not eating enough fruits and vegetables, eating too many foods high in saturated fats (fried foods, fatty cuts of meat) and not getting enough exercise.

Be active. Get at least 30 minutes of physical activity each day. This can be as simple as a brisk walk 15 minutes twice a day. Any amount of physical activity is better than none. Being physically active lowers the risk for colon cancer and may lower the risk of breast cancer.

Limit alcohol consumption. Heavy drinking increases the risk for cancer. People who smoke and drink heavily have a particularly high risk for certain types of cancer. Choosing non-alcoholic beverages (juices, sodas, water) at parties, avoiding occasions centered around alcohol, and seeking professional help to limit alcohol (if needed) will help reduce the risk for cancer. Limiting alcohol consumption – two drinks per day for males and one drink per day for females - may lower the risk of cancers of the breast, colon, esophagus, liver, mouth and throat.

Protect yourself from the sun. Ultraviolet radiation (UV) from the sun causes premature aging of the skin and skin damage that can lead to skin cancer. To avoid skin damage from the sun, limit your midday sun exposure (from 10 AM to 4 PM). Wearing protective clothing (long sleeves and long pants of tightly woven fabrics, broad brimmed hat, and sunglasses that absorb UV) and use of sunscreen (to filter UVA and UVB rays) with a sunscreen protection factor (SPF) of 15 or higher is advised.
- **Get immunized.** Certain cancers are associated with viral infections that can be prevented with immunizations. Talk to your doctor about immunization against:
  - **Hepatitis B:** Hepatitis B can increase your risk of developing liver cancer. Vaccination is recommended for all babies in the United States.
  - **Human papillomavirus (HPV):** HPV is a sexually transmitted virus that can lead to cervical cancer. The vaccine that protects against two cancer-causing types of HPV is recommended for girls ages 11 to 12.

- **Avoid risky behaviors.** Reduce your risk of certain cancers by avoiding risky behaviors that can lead to infections. Some viruses can be transmitted sexually or by sharing contaminated needles. Abstain from sex or use condoms and limit the number of sexual partners you have. Never share needles. Seek help for your addiction if you use drugs.
  - **HPV:** HPV is most often associated with cervical cancer, but it may also increase the risk of cancers of the anus, penis, throat, vulva, and vagina. The more sexual partners you have, the more likely you are to have HPV.
  - **Human Immunodeficiency virus (HIV):** People with HIV or *acquired immunodeficiency syndrome (AIDS)* have an increased risk of anal cancer, cervical cancer, liver cancer, lymphoma, and *Kaposi sarcoma*. People with multiple sexual partners and intravenous (IV) drug users who share needles have an increased risk of HIV.
  - **Hepatitis (B and C):** Chronic hepatitis B or *hepatitis C* infection can increase your risk of liver cancer. Both forms of hepatitis can be passed through sexual contact with an infected person or sharing needles with an infected drug user and have been linked to cancer of the liver. If you are sexually active, follow safe sexual practices to protect yourself and your partner.

- **Get screened.** Regular screening and self-examination for certain cancers may not prevent cancer, but can increase your chances of detecting it early – when treatment is more likely to be successful. Screening should include your skin, moth, colon and rectum. If you are a man, it should also include your prostate and testes. If you are a woman, it should also include breast and cervical screenings. *(See Module 5 for in-depth information on Cancer Screening and Early Detection.)*
### Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td><strong>acquired immunodeficiency virus (AIDS)</strong></td>
<td>A disease caused by the human immunodeficiency virus (HIV). People with AIDS are at an increased risk for developing certain cancers and for infections that usually occur only in individuals with a weak immune system. Also called acquired immunodeficiency syndrome.</td>
</tr>
<tr>
<td><strong>carcinogens</strong></td>
<td>Cancer causing agents.</td>
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<tr>
<td><strong>chromosome</strong></td>
<td>Part of a cell that contains genetic information. Except for sperm and eggs, all human cells contain 46 chromosomes.</td>
</tr>
<tr>
<td><strong>data</strong></td>
<td>Collection of observations.</td>
</tr>
<tr>
<td><strong>genes</strong></td>
<td>Basic unit of heredity.</td>
</tr>
<tr>
<td><strong>Hepatitis B</strong></td>
<td>A virus that causes hepatitis (an inflammation of the liver). It is carried and passed to others through blood or sexual contact.</td>
</tr>
<tr>
<td><strong>Hepatitis C</strong></td>
<td>A virus that causes hepatitis (an inflammation of the liver). It is carried and passed to others through blood or sexual contact.</td>
</tr>
<tr>
<td><strong>heredity</strong></td>
<td>Refers to genetic traits passed from parent to offspring.</td>
</tr>
<tr>
<td><strong>human papilloma virus</strong></td>
<td>Viruses that generally cause warts. Some papillomaviruses are sexually transmitted. Some of these sexually transmitted viruses cause wart-like growths on the genitals. Some human papillomaviruses (HPV’s) cause abnormal changes in cells of the cervix that can lead to the development of cancer.</td>
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<tr>
<td><strong>incidence</strong></td>
<td>The number of new events or cases of disease that develop in a population of individuals at risk during a specified period of time.</td>
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<tr>
<td><strong>Kaposi sarcoma</strong></td>
<td>A type of cancer characterized by the abnormal growth of blood vessels that develop into skin lesions or occur internally.</td>
</tr>
<tr>
<td><strong>mortality</strong></td>
<td>An expression of the incidence of death in a particular population during a period of time.</td>
</tr>
<tr>
<td><strong>risk factors</strong></td>
<td>Conditions related to lifestyle, environment, and/or heredity that increase the chance that cancer might occur.</td>
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</table>
### Sun Protection Factor (SPF)
A scale for rating the level of sunburn protection in sunscreen products. The higher the sun protection factor, the more sunburn protection it gives. Sunscreens with a value of 2 through 11 give minimal protection against sunburns. Sunscreens with a value of 12 through 29 give moderate protection. Sun protection factors of 30 or higher give high protection against sunburn.

### Ultraviolet Radiation (UV)
Invisible rays that are part of the energy that comes from the sun. UV radiation that reaches the earth’s surface is made up of two types of rays, called UVA and UVB. Both types are thought to increase risk for cancers of the skin.

### UVA Radiation
Invisible rays that are part of the energy that comes from the sun. UVA radiation also comes from sun lamps and tanning beds. UVA radiation may cause premature aging of the skin and skin cancer. It may also cause problems with the eyes and the immune system. Skin specialists recommend that people use sunscreens that protect the skin from ultraviolet radiation.

### UVB Radiation
Invisible rays that are part of the energy that comes from the sun. UVB radiation causes sunburn, darkening and thickening of the outer layer of the skin, and melanoma and other types of skin cancer. It may also cause problems with the eyes and the immune system. Skin specialists recommend that people use sunscreens that protect the skin from ultraviolet radiation.

### Virus
In medicine, a very simple microorganism that infects cells and may cause disease. Because viruses can multiply only inside infected cells, they are not considered to be alive.

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For more detailed information about cancer or the glossary terms, please refer to the Dictionary of Cancer Terms at [http://www.cancer.gov](http://www.cancer.gov) or call the National Cancer Institute’s Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).
Resources for Learning More

**American Geriatric Society’s (AGS) Foundation for Health in Aging – For Older Men: Tips for Good Health in Later Life:** This fact sheet provides tips for good health in older life for men.
http://www.healthinaging.org/public_education/menshealth_tips.php

**Agency for Healthcare Research and Quality – Healthy Men:** This web page provides information for men on how to take an active role in their health care.
http://www.ahrq.gov/healthymen/

**Centers for Disease Control & Prevention (CDC) – Men’s Health:** This web page provides information for men on daily steps they can take to prevent disease and injury and stay well.
http://www.cdc.gov/Features/HealthyMen/

**CDC Vital Signs – Obesity:** This web page provides important data on the serious health topic of obesity.
http://www.cdc.gov/vitalsigns/AdultObesity/index.html

**CDC Vital Signs – Tobacco Use:** This web page provides important data on the serious health topic of tobacco use.
http://www.cdc.gov/vitalsigns/TobaccoUse/Smoking/index.html

**CDC – Women’s Health:** This web page provides information for women on daily steps they can take to prevent disease and injury and stay well.
http://www.cdc.gov/Features/womenshealthsupport/

**Inside Cancer – Multimedia Guide to Cancer Biology:** This self-paced multimedia tutorial provides information on the hallmarks of cancer, causes and prevention, diagnosis and treatment.
http://www.insidecancer.org/index.html

**National Cancer Institute (NCI) – Cancer Causes and Risk Factors:** Information about behaviors, exposures, and other factors that can influence the risk of cancer.
http://www.cancer.gov/cancertopics/causes

**NCI – Cancer Prevention Information:** Cancer prevention information from the National Cancer Institute, including prevention information for specific cancers.
http://www.cancer.gov/cancertopics/prevention

**NCI – Cancer Risk: Understanding the Puzzle:** Interactive site about cancer risk. It will help you make informed decisions about how you can lower your risk.
http://understandingrisk.cancer.gov/
NCI – President’s Cancer Panel: Promoting Healthy Lifestyles (2006-2007 Report): This report summarizes the evidence regarding the effects of diet, nutrition, physical activity, tobacco use, and tobacco smoke exposure on cancer risk as well as ongoing and potential actions to reduce the national cancer burden by promoting healthy lifestyles.
http://deainfo.nci.nih.gov/advisory/pcp/annualReports/index.htm

NCI – President’s Cancer Panel: Environmental Factors in Cancer (2008-2009 Report): This report summarizes the Panel’s the Panel’s recommendations, which delineate concrete actions that governments, industry, the research, health care, and advocacy communities, and individuals can take to reduce cancer risk related to environmental contaminants, excess radiation, and other harmful exposures.
http://deainfo.nci.nih.gov/advisory/pcp/annualReports/index.htm

NCI - Understanding Cancer Series: Cancer: This self-paced graphic-rich tutorial can be used for educational use by teachers, medical professionals, and the interested public. Can be downloaded in PDF and PowerPoint format.
http://www.cancer.gov/cancertopics/understandingcancer/cancer

NCI – Understanding Cancer: Cancer and the Environment: This self-paced graphic-rich tutorial can be used for educational use by teachers, medical professionals, and the interested public. Can be downloaded in PDF and PowerPoint format.
http://www.cancer.gov/cancertopics/understandingcancer/environment

NCI – What You Need To Know About™ Cancer: This booklet is part of a series on many types of cancer. The booklet tells about possible risks, symptoms, diagnosis, and treatment and includes a list of questions to ask the doctor.
http://www.cancer.gov/cancertopics/wyntk/cancer

National Library of Medicine (NLM) – Men’s Health (including health check-up information): This web page provides health information for men.

NLM – Women’s Health: This web page provides health information for women.
References


Module 4: The Role of Genes in Cancer

Goals
In this session, participants will gain a basic understanding of what genes are and the role they might play in a person’s risk of developing cancer.

Objectives
At the completion of Learning Module 4, participants will be able to demonstrate the following:

Section 1
a) Describe the role genetics plays in our lives.
b) Describe what is meant by the term “gene”.
c) Describe what genes do.

Section 2
a) Describe what a genetic mutation is.
b) Describe how a genetic mutation might affect health and the development of cancer.
c) Describe how a genetic condition can be acquired or inherited.

Section 3
a) Discuss what a genetic consultation is.
b) Discuss the limitations of genetic testing.
c) Describe the benefits and risks of genetic testing.
d) Discuss the role of targeted and gene therapies in treating certain types of cancer.

Measures of Objective Accomplishment
The presenter will administer a pre self-assessment and a post self-assessment to measure participants’ knowledge of the module’s objectives. The pre self-assessment measures existing knowledge and the post self-assessment measures what was gained through the learning module.

NOTE
- Each major learning point is clearly identified by boldface type throughout the guide and emphasized in the PowerPoint presentation.
- See the glossary (at the end of the module) for words that are in bold blue italics throughout the module.
### Pre/Post Self-Assessment

**The Role of Genes in Cancer**

*Do you agree (A), disagree (D), with these statements, or are you not sure (NS)?*  
*Circle your choice - A, D, or NS.*

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<tr>
<th></th>
<th>A</th>
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<th>NS</th>
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<tr>
<td>1.</td>
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<td>Genes contain the information our bodies need to work and grow.</td>
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<td>2.</td>
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<td>Many, if not most, diseases such as cancer, diabetes, and heart disease, begin in our genes.</td>
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<td>3.</td>
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<td></td>
<td>If you have a gene mutation, or a “faulty” gene, it will cause you to develop cancer.</td>
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<td>4.</td>
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<td></td>
<td>Most cancers are hereditary.</td>
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<tr>
<td>5.</td>
<td></td>
<td></td>
<td>Genetic testing can reveal information about the individual, his/her relatives, and future offspring.</td>
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### Pre/Post Self-Assessment Answer Key

**The Role of Genes in Cancer**

*The correct answer to each question, agree (A) or disagree (D), is underlined and in red.*

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<tr>
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</tr>
<tr>
<td>4.</td>
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<td>5.</td>
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|   | Genes contain the information our bodies need to work and grow.  
Note: Genes (units of heredity) contain the information for our bodies to work and grow. Each gene has the information needed for a particular job in helping our bodies function. |
|   | Many, if not most, diseases such as cancer, diabetes, and heart disease, begin in our genes. |
|   | If you have a gene mutation, or a “faulty” gene, it will cause you to develop cancer.  
Note: Cancer arises from combinations of changes that occur in the same cell over a period of time. These changes build up over many years and when a large number of changes occur in the same cell, it may finally become cancerous. |
|   | Most cancers are hereditary.  
Note: Even though all cancers are genetic, only a small portion - about 5-10% – are inherited. Most cancers come from random mutations that develop in body cells during one’s lifetime - either as a mistake when cells are going through cell division or in response to injuries from environmental agents such as radiation or chemicals. |
|   | Genetic testing can reveal information about the individual, his/her relatives, and future offspring. |
Section 1
What Are Genes?

*Genetics* is a term that refers to the study of *genes*, the basic unit of *heredity*, and their effects on the passing of genetic information and traits (such as eye color and an increased chance of getting a certain disease, such as breast cancer) from parents to offspring.¹

You may be asking, “Why is this important?” Genetics plays a role in health and disease. Health care professionals have known for a long time that common diseases such as heart disease, cancer, and *diabetes*, and rare diseases like *hemophilia, cystic fibrosis*, and *sickle cell disease*, can run in families. If members of one generation of a family have high blood pressure, it is not unusual for members of the next generation to also have high blood pressure. Tracing the illnesses suffered by your parents, grandparents, and other blood relatives can help your doctor predict the disorders for which you may be at risk and take action, such as screening for the disorder and treating it if is present, to keep you and your family healthy.²,³

*What are genes? Where are they found? What do they do?*

Module 2 discusses cells. The human body has trillions of cells. Recall that each cell has a *nucleus*, which acts as the cell’s “brain”. The nucleus also houses *genes*. Genes (units of heredity) contain the information for our bodies to work and grow. Each gene has the information needed for a particular job in helping our bodies function.¹,³
Genes are made up of DNA (deoxyribonucleic acid), which acts as instructions to make molecules and proteins. While almost all cells in a person’s body have the same DNA, different genes are active, or switched ‘on’ or ‘off’, in different cell, tissues and organs. For example, genes that are active in a breast cell are different from genes that are active in a lung cell. There are about 20,000 genes in the human genome, the complete set of instructions for life as we know it.

Since cells are very small, and we have many DNA molecules in each cell, each DNA molecule must be tightly packaged into a gene and each gene has a specific location on a chromosome. Chromosomes are essentially long thread-like strands of bead-like structures that are coiled up like a ball of string. Each one of those bead-like structures is a gene. If we were to take a closer look at these long strands, we would see that it consists of two DNA chains connected and running in opposite directions (the double helix).
Each DNA chain is composed of a series of four basic building blocks called **nucleotides**. The nucleotide bases are Adenine (A) and Guanine (G), and Thymine (T) and Cytosine (C). The string of bases on each of the two DNA chains pair up to form the rungs of the double helix. Since A can only pair with T, and G can only pair with C (and vice versa), the order on one strand dictates the order on its adjoining strand.\(^5,6\)

Chromosomes vary in number among different living things. For example, fruit flies have four pairs of chromosomes, while dogs have 39 pairs of chromosomes. In humans, a cell nucleus contains 46 individual chromosomes, or 23 pairs of chromosomes – half of these come from each biological parent (23 from our mother’s egg and 23 from our father’s sperm). This explains why children inherit traits, such as their hair color and skin color, from their mother and father.\(^7\) The chromosomes are numbered 1 to 22 from largest to smallest. The 23\(^{rd}\) pair is made up of the **sex chromosomes**, which determine a person’s gender (an “XX” pair for females and a “XY” pair for males).\(^8\)

The human genome is the complete set of instructions for life as we know it. Except for red blood cells, which have no nucleus, the human genome is located in the nucleus of every cell in the body.\(^6\)
Chromosomes help ensure that DNA is accurately copied and distributed during cell division. In order for organisms to grow, cells must divide to produce new cells and replace old cells. The structure of chromosomes keeps the DNA in genes tightly wrapped around proteins during this process. Without this packaging, DNA might not remain intact during cell division.

Changes, called mutations, in the number or structure of chromosomes in new cells may lead to serious problems. For example, in humans, one type of leukemia and some other cancers are caused by defective chromosomes made up of joined pieces of broken chromosomes. It is also crucial that reproductive cells, such as eggs and sperm, contain the right number of chromosomes and that those chromosomes have the correct structure. If not, the offspring may not develop properly, such as people with Down Syndrome. People with Down syndrome have three copies of chromosome 21, instead of the two copies found in other people.

As described in Module 2, cancer occurs when cell division gets out of control. Mutations can trigger cancer, whether it is due to an environmental exposure, such as tobacco smoke, a genetic predisposition, or both. Usually, several cancer-promoting factors have to be present for a person to develop a malignant, or cancerous, growth. Section 2 will address gene mutations.
Section 2
Gene Mutations

Cancer is a complex disease, like diabetes, heart disease, and kidney disease. All of these diseases arise from combinations of changes that occur in the same cell over a period of time. In cancer, these changes build up over many years and when a large number of changes occur in the same cell, it may finally become cancerous.

There are many different types of cancer, each with different combinations of changes. What is really interesting is that even within what we have previously thought of as a single type of cancer, such as lung cancer or colon cancer, clinicians have been able to identify subtypes, each showing a unique set of changes. For example, one person diagnosed with breast cancer may have a different subtype than another person also diagnosed with breast cancer, even when the cells look the same under a microscope.

What is a gene mutation?
Mistakes in the cell copying process makes the genes flawed, so that the genetic information contained is not read correctly, or sometimes not read at all. A permanent change in a gene that makes it flawed, or faulty, is called a mutation. A mutated, or flawed or faulty, gene may cause problems with the development and functioning of body systems or organs and can result in an abnormal genetic condition. Mutations can range in size from a single DNA building block, or base, to a large segment of a chromosome.9,10

Changes to genes occur for a number of reasons, including damaging environmental exposures such as radiation, tobacco smoke, or chemicals. Genetic changes also occur with aging. As a person gets older, their cells are constantly being replaced. That means that their cells, and in turn their genes, are copied over and over again. Sometimes, mistakes occur in the copying process, and these mistakes, or changes in the genes build up in their cells.5

How does a genetic mutation affect health and development?
Many, if not most, diseases begin in our genes. Although mistakes occur in DNA often, especially during cell division, a cell has the ability to fix them. But if DNA repair mechanisms fail, mutations can be passed along to future copies of the altered cell.
Gene mutations can be either acquired, or inherited from a parent. Changes in DNA that develop throughout a person’s lifetime are acquired mutations. Acquired mutations cannot be passed on by individuals to their children. Common disorders such as heart disease, diabetes, and most cancers arise from a complex interplay among multiple genes and between genes and factors in the environment. When a mutation occurs in reproductive cells (a man’s sperm or a woman’s egg cells), then the faulty gene can be passed onto children. This would be an example of an inherited mutation. When inherited mutations occur, the mutation will be in all of the offspring’s body cells. The fact that every cell contains the gene change makes it possible to use cheek cells or a blood sample for gene testing. Section 3 will cover genetic testing in more detail.

Interestingly, there are also cases where gene mutations can have a latent effect. This means that the change in the gene only becomes active after exposure to environmental agents, such as radiation, tobacco smoke, alcohol, or chemicals. This may explain why you may meet two smokers, but only one of them gets cancer. Or why one person responds to cancer treatment while another does not.

Due to advances in genomics, the ability to identify the mutation that makes a gene faulty exists through genetic testing. This topic is addressed in Section 3.

**How is a genetic condition inherited?**

More than 4,000 diseases are known to stem from altered genes inherited from one’s mother and/or father. As mentioned earlier, humans have 46 individual chromosomes, or 23 pairs of chromosomes – half from each biological parent (23 from our mother’s egg and 23 from our father’s sperm). Hereditary mutations are carried in the DNA of the reproductive cells. When reproductive cells containing mutations combine to produce offspring, the mutation will be in all of the offspring’s body cells.

Some genetic disorders are more likely to occur among people who trace their ancestry to a particular geographic area. People in an ethnic group often share certain versions of their genes, which have been passed down from common ancestors. If one of these shared genes contains a disease-causing mutation, a particular genetic disorder may be more frequently seen in the group.

Examples of genetic conditions that are more common in particular ethnic groups are sickle cell anemia, which is more common in people of African, African-American, or Mediterranean heritage; and Tay-Sachs disease, which is more likely to occur among people of Ashkenazi (eastern and central European) Jewish or French Canadian ancestry. It is important to note, however, that these disorders can occur in any ethnic group.
Section 3

Genetic Testing

What is the connection between cancer and one’s genes? The answer to this question lies in genetic testing. Understanding more about diseases caused by genes can lead to earlier diagnoses, interventions, and targeted treatments. For example, some populations, such as African Americans, experience disproportionately higher rates of some cancers. Scientists are conducting research to find out if there are some genetic variations that may be more or less common in specific groups. If so, this information can help them understand why certain groups or populations experience higher cancer rates, and in turn lead to better prevention strategies as well as more effective treatments.13

Genetics helps individuals and families learn about how conditions such as sickle cell anemia and cancer, are inherited in families, what screening and testing options are available, and for some genetic conditions, what treatments are available. Since our health is influenced by our family’s health history, family history can be a tool to help us identify the cause of conditions that are influenced by genetics.3

Genetic testing can help identify a gene mutation in a person, which can in some cases lead to the diagnosis of a genetic condition, such as Down Syndrome in unborn babies, or in other cases help assess a person’s risk for developing a particular disease, such as breast cancer.14

Genetic testing involves examining a person’s DNA - typically taken from cells in a sample of blood - for mutations linked to a disease or disorder. Genetic tests serve many purposes. They are widely used to screen newborns for a variety of disorders. Often this information helps doctors reduce the damage caused by the mutation. In oncology, doctors use gene testing to diagnose some types of cancer, to classify some cancers into subtypes, or to predict a patient’s responsiveness to new treatments.11

Gene tests are already available for a number of disorders, including life-threatening diseases such as cystic fibrosis and Tay Sachs disease. Gene tests for some cancers are also available. Specific genetic mutations have been identified as linked to several types of cancer, and, for some cancer types, this information has been used to develop clinical tests. For example, scientists have identified gene mutations that are linked to colon or breast cancer and genetic tests for these cancers are now available.11
Since the development of cancer is triggered by genes that have been altered in some way, whether through an acquired mutation or a hereditary mutation, one could say that all cancers are genetic. However, even though all cancers are genetic, just a small portion - about 5-10% – are inherited. Most cancers come from random mutations that develop in body cells during one's lifetime - either as a mistake when cells are going through cell division or in response to injuries from environmental agents such as radiation or chemicals.11

An accurate gene test can tell if a mutation is present, but that finding does not guarantee that the disease will develop. For example, women with the \textit{BRCA1} breast cancer susceptibility gene have an 80% chance of developing breast cancer by the age of 65. Men with the \textit{BRCA1} mutation also have an increased risk of breast cancer. The risk is high, but not absolute. And family members who test negative for the \textit{BRCA1} mutation are not exempt from breast cancer risk; over time, they can acquire breast cancer-associated genetic changes at the same rate as the general population.11 It is worth noting that mutations in these genes are rare in the general population and are estimated to account for no more than 5-10% of breast cancer cases overall.15

\textbf{The benefits and limitations of genetic testing}

Gene testing offers several benefits. A negative result can create a tremendous sense of relief and may eliminate the need for frequent check-ups and tests that are routine in families with a high risk of cancer. Even a positive result can relieve uncertainty and allow a person to make informed decisions about the future. A positive result can also let a person take steps to reduce risk before disease has a chance to develop.11

Gene testing has several limitations. For example, some disorders that "run in families" can be traced to shared environmental exposures rather than any inherited susceptibility. In addition, some mutations detected by a positive test may never lead to disease. Furthermore, because existing tests look only for the more common mutations in a gene, many disease-causing mutations may escape detection. Perhaps the most serious limitation of gene testing is that test information is not matched by state-of-the-art diagnostics and therapies. To receive positive results when there is no adequate treatment can be tragic.11

Although gene testing poses little physical risk - usually no more than giving a blood sample - it can seriously affect a person's life. A test confirming the risk of a serious disease can trigger profound psychological consequences. Additionally, because gene tests reveal information not only about the individual, but about his/her relatives and future offspring, the results can challenge family and other personal relationships. For example, with whom should a person share test results? Do the other family members want to know?11
Genetic Information Nondiscrimination Act (GINA)

Because gene test results hold a wealth of information, confidentiality is a major concern. In 2008, the Federal government passed the Genetic Information Nondiscrimination Act, also referred to as GINA. Since knowledge about differences in an individual’s DNA that may affect their health could affect decisions made by insurance companies and employers, the law protects a person’s confidentiality concerning the results of gene tests. Starting in 2009, the law prohibits insurance companies from using genetic information of an individual, or the individual’s family members, in decisions regarding coverage, rates, or pre-existing conditions. The law also prohibits most employers from using genetic information for hiring, firing, or promotion decisions, and for any decisions regarding terms of employment. The GINA law was needed to help ease concerns about discrimination that might keep some people from getting genetic tests that could benefit their health. The GINA law also enables people to take part in research studies without fear that their DNA information might be used against them in coverage determinations for health insurance or employment eligibility in the workplace.

Genetic counseling for specific conditions – what to expect

If there is genetic testing available for a specific genetic condition that may affect an individual, the decision to undergo genetic testing is a very personal one, and it should be totally voluntary. Genetic counselors play an important role. These specially trained health professionals are skilled at supporting individuals when testing is being considered, when test results are received, and during the weeks and months afterward. First, a genetic counselor meets with an individual to collect his/her family history and estimate their disease risk and that of family members. The genetic counselor will also provide education on the genetic condition and discuss the potential impact of test results on the individual and his/her family. If the individual agrees to genetic testing, the genetic counselor will also discuss and make arrangements for testing. After testing is complete, the genetic counselor provides follow-up to review results and provide support as needed.

After receiving genetic counseling, a person should agree to the genetic test only if she or he wants the information, not to accommodate relatives, health care providers, or anyone else. An important consideration to weigh is this: If the results are positive, are there available methods for state-of-the-art early prevention? early detection? treatment?
Since gene tests are designed to identify persons who have inherited a gene mutation, the first candidates for study would be members of high-risk families. In the future, tests may be offered to people whose family history is less known. Some day it may be possible to test a single blood sample for a number of gene mutations. However, before gene tests become generally available, there are major technical, ethical, and economic concerns that must be addressed.11

If widespread gene testing becomes a reality, it will be necessary to develop tests that are simple, cost-effective, and accurate. Testing thousands to millions of people will require many new labs and personnel as well as more genetic counselors. And widespread gene testing will require that many health care providers have a basic understanding of genetic principles in order to interpret the tests.11

**Family Health History**

Family members share genes, behaviors, lifestyles, and environments that together may influence their health and their risk of chronic disease. Most people have a family health history of some chronic diseases (e.g., cancer, coronary heart disease, and diabetes) and health conditions (e.g., high blood pressure and hypercholesterolemia). People who have a close family member with a chronic disease may have a higher risk of developing that disease than those without such a family member.18

Family health history is a written or graphic record of the diseases and health conditions present in your family. A useful family health history shows three generations of your biological relatives, the age at diagnosis, and the age and cause of death of deceased family members. Family health history is a useful tool for understanding health risks and preventing disease in individuals and their close relatives.18

Some people may know a lot about their family health history or only a little. It is helpful to talk with family members about your health history, write this information down, and update it from time to time. This way family members will have organized and accurate information ready to share with their health care provider. Family health history information may help health care providers determine which tests and screenings are recommended to help family members know their health risk.18
To help focus attention on the importance of family history, the Surgeon General, in cooperation with other agencies with the U.S. Department of Health and Human Services, has launched a national public health campaign, called the Surgeon General’s Family History Initiative, to encourage all American families to learn more about their family health history. Each year since 2004, the Surgeon General has declared Thanksgiving to be National Family History Day. Over the holiday or at other times when families gather, the Surgeon General encourages Americans to talk about, and to write down, the health problems that seem to run in their family. Learning about their family’s health history may help ensure a longer, healthier future together.2

**Looking to the Future**

As we learn more about the human genome, researchers will continue to seek to identify changes in the human genome involved in the development of cancer. Genetics has the possibility of improving the lives of patients by advancing techniques such as targeted therapy, gene therapy, and personalized medicine.

- **Targeted cancer therapies** are drugs or other substances that block the growth and spread of a cancer by interfering with specific molecules involved in tumor growth and progression.
  - Because scientists often call these molecules “molecular targets,” targeted cancer therapies are sometimes called “molecularly targeted drugs,” “molecularly targeted therapies,” or other similar names.
  - By focusing on molecular and cellular changes that are specific to a unique type of cancer, targeted cancer therapies may be more effective than other types of treatment, including chemotherapy and radiotherapy, and less harmful to normal cells.
  - Many targeted cancer therapies have been approved by the U.S. FDA for the treatment of specific types of cancer, such as *Gleevec* for some types of leukemias and *Herceptin* for certain types of breast cancer, while others are being studied in clinical trials, and many more are in preclinical studies, which is research using animals to find out if the therapies are likely to be useful.19

- **Gene therapy** is an experimental technique for treating disease by altering the patient’s genetic material. Most often, gene therapy works by introducing a healthy copy of a defective gene into the patient’s cell.20
• **Personalized medicine** is a phrase that commonly refers to medical care that is informed by an individual's specific genetic makeup. An example would be the TAILORx clinical trial. The **Trial Assigning Individualized Options for Treatment (Rx)**, or TAILORx, is examining whether genes that are frequently associated with risk of recurrence for women with early-stage breast cancer can be used to assign patients to the most appropriate and effective treatment.\(^{21}\)

The National Cancer Institute (NCI) is focused on ushering in the era when tailored prevention and treatment strategies, based on the unique characteristics of each person and the tumor, are standard practice in research-based clinics as well as community settings.
## Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td><strong>BRCA1/BRCA2</strong></td>
<td>The first two genes found to be associated with inherited forms of breast cancer. Both genes normally act as tumor suppressors, meaning that they help regulate cell division. When these genes are rendered inactive due to mutation, uncontrolled cell growth results, leading to breast cancer. Women with mutations in either gene have a much higher risk for developing breast cancer than women without mutations in the genes.</td>
</tr>
<tr>
<td><strong>chromosome</strong></td>
<td>Part of a cell that contains genetic information. Except for sperm and eggs, all human cells contain 46 chromosomes.</td>
</tr>
<tr>
<td><strong>cystic fibrosis</strong></td>
<td>A hereditary disease characterized by faulty digestion, breathing problems, respiratory infections from mucus buildup, and the loss of salt in sweat. The disease is caused by mutations in a single gene and is inherited as an autosomal recessive trait, meaning that an affected individual inherits two mutated copies of the gene. In the past, cystic fibrosis was almost always fatal in childhood. Today, however, patients commonly live to be 30 years or older.</td>
</tr>
<tr>
<td><strong>DNA</strong> (deoxyribonucleic acid)</td>
<td>The molecules inside cells that carry genetic information and pass it from one generation to the next. Also called deoxyribonucleic acid.</td>
</tr>
<tr>
<td><strong>diabetes</strong></td>
<td>Diabetes mellitus is a disease characterized by an inability to make or use the hormone insulin. Insulin is needed by cells to metabolize glucose, the body's main source of chemical energy. Type I diabetes, also called insulin-dependent diabetes mellitus, is usually caused by an autoimmune destruction of insulin-producing cells. Type II diabetes, also called non-insulin-dependent diabetes mellitus, occurs when cells become resistant to the effects of insulin.</td>
</tr>
<tr>
<td><strong>double helix</strong></td>
<td>The description of the structure of a DNA molecule. A DNA molecule consists of two strands that wind around each other like a twisted ladder. Each strand has a backbone made of alternating groups of sugar (deoxyribose) and phosphate groups. Attached to each sugar is one of four bases: adenine (A), cytosine (C), guanine (G), or thymine (T). The two strands are held together by bonds between the bases, adenine forming a base pair with thymine, and cytosine forming a base pair with guanine.</td>
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### Down Syndrome

Also known as Trisomy 21, Down Syndrome is a genetic disease resulting from a chromosomal abnormality. An individual with Down syndrome inherits all or part of an extra copy of Chromosome 21. Symptoms associated with the syndrome include mental retardation, distinctive facial characteristics, and increased risk for heart defects and digestive problems, which can range from mild to severe. The risk of having a child with Down syndrome rises with the mother's age at the time of conception.

### family history

A record of medical information about an individual and their biological family. Family history can be used to identify individuals who are at increased risk for developing genetic disorders that run in families.

### gene

The functional and physical unit of heredity passed from parent to offspring. Genes are pieces of DNA, and most genes contain the information for making a specific protein.

### gene therapy

Gene therapy is an experimental technique for treating disease by altering the patient's genetic material. Most often, gene therapy works by introducing a healthy copy of a defective gene into the patient's cells.

### genetic counseling

A communication process between a specially trained health professional and a person concerned about the genetic risk of disease. The person's family and personal medical history may be discussed, and counseling may lead to genetic testing.

### Genetic Information Nondiscrimination Act (GINA)

Federal legislation that makes it unlawful to discriminate against individuals on the basis of their genetic profiles in regard to health insurance and employment. These protections are intended to encourage Americans to take advantage of genetic testing as part of their medical care. President George W. Bush signed GINA into law on May 22, 2008.

### genetic testing

The use of a laboratory test to look for genetic variations associated with a disease. The results of a genetic test can be used to confirm or rule out a suspected genetic disease or to determine the likelihood of a person passing on a mutation to their offspring. Genetic testing may be performed prenatally or after birth. Ideally, a person who undergoes a genetic test will discuss the meaning of the test and its results with a genetic counselor.
<table>
<thead>
<tr>
<th><strong>genetic variation</strong></th>
<th>Genetic variation can refer to differences between individuals or to differences between populations. Mutation is the ultimate source of genetic variation, but mechanisms such as sexual reproduction and genetic drift contribute to it as well.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>genetics</strong></td>
<td>The study of genes and heredity.</td>
</tr>
<tr>
<td><strong>genome</strong></td>
<td>The entire set of genetic instructions found in a cell. In humans, the genome consists of 23 pairs of chromosomes, found in the nucleus.</td>
</tr>
<tr>
<td><strong>genomics</strong></td>
<td>The study of the complete genetic material, including genes and their functions, of an organism.</td>
</tr>
<tr>
<td><strong>Gleevec</strong></td>
<td>A drug used to treat different types of leukemia and other cancers of the blood, gastrointestinal stromal tumors, skin tumors called dermatofibrosarcoma protuberans, and a rare condition called systemic mastocytosis. It is also being studied in the treatment of other types of cancer. Gleevec blocks the protein made by the bcr/abl oncogene. It is a type of tyrosine kinase inhibitor. Also called imatinib mesylate and STI571.</td>
</tr>
<tr>
<td><strong>hemophilia</strong></td>
<td>An inherited disease, most commonly affecting males, that is characterized by a deficiency in blood clotting. The responsible gene is located on the X chromosome, and since males inherit only one copy of the X chromosome, if that chromosome carries the mutated gene then they will have the disease. Females have a second, usually normal, copy of the gene on their other X chromosome, so they capable of passing on the disease without experiencing its symptoms.</td>
</tr>
<tr>
<td><strong>Herceptin</strong></td>
<td>A monoclonal antibody that binds to HER2 (human epidermal growth factor receptor 2), and can kill HER2-positive cancer cells. Monoclonal antibodies are made in the laboratory and can locate and bind to substances in the body, including cancer cells. Herceptin is used to treat breast cancer that is HER2-positive and has spread after treatment with other drugs. It is also used with other anticancer drugs to treat HER2-positive breast cancer after surgery. Herceptin is also being studied in the treatment of other types of cancer. Also called trastuzumab.</td>
</tr>
<tr>
<td><strong>heredity</strong></td>
<td>The passing of genetic information and traits (such as eye color and an increased chance of getting a certain disease) from parents to offspring.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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</tr>
<tr>
<td>mutation</td>
<td>Any change in the DNA of a cell. Mutations may be caused by mistakes during cell division, or they may be caused by exposure to DNA-damaging agents in the environment. Mutations can be harmful, beneficial, or have no effect. If they occur in cells that make eggs or sperm, they can be inherited; if mutations occur in other types of cells, they are not inherited. Certain mutations may lead to cancer or other diseases.</td>
</tr>
<tr>
<td>nucleotide</td>
<td>The basic building block of nucleic acids. DNA are made of long chains of nucleotides. A nucleotide consists of a sugar molecule attached to a phosphate group and a nitrogen-containing base. The bases used in DNA are adenine (A), cytosine (C), guanine (G), and thymine (T).</td>
</tr>
<tr>
<td>nucleus</td>
<td>The structure in a cell that contains the chromosomes.</td>
</tr>
<tr>
<td>personalized medicine</td>
<td>An emerging practice of medicine that uses an individual's genetic profile to guide decisions made in regard to the prevention, diagnosis, and treatment of disease. Knowledge of a patient's genetic profile can help doctors select the proper medication or therapy and administer it using the proper dose or regimen.</td>
</tr>
<tr>
<td>preclinical study</td>
<td>Research using animals to find out if a drug, procedure, or treatment is likely to be useful. Preclinical studies take place before any testing in humans is done.</td>
</tr>
<tr>
<td>reproductive cell</td>
<td>An egg or sperm cell. Each mature reproductive cell carries a single set of 23 chromosomes.</td>
</tr>
<tr>
<td>sex chromosomes</td>
<td>A type of chromosome that participates in sex determination. Humans and most other mammals have two sex chromosomes, the X and the Y. Females have two X chromosomes in their cells, while males have both X and a Y chromosome in their cells. Egg cells all contain an X chromosome, while sperm cells contain an X or Y chromosome. This arrangement means that it is the male that determines the sex of the offspring when fertilization occurs.</td>
</tr>
<tr>
<td>sickle cell disease</td>
<td>A hereditary disease seen most often among people of African ancestry. Caused by mutations in one of the genes that encode the hemoglobin protein, the disease is inherited as an autosomal recessive trait. The mutation causes the red blood cells to take on an unusual sickle shape. Individuals affected by sickle cell disease are chronically anemic and experience significant damage to their heart, lungs, and kidneys.</td>
</tr>
<tr>
<td><strong>targeted therapy</strong></td>
<td>A type of treatment that uses drugs or other substances to identify and attack specific cancer cells. Targeted therapy may have fewer side effects than other types of cancer treatments.</td>
</tr>
<tr>
<td><strong>Tay-Sachs disease</strong></td>
<td>A rare, inherited disorder. It causes too much of a fatty substance to build up in tissues and nerve cells of the brain. This buildup destroys the nerve cells, causing mental and physical problems.</td>
</tr>
</tbody>
</table>

For more detailed information about cancer or the glossary terms, please refer to the Dictionary of Cancer Terms at [http://www.cancer.gov/](http://www.cancer.gov/) or call the National Cancer Institute’s Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).
Resources for Learning More

American Society of Clinical Oncology’s (ASCO) Cancer.Net – What to Expect When Meeting With a Genetic Counselor: This link provides information about meeting with a genetic counselor.  
http://www.cancer.net/patient/All+About+Cancer/Genetics/What+to+Expect+When+Meeting+With+a+Genetic+Counselor

ASCO’s Cancer.Net – Sharing Genetic Test Results With Your Family: This link provides supportive information about sharing genetic test results with family members.  
http://www.cancer.net/patient/All+About+Cancer/Genetics/Sharing+Genetic+Test+Results+With+Your+Family

Centers for Disease Control & Prevention (CDC) – Diseases, Genetics, and Family History: This web page provides links to general information about diseases, genetics and family history.  
http://www.cdc.gov/genomics/resources/diseases/index.htm

CDC – Family Health History Awareness: This link provides general information about family history and health.  
http://www.cdc.gov/genomics/resources/diseases/family.htm

CDC – Genomics and Health: Frequently Asked Questions: This link provides information about genomics and health in a question and answer format.  
http://www.cdc.gov/genomics/public/faq.htm

Genetic Health.com: This web site provides the latest information about genetics and health and helps you assess your inherited genetic risk of common diseases like cancer and heart disease.  
http://www.genetichealth.com/index.shtml

National Cancer Institute (NCI) – BRCA1 and BRCA2: Cancer Risk and Gene Testing: A fact sheet that explains what the BRCA genes are, and provides an overview of cancer risk related to these genes.  

NCI – Understanding Cancer Series: Cancer Genomics: This self-paced graphic-rich tutorial can be used for educational use by teachers, medical professionals, and the interested public. Can be downloaded in PDF and PowerPoint format.  
http://www.cancer.gov/cancertopics/understandingcancer/cancergenomics

NCI – Understanding Cancer Series: Gene Testing: This self-paced graphic-rich tutorial can be used for educational use by teachers, medical professionals, and the interested public. Can be downloaded in PDF and PowerPoint format.  
http://www.cancer.gov/cancertopics/understandingcancer/genetesting
**NCI – Understanding Cancer Series: Targeted Therapies:** This link provides tutorials on advances in targeted therapies. Also provided are links for specific information about targeted therapies for breast cancer, multiple myeloma, and lymphoma.

http://www.cancer.gov/cancertopics/understandingcancer/targetedtherapies

**NCI – Targeted Cancer Therapies:** A fact sheet that provides information about targeted therapies in a question and answer format.

http://www.cancer.gov/cancertopics/factsheet/Therapy/targeted

**National Human Genome Research Institute (NHGRI):** Link to access educational materials about genetics and genomics.  
http://www.genome.gov/Education/

**NHGRI – A Brief Guide to Genomics:** A brief guide to DNA, genes, and genomics. 
http://www.genome.gov/18016863

**NHGRI – Genetic Information Nondiscrimination Act of 2008:** Provides specific information about the Genetic Information Nondiscrimination Act. 
http://www.genome.gov/10002328

**NHGRI – Policy and Ethics Issues:** This link provides information about policy and ethical issues in genetic testing.  
http://www.genome.gov/27527631

**NHGRI – Talking Glossary of Genetic Terms:** Glossary which can be used to understand the terms and concepts used in genetic research. In addition to definitions, specialists in the field of genetics share their description of terms, and many terms include images, animation, and links to related terms.  
http://www.genome.gov/Glossary/index.cfm

**National Institute of General Medical Sciences – Human Genetic Variation Fact Sheet:** Provides information about genetics including genetic variation, genome wide association studies, gene tests, genetic research and comparative genomics and evolution. 
http://www.nigms.nih.gov/Publications/Factsheet_GeneticVariation.htm

**National Institutes of Health - Genetic Testing: What It Means for Your Health & Your Family’s Health:** Provides information about genetic testing and what it means for individual and family health. 
http://www.genome.gov/Pages/Health/PatientsPublicInfo/GeneticTestingWhatItMeansForYourHealth.pdf

**National Library of Medicine (NLM) – Genetics Resources and Patient Support:** This web page provides links to relevant genetics resources on the web.  
http://ghr.nlm.nih.gov/Resources
**NLM - Handbook: Help Me Understand Genetics:** This handbook presents basic information about genetics in clear language and provides links to online resources.  

**The University of Utah, Genetics Science Learning Center – Tour of the Basics:** This multimedia tutorial helps clarify basic terms such as DNA, genes, chromosomes, heredity, and traits.  
http://learn.genetics.utah.edu/content/begin/tour/

**The University of Utah, Genetics Science Learning Center – Using Family History to Improve Your Health:** This web site provides information about diseases, such as diabetes and cancer, who is at risk for such diseases, and how one can reduce their risk.  
http://learn.genetics.utah.edu/content/health/history/

**U.S. Department of Health & Human Services – Surgeon General’s Family Health History Initiative:** This web-based tool helps users organize family history information and then print it out for presentation to their family doctor. In addition, the tool helps users save their family history information to their own computer and even share family history information with other family members.  
http://www.hhs.gov/familyhistory/
References


Module 5: Cancer Screening and Early Detection

Goals
In this session, participants will gain an understanding of the components of early detection, the importance of recognizing some of the barriers associated with practicing early detection, and the symptoms of cancer.

Objectives
At the completion of Learning Module 3, participants will be able to demonstrate the following:

Section 1
a) Describe the importance of early detection.
b) Describe two screening methods used in the detection of cancer.

Section 2
Describe two barriers that may be associated with practicing early detection.

Section 3
Describe three symptoms of cancer.

Measures of Objective Accomplishment
The presenter will administer a pre self-assessment and a post self-assessment to measure participants’ knowledge of the module’s objectives. The pre self-assessment measures existing knowledge and the post self-assessment measures what was gained through the learning module.

Target Audience
- Community members
- Staff of Indian health programs, including Community Health Representatives

Contents of Learning Module
- Instructor’s Guide with Pre/Post Self-Assessment
- PowerPoint presentation
- Glossary
- Resources for Learning More
- References

Length
- Introduction of session/module overview (:05)
- Pre self-assessment (:07)
- Presentation of module (:30)
- Post self-assessment (:05)
- Closing (:03)

NOTE
- Each major learning point is clearly identified by **boldface** type throughout the guide and emphasized in the PowerPoint presentation.
- See the glossary (at the end of the module) for words that are in **bold blue italics** throughout the module.
## Pre/Post Self-Assessment

### Cancer Screening and Early Detection

Do you agree (A), disagree (D), with these statements, or are you not sure (NS)?

*Circle your choice - A, D, or NS.*

|   |   |   |  
|---|---|---|---|
| 1 | A | D | NS | The goal of early detection is to discover and stop a cancerous tumor before it grows and spreads. |
| 2 | A | D | NS | Regular physical exams, medical screening tests, and knowledge of changes in your body may help detect early signs of cancer. |
| 3 | A | D | NS | A person’s fears about cancer may be considered a barrier to participating in early detection for cancer. |
| 4 | A | D | NS | There are screening and early detection tests available for most types of cancer. |
| 5 | A | D | NS | A change in some part of the body, such as a lump or thickening in the breast, or a cough that doesn’t go away, always indicates cancer. |
Pre/Post Self-Assessment
Answer Key

Cancer Screening and Early Detection

*The correct answer to each question, agree (A), disagree (D), is underlined and in red.*

<p>| | | |</p>
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<tbody>
<tr>
<td><strong>1.</strong></td>
<td><strong>A</strong></td>
<td><strong>D</strong></td>
</tr>
</tbody>
</table>
|   |   | The goal of early detection is to discover and stop a cancerous tumor before it grows and spreads.  
**Note:** The sooner cancer is detected and treated, the better a person’s chance for a full recovery. |
| **2.** | **A** | **D** |
|   |   | Regular physical exams, medical screening tests, and knowledge of changes in your body may help detect early signs of cancer. |
| **3.** | **A** | **D** |
|   |   | A person’s fears about cancer may be considered a barrier to participating in early detection for cancer.  
**Note:** Fatalism about cancer is very strong in Native populations because their experience has been that nearly everyone who develops cancer dies from it. |
| **4.** | **A** | **D** |
|   |   | There are screening and early detection tests available for most types of cancer.  
**Note:** A few types of cancers have specific screening tests that aid in detecting cancer early (i.e. breast, cervix, colon). |
| **5.** | **A** | **D** |
|   |   | A change in some part of the body, such as a lump or thickening in the breast, or a cough that doesn’t go away, always indicates cancer.  
**Note:** It is important to understand that a symptom is a sign that something is not right in the body and does NOT always indicate cancer. Certain symptoms may be a sign of infection, benign tumor, or another problem. It is important to see the doctor about any symptom or physical change to determine its cause. One should not wait to feel pain: Early cancer usually does not cause pain. |
Section 1
Cancer Screening and Early Detection

The sooner cancer is detected and treated, the better a person’s chance for a full recovery. The chances that cancer will be detected early are greatly improved by having regular medical check-ups and being aware of any changes in your body. A doctor can often find early cancer during a physical exam or with routine tests, even if a person has no symptoms.

Checking for cancer in a person who does not have any symptoms of the disease is called screening. Some people visit the doctor only when they notice changes like a lump in the breast or unusual bleeding or discharge. However, early cancer may not have any symptoms. That is why screening for some cancers can help, particularly as we get older.

Early detection of cancer is key. The goal of early detection is to discover and stop a cancerous tumor before it grows and spreads (metastasizes). For this reason, it is important for individuals to see their doctor on a regular basis for a physical exam. During a routine physical exam, a doctor will look for anything unusual and feel for any lumps or growths. In addition, the doctor may recommend a screening test.

Some screening tests are used because they have been shown to be helpful both in finding cancers early and in decreasing the chance of dying from these cancers. The recommendation to have a screening test is based on the individual, the test, and the cancer that the test is intended to detect. For example, the doctor takes into account the person’s age, medical history and general health, family history and lifestyle. This information assists the doctor in determining a person’s risk for developing cancer.
Medical screening tests are effective tools in the early detection of cancer. A few types of cancers have specific screening tests that aid in detecting cancer early. The following list describes medical screening methods used for common forms of cancer such as breast, cervix, colon, and prostate:

**Breast**

Screening for breast cancer has been shown to reduce the risk of dying from this disease. A screening mammogram is the best tool available to find breast cancer before signs or symptoms appear. A mammogram is an x-ray of the breasts. Screening mammograms usually involved two x-rays of each breast. They make it possible to detect tumors that cannot be felt. Screening mammograms can also find microcalcifications (tiny deposits of calcium) that sometimes indicate the presence of breast cancer.

- The National Cancer Institute (NCI) recommends that women age 40 and older should have mammograms every 1 to 2 years. Women who are at higher than average risk of breast cancer should talk with their health care providers about whether to have mammograms before age 40 and how often to have them.²
- The American Cancer Society (ACS) recommends that women should have yearly mammograms starting at age 40. Women at high risk of breast cancer should get a MRI and a mammogram every year.³

Both organizations recommend clinical breast exams (CBE) as part of a periodic health exam. Some women perform monthly breast self-exams (BSE) to check for changes in their breasts. While BSE may be frequently advocated, the evidence for its effectiveness is weak. Women in their 40’s and older should be aware that a monthly BSE is not a substitute for regularly scheduled mammograms and clinical breast exams.
Cervix

The Pap test is used to screen for cancer of the cervix. Screening for cervical cancer using the Pap test has decreased the number of new cases of cervical cancer and the number of deaths due to cervical cancer since 1950. For this test, cells are collected from the surface of the cervix and vagina. The cells are examined under a microscope to detect cancer or changes that may lead to cancer.

- The NCI recommends that women have a Pap test at least once every three years, beginning about three years after they begin to have sexual intercourse, but no later than at age 21.4

- The ACS recommends that all women should begin cervical cancer screening about 3 years after they begin having vaginal intercourse, but no later than 21 years old. Screening should be done every year with a regular Pap test or every 2 years with a newer liquid-based Pap test. Beginning at age 30, women who have had 3 normal Pap tests in a row may get screened every 2 to 3 years.3

Experts recommend waiting about 3 years after the start of sexual activity to avoid overtreatment for common, temporary abnormal changes. It is safe to wait 3 years, because cervical cancer usually develops slowly.

Women ages 65 to 70 who have had at least three normal Pap tests in a row, and no abnormal Pap tests in the last 10 years, may decide, after talking to their clinician, to stop having Pap tests. Women who have had a hysterectomy (surgery to remove the uterus and cervix) do not need to have a Pap test, unless the surgery was done as a treatment for a precancerous condition or cancer.

More frequent exams are required if the human papillomavirus (HPV), a risk factor for cervical cancer, is present. (HPV is covered in more detail in Module 3 – Cancer Risk Factors and Risk Reduction.) The frequency of Pap tests should be discussed on an individual basis with the health care provider.
Studies show that screening for colorectal cancer helps decrease the number of deaths from the disease. There are several screening tests used for early detection of colon and rectal (colorectal) cancer.* These tests can be divided into two categories: stool/fecal-based tests, which mainly find cancer, and structural tests, which are able to detect both polyps and cancer. While structural tests are preferred if they are available, experts agree that any screening is better than none.

A doctor may recommend one or more of the following tests based on a person’s age, medical history, family history of colorectal cancer, general health, or presence of other risk factors for colorectal cancer.

* Several major organizations, including the U.S. Preventive Services Task Force (a group of experts convened by the U.S. Public Health Service) and the ACS, have developed guidelines for colorectal cancer screening. Although some details of their recommendations vary regarding which screening tests to use and how often to be screened, all of these organizations support screening for colorectal cancer.
Stool/fecal-based Tests

These tests are designed to detect signs of cancer in stool samples. While they are not invasive and do not require bowel preparation, they are less likely to detect polyps for colorectal cancer prevention.

Fecal Occult Blood Test (FOBT). The FOBT checks for hidden blood in fecal material (stool), a possible sign of colon cancer. To perform a FOBT, small samples of stool are placed on special collection cards and sent to a laboratory for testing. If blood is confirmed in the stool, additional tests may be performed to find the source of the bleeding. Studies have shown that FOBT, when performed every 1 to 2 years in people ages 50 to 80, can help reduce the number of deaths due to colorectal cancer by 15 to 33 percent. Currently, two types of FOBT are available:

- Guaiac FOBT is the most common stool test used for colorectal cancer screening. This test uses the chemical guaiac to detect heme in stool. (Heme is the iron-containing component of the blood protein hemoglobin.) Guaiac FOBT should be performed on three successive stool specimens obtained while the patient adheres to a prescribed diet.

- Fecal Immunochemical test (FIT) is the other type of FOBT. This test detects hemoglobin protein in stool. Unlike the guaiac FOBT, FIT does not require dietary restrictions and a single testing sample is used.

Stool DNA Test. This test checks DNA in stool cells for genetic changes that may be a sign of colorectal cancer. A stool DNA test may provide a valuable non-invasive screening option, however, it has not yet been approved by the Food & Drug Administration. More research is necessary to determine the best screening interval.

Structural Tests

These tests are able to find both polyps and colorectal cancer using endoscopy or radiologic imaging. The limitations with these tests are: invasiveness, need for dietary preparation and bowel cleansing, and time needed for the exam.

Sigmoidoscopy. In this test, the rectum and sigmoid (lower) colon are examined for polyps, abnormal areas, or cancer using a thin, tube-like instrument with a light and lens for viewing called a sigmoidoscope. During a sigmoidoscopy, the doctor can remove or biopsy precancerous and cancerous growths. Studies suggest that regular screening with sigmoidoscopy every five years after age 50 can help reduce the number of deaths from colorectal cancer. Compared to colonoscopy, this test does not require sedation and requires less bowel preparation, but is limited to examination of the lower half of the colon.
Colonoscopy. In this test, the rectum and entire colon are examined using a thin, tube-like instrument with a light and lens for viewing called a colonoscope. During a colonoscopy, the doctor can remove or biopsy precancerous and cancerous growths throughout the colon, including the upper part of the colon, where they would be missed by sigmoidoscopy. A thorough cleansing of the colon is necessary before this test and most patients receive some form of sedation. Colonoscopy is the required procedure for confirmation of positive findings from any other tests. It is not yet known for certain whether colonoscopy can help reduce the number of deaths from colorectal cancer, but studies have shown a reduction in the number of new colorectal cancer cases. For people at average risk, the general consensus among health professionals is that a colonoscopy be performed every ten years after age 50.

Double Contrast Barium Enema (DCBE). In this test a series of x-rays of the entire colon and rectum are taken after the patient is given an enema containing a barium solution and air is introduced into the colon. The barium solution and air help outline the colon and rectum on x-rays. Research shows that DCBE may miss small polyps. It detects about 30-50% of the cancers that can be found with standard colonoscopy. Typically, this test is only used as an alternative for patients who cannot undergo colonoscopy. The American Cancer Society (ACS) recommends DCBE every five years after age 50 for people at average risk.

Computed Tomographic (CT) Colonography. Also called virtual colonoscopy, this test is evolving as a promising technique for colorectal cancer screening. In this test, special x-ray equipment is used to produce pictures of the colon and rectum. A computer then assembles these pictures into detailed images that can show polyps and other abnormalities. Because it is less invasive that standard colonoscopy and sedation is not needed, virtual colonoscopy may cause less discomfort and take less time to perform. As with standard colonoscopy, a thorough cleansing of the colon is necessary before this test. Available study data indicate that CT colonography may be useful for the detection of larger polyps. Since it is still an evolving test with regards to screening intervals, the ACS recommends CT colonography every five years after age 50 for people at average risk. Whether virtual colonoscopy can reduce the number of deaths from colorectal cancer is not yet known.

In addition to the tests listed in this section, health care providers may perform a digital rectal exam (DRE). The DRE is an examination in which the doctor inserts a lubricated, gloved finger into the rectum to feel for abnormal areas. DRE allows examination of only the lower part of the rectum. It is often performed as part of a routine physical exam.

People should talk with their health care provider about when to begin screening for colorectal cancer, what tests to have, the benefits and risks of each test, and how often to schedule appointments.
Prostate

Over time recommendations for routine screening for prostate cancer have varied. Some doctors and cancer organizations have encouraged annual prostate cancer screening for all men over the age of 50; others have recommended against routine screening; still others have counseled on an individual basis and encouraged men to make their own informed decisions about screening.

Clinical trials have shown that while annual prostate cancer screening may in fact detect more prostate cancers, it does not lower the number of prostate cancer deaths. Because prostate cancer tends to grow slowly, and most men with prostate cancer do not die from this disease, this may result in more men diagnosed with prostate cancer and suffering from side effects of treatment, such as impotence and incontinence, but receiving little to no benefit. At this time, due to insufficient evidence to show that routine screening decreases a man’s chance of dying from prostate cancer, routine prostate cancer screening is not recommended for men.

Men should talk with their health care provider about their prostate cancer risk and the need for screening tests. Men can ask their provider whether to begin screening for prostate cancer (even though he does not have any symptoms), what tests to have, risks and benefits of each test, and how often to have them. The doctor may suggest either of the tests described below. These tests are used to detect prostate abnormalities, but they cannot show whether abnormalities are cancer or another, less serious condition. The doctor will take the results into account in deciding whether to check the patient further for signs of cancer.

**Digital Rectal Exam** (described previously in the colorectal section) is used to aid in early detection of prostate cancer. The doctor feels the prostate through the wall of the rectum and checks for any hard or lumpy areas.

**Prostate Specific Antigen (PSA) Test.** PSA is a protein produced by the prostate gland. The PSA test measures the level of PSA in the blood. Both benign (non-cancerous) prostate conditions and prostate cancer can cause PSA levels to rise in the blood.
A Reminder about Cancer Screening
In many cases, the available evidence on the effectiveness of cancer screening is not clear-cut. Experts’ opinions about appropriate cancer screening may differ, especially regarding which tests are recommended, at what age, and with what frequency. Also, opinions may change as new evidence becomes available. Printed material may not contain the latest changes in scientific knowledge.

For current screening information, check the following resources:
- National Cancer Institute (Website www.cancer.gov, or 1-800-4-CANCER),
- American Cancer Society (Website www.cancer.org, or 1-800-ACS-2345), or

In addition to regular physical exams and medical screening tests, periodic self-examination may help detect changes in the body that require follow-up with a doctor. A general awareness of one’s body (both appearance and how one feels) will often result in sensitivity to any change that may occur. While the benefits of self-examination are unknown, there are two self-checks that may reveal changes in the body that require follow-up with a doctor. They are the breast self-exam (BSE) and the testicular self-exam (TSE).

Breast Self-Exam (BSE)
Some women perform monthly breast self-exams to look for any changes in their breasts. BSE helps women become familiar with the feel of their own breasts so that changes will be recognized early. While BSE may be frequently advocated, the evidence for its effectiveness is weak. Women in their early forties and older should know that monthly BSE is not a substitute for regularly scheduled screening mammograms and clinical breast exams performed by a health professional.

Testicular Self-Exam (TSE)
Testicular cancer is the most common cancer in men ages 15 to 35 years old. Most testicular cancers are discovered by patients themselves or their partners, either unintentionally or by self-examination. Testicular self-examination aids or helps men become familiar with the feel of their own testicles (what is normal for their own body).

NOTE
For a complete reference guide of major cancer sites (cervical, breast, lung, prostate and colon) please refer to the “Cancer Sites Reference Worksheet” at the end of this module.
Barriers to Cancer Screening and Early Detection

There are many barriers that affect one’s decision to participate in cancer screening and early detection. Some barriers, such as those related to socioeconomic conditions, tend to be more general and are experienced by many populations, for example, lack of access to health care facilities or affordable health insurance coverage. Other barriers, such as cultural beliefs, tend to be more specific to a particular population and play an important role in the decision to participate in cancer screening. For health care providers working with AI/AN, it is important to understand the influence of Native culture on health behavior in order to improve the level of participation of this population in cancer screening and early detection methods. The following list describes some of the cultural beliefs specific to AI/AN that can be a barrier to participating in cancer screening and early detection.

Fear of Cancer

Fatalism about cancer is very strong in Native populations because their experience has been that nearly everyone who develops cancer dies from it. As a result, interest in screening may be limited. Many AI/AN believe that to talk about cancer may bring a similar misfortune upon oneself. Understanding the significance of framing health education messages in a “wellness” context may lessen some of the fears and apprehensions associated with discussing cancer.

Lack of Knowledge

For many AI/AN, cancer is a relatively “new” disease. It has only been within the past few decades that cancer has risen to prominence as one of several chronic diseases, including heart disease and diabetes, affecting AI/AN. Lack of understandable education materials about cancer contributes to a lack of knowledge among AI/AN and may contribute to some misconceptions about this disease.

Language/Literacy

Some Native Americans, especially elders, have limited English skills, and a large majority have limited education. In addition, understanding of cancer and its prevention and treatment is hampered by the fact that of the 217 indigenous languages spoken today, few include a word for “cancer”. As previously mentioned, little written cancer education material is available that is both culturally appropriate and matches the literacy level of the population. Indian Health Service suggest that in order to be most effective, print materials should be written at the
sixth grade level and designed for visual learners and the oral transfer of information (e.g., videos, conferences, story telling, support groups, and talking circles), in keeping with Native oral language traditions.

**Modesty**

Native Americans, particularly women, are quite private and are extremely hesitant to discuss matters having to do with their bodies, especially with strangers. This modesty affects Native Americans’ willingness to be screened for cancer or to discuss symptoms they may be having with providers, especially those who are not Native American.9

For many AI/AN, participating in cancer screening may violate their personal feelings of modesty. This may, in part, be due to forced exposure to religious groups at the turn of the century that emphasized modesty. Subsequent generations have been influenced by these beliefs in contrast to the traditional Indian belief that one’s body a blessing of the Creator and not object of shame.11

**Communication**

AI/AN communication style differs from that used by many Western health care providers. Although communication styles vary among tribes, the following customs are common to many tribes: 1) a slower rate of speech, 2) a respectful “pause” between speakers that allows time for the original speaker to add any other thoughts or ideas prior to the listener responding, and 3) the “circular” or story telling manner of responding to questions versus the direct “linear” response. Use of direct eye contact and violating personal space may also impede communication.11

**Illness Beliefs**

Some AI/AN believe cancer may be caused by witching, evil spirits, and elements beyond one’s control.10 Others believe the disease may have occurred as a result of a childhood event during which contact with the causal agent took place.13

Understanding cultural barriers has the potential to save lives and reduce cancer death in the AI/AN population. Use of culturally acceptable and sensitive intervention is of critical importance to overcoming barriers to cancer screening and early detection. Collaboration between health care providers and community members focused on developing meaningful interventions can lead to positive health behavior change and improved cancer related health outcomes.
Section 3
Possible Symptoms of Cancer

There are many different symptoms known to be associated with certain types of cancers. As cancer grows in the body, it causes changes to take place, producing symptoms. The symptoms produced depend on the size of the cancer, the location, and the surrounding organs or structures. As cancer grows, it produces pressure on nearby organs, blood vessels, and nerves. For example, a small cancer in a critical organ such as the brain can produce early symptoms as it presses on certain areas of the brain disrupting brain function.

It is important to understand that a symptom is a sign that something is not right in the body and does NOT always indicate cancer. Certain symptoms may be a sign of infection, benign tumor, or another problem. It is important to see the doctor about any symptom or physical change to determine its cause. **One should not wait to feel pain:** Early cancer usually does not cause pain.

The National Cancer Institute\(^1,14\) and the American Cancer Society\(^15\) have identified some common symptoms of cancer:

**A change in bowel or bladder function:** Long-term diarrhea, constipation, or changes in the size of stool may indicate colon cancer. Pain with urination, blood in the urine, or change in bladder function can be related to bladder or prostate cancer.

**A sore that does not heal:** Skin cancers may bleed and resemble sores that do not heal. Sores in the mouth that do not heal may indicate oral cancer, especially if the person is a smoker, chews tobacco, or frequently uses alcohol. Sores on the penis and vagina should also be evaluated by a doctor.

**Unusual bleeding or discharge:** Blood in the sputum (spit or saliva) may indicate lung cancer. Blood in the stool may indicate cancer of the colon or rectum. Abnormal bleeding not related to menstrual periods may indicate cancer of cervix, vagina, or uterus. Blood in the urine may indicate kidney or bladder cancer. Bloody discharge from the nipple may indicate breast cancer.

**Thickening or lump in breast or other parts of the body:** Many cancers can be felt through the skin, particularly in the breast, testicle, lymph nodes (glands), and the soft tissues of the body. Any lump or thickening should be reported to your doctor.
**Persistent indigestion or difficulty swallowing:** These symptoms may indicate cancer of the esophagus, stomach, or pharynx (throat).

**Recent change in wart or mole:** A change in color, loss of definite borders, or an increase in size should be reported to the doctor without delay. The skin lesion may be a melanoma, which, if diagnosed early, can be treated successfully.

**A nagging cough or hoarseness:** A persistent cough that does not go away may be a sign of lung cancer. Hoarseness can be a sign of cancer of the larynx (voice box) or thyroid.

In addition to the common symptoms listed above, there are a few general symptoms that may be associated with cancer. These symptoms should be evaluated by a doctor to determine their cause, particularly if they have been present for a period of time (such as several weeks). They are:

- unexplained changes in weight,
- fever,
- skin changes (darker looking skin, yellowing skin and eyes, reddened skin, itching, or excessive hair growth),
- fatigue (extreme tiredness that does not get better with rest), and
- pain.

If symptoms occur, a doctor may perform a physical examination, order blood work and other tests, and/or recommend a biopsy. In most cases, a biopsy is the only way to know for certain whether cancer is present.
# Cancer Sites Reference Worksheet

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>Possible Signs and Symptoms</th>
<th>Common Sites of Metastasis</th>
<th>Common Treatment</th>
<th>Risk Factors</th>
<th>Behaviors to Reduce Risk</th>
<th>Screening &amp; Early Detection Methods</th>
</tr>
</thead>
</table>
| **Breast Cancer** | A lump or thickening in or near the breast or underarm area  
A change in the shape or size of the breast  
Dimpling or puckering in the skin of the breast  
A nipple turned inward into the breast  
Nipple discharge  
Scaly, red or swollen skin on the breast, nipple or areola | Lymph nodes  
Bones  
Liver  
Lungs  
Brain | Surgery  
Radiation Therapy  
Hormone Therapy  
Chemotherapy  
Biological or Targeted Therapy | Age  
Personal breast health history  
Family health history  
Genetic factors  
Radiation therapy to the chest  
Reproductive and menstrual history  
Breast density  
History of taking DES  
Being overweight after menopause | Regular exercise  
Maintain a healthy weight  
Limit alcohol consumption | Mammogram  
Clinical breast exam  
Breast self-exam  
Ultrasound  
MRI  
Biopsy |
<table>
<thead>
<tr>
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<th>Behaviors to Reduce Risk</th>
<th>Screening &amp; Early Detection Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cervical Cancer</td>
<td>Abnormal bleeding such as bleeding between menstrual periods or after menopause, and/or after sexual intercourse, Unusual vaginal discharge</td>
<td>Lymph nodes Bladder Rectum Lungs Liver Bones</td>
<td>Surgery Radiation Therapy Chemotherapy</td>
<td>HPV infection (causal) Multiple sexual partners Early first intercourse Lack of regular Pap tests Smoking Weakened immune system Women whose mothers used synthetic estrogen diethylstilbestrol (DES) during pregnancy</td>
<td>Safe sex practices Limit number of sexual partners Regular screening for early detection and treatment of precancerous tissue Stop smoking</td>
<td>Pap smear/test Biopsy</td>
</tr>
</tbody>
</table>

M5 -17
<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>Possible Signs and Symptoms</th>
<th>Common Sites of Metastasis</th>
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<th>Screening &amp; Early Detection Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colon Cancer</td>
<td>Diarrhea or constipation</td>
<td>Lymph nodes, Liver, Lungs</td>
<td>Surgery, Chemotherapy, Biological therapy, Radiation therapy</td>
<td>Age over 50, Colorectal polyps, Family or personal history of colorectal cancer, Genetic alterations, Ulcerative colitis or Crohn’s disease, Diet</td>
<td>Polyp removal, Low-fat, high-fiber diet, Regular exercise, Maintaining healthy weight, Limit alcohol consumption, Don’t smoke or quit smoking</td>
<td>Fecal Occult Blood Test, Sigmoidoscopy, Colonoscopy, Double contrast barium enema, Digital rectal exam, Virtual colonoscopy, Polypectomy</td>
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<td></td>
<td>Feeling that bowel does not empty completely</td>
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<td>Blood in your stool</td>
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<td></td>
<td>Stools that are narrower than usual</td>
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<tr>
<td></td>
<td>Frequent gas pains, cramps, or feeling full or bloated</td>
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<tr>
<td></td>
<td>Unexplained weight loss</td>
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<td></td>
<td>Constant tiredness</td>
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<td></td>
<td>Nausea or vomiting</td>
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<tr>
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<tr>
<td>Lung Cancer</td>
<td>Cough that gets worse or does not go away</td>
<td>Lymph nodes</td>
<td>Surgery</td>
<td>Cigarettes</td>
<td>Don't smoke or quit smoking</td>
<td>Currently there are no screening methods for early detection of lung cancer</td>
</tr>
<tr>
<td></td>
<td>Breathing trouble, such as shortness of breath</td>
<td>Heart</td>
<td>Radiation Therapy</td>
<td>Cigars</td>
<td>Avoid secondhand smoke</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Constant chest pain</td>
<td>Esophagus</td>
<td>Chemotherapy</td>
<td>Pipes</td>
<td>Avoid radon exposure</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Coughing up blood</td>
<td>Trachea</td>
<td>Targeted Therapy</td>
<td>Secondhand smoke (Environmental Tobacco Smoke)</td>
<td>Asbestos workers should use protective equipment</td>
<td></td>
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<tr>
<td></td>
<td>A hoarse voice</td>
<td>Brain</td>
<td></td>
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<tr>
<td></td>
<td>Frequent lung infections such as pneumonia</td>
<td>Bones</td>
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<tr>
<td></td>
<td>Feeling very tired all the time</td>
<td>Liver</td>
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<td>Adrenal glands</td>
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<tr>
<td>Prostate Cancer</td>
<td>Not being able to pass urine</td>
<td>Lymph nodes</td>
<td>Watchful waiting/active surveillance</td>
<td>Age over 65</td>
<td>Digital Rectal Exam</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hard time starting or stopping urine flow</td>
<td>Bones</td>
<td>Surgery</td>
<td>Family history</td>
<td>Blood test for Prostate Specific Antigen</td>
<td></td>
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<tr>
<td></td>
<td>Needing to urinate frequently, especially at night</td>
<td>Seminal vesicles</td>
<td>Radiation therapy</td>
<td>Race (more common among Black men)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Weak flow of urine</td>
<td>Bladder</td>
<td>Hormone therapy</td>
<td>Certain prostate changes</td>
<td>Transrectal ultrasound</td>
<td></td>
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<td></td>
<td>Urine flow that starts and stops</td>
<td>Rectum</td>
<td>Chemotherapy</td>
<td>Genetic alterations</td>
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<tr>
<td></td>
<td>Pain or burning during urination</td>
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<td></td>
<td>Difficulty having an erection</td>
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<tr>
<td></td>
<td>Blood in urine or semen</td>
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<tr>
<td></td>
<td>Frequent pain in the lower back, hips, or upper thighs</td>
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</tr>
</tbody>
</table>

For more detailed information about cancer or the glossary terms, please refer to the Dictionary of Cancer Terms at [http://www.cancer.gov](http://www.cancer.gov/) or call the National Cancer Institute’s Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).
### Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>breast self-exam (BSE)</td>
<td>An exam by a woman of her breasts to check for lumps or other changes.</td>
</tr>
<tr>
<td>clinical breast exam (CBE)</td>
<td>A physical exam of the breast performed by a health care provider to check for lumps or other changes.</td>
</tr>
<tr>
<td>colonoscopy</td>
<td>Examination of the inside of the colon using a colonoscope, inserted into the rectum. A colonoscope is a thin, tube-like instrument with a light and lens for viewing. It may also have a tool to remove tissue to be checked under a microscope for signs of disease.</td>
</tr>
<tr>
<td>DNA (deoxyribonucleic acid)</td>
<td>The molecules inside cells that carry genetic information and pass it from one generation to the next. Also called deoxyribonucleic acid.</td>
</tr>
<tr>
<td>discharge</td>
<td>Fluid secretions typically coming from an opening in the body such as the vagina. Discharge can be normal or a sign of disease.</td>
</tr>
<tr>
<td>digital rectal exam (DRE)</td>
<td>An exam in which a physician inserts a lubricated, gloved finger into the rectum to feel for abnormalities of the rectum and prostate. Also called DRE.</td>
</tr>
<tr>
<td>double contrast barium enema</td>
<td>A procedure in which a liquid with barium is put into the rectum and colon by way of the anus. Barium is a silver-white metallic compound that helps to show the image of the lower gastrointestinal tract on an x-ray.</td>
</tr>
<tr>
<td>endoscopy</td>
<td>Endoscopy is a procedure that lets a doctor look inside a person’s body. It uses an instrument called an endoscope, or scope for short. Scopes have a tiny camera attached to a long, thin tube. The doctor moves it through a body passageway or opening to see inside an organ. Sometimes scopes are used for surgery, such as for removing polyps from the colon. The two types of scopes used for colorectal cancer screening are colonoscopy and sigmoidoscopy.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
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</tr>
<tr>
<td>fecal occult blood test (FOBT)</td>
<td>A test used to check for blood in the stool, which may be a sign of colorectal cancer. A small sample of stool is placed on a chemically treated card, which is then tested in a laboratory for blood. If blood is detected, additional testing may be needed to determine the source of the bleeding.</td>
</tr>
<tr>
<td>guaiac</td>
<td>A substance from a type of tree called Guaiacum that grows in the Caribbean. Guaiac is used in the fecal occult blood test.</td>
</tr>
<tr>
<td>human papillomavirus (HPV)</td>
<td>Also called HPV. A type of virus that can cause abnormal tissue growth (for example, warts) and other changes to cells. Some papilloma viruses are sexually transmitted. Infection for a long time with certain types of HPV can cause abnormal changes in cells of the cervix that can lead to the development of cervical cancer. HPV can also play a role in some other types of cancer, such as anal, vaginal, vulvar, penile, and oropharyngeal cancers.</td>
</tr>
<tr>
<td>localized</td>
<td>Within the site of origin, without evidence of spread.</td>
</tr>
<tr>
<td>magnetic resonance imaging (MRI)</td>
<td>A procedure in which radio waves and a powerful magnet linked to a computer is used to create detailed pictures of areas inside the body. These pictures show the difference between normal and diseased tissue.</td>
</tr>
<tr>
<td>mammogram</td>
<td>An x-ray used to screen for cancer of the breast.</td>
</tr>
<tr>
<td>menstrual/menstruation</td>
<td>A woman’s monthly cycle during which the uterus sheds its lining causing a discharge of blood and tissue through the vagina. From puberty until menopause, menstruation occurs about every 28 days when a woman is not pregnant.</td>
</tr>
<tr>
<td>metastasize</td>
<td>When cancer spreads from one part of the body to another. When cancer cells metastasize and form secondary tumors, the cells in the metastatic tumor are like those in the original (primary) tumor.</td>
</tr>
<tr>
<td>Pap test</td>
<td>Also known as a Papanicolaou test or a Pap smear, a procedure used to screen for cancer of the cervix and other conditions such as inflammation or infection. Cells from the cervix are examined under a microscope to detect cancer and changes that may lead to cancer.</td>
</tr>
<tr>
<td>polyp</td>
<td>A growth that protrudes from a mucous membrane.</td>
</tr>
<tr>
<td>precancerous</td>
<td>A term used to describe a condition that may, or is likely to become, cancer.</td>
</tr>
</tbody>
</table>
**prostate specific antigen (PSA)**

PSA is a protein produced by the cells of the prostate gland. The PSA test measures the level of PSA in the blood. The amount of PSA may be higher in men who have prostate cancer, benign prostate disease, or infection or inflammation of the prostate.

**screening**

Checking for disease in a person who does not have any symptoms. Since screening may find diseases at an early stage, there may be a better chance of curing the disease.

**sigmoidoscopy**

Examination of the lower colon and rectum using a sigmoidoscope inserted into the rectum. A sigmoidoscope is a thin, tube-like instrument with a light and lens for viewing. It may also have a tool to remove tissue to be checked under a microscope for signs of disease.

**testicular self-exam**

An exam by a man of his testes to check for lumps or other changes.

**tumor**

An abnormal mass of tissue that results when cells divide more than they should or do not die when they should. Tumors may be benign (not cancer), or malignant (cancer).
Resources for Learning More

**Centers for Disease Control & Prevention (CDC) Vital Signs – Breast Cancer Screening:** Vital Signs offers recent data and calls to action for important public health issues. This issue focuses on breast cancer.  
[http://www.cdc.gov/vitalsigns/CancerScreening/indexBC.html](http://www.cdc.gov/vitalsigns/CancerScreening/indexBC.html)

**CDC Vital Signs – Colorectal Cancer Screening:** Vital Signs offers recent data and calls to action for important public health issues. This issue focuses on colorectal cancer.  
[http://www.cdc.gov/vitalsigns/CancerScreening/indexCC.html](http://www.cdc.gov/vitalsigns/CancerScreening/indexCC.html)

**National Cancer Institute (NCI) – Cancer Screening Overview (PDQ®):** The Physician Data Query (PDQ®) is NCI’s comprehensive cancer database. It contains summaries on a wide range of cancer topics. This summary provides information about measuring the effectiveness of cancer screening tests and about weighing the strength of evidence obtained from cancer screening research studies.  

**NCI – Screening and Testing to Detect Cancer (Site specific information):** This web page provides information on what cancer screening is as well as links to information on screening for specific types of cancer.  

**NCI – Types of Tests to Detect Cancer (Specific imaging and laboratory test information):** This web page provides links to information about cancer screening and the types of tests used to find cancer.  

**NCI – Fact Sheet: Colorectal Cancer Screening:** This fact sheet discusses the advantages and disadvantages of several colorectal cancer screening tests.  

**NCI – Fact Sheet: Mammograms:** A fact sheet that defines screening and diagnostic mammograms. Discusses mammography screening guidelines and risk factors for breast cancer.  

**NCI – Fact Sheet: Pap Test:** A fact sheet that describes the Pap test procedure, possible results, and the link between HPV and cervical cancer.  

**NCI – Fact Sheet: Tumor Markers: Questions and Answers:** A fact sheet that explains tumor markers and answers questions about use in screening.  
NCI – Special Report: Experts Recommend Steps to Increase Colorectal Cancer Screening in Primary Care: This special report provides a summary of steps needed to increase colorectal cancer screening in primary care practices.  
http://www.cancer.gov/ncicancerbulletin/020910/page5

NCI – Understanding Cancer Series: Cancer: This self-paced graphic-rich tutorial can be used for educational use by teachers, medical professionals, and the interested public. Can be downloaded in PDF and PowerPoint format.  
http://www.cancer.gov/cancertopics/understandingcancer/cancer

NCI - What You Need To Know About™ Cancer Index: A series of booklets on cancer. Each booklet explains possible risks, symptoms, diagnosis, and treatment and includes a list of questions to ask the doctor. Booklets are available for a number of different cancers.  
http://www.cancer.gov/cancertopics/wyntk/
References


Module 6: Cancer Diagnosis and Staging

Goals
In this session, participants will gain an understanding of how cancer is diagnosed and how the extent or stage of cancer is determined.

Objectives
At the completion of Learning Module 6, participants will be able to demonstrate the following:

Section 1
a) Describe what is meant by the term “biopsy”.
b) Describe how tumors may behave differently from one another (e.g., well differentiated versus poorly differentiated).

Section 2
a) Give two examples of the stages of cancer and their meaning.
b) Give two reasons why staging is important.

Measures of Objective Accomplishment
The presenter will administer a pre self-assessment and a post self-assessment to measure participants’ knowledge of the module’s objectives. The pre self-assessment measures existing knowledge and the post self-assessment measures what was gained through the learning module.

NOTE
- Each major learning point is clearly identified by **boldface** type throughout the guide and emphasized in the PowerPoint presentation.
- See the glossary (at the end of the module) for words that are in **bold blue italics** throughout the module.
### Pre/Post Self-Assessment

**Cancer Diagnosis and Staging**

*Do you agree (A), disagree (D), with these statements, or are you not sure (NS)? Circle your choice - A, D, or NS.*

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<tbody>
<tr>
<td>1.</td>
<td>A</td>
<td>D</td>
<td>NS</td>
<td>A biopsy helps determine whether or not a tumor is benign (non-cancerous) or malignant (cancerous).</td>
</tr>
<tr>
<td>2.</td>
<td>A</td>
<td>D</td>
<td>NS</td>
<td>Microscopic examination of the tumor is an important part of a cancer diagnosis.</td>
</tr>
<tr>
<td>3.</td>
<td>A</td>
<td>D</td>
<td>NS</td>
<td>Cancer in situ is an early cancer that has not yet spread to neighboring tissue and has a very poor outcome.</td>
</tr>
<tr>
<td>4.</td>
<td>A</td>
<td>D</td>
<td>NS</td>
<td>A cancer that is localized (has not spread to other areas of the body) has a good chance for control or cure.</td>
</tr>
<tr>
<td>5.</td>
<td>A</td>
<td>D</td>
<td>NS</td>
<td>The “staging” of cancer (determining the extent of disease) is an important part of determining treatment, disease outcome, and how the patient will respond to treatment.</td>
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## Pre/Post Self-Assessment Answer Key

### Cancer Diagnosis and Staging

*The correct answer to each question, agree (A), disagree (D), is underlined and in red.*

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</table>
|1. | A | D | A biopsy helps determine whether or not a tumor is benign (non-cancerous) or malignant (cancerous).  
**Note:** To diagnose the presence of cancer, a doctor must look at a biopsy sample of the affected tissue under a microscope. |
|2. | A | D | Microscopic examination of the tumor is an important part of a cancer diagnosis.  
**Note:** Microscopic examination will help determine tumor grade, or how aggressive the cancer is and how fast it is growing. |
|3. | A | D | Cancer in situ is an early cancer that has not yet spread to neighboring tissue and has a very poor outcome.  
**Note:** Cancer in situ is an early stage cancer with no invasion to surrounding tissue. It carries a very good prognosis for complete cure. |
|4. | A | D | A cancer that is localized (has not spread to other sites of the body) has a good chance for control or cure.  
**Note:** Localized cancers also have a good chance for control or cure. |
|5. | A | D | The “staging” of cancer (determining the extent of disease) is an important part of determining treatment, disease outcome, and how the patient will respond to treatment.  
**Note:** Staging determines the extent of the disease, determines treatment, and helps determine a patient’s prognosis. |
Section 1
Cancer Diagnosis and Staging

If you have a symptom, or your screening test result suggests cancer, the doctor must find out if it is due to cancer or some other cause. The doctor may ask about your personal and family medical history and do a physical exam. The doctor may also order lab tests, x-rays, or other tests or procedures.

Tests of the blood, urine, or other fluids can show how well an organ is doing its job. Also, high amounts of substances called tumor markers may be a sign of cancer\(^1\). However, doctors cannot rely on lab tests alone to diagnose cancer\(^2\).

Imaging procedures create pictures of areas inside your body that help the doctor see whether a tumor is present. These pictures can be made in several ways:

- **X-rays**: X-rays are the most common way to view organs and bones inside the body.

- **CT scan**: An x-ray machine linked to a computer takes a series of detailed pictures of your organs. You may receive a contrast material, such as a dye, to make these pictures easier to read.

- **Radionuclide scan**: You receive an injection of a small amount of radioactive material. It flows through your bloodstream and collects in certain bones or organs. A machine, called a scanner, detects and measure the radioactivity. The scanner creates pictures of bones or organs on a computer screen or on film. Your body gets rid of the radioactive substances quickly.

- **Ultrasound**: An ultrasound device sends out sound waves that people cannot hear. The waves bounce off tissues inside your body like an echo. A computer uses these echoes to create a picture called a sonogram.

- **MRI**: A strong magnet linked to a computer is used to make detailed pictures of areas in your body. Your doctor can view these pictures on a monitor and can print them on film.

- **PET scan**: You receive an injection of a small amount of radioactive material. A machine makes pictures that show chemical activities in the body. Cancer cells sometimes show up as areas of high activity.
To diagnose the presence of cancer, a doctor must look at a sample of the affected tissue under a microscope, also known as a biopsy. A biopsy is the surgical removal of a small piece of tissue for microscopic examination. Microscopic examination will tell the doctor whether a tumor is actually present and if so, whether it is malignant (cancerous) or benign (non-cancerous).

There are three ways tissue can be removed for biopsy: endoscopy, needle biopsy, or surgical biopsy.

**Endoscopy**
By using a thin lighted tube, the doctor is able to look at areas inside the body and see what’s going on, take pictures, and remove tissue or cells for examination, if necessary.

**Needle Biopsy**
The doctor takes a small tissue or fluid sample by inserting a needle into the abnormal (suspicious) area.

**Surgical Biopsy**
There are two types of surgical biopsies. An excisional biopsy is performed when the doctor removes the entire tumor, often with some surrounding normal tissue. An incisional biopsy is performed when the doctor removes just a portion of the tumor. If cancer is found to be present, the entire tumor may be removed immediately or during another operation.

Once the doctor has removed the tumor and determined the presence of cancer, he will want to determine the “aggressiveness” of the cancer, or how fast the cancer is growing. To do this, the doctor will look at the tumor under the microscope to determine tumor grade, or how alike or different the cancer cells are from one another.
Under the microscope, some tumor cells look very much like the normal tissue they came from. If they do, they are called **well differentiated**. Cells in well differentiated tumors tend to grow and multiply slowly.

Other tumors may only slightly resemble the normal tissue that they came from or they may not resemble any specific tissues. These tumor cells are called **poorly differentiated** or **undifferentiated tumor cells**. Generally speaking, tumors that are undifferentiated or poorly differentiated tend to be more aggressive in their behavior. They grow faster, spread earlier, and have poorer outcomes than well differentiated tumors.

**In summary, the biopsy has provided the doctor with the following important information:**

- Whether or not the tumor is benign (non-cancerous) or malignant (cancer).
- The “type” of cancer (e.g., carcinoma versus sarcoma). See Module 2, Section 3: Types of Cancer.
- The “aggressiveness” or behavior of the tumor (e.g., well differentiated versus poorly differentiated).
Once the diagnosis of cancer has been made, the doctor will want to learn the stage, or extent, of the disease. This process is referred to as “staging” and tells the doctor how far the cancer in the original or primary tumor has spread in the body. Treatment decisions are based on the results of staging.

The common stages of cancer are:

**In situ**
Early cancer that has not spread to neighboring tissue. It is present only in the layer of cells in which it began.

**Localized**
Cancer is found only in the organ where it started to grow.

**Regional**
Cancer has spread beyond the original or primary site to the surrounding tissues or lymph nodes.

**Distant**
Cancer has spread to other organs and systems of the body.

**Recurrent**
Cancer that has come back after a period of time during which it could not be found. The cancer may come back to the same place as the original tumor or to another place in the body.

**Unknown**
Cancer cases in which there is not enough information to indicate a stage.

Staging is an important part of making a good diagnosis. Cancer in situ, cancer of an early stage with no invasion to surrounding tissue, carries a very good prognosis for complete cure. When cancer is more extensive (involving larger areas) but still has not spread to other sites, it is considered to be localized. Localized cancers also have a good chance for control or cure.
Cancers that have begun to spread are classified according to the manner and extent of spread: by direct extension, by involvement of the lymph nodes, and by evidence of distant metastasis or spread. Though each type of cancer has its own progression of disease and the medical community has various methods of staging classification, staging can be generally described as follows:

**Stage 0** Carcinoma in situ. Early cancer that is present only in the layer of cells in which it began.

**Stage 1** A cancerous tumor is found to be limited to the organ of origin.

**Stage 2** The cancer has spread to the surrounding tissues and possibly to the local lymph nodes.

**Stage 3** There is extensive growth of the primary tumor and possible other organ involvement.

**Stage 4** The cancer has spread far into the other organs and systems of the body away from the original tumor site.

Each cancer grows differently. The stage of cancer at the time of diagnosis means different things for different cancers. For example, lymph node involvement does not necessarily mean the same thing in every kind of cancer. Thus, the information about the extent of the cancer must be considered in light of the tissue diagnosis obtained from the biopsy.

Staging is performed using a number of methods such as physical exams, imaging procedures (such as those described in Section 1, ultrasound, magnetic resonance imaging (MRI), and computed tomography (CT or CAT scan), x-rays), laboratory tests (blood tests, urine sample, *bone marrow biopsy*), and even special surgery.

**In summary, the staging of cancer is important for three reasons:**

1) **Staging determines the extent of the disease;**

2) **Treatment is determined by the stage of the specific cancer;**

3) **Staging helps determine the patient’s prognosis.**
### Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>biopsy</strong></td>
<td>The surgical removal of a small piece of tissue for microscopic examination to check for cancer cells.</td>
</tr>
<tr>
<td><strong>bone marrow biopsy</strong></td>
<td>A procedure in which a needle is inserted into either the breast or pelvic bone to remove a small amount of liquid bone marrow (blood forming cells) for examination under a microscope.</td>
</tr>
<tr>
<td><strong>CT scan (computed tomography)</strong></td>
<td>An x-ray test using a computer to produce a detailed ((CT\ or\ CAT\ scan)\ picture of a cross-section of the body.</td>
</tr>
<tr>
<td><strong>distant (cancer or metastasis)</strong></td>
<td>Refers to cancer that has spread from the original (primary) tumor to distant organs or distant lymph nodes.</td>
</tr>
<tr>
<td><strong>endoscopy</strong></td>
<td>Endoscopy is a procedure that lets a doctor look inside a person’s body. It uses an instrument called an endoscope, or scope for short. Scopes have a tiny camera attached to a long, thin lighted tube. The doctor moves it through a body passageway or opening to see inside an organ. Endoscopy can be used to take pictures, and remove tissue or cells for examination, if necessary.</td>
</tr>
<tr>
<td><strong>imaging procedures</strong></td>
<td>Special tests that give detailed images of a person’s body including x-rays, ultrasound, magnetic resonance imaging (MRI), and computed tomography (CT or CAT scan).</td>
</tr>
<tr>
<td><strong>in situ</strong></td>
<td>Early cancer that has not spread to neighboring tissue.</td>
</tr>
<tr>
<td><strong>localized</strong></td>
<td>Within the site of origin, without evidence of spread.</td>
</tr>
<tr>
<td><strong>magnetic resonance imaging (MRI)</strong></td>
<td>A procedure in which radio waves and a powerful magnet linked to a computer is used to create detailed pictures of areas inside the body. These pictures show the difference between normal and diseased tissue.</td>
</tr>
<tr>
<td><strong>microscopic examination</strong></td>
<td>Use of a microscope to visualize cells.</td>
</tr>
<tr>
<td><strong>needle biopsy</strong></td>
<td>Type of biopsy by which the doctor inserts a needle into an abnormal (suspicious) area to remove a small tissue sample for diagnosis.</td>
</tr>
<tr>
<td>Term</td>
<td>Description</td>
</tr>
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</tr>
<tr>
<td><strong>poorly differentiated or undifferentiated tumor cells</strong></td>
<td>Tumor cells that may only slightly resemble the normal tissue that they came from; this type of tumor may tend to be more aggressive in their behavior, spread faster, and have a poorer outcome.</td>
</tr>
<tr>
<td><strong>recurrent</strong></td>
<td>Cancer that has recurred (come back), usually after a period of time during which the cancer could not be detected. The cancer may come back to the same place as the original (primary) tumor or to another place in the body. Also called recurrence.</td>
</tr>
<tr>
<td><strong>regional</strong></td>
<td>In oncology, describes the body area right around a tumor.</td>
</tr>
<tr>
<td><strong>staging</strong></td>
<td>Describes how far the cancer has spread from the original site to other parts of the body (i.e. in situ, local, regional, or distant).</td>
</tr>
<tr>
<td><strong>surgical biopsy</strong></td>
<td>There are two types of surgical biopsies. An excisional biopsy is performed when the doctor removes the entire tumor, often with some surrounding normal tissue. An incisional biopsy is performed when the doctor removes just a portion of the tumor.</td>
</tr>
<tr>
<td><strong>tumor grade</strong></td>
<td>A description of a tumor based on how abnormal the cancer cells look under a microscope and how quickly the tumor is likely to grow and spread. Grading systems are different for each type of cancer.</td>
</tr>
<tr>
<td><strong>tumor markers</strong></td>
<td>A substance that may be found in tumor tissue or released from a tumor into the blood or other body fluids. A high level of a tumor marker may mean that a certain type of cancer is in the body. Examples of tumor markers include CA 125 (in ovarian cancer), CA 15-3 (in breast cancer), CEA (in ovarian, lung, breast, pancreas, and gastrointestinal tract cancers), and PSA (in prostate cancer).</td>
</tr>
<tr>
<td><strong>ultrasound</strong></td>
<td>An exam in which sound waves are bounced off tissues and the echoes are converted into a picture.</td>
</tr>
<tr>
<td><strong>well differentiated tumor cells</strong></td>
<td>Cells that look and function similar to normal cells of the same type.</td>
</tr>
</tbody>
</table>

For more detailed information about cancer or the glossary terms, please refer to the Dictionary of Cancer Terms at http://www.cancer.gov/ or call the National Cancer Institute’s Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).
Resources for Learning More

**Northwest Portland Area Indian Health Board Northwest Tribal Comprehensive Cancer Project:** On this web page you can access the Northwest Tribal Cancer Resource Guide, full of resources for cancer survivors and caregivers. You can also access The Appointment Companion, a tool to help cancer survivors keep track of appointments and treatment.  

**National Cancer Institute (NCI) – Cancer Information Summaries: Adult Treatment (PDQ®):** The Physician Data Query (PDQ®) is NCI’s comprehensive cancer database. It contains summaries on a wide range of cancer topics. This page links to an alphabetical list of PDQ® adult cancer treatment summaries. These summaries provide site specific information on diagnosis and staging.  

**NCI – Fact Sheet: Cancer Staging:** This fact sheet explains the process of grouping cancer cases in categories (stages) based on the size of the tumor and the extent of the cancer in the body.  

**NCI – Fact Sheet: Computed Tomography:** A fact sheet that describes the CT scan procedure and technology and its uses in diagnosis and treatment.  

**NCI – Fact Sheet: Pathology Reports:** A fact sheet that describes the type of information that may be found in a pathology report, the document that contains results of the visual and microscopic examination of tissue removed during a biopsy or surgery.  

**NCI – Fact Sheet: Tumor Grade:** A fact sheet that discusses tumor grade and its role in prognosis. Explains concepts like normal cell biology and cell differentiation.  

**NCI – Fact Sheet: Tumor Markers: Questions and Answers:** A fact sheet that explains tumor markers and answers questions about use in screening.  

**NCI – Understanding Cancer Series: Cancer:** This self-paced graphic-rich tutorial can be used for educational use by teachers, medical professionals, and the interested public. Can be downloaded in PDF and PowerPoint format.  

**NCI - What You Need To Know About™ Cancer Index:** A series of booklets on cancer. Each booklet explains possible risks, symptoms, diagnosis, and treatment and includes a list of questions to ask the doctor. Booklets are available for a number of different cancers.  
References


Module 7: Basics of Cancer Treatment

Goals
In this session, participants will gain an understanding of the common cancer treatments and their potential side effects.

Objectives
At the completion of Learning Module 7, participants will be able to demonstrate the following:

Section 1
a) Discuss the Western and traditional approach to cancer treatment and why both are important to use in the fight against cancer.
b) Discuss the difference between local and systemic treatment for cancer.
c) Describe the reason side effects commonly occur with cancer treatment.

Section 2
a) Describe at least two side effects that can occur as a result of cancer treatment.

Section 3
a) Discuss the benefits of managing physical effects of cancer and cancer treatment.

Measures of Objective Accomplishment
The presenter will administer a pre self-assessment and a post self-assessment to measure participants’ knowledge of the module’s objectives. The pre self-assessment measures existing knowledge and the post self-assessment measures what was gained through the learning module.

NOTE
- Each major learning point is clearly identified by **boldface** type throughout the guide and emphasized in the PowerPoint presentation.
- See the glossary (at the end of the module) for words that are in **bold blue italics** throughout the module.
**Pre/Post Self-Assessment**

**Basics of Cancer Treatment**

*Do you agree (A), disagree (D), with these statements, or are you not sure (NS)? Circle your choice - A, D, or NS.*

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<td>1.</td>
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<td>D</td>
<td>NS</td>
<td>Cancer treatment may consist of several methods such as surgery, chemotherapy, radiation therapy, hormonal therapy, and biological therapies.</td>
</tr>
<tr>
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</tr>
<tr>
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<td>The purpose of clinical trials is to find better ways to treat cancer.</td>
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<td>NS</td>
<td>Systemic treatments travel through the bloodstream, reaching cancer cells all over the body.</td>
</tr>
</tbody>
</table>
## Pre/Post Self-Assessment

### Answer Key

#### Basics of Cancer Treatment

The correct answer to each question, (A), disagree (D), is underlined and in red.

<p>| | | |</p>
<table>
<thead>
<tr>
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</table>
| 1. | A | Cancer treatment may consist of several methods such as surgery, chemotherapy, radiation therapy, hormonal therapy, and biological therapies.  
**Note:** There are a number of different ways to treat cancers. A team of doctor’s develop a treatment plan to fit each person’s situation based on their cancer diagnosis. |
| 2. | A | Side effects of cancer treatment are the same for all people.  
**Note:** Side effects of cancer treatment depend mainly on the type and extent of the treatment. Also, the effects may not be the same for each person, and they may change for a person from one treatment to the next. |
| 3. | A | Biological therapies tend to cause flu-like symptoms.         |
| 4. | A | The purpose of clinical trials is to find better ways to treat cancer.  
**Note:** Clinical trials try to find better ways to prevent, detect, diagnose, and treat cancer. |
| 5. | A | Systemic treatments travel through the bloodstream, reaching cancer cells all over the body. |
Section 1

How We Become Well Again

There are a number of different ways to treat cancers. For many AI/AN diagnosed with cancer, treatment often involves a blend of both Western and traditional medicine. While Western medicine uses an approach based on science and is focused on the physical aspect of disease, traditional medicine emphasizes the use of sacred rituals and healing ceremonies to restore a person to a state of wellness that includes the physical, emotional, mental and spiritual dimensions of health. Both methods are necessary in the fight against cancer.

For many AI/AN facing cancer treatment, the use of traditional healers and traditional medicine is also an important part of becoming well again. Traditional healers who work with AI/AN generally establish a long-term relationship with the person affected by the disease. This relationship often extends beyond the affected individual to include the family. The healer uses a variety of skills that are culturally acquired to design a treatment plan that will focus on the “whole person”.

Traditional healers working with AI/AN undergoing treatment for cancer provide the spiritual and emotional support necessary to aid the individual in their fight against cancer.¹ The goal of treatment is centered on using the power of the mind, the body, the spirit, and the natural environment in the healing process to restore harmony and balance.²

The Western medical approach to cancer involves a team of doctors (surgeons, medical oncologists, radiation oncologists, and others) who specialize in the treatment of people with cancer. The team of doctors develop a treatment plan to fit each person’s situation based on their cancer diagnosis. The treatment plan may include surgery, chemotherapy, radiation therapy, hormone therapy, biological therapy, stem cell transplantation, complementary medicine, or participation in a clinical trial.
Treatment for cancer depends on the type of cancer, the size, location and stage of the disease, the person’s general health, and other factors. Treatment for cancer can be either local or systemic. **Local treatments** affect cancer cells in the tumor and the area near it. **Systemic treatments** travel through the bloodstream, reaching cancer cells all over the body. Surgery and radiation therapy are types of local treatment. Chemotherapy, hormone therapy, and biological therapy are examples of systemic treatment.

Because cancer treatment damages healthy cells and tissues in addition to cancer cells, it often causes **side effects**. Side effects of cancer treatment depend mainly on the type and extent of the treatment. Also, the effects may not be the same for each person, and they may change for a person from one treatment to the next. Patients undergoing treatment for cancer are closely monitored by the specialists (medical oncologists and others) involved in their care. This team of specialists provides education on side effects that may occur during and after treatment, and ways to manage or lessen the effects.

When traditional medicine is combined with Western medicine in the treatment of cancer, sharing information about treatment is important. The use of traditional practices such as sweat baths or hot springs baths, etc. may affect some medications and therapies. Thus, both the medical specialist and healer should be aware that the patient is using both approaches.

The goals of treatment vary according to the situation. A particular treatment might be recommended because it offers the best chance of a cure. When cure is not possible, treatment may improve the quality of life by relieving pain, pressure and other symptoms of cancer.

Whatever treatment plan is used, AI/AN are most likely to benefit when the plan is focused on a holistic approach to care that may involve a blending of Western and traditional medicine. Such an approach addresses not only the physical illness but also the mental, emotional, and spiritual dimensions of the disease.
Section 2

Treatment Methods

The following is a description of common methods used in the treatment of cancer in Western medicine:

**Surgery**

Refers to removing the cancerous tumor and possibly the removal of surrounding tissue and lymph nodes near the tumor. Surgery is most effective when the cancer is still confined to its original site and when the tumor can be completely removed. Sometimes surgery is done on an outpatient basis (in and out the same day), or the patient may stay overnight in the hospital. This decision depends mainly on the type of surgery and the type of anesthesia.

The side effects of surgery depend on many factors, including the size and location of the tumor, the type of operation, and the patient’s general health. The discomfort that may occur after surgery can be controlled with medicine. Patients may also feel tired or weak for a while after surgery. The length of time it takes to recover from an operation varies among patients.

Some patients have concerns that cancer will spread during surgery. This is a very rare occurrence. Surgeons use special techniques and take many precautions to prevent cancer from spreading during surgery. For example, if tissue samples must be removed from more than one site, they use different instruments for each one. Also, a margin of normal tissue is often removed along with the tumor. Such efforts reduce the chance that cancer cells will spread into healthy tissue.

Similarly, some people worry that exposing cancer to air during surgery will cause the disease to spread. This is not true. Air does not make cancer spread.

**Chemotherapy**

Refers to the use of drugs to kill cancer cells. Most patients receive chemotherapy by mouth or through a vein. It is a systemic treatment, meaning that the drugs flow through the bloodstream to nearly every part of the body. Chemotherapy primarily works by attacking cells that divide and grow rapidly, such as cancer cells. The doctor may use one drug or a combination of drugs.
Chemotherapy is used most often when there is a possibility that cancer cells may be located somewhere other than the primary tumor. It may be the only kind of treatment a patient needs, or it may be combined with other forms of treatment. **Neoadjuvant chemotherapy** refers to drugs given before surgery to shrink a tumor; **adjuvant chemotherapy** refers to drugs given after surgery to help prevent the cancer from recurring. **Chemotherapy also may be used (alone or along with other forms of treatment) to relieve symptoms of the disease.**

Chemotherapy is usually given in “cycles”. A cycle includes a treatment period (one or more days when treatment is given) followed by a recovery period (several days or weeks), then the cycle repeats. Most anticancer drugs are given by intravenous (IV) injection into a vein; some are injected into a muscle or under the skin; and some are given by mouth. For some types of cancer, doctors are studying whether it helps to put anticancer drugs directly into the affected area.

Often, patients who need many doses of intravenous chemotherapy receive the drugs through a catheter (a thin, flexible tube) that stays in place until treatment is over. Usually a patient has chemotherapy as an outpatient (at the hospital, at the doctor’s office, or at home). However, depending on which drugs are given, the dose, how they are given, and the patient’s general health, a short hospital stay may be needed.

**The side effects of chemotherapy depend mainly on the drugs and the doses the patient receives.** As with other types of treatment, side effects **vary from person to person.** Generally, anticancer drugs affect cells that divide rapidly. In addition to cancer cells, these include blood cells, which fight infection, help the blood to clot, and carry oxygen to all parts of the body. When blood cells are affected, patients are more likely to get infections, may bruise or bleed easily, and may feel unusually weak and very tired.

Rapidly dividing cells in hair roots and cells that line the digestive tract may also be affected. As a result, side effects may include loss of hair, poor appetite, nausea and vomiting, diarrhea, or mouth and lip sores.

Chemotherapy may also affect cells that line the digestive tract, in which case side effects include poor appetite, nausea and vomiting, diarrhea, or mouth and lip sores. Some chemotherapy drugs also affect fertility. Women may be unable to become pregnant, and men may not be able to father a child.

Although the side effects of chemotherapy can be distressing, most of them are temporary and they can usually be treated or controlled.
Biological Therapy (immunotherapy)

Another type of systemic therapy. Biological therapy helps the body's natural ability (immune system) to fight disease or protects the body from some of the side effects of cancer treatment. Monoclonal antibodies, interferons, interleukins, colony-stimulating factors, and vaccines are some types of biological therapies. The side effects caused by biological therapy vary with the specific treatment. In general, these treatments tend to cause flu-like symptoms, such as chills, fever, muscle aches, weakness, loss of appetite, nausea, vomiting, and diarrhea. Patients also may bleed or bruise easily, get a skin rash, or have swelling. These problems can be severe, but they go away after the treatment stops.

Radiation Therapy (radiotherapy)

The use of high-energy rays to kill cancer cells or stop them from growing and dividing. For some types of cancer, radiation might be used instead of surgery as the primary treatment. In other cases, radiation might be given after surgery to destroy any cancer cells that remain in the area.

There are two forms of radiation: external and internal. External radiation comes from a machine outside the body. Most people go to a hospital or clinic for treatment 5 days a week for several weeks. With internal radiation, radioactive material is sealed in a container (needles, tubes, seeds, etc.) and placed directly in or near the tumor. Radiation is a local treatment; it can only affect cancer cells in that area.

The side effects of radiation depend on the amount of radiation given (the dose), the part of the body that is treated, and the individual patient's response. For example, radiation to your abdomen can cause nausea, vomiting and diarrhea. A common side effect is extreme tiredness and skin changes in the treated area. Most side effects will go away in time.
**Hormone Therapy**

*Used against certain cancers that depend on hormones for their growth.*

Some types of cancer (such as most breast and prostate cancers) depend upon hormones (natural substances produced in the body) to grow. This treatment may involve using drugs that stop the production of hormones, or that change the way the hormones work in the body. Another type of hormone therapy is to remove organs (such as the ovaries or testicles) that make the hormones. **Hormone therapy is a systemic treatment; it affects cancer cells throughout the body.**

Depending on which hormone is targeted, hormone therapy can cause a variety of side effects. Some of the side effects include weight gain, hot flashes and nausea. In women, hormone therapy may make menstrual periods stop or become irregular and may cause vaginal dryness. Men may experience *impotence*, loss of sexual desire, and breast growth or tenderness. Patients may want to discuss these and other side effects with their doctor.

**Stem Cell Transplantation**

Transplantation of blood-forming *stem cells* enables patients to receive high doses of chemotherapy, radiation, or both. The high doses destroy both cancer cells and normal blood cells in the *bone marrow*. After the treatment, the patient receives healthy, blood-forming stem cells. New blood cells develop from transplanted stem cells. Stem cells may be taken from the patient before the high-dose treatment, or they may come from another person. Patients stay in the hospital for this procedure.

**Clinical Trials**

*Research studies that evaluate promising new therapies and answer scientific questions.* The purpose of these research studies is to find better ways to treat cancer and help cancer patients. They include studies of ways to prevent, detect, diagnose, and treat cancer; studies of the psychological effects of the disease; and studies of ways to improve comfort and quality of life.

Clinical trials offer important treatment options for many people with cancer and may be a part of a person’s treatment plan for cancer. Patients who take part in clinical trials may have the first chance to benefit from new approaches. They also make contributions to knowledge and progress against cancer. As with any other treatment, there are risks involved with taking part in a clinical trial, but researchers are very careful to protect the patients who enroll in research studies.
Complementary and Alternative Medicine

Some people with cancer use complementary and alternative medicine (CAM). An approach is generally called complementary medicine when it is used along with standard treatment. An approach is called alternative medicine when it is used instead of standard treatment. Acupuncture, massage therapy, herbal products vitamins or special diets, visualization, meditation and spiritual healing are types of CAM.

Some types of CAM may change the way standard treatment works, which could be harmful. Other types of CAM could be harmful even if used alone. In order to ensure a safe and coordinated course of care, it is important that patients inform their health care providers about any therapies they are using or considering.
Section 3

Managing Physical Effects

Many people who have cancer or who have been treated for cancer develop symptoms or side effects that affect their quality of life. Care given to help patients cope with these symptoms or side effects is called palliative care, comfort care, supportive care, or symptom management.

Palliative care is given in addition to cancer treatment to improve the quality of life of patients. The goal of palliative care is to prevent or treat, as early as possible, the symptoms and side effects of the disease and its treatment, in addition to the related psychological, social, and spiritual problems. Palliative care is given throughout a patient’s experience with cancer. It should begin at diagnosis and continue through treatment, follow-up care, and the end of life.

Every person is different. For example, differences in age, cultural background, or support systems may result in very different palliative care needs. In addition, as outlined in Section 2, the side effects of treatment will depend on the type of cancer as well as the type of treatment received. Examples of symptoms and side effects include fatigue, pain, nausea and vomiting, constipation and diarrhea, anemia and bleeding problems, fever and infection, confusion and memory problems, lymphedema, skin changes, and sexuality and fertility changes.

Research shows that palliative care and its many components are beneficial to patient and family health and well-being. A number of studies in recent years have shown that patients who have their symptoms controlled and are better able to communicate their emotional needs have a better experience with their medical care. Their quality of life and physical symptoms improve.

A person with cancer should talk to his/her health care team to find out how to manage these side effects and get practical tips to help lesson the symptoms. The National Cancer Institute (NCI) offers a number of resources around managing physical effects of cancer. Call the NCI’s Cancer Information Service at 1-800-4-CANCER, or visit http://www.cancer.gov/cancertopics/coping/physicaleffects to learn more.
## Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>adjuvant chemotherapy</strong></td>
<td>Refers to drugs given after surgery to help prevent the cancer from recurring.</td>
</tr>
<tr>
<td><strong>alternative medicine</strong></td>
<td>Practices used instead of standard treatments. They generally are not recognized by the medical community as standard or conventional medicine approaches. Examples of alternative medicine include dietary supplements, megadose vitamins, herbal preparations, special teas, acupuncture, massage therapy, magnet therapy, spiritual healing, and meditation.</td>
</tr>
<tr>
<td><strong>anesthesia</strong></td>
<td>Loss of feeling or awareness. Local anesthetics cause a loss of feeling in a part of the body. General anesthetics put the person to sleep.</td>
</tr>
<tr>
<td><strong>biological therapy</strong></td>
<td>Treatment to try to get the body to fight cancer. It uses materials made by the body or made in a laboratory to improve the body’s natural response to disease. Also called immunotherapy.</td>
</tr>
<tr>
<td><strong>bone marrow</strong></td>
<td>The soft sponge-like tissue in the center of most bones. It produces white blood cells, red blood cells, and platelets.</td>
</tr>
<tr>
<td><strong>chemotherapy</strong></td>
<td>Treatment with drugs that kill the cancer cells.</td>
</tr>
<tr>
<td><strong>clinical trials</strong></td>
<td>Research studies that evaluate promising new therapies and answer scientific questions about ways to prevent, detect, diagnose, and treat cancer; the psychological effects of the disease; and ways to improve comfort and quality of life.</td>
</tr>
<tr>
<td><strong>colony-stimulating factors</strong></td>
<td>Substances that stimulate the production of blood cells.</td>
</tr>
<tr>
<td><strong>complementary medicine</strong></td>
<td>Practices often used to enhance or complement standard treatment; these include dietary supplements, megadose vitamins, herbal preparations, special teas, acupuncture, massage therapy, magnet therapy, spiritual healing, and meditation.</td>
</tr>
<tr>
<td><strong>hormone therapy</strong></td>
<td>Treatment of cancer by removing, blocking, or adding hormones.</td>
</tr>
<tr>
<td><strong>hormones</strong></td>
<td>Chemicals produced by glands in the body and circulated in the bloodstream. Hormones control the actions of certain cells or organs.</td>
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<tr>
<td>Term</td>
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<tr>
<td>impotence</td>
<td>Inability to have an erection and/or ejaculate semen.</td>
</tr>
<tr>
<td>interferon</td>
<td>A type of biological treatment that interferes with the division of cancer cells and slows the growth of the tumor.</td>
</tr>
<tr>
<td>interleukin</td>
<td>One of a group of related proteins made by white blood cells (leukocytes) and other cells in the body. Interleukins regulate immune responses. Interleukins made in the laboratory are used to boost the immune system in cancer therapy.</td>
</tr>
<tr>
<td>local treatment</td>
<td>Treatment that affects cells in the tumor and the area close to it.</td>
</tr>
<tr>
<td>medical oncologist</td>
<td>A doctor who specializes in diagnosing and treating cancer using chemotherapy, hormone therapy and biologic therapy. A medical oncologist often serves as the person’s main caretaker and coordinates treatment provided by the other specialists.</td>
</tr>
<tr>
<td>monoclonal antibodies</td>
<td>Substances produced in a laboratory that can locate cancer cells and bind to them wherever they are in the body. Monoclonal antibodies can be used alone or they can be used to deliver drugs, toxins, or radioactive material directly to the tumor.</td>
</tr>
<tr>
<td>neoadjuvant chemotherapy</td>
<td>Refers to drugs given before surgery to shrink a tumor.</td>
</tr>
<tr>
<td>radiation oncologist</td>
<td>A doctor who specializes in using radiation to treat cancer.</td>
</tr>
<tr>
<td>radiation therapy</td>
<td>Treatment with high-energy radiation from x-rays, neutrons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy). Also called irradiation and radiotherapy.</td>
</tr>
<tr>
<td>side effects</td>
<td>Problems that occur when treatment affects healthy cells. Common side effects of cancer treatment are fatigue, nausea, vomiting, decreased blood cell counts, hair loss, and mouth sores.</td>
</tr>
<tr>
<td>stem cells</td>
<td>Cells from which other types of cells develop. For example, blood cells develop from blood-forming stem cells.</td>
</tr>
<tr>
<td><strong>stem cell transplantation</strong></td>
<td>A method of replacing immature blood-forming cells in the bone marrow that have been destroyed by drugs, radiation, or disease. Stem cells are injected into the patient and make health blood cells. A stem cell transplant may be autologous (using a patient’s own stem cells that were saved before treatment), allogeneic (using stem cells donated by someone who is not an identical twin), or syngeneic (using stems cells donated by an identical twin).</td>
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<tr>
<td><strong>surgeon</strong></td>
<td>A doctor who specializes in surgery - removing or repairing a part of the body.</td>
</tr>
<tr>
<td><strong>surgery</strong></td>
<td>Treatment to remove or repair a part of the body.</td>
</tr>
<tr>
<td><strong>systemic treatment</strong></td>
<td>Treatment that uses substances that travel through the bloodstream, reaching and affecting cells all over the body.</td>
</tr>
<tr>
<td><strong>vaccines</strong></td>
<td>A substance or group of substances meant to cause the immune system to respond to a tumor or to microorganisms, such as bacteria or viruses. A vaccine can help the body recognize and destroy cancer cells or microorganisms.</td>
</tr>
</tbody>
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For more detailed information about cancer or the glossary terms, please refer to the Dictionary of Cancer Terms at [http://www.cancer.gov/](http://www.cancer.gov/) or call the National Cancer Institute's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).
Resources for Learning More

**Northwest Portland Area Indian Health Board Northwest Tribal Comprehensive Cancer Project:** On this web page you can access the Northwest Tribal Cancer Resource Guide, full of resources for cancer survivors and caregivers. You can also access The Appointment Companion, a tool to help cancer survivors keep track of appointments and treatment.
http://www.npaihb.org/programs/project/nwtccp_reports_publications_media_materials/

**National Cancer Institute (NCI) – Cancer Information Summaries: Adult Treatment (PDQ®):** The Physician Data Query (PDQ®) is NCI’s comprehensive cancer database. It contains summaries on a wide range of cancer topics. This page links to an alphabetical list of PDQ® adult cancer treatment summaries. These summaries provide site specific information on diagnosis and staging.
http://cancer.gov/cancertopics/pdq/adulttreatment

**NCI - What You Need To Know About™ Cancer Index:** A series of booklets on cancer. Each booklet explains possible risks, symptoms, diagnosis, and treatment and includes a list of questions to ask the doctor. Booklets are available for a number of different cancers. http://www.cancer.gov/cancertopics/wyntk/

**NCI – Understanding Cancer Series: Blood Stem Cell Transplants:** This self-paced graphic-rich tutorial can be used for educational use by teachers, medical professionals, and the interested public. Can be downloaded in PDF and PowerPoint format.
http://www.cancer.gov/cancertopics/understandingcancer/StemCells

**NCI – Fact Sheet - Bone Marrow Transplantation and Peripheral Blood Stem Cell Transplantation:** This fact sheet provides an overview of what bone marrow and stem cells. It also describes what bone marrow and peripheral blood stem cell transplants are. The fact sheet provides the information using a question and answer format.

**NCI – Chemotherapy and You: Support for People With Cancer:** This book is a guide that patients can refer to throughout chemotherapy treatment. It includes facts about chemotherapy and its side effects and also highlights ways a patient can care for him/her self before, during, and after treatment.

**NCI – Chemotherapy Side Effects Fact Sheets:** This series of chemotherapy side effects sheets has medical advice and practical tips to help a patient during chemotherapy. http://www.cancer.gov/cancertopics/coping/chemo-side-effects

**NCI – Radiation Therapy and You: Support for People With Cancer:** This book is a guide that patients can refer to throughout radiation therapy. It has facts about radiation therapy and side effects and describes how he/she can care for him/her self during and after treatment. http://www.cancer.gov/cancertopics/coping/radiation-therapy-and-you
NCI – Radiation Therapy Side Effects Fact Sheets: This series of radiation therapy side effects sheets has medical advice and practical tips to help a patient during radiation therapy.  http://www.cancer.gov/cancertopics/coping/radiation-side-effects

NCI – Booklet: Biological Therapy: Treatments That Use Your Immune System to Fight Cancer: This booklet describes biological therapy, a type of cancer treatment that work with the patient’s immune system.  http://www.cancer.gov/cancertopics/treatment/biologicaltherapy


NCI – Complementary and Alternative Medicine (CAM): This web page provides information on CAM as well as links to other resources that provide an overview of CAM approaches.  http://www.cancer.gov/cancertopics/cam

NCI – Booklet: Thinking About CAM: A Guide for People With Cancer: This booklet describes how to make informed choices when looking for CAM. It provides an overview and examples of the six domains of CAM.  http://www.cancer.gov/cancertopics/cam/thinking-about-CAM


NCI Features – Clinical Trials Shape Cancer Care: This web page links to information about improving the clinical trials process and informing patients about clinical trials.  http://www.cancer.gov/features/clinicaltrials2010

NCI – Educational Materials About Clinical Trials: This web page provides links to all the educational materials NCI has on the topic of clinical trials.  http://www.cancer.gov/clinicaltrials/learning

NCI – AccrualNet: Strategies, Tools & Resources to Support Accrual to Clinical Trials: This web site provides strategies, tools, and resources to support accrual to clinical trials.  https://accrualnet.cancer.gov/
**Education Network to Advance Cancer Clinical Trials (ENACCT) – Your Role In Cancer Clinical Trials Free E-Learning Series:** This web page provides links to clinical trial education courses tailored for community leaders, patient advocates, primary care providers, and clinical trial staff.  [http://www.enacct.org/yourrole](http://www.enacct.org/yourrole)

**NCI – Coping with Cancer: Supportive and Palliative Care:** This web page provides links to information on supportive and palliative care.  [http://www.cancer.gov/cancertopics/coping](http://www.cancer.gov/cancertopics/coping)

**National Institute of Nursing Research – Palliative Care: The Relief You Need When You’re Experiencing Symptoms of Serious Illness:** This booklet describes what palliative care is, how it improves quality of life, and how to get it.  [http://www.ninr.nih.gov/NR/rdonlyres/01CC45F1-048B-468A-BD9F-3AB727A381D2/0/NINR_PalliativeCare_Brochure_508C.pdf](http://www.ninr.nih.gov/NR/rdonlyres/01CC45F1-048B-468A-BD9F-3AB727A381D2/0/NINR_PalliativeCare_Brochure_508C.pdf)

**Center to Advance Palliative Care – What is Palliative Care?:** This link provides a video which shows Dr. Diane Meier, Director of the Center to Advance Palliative Care, talking about what palliative care is.  [http://www.getpalliativecare.org/videos/0D790426C0604C9E](http://www.getpalliativecare.org/videos/0D790426C0604C9E)

**Hospital and Palliative Nurses Association – Managing Pain:** This patient and family teaching sheet describes how to manage pain.  [http://www.hpna.org/pdf/teachingsheet_managingpain.pdf](http://www.hpna.org/pdf/teachingsheet_managingpain.pdf)
References


Module 8: Biospecimens and Biobanking

Goals
In this session, participants gain a basic understanding of what biospecimens are and how they are used.

Objectives
At the completion of Learning Module 8, participants will be able to demonstrate the following:

Section 1
1) Define what a biospecimen is.
2) Describe how biospecimens are collected.
3) Define what a biobank, or biorepository, is.
4) Explain how biobanks protect a donor’s personal and medical information.

Section 2
1) Describe why biospecimens are important in research.
2) Explain how biospecimens can be used to advance cancer prevention and treatment.

Section 3
1) Discuss ethical, legal and social considerations related to tissue donation for research.
2) Discuss what informed consent is.
3) Describe the Genetic Information Nondiscrimination Act.

Measures of Objective Accomplishment
The presenter will administer a pre self-assessment and a post self-assessment to measure participants’ knowledge of the module’s objectives. The pre self-assessment measures existing knowledge and the post self-assessment measures what was gained through the learning module.

Target Audience
- Community members
- Staff of Indian health programs including Community Health Representatives

Contents of Learning Module
- Instructor’s Guide with Pre/Post Self-Assessment
- PowerPoint presentation
- Glossary
- Resources for Learning More
- References

Length
- Introduction of session/module overview (.05)
- Pre self-assessment (.07)
- Presentation of module (.30)
- Post self-assessment (.05)
- Closing (.03)

NOTE
- Each major learning point is clearly identified by boldface type throughout the guide and emphasized in the PowerPoint presentation.
- See the glossary (at the end of the module) for words that are in bold blue italics throughout the module.
**Pre/Post Self-Assessment**

*Biospecimens and Biobanking*

Do you agree (A), disagree (D), with these statements, or are you not sure (NS)?

*Circle your choice - A, D, or NS.*

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1. “Biospecimens” refers to materials, such as cells, blood, and urine, taken from laboratory animals for research.

2. Biospecimens play an important role in helping researchers learn about how to treat cancer.

3. A person’s tissue, such as cancer cells removed during surgery, can be stored for future research.

4. If a person donates their tissue or blood, they always get to decide what kind of research those samples are used for.

5. Informed consent involves two components: 1) a document and 2) a speech.
### Pre/Post Self-Assessment

#### Answer Key

**Biospecimens and Biobanking**

*The correct answer to each question, agree (A), disagree (D), is underlined and in red.*

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<td>2.</td>
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<td>Biospecimens play an important role in helping researchers learn about how to treat cancer. <strong>Note:</strong> Research on biospecimens can help increase understanding about how to fight cancer and other diseases. <strong>Biospecimen research helps advance cancer care.</strong></td>
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Section 1

What Are Biospecimens?

In order to find cancer cures, one could think of a person’s fight with cancer as a mystery to be solved. As in any mystery, one needs to look for clues. Where would you look for clues? The best place to look is in the very people who have cancer. The “clues” can be found in their body – in samples of material such as urine, blood, tissue, cells, DNA, RNA, and protein. These materials are called biological materials, biological specimens, or biospecimens. The molecular changes trapped in cancer biospecimens provide insightful clues about what went wrong in a person’s cells.

What are biospecimens?

When we hear the term biospecimens, this refers to materials taken from the human body; this means tissue such as skin, hair, nails, cheek cells, and fluids such as blood, urine, or saliva. As mentioned in Module 4, all cells in a person’s body contain DNA, which houses our genetic information. Therefore, biospecimens contain information about the human being, and also about their disease.

How are biospecimens collected?

Biospecimens have been collected for quite a long time and can be used to diagnose and treat a person’s disease, for research, to educate medical students, and in forensics.¹

There are typically three kinds of biospecimens used in research. One of the types includes residual or extra tissue or fluid taken during a patient’s diagnosis and treatment. When cancer patients undergo procedures such as a blood draw, biopsy or surgery in which a specimen is removed for diagnostic or therapeutic purposes, a patient may choose to allow for a small amount of leftover specimen to be stored and later used for research. Each specimen may contain DNA, RNA, proteins, or other molecules that will help researchers better understand why and how the cancer developed and, perhaps, provide insight toward the development of new therapies.

The two other types of tissue used in research include tissue taken specifically for research, and excess normal tissue. Tissue donated for research is not used for organ transplants or blood transfusions.²
How are biospecimens labeled?

Each specimen may also come with associated personal and medical information—known as annotation—that is collected from patients through interviews at the time the biospecimens are donated. This information can also be gathered from medical records. Annotations may include information about the patient’s age, sex, and ethnicity as well as information about disease and the environmental exposures (diet, tobacco smoke, sunlight, toxic chemicals, infectious agents, etc.) that the patient has experienced during his or her lifetime.

The quality of a biospecimen’s annotation is as important as the quality of the specimen itself. Just as it is a person’s choice whether or not to donate biospecimens for research, it is also their choice as to how much personal and medical information they want to share. However, knowing details like a patient’s age and ethnic group may help researchers understand how these factors affected their risk of getting cancer.

Where are biospecimens kept?

Biospecimens play a critical role in our emerging understanding of cancer. However, the use of biospecimens for research ultimately depends on the willingness of patients to donate tissue. Additionally, the manner in which biospecimens are collected from patients and subsequently handled, the quality of the biospecimen-associated information, and ethical, legal, and policy parameters, can affect biospecimen quality and usefulness in cancer research. Scientific advances depend on the availability of biospecimens that have been collected according to the highest scientific and ethical standards.

With a person’s written consent, after a donor’s doctor completes all medical tests, the doctor will send the tissue to a tissue bank, or biorepository. Biorepositories (also known as biobanks) are “libraries” of stored biospecimens that are made available to scientists for research purposes (not for transplants). Annotations, which are relevant personal (gender, racial or ethnic group, age, etc.) and medical (date of diagnosis, treatment received, family history, etc.) information about the people who donated the specimens, may be provided with the tissue or fluid samples. This is discussed in more detail in the following section.

In the United States there are thousands of biorepositories, which vary widely in their size, type of biospecimens collected, and purpose. Biorepositories can be owned and run by individual investigators, companies, universities, or other private interests.
How are biospecimens stored?

Great care must be taken to keep biospecimens biologically viable because they are vulnerable to environmental and biological stresses introduced by:

- routine handling during collection (nurse handling specimen in operating room and delivering it to a pathologist),
- processing (time specimen spends at room temperature, temperature of room, type of fixative, time in fixative, method and rate of freezing),
- storage (storage temperature and duration of storage) and
- transport (variations in packaging, transport and delivery).

If biospecimens are not properly handled, their molecular properties may change before they ever reach the doctor or researcher for analysis. The molecular changes may be misread as representative of the patient’s disease rather than an effect of the handling process.

Biorepositories carefully store biospecimens by monitoring temperature and conditions to properly support the integrity of the tissue. Biospecimens can be stored in multiple forms such as slides, formalin fixed – paraffin wax embedded blocks, frozen, tissue culture, or extracted DNA. Preserving biospecimens in the correct manner will be essential for the development and use of molecular tests that diagnose disease, as well as therapies that target the molecular changes of the patient’s cancer. High-quality biospecimens give researchers and doctors the confidence that the molecular changes seen are a result of the patient’s disease (and not a result of the handling process.)

Biorepositories are crucial in making molecular-based research possible. Molecular research includes genomics and proteomics; this type of research will guide the development of new targeted diagnostics and therapies (i.e., personalized medicine) to improve clinical outcomes for patients. The availability of high-quality biospecimens is dependent upon:

- Standardized collection, processing, annotation, storage and transport procedures to ensure molecular properties and usefulness are kept intact.
- Removal of competitive barriers to biospecimen access.
- Strict ethical, legal and policy practices that ensure the highest standards are attained in the protection of patient rights and privacy.
How is a donor’s privacy protected?

Federal laws and regulations protect a donor’s privacy and confidentiality of their information (see Section 3 for more detail). One of a biorepository’s highest priorities is to protect the privacy and integrity of this personal and medical information. The biorepository, or tissue bank, is in charge of keeping a patient’s information private. They must take careful steps to prevent the misuse of records and are not permitted to release a patient’s personal information without his or her consent.

There are a few terms used to categorize donated human biospecimens:

- **Identified**: A person’s identity is directly linked to the biospecimen sample. Examples of patient identifiers include a name, or Medical Record Number.

- **Identifiable**: A person’s identity can be linked to the biospecimen sample through a code (random number and/or barcode), but the identity is not known unless the link is traced. Sometimes also called “coded” or “linked”.

- **Anonymized**: A person’s identity is unlinked from the biospecimen sample so that a sample cannot be linked to a specific person. Sometimes also called “unlinked samples”.

- **Anonymous**: A biospecimen sample is collected with no identifiers. Sometimes also called “unidentified”, “unidentifiable” or “de-identified” samples”.

Studying human biological specimens without identifiers, such as the patient’s name, address, phone number, Social Security number, date of birth, and anything else that could identify him or her, protects the identity of the person without compromising the goals of meaningful research.

While donating anonymous biospecimen samples is the best way to protect a patient’s privacy, anonymous samples may not always be as useful in research. For example, any findings from research with anonymous samples cannot be linked to the donor, or any characteristics of the donor, such as race, ethnicity, disease, family history, etc. This can be important information when a characteristic such as gender or race plays a significant role in the results gathered from the research.
Section 2

Why Are Biospecimens Important?

Research on biospecimens can help increase understanding about how to fight cancer and other diseases. People may give consent for their biospecimens to be used in research in order to help researchers find new ways to prevent and treat diseases. This type of knowledge might help save the lives of other people in future years.

Why are biospecimens important in research?

Biospecimens are important in cancer research because they contain a tremendous amount of biological (cellular, molecular and chemical) information, written in the language of cells, genes and proteins that define a person’s disease. They can also be processed and stored for later research aimed at finding new ways to prevent, diagnose, or treat diseases and conditions such as cancer, diabetes and Alzheimer’s. Biospecimens can also be used in research to develop new tests to diagnose, or drugs to treat diseases and to study diseases that are passed on in families. This type of research helps scientists better understand how genes affect health and illness.

Biospecimen research helps advance cancer care because it gives researchers the opportunity to look at the genetic basis of disease as well as the genetic basis of response to treatment. For example, research on biospecimens can help determine a patient’s prognosis, select appropriate treatments, or measure responses to treatment.

In addition, advances in medical science offer the opportunity to understand cancer at a molecular level – that is identifying genes and their function, and understanding the role genetics plays in the origin and progression of disease. This may lead to more specific and targeted approaches to detecting, treating and preventing disease for each individual.

The availability of an ample supply of high-quality biospecimens is essential to ongoing cancer research. These resources allow researchers to frame questions that can be answered only by examining hundreds or thousands of patient specimens. For example, researchers may analyze biospecimens to identify the molecular characteristics of a particular type of cancer at various stages in its development and then determine whether these characteristics can be aligned with stages in the clinical course of the disease. Such an analysis would provide greater insight into how the cancer progresses and uncover potential new interventions to disrupt the malignant process.
Can biospecimens be used to advance cancer prevention and treatment?

Research on biospecimens helps doctors learn about cancer – such as why does it develop? How does it grow? Who is at greater risk of developing it? Answering these types of questions can help develop tests that diagnose cancer earlier and more precisely, and treatments that are better targeted.\(^2\) For example, research on biospecimens led to the development of *Herceptin*\(^\circledast\) for breast cancer and *Gleevec*\(^\circledast\) for *gastrointestinal stromal tumors (GIST)*.

- The development of Herceptin\(^\circledast\) (trastuzumab) for the treatment of breast cancer shows how access to high-quality tissue samples can help researchers.
  - Human *epidermal growth factor receptor* \(^2\) (EGRF-2) normally controls aspects of cell growth and division.
  - Biospecimens taken from tumors that were stored in the NCI Cooperative Breast Cancer Tissue Resource showed that EGFR-2 can be found in higher than normal numbers in 20 to 30 percent of breast cancer cases, where it is known as HER-2.
  - By studying breast cancer cases make too much of this problematic protein, researchers developed trastuzumab as an *antibody* that attaches to HER-2 positive cancer cells to slow or stop the growth of those cells.
  - It may not have been possible to test this approach on the general breast cancer patient population. Therefore, the use of biospecimens allowed researchers to develop a highly effective therapy targeted specifically for a sub-population of breast cancer patients.

- Gleevec\(^\circledast\) (imatinib) was originally developed for the treatment of a form of leukemia by targeting the BCR-ABL protein.
  - After analyzing biospecimens collected from different tumor types, scientists discovered that a mutant form of a related protein is responsible for the progression of a rare but deadly type of cancer, gastrointestinal stromal tumors.
  - Because of the similarity between this mutant protein and the BCR-ABL protein, researchers thought that Gleevec\(^\circledast\) might be effective against GIST tumors.
  - Subsequent clinical trials showed that Gleevec\(^\circledast\) was effective against GIST because it can pass through cell membranes to reach the inside of the cell and target the protein responsible for the progression of GIST; it was approved for that use by the Food and Drug Administration.
As shown in these two examples, biospecimens can provide a bridge between molecular and clinical information that will ultimately allow doctors to tailor treatments based on the genetic profile of a patient’s disease instead of using the current one-size-fits-all approach to cancer treatment. This is called personalized medicine and it allows doctors to select the best treatment for a patient without exposing them to drugs that will not be effective against their cancer. It also results in less toxicity to healthy cells in the body.

In more general terms, personalized medicine includes:

- Treatments that target and block specific molecular changes that allow a person’s cancer cells to grow and survive.
- Molecular screening methods that allow a person’s cancer to be detected early and treated before the onset of symptoms.
- Individualized cancer prevention strategies that are based on a person’s genetic makeup.

**What happens after the research is completed?**

Research on biospecimens takes a long time and requires tissue samples from many people before the results are known; results may not be ready for many years. As a donor, a person:

- will receive the results of their own medical tests (e.g. biopsy, blood test), but they will not usually get the results of the research performed with their leftover tissue.
- who donates their tissue or fluids will not usually profit from any of the products developed from the research. However, while the donors do not benefit directly, others may benefit in the future through the results of the research.

These things should be addressed in the *informed consent* process (See Section 3).
Section 3

How Are Participants Protected?

Many people may be hesitant about donating their tissue for research for fear that their genetic or personal information may be used against them. This is a valid concern due to past incidences where biological specimens used in research have come from individuals that have not always given consent for their use in research.

**Henrietta Lacks’ “immortal” cells**

One example are Henrietta Lacks’ “immortal” cells. Henrietta’s cells, called HeLa for short, were the first human cells to live outside the body. In 1951, Henrietta Lacks was diagnosed with cervical cancer at the age 30. As an African American woman, she had treatment in the segregated ward at Johns Hopkins Hospital in Baltimore, Maryland. Unbeknownst to her or her family, while Mrs. Lacks received treatment there, a sample of her tumor was sent to Dr. George Gey, a researcher at Hopkins, who had been collecting cancer cells from humans and unsuccessfully trying to make them grow.

Although Mrs. Lacks died a few months after her diagnosis, her cells still live to this day. During the 1950s, Dr. Gey donated her cells to other scientists as requested – without the permission of Mrs. Lacks or her next of kin. With widespread distribution, HeLa cells played an important role in developing a polio vaccine and have been used in a great deal of research.

“It’s a sad commentary on how the biomedical research community throughout thought about research in the 50s, but it was not at all uncommon for physicians to conduct research on patients without their knowledge or consent,” said Ruth Faden, Executive Director of the Johns Hopkins Bioethics Institute.

**Havasupai Indian Case**

Another example of this is the Havasupai Indian case. In 1989-1990, Havasupai tribal members were approached by Arizona State University to donate blood for a research study that would analyze their DNA to try to find out reasons for the high incidence of diabetes among tribal members. Later on, tribal members learned that their blood samples were used to study other things, such as mental illness and a theory about the tribe’s geographic origin – which contradicts traditional stories about the tribe’s origin.
The Belmont Report

There are certainly a number of ethical, legal and social issues which come up around the topic of biospecimens provided for research. For example, how do we help people make informed choices about biospecimen donation and research? Once a specimen is donated for research, who owns the information that is discovered as a result of the research? How will the discovery be used? And do the research findings affect an individual or a minority community? If so, how does that affect society’s perception of that individual or community?4 These are complex questions, and there are no easy answers.

After four years of work, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research issued "The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research" in 1979. The report sets forth three principles underlying the ethical conduct of research:

1) respect for persons: recognizing the autonomy and dignity of individuals, and the need to protect those with diminished autonomy (i.e., impaired decision-making skills), such as children, the aged, and the disabled;

2) beneficence: an obligation to protect persons from harm by maximizing benefits and minimizing risks;

3) justice: fair distribution of the benefits and burdens of research.9

The Belmont Report explains how these apply to research practices; for example, it identifies informed consent as a process that is essential to the principle of respect. Ethically, all research should be reviewed by an Institutional Review Board (IRB), which approves the research after analyzing data and ensuring that potential benefits outweigh risks. Additionally, an IRB ensures that the rules and regulations that apply to research with human beings are followed throughout a study.

What is informed consent?

Informed consent involves two fundamental components: a document and a process.

The informed consent document provides a summary of the research project (including the study’s purpose, research procedures, potential risks and benefits, etc.) and explains the individual’s rights as a research participant. This document is part of an informed consent process, which consists of conversations between the research team and the participant and may include other supporting material such as study brochures. The informed consent process provides research participants with ongoing
explanations that will help them make informed decisions about whether to begin or continue participating in the research project. Thus, informed consent is an ongoing, interactive process, rather than a one-time information session. Informed consent is required for all types of biospecimen collection and banking.

According to The Belmont Report, the informed consent process relies on three principles:

- adequate information is provided (generally, what a "reasonable person" would want to know to make a decision);
- participants comprehend the information; and
- consent is given voluntarily.

While this process and informed consent documents vary among different research institutions and clinical centers, they should communicate all of the information described below in language that you can understand, with some help from the research team if needed.

Most biospecimens stored in biorepositories in the U.S. today were collected from diagnostic or therapeutic procedures. They were collected with varied consent processes that may or may not have addressed future research. The informed consent document should address the collection and storage of a person's biological specimen for future analysis and use. There are three main things to make sure are covered in the informed consent process:

1) Collection of the biospecimen(s) for the intervention: Informed consent should provide the donor an understanding of the risks and benefits of donating a biospecimen, how the biospecimen will be removed, or collected, how much of it will be removed, and if applicable, how the collection procedure might affect the appearance or function of the body part where the sample is taken from. The donor should also be given a clear description about how the tissue sample will be stored, the operation of the biorepository, the specific types of research to be conducted, the conditions under which data and specimens would be released to investigators, and procedures for protecting the privacy of participants and maintaining the confidentiality of data.

2) Anticipated uses of the biospecimen(s) after the intervention: Informed consent should provide information on whether the biospecimen(s) may be kept in a repository, for how long (months, years, indefinitely), if it may be used for research on other health issues at a later time, and if it may be given to other researchers.
Sometimes patients give consent for collection of biospecimen(s) for a medical or surgical procedure, and may not be aware that the residual biospecimen(s) may also be stored and used in the future for research.\textsuperscript{1} A small study of 76 breast and colorectal cancer patients conducted in 2007 in the Netherlands found that many patients felt that residual tissue was still a part of them and few patients considered that residual tissue to be “waste”. Additionally, most patients wanted to be informed about possible research to be done with the residual tissue and also wanted the chance to “opt-out” of the research.\textsuperscript{15} That being said, donors cannot be re-contacted if samples have been anonymized, or are anonymous.

3) \textit{Findings from research on the biospecimen(s)}: Informed consent should also address what will become of information gained from research on the biospecimens. Additionally, a donor may want to know if findings will be communicated to donors, and whether the donor can share in any profits that the research generates.\textsuperscript{5} Again, donors cannot be re-contacted if samples have been anonymized, or are anonymous.

At any time, a person can change their mind about letting researchers use their biospecimen(s) if the specimens are identified or identifiable. While existing biospecimen(s) can be destroyed, those already used for research cannot be returned and the data resulting from study of that tissue may be used in published research.

\textbf{Are there risks associated with donating biospecimens?\textsuperscript{16,17}}

A potential donor should speak with their provider, or research investigator about possible risks associated with donating biospecimens.

Depending on the type of research, you may experience physical risks, such as: pain at the excision site, bruising or swelling at the excision site, and possible infection. Non-physical risks include the potential loss of privacy, and breach of confidentiality as a result of the release of information from a person’s health records. A biorepository has a responsibility to protect donors’ records so that information is kept private.

In the past, people may have had concern about insurance or employment discrimination, however in 2008, the \textit{Genetic Information Nondiscrimination Act} was established to address these concerns.
What is the Genetic Information Nondiscrimination Act?¹⁸

The Genetic Information Nondiscrimination Act of 2008, also known as GINA, is a law created to assist patients and their families as well as those involved in clinical research. GINA is a federal law that prohibits discrimination in health coverage and employment based on genetic information.

GINA, together with already existing nondiscrimination provisions of the Health Insurance Portability and Accountability Act (HIPAA), generally prohibits health insurers or health plan administrators from requesting or requiring genetic information of an individual or the individual’s family members, or using it for decisions regarding coverage, rates, or preexisting conditions. The law also prohibits most employers from using genetic information for hiring, firing, or promotion decisions, and for any decisions regarding terms of employment.

How does a person decide if they want to donate biospecimens?

Donating biospecimens is entirely voluntary. A person should talk with their provider and discuss the topic with family and friends. They can also find more resources that address biospecimens and biobanking in the “Resources for Learning More” section at the end of this module.
# Glossary of Terms

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<th>Term</th>
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<td><strong>annotation</strong></td>
<td>Explanatory or extra information associated with a particular biospecimen. Annotations may be added by either the pathologist or the resource collector.</td>
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<tr>
<td><strong>anonymous</strong></td>
<td>Tissue, or biospecimen sample, for which identifiable information was not collected. Sometimes referred to “unidentified”, “unidentifiable”, or “de-identified” samples.</td>
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<td><strong>antibody</strong></td>
<td>A protein made by plasma cells (a type of white blood cell) in response to an antigen (a substance that causes the body to make a specific immune response). Each antibody can bind to only one specific antigen. The purpose of this binding is to help destroy the antigen. Some antibodies destroy antigens directly. Others make it easier for white blood cells to destroy the antigen.</td>
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<td><strong>biorepository</strong></td>
<td>A facility that collects, catalogs, and stores samples of biological material, such as urine, blood, tissue, cells, DNA, RNA, and protein, from humans, animals, or plants for laboratory research. If the samples are from people, medical information may also be stored along with a written consent to use the samples in laboratory studies.</td>
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<tr>
<td><strong>biospecimen</strong></td>
<td>Samples of material, such as urine, blood, tissue, cells, DNA, RNA, and protein from humans, animals, or plants. Biospecimens are stored in a biorepository and are used for laboratory research. If the samples are from people, medical information may also be stored along with a written consent to use the samples in laboratory studies.</td>
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<td><strong>epidermal growth factor receptor</strong></td>
<td>The protein found on the surface of some cells and to which epidermal growth factor binds, causing cells to divide. It is found at abnormally high levels on the surface of many types of cancer cells, so these cells may divide excessively in the presence of epidermal growth factor. Also called EGFR, ErbB1, and HER1.</td>
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<tr>
<td><strong>gastrointestinal stromal tumors (GIST)</strong></td>
<td>A type of tumor that usually begins in cells in the wall of the gastrointestinal tract. It can be benign or malignant.</td>
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<tr>
<td><strong>Genetic Information Nondiscrimination Act</strong></td>
<td>The Genetic Information Nondiscrimination Act (GINA) is federal legislation that makes it unlawful to discriminate against individuals on the basis of their genetic profiles in regard to health insurance and employment. These protections are intended to encourage Americans to take advantage of genetic testing as part of their medical care. President George W. Bush signed GINA into law on May 22, 2008.</td>
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<td><strong>genomics</strong></td>
<td>The study of the entire genome of an organism, whereas genetics refers to the study of a particular gene. The genome is the entire set of genetic instructions found in a cell. In humans, the genome consists of 23 pairs of chromosomes.</td>
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<td><strong>Gleevec®</strong></td>
<td>A drug used to treat different types of leukemia and other cancers of the blood, gastrointestinal stromal tumors, skin tumors called dermatofibrosarcoma protuberans, and a rare condition called systemic mastocytosis. It is also being studied in the treatment of other types of cancer. Gleevec blocks the protein made by the bcr/abl oncogene. It is a type of tyrosine kinase inhibitor. Also called imatinib mesylate and STI571.</td>
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<tr>
<td><strong>Health Insurance Portability and Accountability Act (HIPAA)</strong></td>
<td>A 1996 U.S. law that allows workers and their families to keep their health insurance when they change or lose their jobs. The law also includes standards for setting up secure electronic health records and to protect the privacy of a person’s health information and to keep it from being misused.</td>
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<tr>
<td><strong>Herceptin®</strong></td>
<td>A monoclonal antibody that binds to HER2 (human epidermal growth factor receptor 2), and can kill HER2-positive cancer cells. Monoclonal antibodies are made in the laboratory and can locate and bind to substances in the body, including cancer cells. Herceptin is used to treat breast cancer that is HER2-positive and has spread after treatment with other drugs. It is also used with other anticancer drugs to treat HER2-positive breast cancer after surgery. Herceptin is also being studied in the treatment of other types of cancer. Also called trastuzumab.</td>
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<tr>
<td><strong>identifiable</strong></td>
<td>Tissue, or biospecimen sample, for which the identity of the donor can be identified by tracing the code on the sample label. Sometimes referred to “coded” or “linked” samples.</td>
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<tr>
<td><strong>informed consent</strong></td>
<td>A process in which a person is given important facts about a medical procedure or treatment, a clinical trial, or genetic testing before deciding whether or not to participate. It also includes informing the patient when there is new information that may affect his or her decision to continue. Informed consent includes information about the possible risks, benefits, and limits of the procedure, treatment, trial, or genetic testing. Also called consent process.</td>
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### Institutional Review Board
A group of scientists, doctors, clergy, and consumers that reviews and approves the action plan for every clinical trial. There is an Institutional Review Board at, or available to, every health care facility that does clinical research. Institutional Review Boards are designed to protect the people who take part in a clinical trial. Institutional Review Boards check to see that the trial is well designed, legal, ethical, does not involve unnecessary risks, and includes safeguards for patients. Also called IRB.

### personalized medicine
A form of medicine that uses information about a person’s genes, proteins, and environment to prevent, diagnose, and treat disease.

### prognosis
The likely outcome or course of a disease; the chance of recovery or recurrence.

### proteomics
The study of the structure and function of proteins, including the way they work and interact with each other inside cells.

### tissue
A group or layer of cells that work together to perform a specific function.

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For more detailed information about cancer or the glossary terms, please refer to the Dictionary of Cancer Terms at [http://www.cancer.gov/](http://www.cancer.gov/) or call the National Cancer Institute’s Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).
Resources for Learning More

**Dana Farber Cancer Institute (DFCI) – Tissue Banking: Advancing Cancer Care (Video):** This video explains what tissue banking is, how it helps researchers develop new cancer treatments, and what patients should consider as they decide whether to donate tissue. (Runtime:10:47) http://www.dana-farber.org/res/flash/tissue.html

**DFCI – Tissue Banking: Advancing Cancer Care (Booklet):** This booklet provides information about tissue banking, including questions and answers about donating tissue and privacy protections. http://www.dana-farber.org/res/docs/tissue-banking-booklet.pdf

**National Cancer Institute’s (NCI) Office of Biorepositories and Biospecimen Research (OBBR) – Moving Forward (Video):** This video provides information about the importance of biospecimens for cancer research and patient care. http://biospecimens.cancer.gov/default.asp


**NCI Fact Sheet – Donating Tissue for Cancer Research: Biospecimens and Biorepositories:** This fact sheet describes the importance of biospecimens and biorepositories in cancer research. Also explains how patients and others can help support research that uses biospecimens. http://www.cancer.gov/cancertopics/factsheet/information/donating-tissue-research

**NCI Publication (P067) – Providing Your Tissue for Research: What You Need to Know:** This booklet provides a balanced discussion of why people do research with tissue and how tissue specimens are collected and used in research. Also addresses the issues of privacy and risk. http://biospecimens.cancer.gov/global/pdfs/ProvidingYourTissueforResearch.pdf

**NCI – A Guide to Understanding Informed Consent:** Provides information about the informed consent - a process in which a person is given important facts about a medical procedure or treatment, a clinical trial, or genetic testing before deciding whether or not to participate. http://www.cancer.gov/clinicaltrials/conducting/informed-consent-guide
NCI – Understanding Cancer Series: Biospecimen Collection: Contains a graphic-rich tutorial about biospecimen collection for educational use by life science teachers, medical professionals, and the interested public.  
http://www.cancer.gov/cancertopics/understandingcancer/biospecimen

National Human Genome Research Institute – Genetic Information Nondiscrimination Act (GINA) of 2008: Information that explains this act.  
http://www.genome.gov/24519851

Research Advocacy Network (RAN) – The Importance of Tissue Samples in Research: This booklet provides background information for Institutional or Ethical Review Boards (IRBs or ERBs) on studies that involve collections of tissue for research.  

RAN - Why Is It Important For Me To Consider Donating My Tissue For Research? A Booklet For Prospective Donors: This booklet provides general information about tissue donation.  

RAN – The Promise of Personalized Medicine: This publication provides information about tailoring medical treatments to the individual characteristic of each patient.  
References


12 Fred Hutchinson Cancer Research Center Institutional Review Board (August 2007). Repository, Registry or Databank Supplement Application.


16 Research Advocacy Network, Inc. (2005). Why is it important for me to consider donating my tissue for research? A booklet for prospective donors.

Module 9: Chronic Conditions and Cancer

Goals
In this session, participants will gain an understanding of the common cancer treatments and their potential side effects.

Objectives
At the completion of Learning Module 9, participants will be able to demonstrate the following:

Section 1
1) Define chronic disease, or chronic conditions.
2) Describe factors that contribute to developing a chronic condition.
3) Describe reasons why chronic conditions are a growing health concern.

Section 2
1) Describe common types of chronic conditions.
2) Describe risk factors for chronic conditions.
3) Describe signs and symptoms for chronic conditions.

Section 3
1) Describe concerns about chronic conditions for persons with cancer.
2) Describe what is meant by the term “late effects” of cancer.
3) Describe chronic conditions that result from cancer treatment.
4) Describe what is meant by the term “second cancers” and factors that contribute to their development.

Section 4
1) Describe important factors to consider when thinking about ways to reduce risk and prevent chronic conditions.
2) Describe who should participate in planning activities to reduce risk and prevent chronic conditions.
3) Describe examples of action steps to reduce risk and prevent chronic conditions.

Measures of Objective Accomplishment
The presenter will administer a pre self-assessment and a post self-assessment to measure participants’ knowledge of the module’s objectives. The pre self-assessment measures existing knowledge and the post self-assessment measures what was gained through the learning module.

NOTE
- Each major learning point is clearly identified by **boldface** type throughout the guide and emphasized in the PowerPoint presentation.
- See the glossary (at the end of the module) for words that are in **bold blue italics** throughout the module.
**Pre/Post Self-Assessment**

**Chronic Conditions and Cancer**

*Do you agree (A), disagree (D), with these statements, or are you not sure (NS)? Circle your choice - A, D, or NS.*

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<tr>
<th></th>
<th>A</th>
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<td>1.</td>
<td>A</td>
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<td></td>
<td>A chronic disease or condition lasts for only a few days and does not require medical attention.</td>
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<td>2.</td>
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<td></td>
<td>Lack of physical activity, poor diet, smoking, and lack of access to health care are factors that contribute to chronic conditions.</td>
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<td>Our risk for chronic conditions decreases as we grow older.</td>
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<td>Cancer survivors are at increased risk for chronic conditions as a result of cancer treatment.</td>
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<td>Action steps to reduce risk for chronic conditions include working with individuals, communities, and systems.</td>
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Pre/Post Self-Assessment
Answer Key

Chronic Disease and Cancer

The correct answer to each question, (A), disagree (D), is underlined and in red.

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<tr>
<td>1.</td>
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<tr>
<td></td>
<td></td>
<td>A chronic disease or condition lasts for only a few days and does not require medical attention. <strong>Note:</strong> A chronic condition lasts for a year or longer, requires ongoing medical attention, and/or limits activities of daily living.</td>
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<tr>
<td>2.</td>
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<tr>
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<td>Lack of physical activity, poor diet, smoking, and lack of access to health care are factors that contribute to chronic conditions. <strong>Note:</strong> There are many factors that contribute to whether or not a person develops a chronic condition; this includes lifestyle and health risk behaviors.</td>
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<td>3.</td>
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<td>Our risk for chronic conditions decreases as we grow older. <strong>Note:</strong> While the number of persons with chronic conditions under age 65 continues to grow, most people with chronic conditions are over age 65.</td>
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<td>Cancer survivors are at increased risk for chronic conditions as a result of cancer treatment. <strong>Note:</strong> Cancer treatment can result in a number of physical and emotional changes that may occur months to years following primary treatment. These changes are sometimes referred to as the “late effects” of cancer and include an increased risk for developing chronic conditions that limit function and impact overall quality of life.</td>
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<td>5.</td>
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<td>Action steps to reduce risk for chronic conditions include working with individuals, communities, and systems. <strong>Note:</strong> To prevent chronic conditions, strategies to promote health change must target multiple levels including individuals, communities, and systems. Interventions need to be holistic and tailored to the individual, their living environment and resources at hand.</td>
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Section 1

What is a Chronic Disease?

A *chronic disease*, also referred to as a chronic illness or condition, is any disease that "lasts for a year or longer, requires ongoing medical attention, and/or limits activities of daily living."¹ For the purpose of this learning module, we will use *chronic condition* when talking about chronic disease or illness.

Chronic conditions tend to develop slowly over the course of one’s lifetime. They are difficult to treat and often cannot be cured. People who are living with more than one chronic condition are at greater risk for a poorer quality of life.² This has to do with a decline in the physical, emotional and social functioning often seen in those who struggle with more than one chronic condition.

There are many factors that contribute to whether or not a person develops a chronic condition. They include:

- **Lifestyle and health risk behaviors:** Are we physically active, eating a healthy diet, avoiding smoking or exposure to second hand smoke, and avoiding drinking excessive amounts of alcohol?
- **Health care access:** Do we have access to appropriate, affordable, and culturally meaningful health care?
- **Physical environment:** Do we live and work in a place that is safe, free of toxins, and promotes healthy lifestyles and choices?
- **Social, cultural, and economic factors:** Do we have supportive family and community networks, access to culturally tailored and easy to understand health information, and stable income?

The most common, costly, and preventable chronic conditions in the U.S. today include cancer, heart disease, stroke, diabetes, and arthritis. Of these, heart disease, cancer and stroke account for half of all deaths each year³ with arthritis accounting for the most common cause of disability in the U.S.⁴ Over the past three decades, overweight and obesity have also become major health concerns. In the U.S., the number of adults and children who meet the definition for obesity has now more than doubled.⁵
Other chronic conditions that have an impact on length and quality of one’s life include:

- behavioral health problems such as substance use and \textit{addiction disorders},
- \textit{mental illness} (e.g. depression, anxiety),
- \textit{dementia} (decline in memory and brain function and eventually leads to overall decline in physical functioning),
- other \textit{cognitive impairment} disorders (e.g. ability to process information and reason),
- and \textit{developmental disabilities} (life-long birth defects that affect how the body or body systems work).\(^6\)

\textbf{Why are chronic conditions a concern?}

The number of people affected by multiple chronic conditions is rising. In 2005, about one out of every two adults was affected by at least one chronic condition.\(^7\) Today, more than one in four people are living with multiple (two or more) chronic conditions at the same time.\(^8\) Most of these individuals are over age 65, however, the number of persons with multiple chronic conditions under age 65 continues to grow. Women are more likely than men to be disabled from chronic conditions.\(^9\)

A person’s race and ethnicity may also play a role in whether or not they develop and are able to survive the experience of one or more chronic condition(s). For example, American Indians and Alaska Natives have higher rates for diabetes than whites, and African Americans are less likely to survive heart disease and stroke than whites.\(^3\) (See Module 1 for more specific data regarding variations in cancer rates among different populations.)

The more chronic conditions a person has, the greater their risk for poorer health outcomes including disability and death. Persons with two or more chronic conditions are likely to spend more time in the hospital, experience harmful effects from drugs, undergo tests that are not needed, and receive medical advice that is unclear.\(^6,\, 7\)

A large portion of our healthcare dollars and resources are spent on the care and treatment of persons with one or more chronic conditions. Many of these individuals are over the age of 65 and depend on the \textit{Medicare} program for care and services. As the numbers of those who are aging and chronically ill continue to grow, resources are likely to be stretched beyond their capacity to meet healthcare and service needs. In addition, many of these same individuals will face increased out-of-pocket costs for their care, including higher costs for prescriptions and support services.\(^10\)
In Section 3 of this module, we explore concerns of chronic conditions and cancer. This discussion is followed by suggestions on how we can take personal action to reduce our risk and, in some cases, prevent the development of chronic conditions, including cancer, in Section 4. But first, let's review six of the most common and preventable chronic conditions we face in the U.S. today.
Section 2

Common Chronic Conditions

What are the most common chronic conditions in the U.S.?

1. **Heart Disease**

   *Heart disease* is the leading cause of death in the U.S. and is a major cause of disability.\(^3,9\) The most common type of heart disease is coronary artery disease (CAD), which can lead to heart attack. CAD occurs when a substance called plaque builds up in the arteries that supply blood to the heart (called coronary arteries). Plaque is made up of cholesterol deposits; cholesterol is a waxy, fat-like substance that your body needs. But, when you have too much in your blood, it can build up on the walls of your arteries. This can lead to heart disease and stroke, which is covered later on.\(^11,12,13\)

![Diagram of normal and narrowed arteries](http://www.nhlbi.nih.gov/health/dci/Diseases/Cad/CAD_WhatIs.html)

**Are you at risk for heart disease?**

Anyone, including children, can develop heart disease. The most important risk factors for heart disease are high blood pressure, high blood cholesterol, cigarette smoking, diabetes, and obesity. Genetics, or a history of heart disease in one’s family, is also a risk factor.
What are the signs and symptoms of heart disease?
The symptoms vary depending on the type of heart disease. For many people, chest discomfort or a heart attack is the first sign. Someone having a heart attack may experience several symptoms including:

- Chest pain or discomfort that doesn’t go away after a few minutes.
- Pain or discomfort in one or both arms, the jaw, neck, back, or stomach.
- Weakness, light-headedness, nausea (feeling sick to your stomach), or a cold sweat.
- Shortness of breath.

*If you think that you or someone you know is having a heart attack, call 9-1-1 immediately!

2. Cancer
Over the last two decades, major progress has been made in the effort to prevent, detect, and treat cancer. Although the number of people surviving cancer continues to grow, cancer remains the second leading cause of death in the U.S.  

See Module 1 for information on cancer as a health concern, Module 2 for information on what cancer is, and Module 6 for information on cancer diagnosis and staging.

3. Stroke
A stroke, sometimes called a “brain attack”, is the third leading cause of death and a major cause of disability in the U.S.  

A stroke occurs when the blood supply to part of the brain is blocked (an ischemic stroke) or when a blood vessel in the brain bursts (a hemorrhagic stroke). In either case, parts of the brain become damaged or die.  

See the following page for illustrations of each kind of stroke.
ISCHEMIC STROKE

Embolus (blood clot) in cerebral artery blocks blood flow to part of the brain.

Location of brain tissue death

Blood clot breaks off (embolus) from plaque buildup in carotid (neck) artery

Cerebral arteries within brain

Direction of blood flow

HEMORRHAGIC STROKE

Aneurysm in cerebral artery breaks open, causing bleeding around the brain

Pressure of blood on brain causes brain tissue death

Bleeding caused by broken open aneurysm

Cerebral arteries within brain

Brain tissue death

Are you at risk for a stroke?
Several conditions and certain lifestyle choices can put people at higher risk for stroke. The most important risk factors include high blood pressure, heart disease, diabetes, cigarette smoking, and history of a prior stroke.

What are the signs and symptoms of a stroke?
The major signs of stroke include:

- Sudden numbness or weakness of the face, arm, or leg.
- Sudden confusion or trouble speaking or understanding others.
- Sudden trouble seeing in one or both eyes.
- Sudden dizziness, trouble walking, or loss of balance or coordination.
- Sudden severe headache with no known cause.

*If you think that you or someone you know is having a stroke, call 9-1-1 immediately!*

4. Diabetes

Diabetes is the sixth leading cause of death and the numbers of those affected continues to rise. Diabetes refers to a group of diseases that affect how the body uses blood glucose (commonly called blood sugar). Glucose is a major source of energy for our cells that make up our muscles and tissues and helps to fuel our brain. If you have diabetes, you have too much blood glucose in your blood. Insulin is a hormone that helps the body use glucose for energy. When you eat food, the body breaks down all of the sugars and starches into glucose, which fuels the cells in the body. Insulin helps to move the sugar from the blood into the cells. When glucose builds up in the blood instead of going into cells, it can lead to diabetes and serious health complications.

American Indian and Alaska Native adults are twice as likely than white adults to have diabetes. Diabetes is the leading cause of kidney failure, non-traumatic lower-extremity amputations, and blindness among adults aged 20–74.

There are three forms of diabetes:

1. **Type 1 diabetes** (previously known as juvenile diabetes) affects about 5 out of every 100 people and is most common in children and young adults. In Type 1 diabetes, the body does not produce insulin. Treatment includes insulin therapy among other treatments.
2. **Type 2 diabetes** is the most common form of diabetes and affects millions of Americans with many more unaware that they are at increased risk. African Americans, Hispanics/Latinos, Native Americans, and Asian Americans, Native Hawaiians and other Pacific Islanders, and the aged population are among groups that are at higher risk for developing diabetes. In type 2 diabetes the cells become resistant to insulin, so cells do not take up glucose and it remains in the bloodstream.

3. **Gestational diabetes** occurs in pregnant women who have never had diabetes before, but who have high blood sugar (glucose) levels during pregnancy. Gestational diabetes is caused by the body’s inability to make and use all the insulin it needs for pregnancy. Glucose cannot leave the blood and begins to build up in the blood causing hyperglycemia (high blood sugar). Women who develop gestational diabetes are at greater risk for complications during pregnancy and delivery and have a higher risk for developing type 2 diabetes later in life and are also at greater risk for complications during pregnancy and delivery.

**Are you at risk for diabetes?**
Your risk for diabetes includes: being overweight or obese, physical inactivity, unhealthy eating habits, family history of diabetes, genetics, older age (60 and over), history of high blood pressure or high cholesterol, or history of gestational diabetes.

**What are the signs and symptoms of diabetes?**

- **Type 1 Diabetes**
  - Frequent urination
  - Unusual thirst
  - Extreme hunger
  - Unusual weight loss
  - Extreme fatigue and Irritability

- **Type 2 Diabetes**
  - Any of the type 1 symptoms
  - Frequent infections
  - Blurred vision
  - Cuts/bruises that are slow to heal
  - Tingling/numbness in the hands/feet
  - Recurring skin, gum, or bladder infections
  *Often people with type 2 diabetes have no symptoms*
5. **Arthritis**

*Arthritis* is disease that involves inflammation of one or more joints of the body causing pain, swelling, stiffness, and limitation, or loss of movement. About one out of every 5 adults in the U.S. is affected making it one of the most common causes of physical disability.\(^4\) The number of adults who have arthritis is expected to grow as the population ages with an increase from 46 million to 67 million by 2030.\(^{13}\)

There are more than 100 different forms of arthritis. *Osteoarthritis* is the most common type and is more likely to occur as you age. Arthritis involves the breakdown of cartilage that normally protects the joint and allows for smooth movement. Cartilage acts like a cushion to absorb shock when pressure is placed on the *joint* with activities like walking or running. When this cushion (*cartilage*) is missing, our bones rub together, causing pain, swelling (*inflammation*), and stiffness. The joints of the hips, knees and fingers are most commonly affected but any joint of the body is at risk.\(^{19}\)

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**HEALTHY JOINT**

**JOINT WITH SEVERE OSTEOARTHRITIS**


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**Are you at risk for arthritis?**

There are more than 100 different forms of arthritis. Some risk factors for arthritis can be modified. These include overweight or obesity, joint injuries, infection and occupation. Other risk factors that cannot be modified are age, gender (women are more affected than men), and genetics. *Autoimmune diseases* (e.g. systemic *lupus erythematosus* – lupus) that cause the body to attack itself can also increase the risk for arthritis.\(^{19}\)
What are the signs and symptoms of arthritis?

- Joint pain
- Joint swelling
- Limited ability to move the joint
- Redness or warmth of the skin around the joint
- Stiffness with use, especially in the morning

6. Overweight and Obesity

Overweight and obesity among adults and children are major health concerns that increase the risk for certain diseases including heart disease, diabetes, certain cancers (endometrial, breast and colon), stroke, arthritis and disability. The terms ‘overweight’ and ‘obesity’ are used to describe a range of weight that is greater than what is commonly considered healthy for a given height.

A calculation called the “body mass index” (BMI) is used to determine where a person falls within a healthy range for their height and weight. The BMI is used because it is a good indicator of the amount of a person’s body fat. An adult with a BMI between 25 and 29.9 is considered overweight and obese if the BMI is 30 or above. Results from the 2005-2006 National Health and Nutrition Examination Survey (NHANES) indicate that about 32 out of every one hundred adults are overweight and about 34 out of every one hundred are considered obese. In 2007-2008, results from the NHANES showed that about 17 out of every one hundred children and adolescents ages 2-19 years were obese.

There are many factors that contribute to whether or not a person becomes overweight or obese in their lifetime. A person’s behavior (how much food they eat and how active they are), environment (where they live, their resources, culture, and social practices), and genetics (genes they are born with) all have an effect on their weight. A person can reduce their risk for overweight and obesity by eating a balanced diet (low in calories and fat, rich in nutritious foods) and being physically active. Communities can support the efforts of individuals to reduce their risk for overweight and obesity by promoting healthy choices and portion sizes at local eateries or community gatherings, creating community gardens, making available affordable healthy foods for purchase, and creating places for safe and fun physical activities.
Section 3

Concerns About Chronic Conditions

Why should we be concerned about chronic conditions and cancer?

As we grow older, our risks for developing chronic conditions like cancer increases. Most cancers are diagnosed in adults who are 55 years or older. Cancer is now considered one of the most common chronic conditions people live and deal with every day. In the past, many individuals who were diagnosed with cancer did not live beyond five years. In recent years, advances in cancer research and treatment have made it possible for many people to survive and thrive for years beyond their initial diagnosis.

Like those who live with diabetes and heart disease, persons living with cancer require care and management over their life span (see Module 10 Support for Patients and Caregivers for information about survivorship). Researchers estimate that there were 13.8 million cancer survivors alive in 2010. If the rate (the number of people with an illness based on a larger group of people) of people who are diagnosed with cancer and survive remain stable, the number of cancer survivors in 2020 will increase by about one third, to 18.1 million. Because of the aging of the U.S. population, researchers expect the largest increase in cancer survivors over the next 10 years to be among Americans age 65 and older.

Many older adults who experience a cancer diagnosis often suffer from one or more other chronic conditions (e.g. diabetes, heart disease). The degree to which a person is affected by existing chronic conditions may have an impact on the type of treatment they receive and treatment outcomes.

What are the concerns about existing chronic conditions and cancer?

Because many older adults with chronic conditions have not participated in clinical trials, not much is known about their experience with cancer and cancer treatment. We do know that older adults who experience a cancer diagnosis are concerned about the impact treatment may have on their quality of life. These concerns include whether or not they can withstand the side effects of treatments such as chemotherapy, radiation, and surgery and the decline in their ability for self-care that may result.

Persons under treatment for chronic conditions such as diabetes or heart disease may be at greater risk for drug interactions and the toxic effects of chemotherapy. Over time, chronic conditions may lead to a decrease in how body organs like the heart and kidney function. This may affect how chemotherapy drugs are absorbed and processed in the body.
Older adults who are living with chronic conditions may also be frail and less likely to remain independent during or after cancer treatment. They are also more likely to be widowed or living alone, on a fixed income, and dependent on others for transportation. More research is needed to better understand the effect of cancer treatment on those who suffer from chronic conditions. Lessons learned from this research will help to address concerns, develop appropriate plans for care and treatment, and improve quality of life for those with chronic conditions who undergo treatment for cancer.

**Chronic conditions that result from cancer treatment**

Cancer treatment (chemotherapy, radiation, and surgery) can result in a number of physical and emotional changes that may occur months to years following primary treatment. These changes are sometimes referred to as the “late effects” of cancer and include an increased risk for developing chronic conditions that limit function and impact overall quality of life. Whether a person develops a late effect from cancer treatment and the type of late effect may vary from person to person, as well as the type of surgery, chemotherapy given, and/or the area of the body that receives radiation.

Possible late effects of cancer treatment include:

1. **Changes in the body from chemotherapy and radiation:**
   
   **Heart** – Radiation to the chest and chemotherapy can cause changes to the heart decreasing its ability to function. Changes include inflammation of the heart muscle, congestive heart failure (condition where there is a decrease in the heart’s ability to pump blood), and heart disease. Examples of chemotherapy drugs that are known to cause damage to the heart cells include doxorubicin [Adriamycin] and cyclophosphamide [Cytoxan].

   **Lung** – Radiation to the chest and chemotherapy can cause changes to the lungs that impact function including inflammation, thickening of the lining, and difficulty in breathing. These effects are usually not reversible and increase over time. This is especially true for survivors who have had both chemotherapy and radiation. Examples of chemotherapy drugs that can cause damage to the lungs are bleomycin [Blenoxane], carmustine [Carmubris], and catarabine [Cytosar-U].

   **Brain, Spinal Cord, and Nerves** – High doses of radiation used to treat brain tumors increase the risk for stroke. Radiation to the spinal cord may increase risk for spinal cord injury resulting in a decrease in function and sensation. High doses of chemotherapy drugs like cisplatin [Platinol] may result in damage to the nerves in the arms and legs causing numbness, tingling, and loss of function.
Kidney and Bladder – Chemotherapy and radiation can cause damage to the kidneys and bladder that may not resolve over time. Examples of chemotherapy drugs that may cause severe irritation and a decrease in how the kidneys and bladder function include Cisplatin, Cytoxan, and Ifosfamide. The risk for damage increases when chemotherapy is combined with radiation to the pelvis.

Digestive System – Radiation and/or chemotherapy drugs can cause injury to the gastrointestinal tract. In addition, some chemotherapy drugs can enhance the effects of radiation and can cause damage to the body structures that process and absorb nutrients from the food we eat. Structures at risk include the esophagus, stomach, small intestine, and liver. Damage may include irritation or ulceration of the lining of the esophagus, stomach, and intestines, an increase in bowel motility or movements, scarring or injury to the cells of the liver, or a change in how nutrients like fats or Vitamin B₁₂ are absorbed from the small intestine.

Endocrine (Hormone) – Chemotherapy and radiation can cause changes in hormone levels and affect the parts of the body involved in reproduction (e.g. ovaries, testis). Changes may include early menopause and osteoporosis (thinning of the bones) in women and infertility (inability to conceive a child) in both men and women. Radiation to the head and neck may cause changes in levels of hormones produced by the thyroid gland which regulates key body systems and functions.

Bone, Joint, and Soft Tissues – Chemotherapy that includes the use of hormones and steroid medications increases the risk for problems with bones and joints, especially osteoporosis. Radiation to the body’s soft tissues can lead to fibrosis, or loss of flexibility. The most common areas affected are the breast, head and neck, bone and joints.

Vision, Hearing and Dental – Chemotherapy and radiation can increase the risk for long-term vision, hearing, and dental problems. Chemotherapy may cause damage to tooth enamel and radiation to the head and neck area increases the risk for dry mouth, and gum disease. Hearing loss, especially in the high-tone range is commonly associated with Cisplatin chemotherapy. The risk for hearing loss increases when chemotherapy is combined with radiation to the brain. Chemotherapy and radiation that involves the head and other facial structures can result in cataracts and other types of injury to the eye that may not be reversible.

2. Changes in the body from surgery:

Lymphedema – Removal of lymph nodes may cause a build-up of fluid in the arms and legs called lymphedema. The swelling that results from lymphedema may cause discomfort, lack of sensation, and a decrease in movement or function.
**Loss of a limb** – Survivors of cancer of the bone or soft tissues may face the psychological and physical effects of losing part or all of a limb. They may also experience the sensation of pain in the limb that has been removed, sometimes called phantom pain.

**Infection** – Survivors of Hodgkin’s lymphoma who have had their spleen removed are at greater risk for serious infections. The spleen plays a role in the body’s immune response or how the body recognizes and defends itself against bacteria, viruses, and substances that may be harmful.

### 3. Changes in cognitive function as a result of cancer treatment:

**Attention, concentration, and memory** – Chemotherapy, radiation, and hormonal changes contribute to changes in cognitive function (how we handle or process information). Survivors sometimes refer to these changes as “chemo brain” or “chemo clutter” and describe the effects as difficulty with finding the right words, remembering, or trying to think. The most common cognitive changes associated with chemotherapy and with radiation to the brain are a change in attention span, short-term memory loss, and decreased concentration.

### 4. Emotional changes as a result of cancer treatment:

**Anxiety, depression, anger, stress, grief and loss, and fear of recurrence** are examples of emotions that are a result of the cancer experience. Survivors often face many challenges in the months and years following treatment. Issues related to change in one’s body, relationships with others, sexuality or intimacy, infertility, spirituality, finances, insurance, and employment are often concerns that require attention and support beyond treatment for primary cancer.

### 5. Fatigue – cancer related fatigue (CRF) is one of the most commonly reported symptoms among cancer survivors. CRF differs from general fatigue experienced among persons who do not have cancer in that it occurs in the absence of physical exertion. CRF tends to develop and increase over time as a result of cancer treatment (chemotherapy, radiation, surgery). Fatigue that lingers long after treatment has ended impacts physical and psychological function, increases distress, and decreases quality of life.29,30,31,32
Second cancers that result from cancer treatment

The late effects of cancer may also include the development of a second cancer. A second cancer is a new or different cancer in a person with a history of cancer. Although the numbers of those affected are small, about one to three out of every 100 cancer survivors, understanding risk for second cancers is an important part of follow-up care for survivors.

Second cancers can develop as a result of previous cancer treatment (chemotherapy, radiation, or other hormonal therapies). A person’s risk for developing a second cancer depends on several factors including age, amount of treatment received, genetics, and family history. Other factors that increase a person’s risk for second cancers include environmental exposures, such as diet and tobacco, and hormonal exposures.

Examples of persons at risk for developing second cancers from treatment include those who have received radiation treatment for Hodgkin’s Lymphoma, who are at increased risk for developing thyroid, breast, and lung cancer; breast cancer patients treated with Tamoxifen (a hormonal agent) have an increased risk of uterine cancer; and cancer patients treated with certain types of chemotherapy drugs called alkylating agents are at increased risk of developing acute non-lymphocytic leukemia (a type of cancer affecting the blood cells).

An important time point for planning and education about what may follow cancer treatment is the transition from the end of a person’s primary cancer treatment to follow-up care. Quality of life for the cancer survivor depends upon an approach to follow-up care that addresses the unique needs of the survivor (See Module 7 – Support for Patients and Caregivers for discussion of new tools to enhance follow-up care for survivors). This includes attention to existing symptoms, screening, and early recognition and intervention to lessen the severity of chronic conditions.
Section 4
Preventing Chronic Conditions

What can we do to reduce our risk or prevent chronic conditions?

To reduce our risk for chronic conditions that include heart disease, cancer, diabetes, among others, we must take a close look at the factors that contribute to their development. These factors include lack of physical activity, poor nutrition, tobacco use and exposure, and excessive alcohol consumption. We must also consider factors that are vital to improving and sustaining health and wellness such as social setting, culture, lifestyle behaviors, environment, resources, health policies, education, and access to health care.

To prevent chronic conditions, strategies to promote health change must target multiple levels including individuals, communities, and systems. Interventions need to be holistic and tailored to the individual, their living environment and resources at hand.  

At the individual level, we can take action to reduce our risk or prevent chronic conditions:

- Get active and stay active – engage in moderate physical activity (brisk walking) for 30 minutes at least 5 times per week.
- Eat a healthy diet – foods that are high in fiber, vitamins, and minerals. This includes whole-grain breads and cereals and 5 to 9 servings of fruits and vegetables every day. Limit foods high in fat (such as butter, whole milk, fried foods, and red meat).
- Don’t smoke or don’t use smokeless tobacco (chew of snuff) – If you do smoke, get help to quit.
- Reduce your exposure to second hand smoke – avoid being around people when they are smoking.
- Limit alcohol consumption – no more than one drink per day for women and no more than two drinks per day for men.
- Participate in regular health checkups and screening tests (e.g. blood pressure, blood sugar, mammogram, Pap test, colon cancer screening).

At the community level, we can take action to reduce our risk or prevent chronic conditions by advocating for:

- Healthy food choices in schools, restaurants, and work place cafeterias.
- Fresh and affordable choices for fruits and vegetables in local groceries and convenience stores.
- Accessible and safe places to engage in physical activities including sidewalks and nearby parks.
At the *systems level*, we can *take action* to reduce our risk or prevent chronic conditions by engaging in the following activities:

- Encourage healthcare providers to provide information about how to prevent chronic conditions that is easy to understand and addresses the unique needs of the individual where they work and live.

- Become active in our children’s schools and encourage health education in the classroom and health checks to promote health among our youth.

- Advocate for workplace wellness programs that focus on reducing risks for chronic conditions and provide education about nutrition, physical activity, stress reduction, and quitting smoking.

- Advocate for policies at the local, state, and national level that result in positive changes in health for the public.
## Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>addiction disorders</strong></td>
<td>A compulsive dependence on a substance (e.g. alcohol, drugs, or gambling) that can have an impact on the length and quality of one’s life.</td>
</tr>
<tr>
<td><strong>arthritis</strong></td>
<td>A chronic disease that involves inflammation of one or more joints of the body causing pain, swelling, stiffness, and limited or loss of movement.</td>
</tr>
<tr>
<td><strong>autoimmune disease</strong></td>
<td>A chronic condition in which the body recognizes its own tissues as foreign and causes the body to attack itself.</td>
</tr>
<tr>
<td><strong>bleomycin</strong></td>
<td>A chemotherapy drug that is used to slow or stop the growth of cancer cells in the body. This drug can also cause damage to the lungs.</td>
</tr>
<tr>
<td><strong>body mass index (BMI)</strong></td>
<td>A calculation used to measure body fat based on an individual’s height and weight.</td>
</tr>
<tr>
<td><strong>cancer</strong></td>
<td>A term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems.</td>
</tr>
<tr>
<td><strong>cancer survivor</strong></td>
<td>One who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life.</td>
</tr>
<tr>
<td><strong>cartilage</strong></td>
<td>A tough, flexible tissue that lines joints and gives structure to the nose, ears, larynx, and other parts of the body.</td>
</tr>
<tr>
<td><strong>carmustine</strong></td>
<td>A chemotherapy drug that treats cancer. This drug can also cause damage to the lungs known as “late effects” of cancer.</td>
</tr>
<tr>
<td><strong>chemotherapy</strong></td>
<td>Treatment with drugs that kill cancer cells.</td>
</tr>
<tr>
<td><strong>chronic condition (disease)</strong></td>
<td>A chronic condition tends to develop slowly over the course of one’s lifetime. They are difficult to treat and often cannot be cured. Also known as a chronic disease or chronic illness.</td>
</tr>
<tr>
<td><strong>cisplatin</strong></td>
<td>A drug used to treat many types of cancer. It may also result in damage to the nerves in the arms and legs causing numbness, tingling, and loss of function.</td>
</tr>
<tr>
<td><strong>clinical trial</strong></td>
<td>A type of research study that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease. Also called a clinical study.</td>
</tr>
<tr>
<td><strong>cognitive impairment</strong></td>
<td>Difficulty in the ability to process information and reason.</td>
</tr>
<tr>
<td><strong>cyclophosphamide</strong></td>
<td>A chemotherapy drug that is used to treat many types of cancer and may cause “late effects” damage to the heart.</td>
</tr>
<tr>
<td><strong>cytarabine</strong></td>
<td>A drug used to treat certain types of leukemia. This drug has also been shown to cause damage to the lungs known as “late effects”.</td>
</tr>
<tr>
<td><strong>dementia</strong></td>
<td>A decline in memory and brain function that can have an impact on the length and quality of one’s life.</td>
</tr>
<tr>
<td><strong>developmental disabilities</strong></td>
<td>Life-long birth defects that affect how the body or body systems work.</td>
</tr>
<tr>
<td><strong>diabetes</strong></td>
<td>Diabetes refers to a group of diseases that affect how the body uses blood glucose (commonly called blood sugar).</td>
</tr>
<tr>
<td><strong>doxorubicin</strong></td>
<td>A chemotherapy drug used to treat different types of cancer. This drug has also been shown to cause heart damage also referred to as “late effects” of cancer.</td>
</tr>
<tr>
<td><strong>fibrosis</strong></td>
<td>The growth of fibrous tissue causing the loss of flexibility.</td>
</tr>
<tr>
<td><strong>genetics</strong></td>
<td>The study of genes and heredity</td>
</tr>
<tr>
<td><strong>gestational diabetes</strong></td>
<td>Gestational diabetes occurs in pregnant women who have never had diabetes before, but who have high blood sugar (glucose) levels during pregnancy. Gestational diabetes is caused by the body’s inability to make and use all the insulin it needs for pregnancy.</td>
</tr>
<tr>
<td><strong>heart disease</strong></td>
<td>The leading cause of death and the major cause of disability in the United States. There are many forms of heart disease. The most common cause of heart disease is narrowing or blockage of the coronary arteries, the blood vessels that supply blood to the heart itself. This is called coronary heart disease. Other kinds of heart problems may happen to the valves in the heart, or the heart may no pump well and cause heart failure. Some people are born with heart disease.</td>
</tr>
<tr>
<td><strong>hormone</strong></td>
<td>One of many chemicals made by glands in the body. Hormones circulate in the bloodstream and control the actions of certain cells or organs.</td>
</tr>
<tr>
<td><strong>ifosfamide</strong></td>
<td>A chemotherapy drug used to treat cancer that may cause severe irritation and a decrease in how the kidneys and bladder function.</td>
</tr>
<tr>
<td><strong>inflammation</strong></td>
<td>Redness, swelling, pain, and/or a feeling of heat in an area of the body. This is a protective reaction to injury, disease, or irritation of the tissues.</td>
</tr>
<tr>
<td><strong>joint</strong></td>
<td>The place where two or more bones are connected. Examples include the shoulder, elbow, knee, and jaw.</td>
</tr>
<tr>
<td><strong>late effects of cancer treatment</strong></td>
<td>Side effects of cancer treatment that appear months or years after treatment has ended. Late effects include physical and mental problems and second cancers.</td>
</tr>
<tr>
<td><strong>lupus erythematosus</strong></td>
<td>An autoimmune disease that causes the body to attack itself and can increase the risk for arthritis.</td>
</tr>
<tr>
<td><strong>lymphedema</strong></td>
<td>A condition in which extra lymph fluid builds up in tissues and causes swelling. It may occur in an arm or leg if lymph vessels are blocked, damaged, or removed by surgery.</td>
</tr>
<tr>
<td><strong>Medicare</strong></td>
<td>Medicare is a federal government health insurance program that is administered by the Centers for Medicare &amp; Medicaid Services (CMS). Medicare is health insurance for people age 65 or older, under age 65 with certain disabilities, and people of any age with End-Stage Renal Disease.</td>
</tr>
<tr>
<td><strong>mental illness</strong></td>
<td>A chronic mental condition that seriously impairs the normal psychological functioning of an individual (e.g., depression, anxiety).</td>
</tr>
<tr>
<td><strong>obesity</strong></td>
<td>If an individual’s Body Mass Index (BMI) is 30 or higher, this individual is considered obese.</td>
</tr>
<tr>
<td><strong>overweight</strong></td>
<td>If an individual’s Body Mass Index (BMI) is between 25 and 29.9 this individual is considered overweight.</td>
</tr>
<tr>
<td><strong>osteoarthritis</strong></td>
<td>Osteoarthritis is the most common type of arthritis and is more likely to occur as one ages. It causes pain, swelling and reduced motion in your joints. It can occur in any joint, but usually it affects your hands, knees, hips or spine.</td>
</tr>
<tr>
<td><strong>second cancer</strong></td>
<td>Second cancer is a new or different cancer in a person with a history of cancer.</td>
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<tr>
<td><strong>stroke</strong></td>
<td>A stroke occurs when the blood supply to part of the brain is blocked or when a blood vessel in the brain bursts. In either case, parts of the brain become damaged. Stroke is one of the most common, costly, and preventable chronic conditions in the U.S. today.</td>
</tr>
<tr>
<td><strong>Type 1 diabetes</strong></td>
<td>Formerly called juvenile diabetes, or insulin-dependent diabetes, it is usually first diagnosed in children, teenagers, or young adults. With this form of diabetes, cells in the pancreas are no longer able to make insulin because the body’s immune system has attacked and destroyed them.</td>
</tr>
<tr>
<td><strong>Type 2 diabetes</strong></td>
<td>Formerly called adult onset diabetes, or non-insulin dependent diabetes, it is the most common form of diabetes. People can develop type 2 diabetes at any age—even during childhood. This form of diabetes usually begins with insulin resistance, a condition in which fat, muscle, and liver cells do not use insulin properly. At first, the pancreas keeps up with the added demand by producing more insulin. In time, however, it loses the ability to secrete enough insulin in response to meals.</td>
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</table>

For more detailed information about cancer or the glossary terms, please refer to the Dictionary of Cancer Terms at [http://www.cancer.gov](http://www.cancer.gov) or call the National Cancer Institute’s Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).
Resources for Learning More

**American Diabetes Association:** Provides descriptions of the various types of diabetes, prevention, treatment and care and coping among other topics.  
http://www.diabetes.org/

**American Heart Association:** Provides information about a variety of conditions that affect the heart as well as resources on how to prevent heart disease. 
http://www.heart.org/HEARTORG/

**American Lung Association:** The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through Education, Advocacy and Research.  http://www.lungusa.org/

**Arthritis Foundation:** Provides information about the types of arthritis, symptoms, treatment, pain management, among other topics.  http://www.arthritis.org/

**Cancer.Net:** Provides information about cancer survivorship including coping with the physical, psychological, emotional effects of cancer treatment. Discusses late effects of cancer treatment, describes survivorship care plans and cancer treatment summaries.  
http://www.cancer.net/patient/Survivorship/About+Survivorship

**Centers for Disease Control and Prevention:** Provides information about promoting health and well-being to reduce the risk and prevent chronic disease and conditions including overweight and obesity.  http://www.cdc.gov/chronicdisease/

**MedlinePlus®:** MedlinePlus is the National Institutes of Health's Web site for patients and their families and friends. Produced by the National Library of Medicine, it brings you information about diseases, conditions, and wellness issues in language you can understand. MedlinePlus offers reliable, up-to-date health information, anytime, anywhere, for free. You can use MedlinePlus to learn about the latest treatments, look up information on a drug or supplement, find out the meanings of words, or view medical videos or illustrations. You can also get links to the latest medical research on your topic or find out about clinical trials on a disease or condition.  
http://www.nlm.nih.gov/medlineplus/

**National Cancer Institute:** Provides information about a variety of topics related to cancer survivorship including information about life after cancer treatment, coping and supportive care for survivors and caregiver, the late effects of cancer treatment, and links to data on second cancers.  
http://www.cancer.gov/cancertopics/coping/survivorship

**National Stroke Association:** Provides information on types of stroke, risk factors, prevention, treatment, rehabilitation, survivor and caregiver support among other topics.  
http://www.stroke.org/site/PageNavigator/HOME
References


12 American Heart Association [http://www.heart.org/HEARTORG/Conditions/HeartAttack/Heart-Attack_UCM_001092_SubHomePage.jsp](http://www.heart.org/HEARTORG/Conditions/HeartAttack/Heart-Attack_UCM_001092_SubHomePage.jsp). Accessed March 31, 2011.


Module 10: Support for Patients and Caregivers

Goals
In this session, participants will gain an understanding of the psychological and social issues that affect cancer patients and their caregivers.

Objectives
At the completion of Learning Module 10, participants will be able to demonstrate the following:

Section 1
a) Describe two emotions a cancer patient might experience after diagnosis.
b) Describe two ways to provide support to a patient facing cancer.
c) Describe two ways that make caregiving less stressful.

Section 2
Give two examples of how cancer survivors bring a sense of balance back into their lives after cancer treatment.

Section 3
Describe the role Survivorship Plans play in follow-up care after cancer treatment ends.

Measures of Objective Accomplishment
The presenter will administer a pre self-assessment and a post self-assessment to measure participants’ knowledge of the module’s objectives. The pre self-assessment measures existing knowledge and the post self-assessment measures what was gained through the learning module.

Target Audience
- Community members
- Staff of Indian health programs, including Community Health Representatives

Contents of Learning Module
- Instructor’s Guide with Pre/Post Self-Assessment and Self-Assessment Answer Key
- PowerPoint presentation
- Glossary
- Resources for Learning More
- References

Length
- Introduction of session/module overview (:05)
- Pre self-assessment (:07)
- Presentation of module (:30)
- Post self-assessment (:05)
- Closing (:03)

NOTE
- Each major learning point is clearly identified by **boldface** type throughout the guide and emphasized in the PowerPoint presentation.
- See the glossary (at the end of the module) for words that are in **bold blue italics** throughout the module.
Pre/Post Self-Assessment

Support for Patients and Caregivers

Do you agree (A), disagree (D), with these statements, or are you not sure (NS)?
Circle your choice - A, D, or NS.

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>D</th>
<th>NS</th>
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<td>3.</td>
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<td>4.</td>
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## Pre/Post Self-Assessment Answer Key

### What is Cancer?

*The correct answer to each question, agree (A) or disagree (D), is underlined and in red.*

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<tbody>
<tr>
<td>1.</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td></td>
<td>Feelings of denial, anger, stress, and anxiety are common for a person who has just been diagnosed with cancer.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>A</td>
<td>D</td>
</tr>
</tbody>
</table>
|   | Cancer is a disease that is best faced alone.  
*Note:* Many people can help provide a cancer patient with emotional, spiritual, and practical support. They include family members, friends, other cancer patients, community members, support groups, and health providers. |
| 3. | A | D |
|   | A cancer survivor is someone who successfully completes cancer treatment and goes into remission.  
*Note:* A cancer survivor is anyone who has been diagnosed with cancer, from the time of diagnosis through the rest of his or her life. |
| 4. | A | D |
|   | People who provide care for cancer patients may need periodic breaks to maintain their own emotional and physical health.  
*Note:* Offering caregivers regular relief from daily responsibilities can help them avoid overwork and burnout. Caregivers need to be realistic about their limits. |
| 5. | A | D |
|   | Once a person has finished cancer treatment and they are in remission, they no longer need to worry about follow-up care.  
*Note:* All cancer survivors should have follow-up care. Follow-up care means seeing a doctor for regular medical check-ups. |
Section 1

Coping with the Cancer Diagnosis - How to be Supportive

Coping with Feelings after the Diagnosis
The first few weeks after the diagnosis are often the most emotional time of the entire cancer experience. Feelings change rapidly from day to day or even hour to hour. A person may feel denial, anger, fear, stress, and anxiety. At times people with cancer and the people closest to them may also feel depressed, guilty, or lonely.

People who have faced cancer say that these intense feelings don’t last long. After a time of adjustment to the diagnosis, most people are able to move on and look forward to healing. It is important to remember that more and more people are surviving cancer and living many years beyond their diagnosis.

It’s a Family Matter
Families are not all alike. Family refers to the person diagnosed with cancer and those who love and support him or her. Cancer will change a person’s life and the lives of the people, or his/her family, around them. Routines may be altered, roles and duties may change, and relationships can be strained or strengthened.

How a family reacts to a cancer diagnosis may depend on how they have faced hard times in the past. Some families find it easy to talk about cancer. They may easily share their feelings about the changes that cancer brings to their lives. Other families may find it harder to talk about cancer. The people in these families may be used to solving problems alone and not want to talk about their feelings.

Many families find that even though it can be hard to do, they feel closer to each other when they deal with cancer together. A doctor or nurse can make a referral to a counselor that can help a family talk about the cancer diagnosis and what it means to them.

Keep in mind that when someone in a family has cancer, there may be changes to the roles and responsibilities in the family. For example, a child may be asked to do more chores or a spouse or partner may need to help pay bills, shop, or do yard work. Sometimes families may have trouble getting used to role changes that may be required when a loved one has cancer.
Sharing Feelings About Cancer

Just as a person diagnosed with cancer may have strong feelings about cancer, their friends and family will react to it as well. For instance, friends and family may:

- Hide or deny their sad feelings
- Find someone to blame
- Act mad for no real reason
- Make jokes about cancer
- Pretend to be cheerful all the time
- Avoid talking about cancer
- Stay away from the diagnosed person, or keep visits short.

It can be hard to talk about how it feels to have cancer, but talking can help. Many people find that they feel better when they share their thoughts and feelings with their close family and friends. Friends and family may not always know what to say, but they can help by just being good listeners. They don’t need to give advice or way what they think. They simply need to show that they care and are concerned.

Some people need time before they can talk about their feelings. And sometimes when they are ready to talk, their friends and family may not be ready to listen. Sometimes people can’t put their feelings into words. Sometimes they just want to hug each other or cry together.

For many it is hard to talk about being sick. Others may feel that cancer is a personal or private matter and find it hard to talk openly about it. In cases like this, it may be good to think about other ways to share feelings. For example, it may be helpful to write about feelings in a journal or diary.

Writing about feelings is a good way to sort through them and a good way to begin to deal with them. Journals can be personal or shared. Some people use a journal as a way of talking to each other by leaving it in a private place where there loved ones can access it, read it, and also write in it. In this way, they know how the other is feeling without speaking aloud. This can also be done with e-mail or through a blog.
Sources of Support

No one needs to face cancer alone. Many people can help provide a cancer patient with emotional, spiritual, and practical support. They include family members, friends, other cancer patients, community members, support groups, and health providers. For many American Indians and Alaska Natives (AI/AN) traditional healers are also an important part of supportive care. Traditional healers may conduct ceremonies for patients and their loved ones. These ceremonies may help individuals express their feelings and increase the bonds of support between those affected by the diagnosis. Many AI/AN are also active in formal religious organizations. These organizations may serve as a source of support for both the patient and the family. In addition to offering special prayers for recovery, some churches may provide services such as meal preparation and house cleaning.

People facing cancer who seek and receive support during their illness may find that they are often better able to cope with their problems. Many speak of how the support of other people cheered them and improved their outlook on life. Those who help also benefit. Having the chance to help with practical things can help put others at ease, and make them feel good about being able to do something meaningful.

Suggestions to make caregiving less stressful

Caregivers are the people who help a person diagnosed with cancer with their day-to-day activities such as bathing, getting dressed, or preparing food and eating. Caregivers are often family members or close friends. It may be helpful to build a team of caregivers so that one person isn’t depended on for everything, because just like the person diagnosed with cancer, caregivers need help and support.

People who provide care may need periodic breaks from caring for their loved one to take care of themselves both emotionally and physically. Offering caregivers regular relief from daily responsibilities can help them avoid overwork and burnout. Caregivers need to be realistic about their limits. They should ease into helping and should not try to do everything at once. This will lessen the chance of becoming overworked and stressed. Attending a support group and talking to other caregivers can be helpful. Sharing emotions by trusting and talking to family and friends and making time for yourself is also important. Finding volunteers, community resources, or relatives to help can lessen the likelihood of becoming overwhelmed.
Section 2

Life After Cancer Treatment – On the Path to Recovery

Facing a cancer diagnosis and surviving cancer treatment may be the greatest challenge a person will face in their lifetime. It is an important time during which many individuals work through their own personal feelings about death and how they may want to live the rest of their life.

The end of cancer treatment is often a time to rejoice. When treatment ends, some people may expect life to return to the way it was before they were diagnosed with cancer...but it can take time to recover. The person diagnosed with cancer and their loved ones need to come to terms with what has happened and figure out a “new normal”. This means getting back to the old life, but in a way that is probably different than before.

Attaining and maintaining balance becomes an important part of recovery. Some people may find it easy to bring a sense of balance back into their lives by returning to work and getting back into a routine. Choosing activities that provide a sense of purpose may also be helpful. Having fun and spending time with family and friends is important. It is important to remember that energy levels may be low after treatment, and recognizing physical limitations will prevent becoming overly tired. Getting enough rest is important for keeping physical and emotional defenses strong.

Some people say that putting their lives in order makes them less fearful of cancer returning. Setting a daily schedule, being a participant in health care decisions, keeping appointments, and making lifestyle changes are among the things a cancer survivor can control.

Some cancer survivors become active in their community after recovery from treatment. Getting involved in cancer-related activities is like a two-way street. When survivors help others, they also help themselves.
Section 3

Life After Cancer Treatment – Survivorship

Who is a survivor? A cancer survivor is anyone who has been diagnosed with cancer, from the time of diagnosis through the rest of his or her life. Family members, friends and caregivers are also part of the survivorship experience. The word “survivor” helps many people think about embracing their lives beyond their illness.

There are more than 10 million people in the U.S. today who are cancer survivors. Three out of every four American families will have at least one family member diagnosed with cancer. While cancer is a major event for all who are diagnosed, it brings with it the chance for growth. As hard as treatment can be, the cancer experience leads many survivors to make important changes in their lives. They take time to appreciate each new day. They also learn how to take better care of themselves and value how others care for them. Others draw from their experience to become advocates to improve cancer research, treatment, and care.

Worrying about cancer coming back is normal, especially during the first year after treatment. This is one of the most common fears people have after cancer treatment. As time goes by, many survivors report that they think about their cancer less often.

Survivorship Care Plans

In 2005, the Institute of Medicine issued a landmark report, From Cancer Patient to Cancer Survivor: Lost in Transition, which called for the development of a “survivorship care plan” by each cancer survivor. A survivorship care plan should include a record of the person’s medical history, a summary of their cancer diagnosis and treatment, and a follow-up plan for health care. Cancer survivors should work with their healthcare team to create a survivorship care plan. Resources are available to assist with the development of a survivorship care plan. Survivorship care plan templates are available from the American Society of Clinical Oncology, American Cancer Society, National Coalition of Cancer Survivorship, and the Lance Armstrong Foundation.
All cancer survivors should have follow-up care. Follow-up care means seeing a doctor for regular medical check-ups. A person’s follow-up care will depend on the type of cancer and type of treatment they had, along with overall health status. In general, survivors usually return to the doctor every 3 to 4 months during the first 2 to 3 years after treatment and once or twice a year after that. At these visits, the doctor will look for side effects from treatment and check if the cancer has returned or spread to another part of the body (recurrence).

After cancer treatment, many survivors want to find ways to reduce the chances of their cancer coming back. Some worry that the way they eat, the stress in their lives, or their exposure to chemicals may put them at risk. When a survivor meets with the doctor about follow-up care, they should ask about developing a wellness plan that includes ways to take care of their physical, emotional, social, and spiritual needs.

Needed for AI/AN cancer survivors is a more holistic approach to care that acknowledges cultural differences and practices, addresses learning needs about survivorship, and incorporates family and community resources as part of the overall plan. Use of survivorship care plans can provide benefit to AI/AN survivors by serving as a method to help their primary care providers increase their knowledge and understanding of their cancer treatment history and future care needs. These tools can also aid in helping primary care providers feel more connected to the cancer specialty care team in the larger care network thus increasing their level of comfort providing for the care of survivors.

Cancer survivorship care plans can empower AI/AN cancer survivors by helping them become active participants in their care. As new strategies, they hold potential for helping survivors communicate and advocate for what they need not just to survive, but to thrive during their experience. Use of these tools may ultimately help reduce the burden of this disease among AI/AN and help them achieve the highest quality of life and survivorship possible.

For more detailed information about cancer or the glossary terms, please refer to the Dictionary of Cancer Terms at http://www.cancer.gov/ or call the National Cancer Institute’s Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).
# Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>caregiver</strong></td>
<td>A person who gives care to people who need help taking care of themselves. Examples include children, the elderly, or patients who have chronic illnesses or are disabled. Caregivers may be health professionals, family members, friends, social workers, or members of the clergy. They may give care at home or in a hospital or other health care setting.</td>
</tr>
<tr>
<td><strong>diagnosis</strong></td>
<td>The process of identifying a disease, such as cancer.</td>
</tr>
<tr>
<td><strong>recurrence</strong></td>
<td>Cancer the has recurred (come back), usually after a period of time during which the cancer could not be detected. The cancer may come back to the same place as the original (primary) tumor or to another place in the body. Also called recurrent cancer.</td>
</tr>
<tr>
<td><strong>support group</strong></td>
<td>A group of people with similar disease or concerns who help each other cope by sharing experiences and information.</td>
</tr>
<tr>
<td><strong>survivor</strong></td>
<td>One who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life.</td>
</tr>
<tr>
<td><strong>survivorship</strong></td>
<td>In cancer, survivorship covers the physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also part of the survivorship experience.</td>
</tr>
<tr>
<td><strong>survivorship care plan</strong></td>
<td>A survivorship care plan is a coordinated post-treatment plan between a cancer survivor’s oncology team, primary care physician, and other healthcare professionals. It serves as a record of a patient’s cancer history, cancer treatment, and recommendations for follow-up care.</td>
</tr>
</tbody>
</table>
Resources for Learning More

Northwest Portland Area Indian Health Board Northwest Tribal Comprehensive Cancer Project: On this web page you can access the Northwest Tribal Cancer Resource Guide, full of resources for cancer survivors and caregivers. You can also access The Appointment Companion, a tool to help cancer survivors keep track of appointments and treatment. 
http://www.npaihb.org/programs/project/nwtccp_reports_publications_media_materials/

CancerCare – Caregiving: CancerCare provides free support for anyone affected by cancer. Find support and helpful information for people taking care of loved ones with cancer on this web page. http://www.cancercare.org/tagged/caregiving


Journey Forward - Survivorship Care Plan Builder: Journey Forward is a program, designed for doctors and their patients who have recently completed active cancer treatment, that promotes the use of survivorship care plans. http://journeyforward.org/

Lance Armstrong Foundation – LIVESTRONG Guidebook: The LIVESTRONG Guidebook is a companion for cancer survivors as they navigate the health care system. This two-volume set contains helpful information and journal spaces that help survivors address the physical, emotional, and practical concerns that they may have during the cancer journey. http://www.livestrong.org/Get-Help/Learn-About-Cancer/LIVESTRONG-Guidebook

National Institutes of Health (NIH) Senior Health – Life After Cancer: This web page, designed specifically for elders/seniors, provides information about “Life After Cancer”. http://nihseniorhealth.gov/lifeaftercancer/toc.html

National Library of Medicine (NLM) – MedlinePlus - Living With Cancer: This web page provides overview information on “Living With Cancer”. It also provides links to other sites of interest on the same topic. http://www.nlm.nih.gov/medlineplus/cancerlivingwithcancer.html
National Cancer Institute (NCI) – Taking Time: Support for People With Cancer:
This booklet addresses the feelings and concerns of people with cancer and their families. Suggests ways to manage and cope with the special problems that cancer can bring.  http://www.cancer.gov/cancertopics/takingtime

NCI – Caring for the Caregiver: Support for Cancer Caregivers:  This booklet provides practical and supportive information to help cancer caregivers cope during this stressful time.  This is a condensed version of the larger booklet, “When Someone You Love Is Being Treated for Cancer”, that is meant to address the needs of caregivers with lower reading levels.  Written at the fourth to fifth grade level.  http://www.cancer.gov/cancertopics/coping/caring-for-the-caregiver


NCI – Facing Forward: When Someone You Love Has Completed Cancer Treatment:  This booklet provides caregivers with coping strategies to help them shift their focus from treatment to recovery. Discusses the transition to a “new normal”, communication skills and feelings, ways to get support, ahelping with follow-up care, and the need for self-care.  http://www.cancer.gov/cancertopics/coping/someone-you-love-completed-cancer-treatment

NCI – Facing Forward: Life After Cancer Treatment:  This booklet covers post-treatment issues such as follow-up medical care, physical and emotional changes, and changes in social and work relationships.  http://www.cancer.gov/cancertopics/coping/life-after-treatment

NCI Fact Sheet – Follow-up Care After Cancer Treatment :  This fact sheet provides information about follow-up medical care for patients who have completed cancer treatment.  http://www.cancer.gov/cancertopics/factsheet/Therapy/followup

NCI – Facing Forward: Making a Difference in Cancer:  This booklet reviews the potential benefits of becoming involved in cancer-related activities, such as helping with outreach and education, fundraising, or raising awareness about research or public health issues. Designed for anyone who has been diagnosed with cancer or affected by it in some way.  http://www.cancer.gov/cancertopics/coping/make-a-difference
NCI – Coping With Cancer: Survivorship: Living with and Beyond Cancer: This web page provides links to resources that address cancer survivorship. http://www.cancer.gov/cancertopics/coping/survivorship


NCI – Cancer Survivorship Research: This is the home page for the NCI’s Office of Cancer Survivorship (OCS). The mission of OCS is to enhance the quality and length of survival of all persons diagnosed with cancer and to minimize or stabilize the adverse effects experienced during cancer survivorship. http://dccps.nci.nih.gov/ocs/


National Coalition for Cancer Survivorship – The Cancer Survival Toolbox®: The award-winning Cancer Survival Toolbox® is a free, self-learning audio program to help people develop important skills to better meet and understand the challenges of their illness. The audio programs address scenarios for many topics and issues cancer patients/survivors face during their cancer journey. The conversations touch on issues from how to communicate with your doctor, family and loved ones, to understanding complicated financial issues. Each scenario is inspired by true stories of real cancer patients/survivors. http://www.canceradvocacy.org/toolbox/
References


4 Lance Armstrong Foundation (2009). LIVESTRONG Guidebook


Section 1

Cancer 101 Adaptation Guidelines

Note: The Cancer 101 Adaptation Guidelines were originally developed in March 2008 and were updated in October 2011.

Purpose: The purpose of these guidelines is two-fold: 1) to provide background information and guidance on the future adaptation of the Cancer 101 curriculum for cultural and/or linguistic appropriateness, and 2) to create uniformity of practice in the adaptation process.

Key points to consider when adapting the Cancer 101 curriculum:\(^1\):

1. Determine the needs of the target audience regarding communicating health information about cancer contained within the Cancer 101 curriculum. Needs assessment should include primary (i.e. in-depth interviews with community leaders, focus groups, surveys, direct observation) and secondary (health status data, literature search) data collection.

2. Determine the extent of modifications necessary to address these needs (i.e. language, culture, literacy, age, social context, etc.).

3. Engage members of the target audience in the adaptation process to ensure the adaptation’s appropriateness to the audience.

4. Employ measures to ensure that the adapted materials maintain the accuracy of the original Cancer 101 content.

5. Pilot test the adaptation with representatives from the target audience to ensure adaptation is culturally relevant and meets intended program goals and objectives.

6. Make modifications based on feedback from pilot testing.

7. Evaluate the effectiveness of the adaptation.

\(^1\) Based on NCI’s Research-tested Intervention Programs (RTIPS)
STEP ONE: Define the rationale for adapting the materials. Rationale for adaptation of the materials may include one or more of the following considerations listed below. (See last two pages of Section 1 for additional resources.)

1. Language\(^2\): Use of materials with non-English or limited English proficiency populations requires translation of content. Key considerations for translation include identification of qualified translator, definition of translator role, and verification of translation.

   Suggested guidelines for translation may include the following:
   
   - **Key characteristics of an appropriate translator:**
     - Proficient in reading in the source language
     - Native speaker of the target language
     - Demonstrated strong writing skills in the target language
     - Work experience in the target language in healthcare education settings
   
   - **Translator should be asked to do the following:**
     - Identify cultural differences
     - Find equivalent word and phrases
     - Ensure essential meaning does not change
   
   - **Method(s) used to verify the translation:**
     - Multiple forward translations
     - Back-translation
     - Translation review by bilingual experts
     - Pilot test

2. Culture: Information within modules can be tailored to address the cultural context of the target audience. This information may include knowledge, attitudes, beliefs, customs, and practices surrounding health, illness, and disease (cancer).

3. Literacy: Most of the Cancer 101 content is written at about an 8\(^{th}\) grade reading level. Therefore, content may require modification for those individuals with reading levels that fall below this level.

   In addition to general literacy, it will be important to assess the “health” literacy of the target audience. Health literacy refers to the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate decisions\(^3\).

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\(^3\) Institute of Medicine, 2004.
Lastly, patterns of communication vary from one population to another. Assessment of these patterns and how to address them must be included in the adaptation process.

4. **Age and Gender:** What is the generational mix of the target audience? For example, content may need to be modified to adjust for learning style (e.g. youth vs. elder). Is it a single sex or mixed group? If so, consider any issues or concerns related to modesty and comfort level with the topics to be discussed.

5. **Social context:** It is important to integrate relevant information about factors related to the physical environment (community setting), geographical location, and available health resources for a particular community.

6. **Type and length of training:** *Cancer 101* content can be tailored based on the goals and objectives of a particular training providing “general” information about cancer basics or “site specific” information. Learning modules are designed to be presented in 30- to 40- minute education sessions or the entire curriculum can be presented as a one or two-day workshop on cancer education.

**STEP TWO:** Identify content that requires modification (modules, PowerPoints, pre/post self-assessment, etc.) and define approach that will be utilized to adapt content. Content and format may be adapted to reflect issues, concerns, and realities of target audience.

1. **Module One – Cancer Among American Indians and Alaska Natives:** This module can be tailored to reflect the rationale for why cancer has become a health concern for the target population. Information pertaining to the history of cancer in the population along with a brief description of factors that may have impacted cancer incidence rates expands the understanding of the problem. Representation of data should be population specific (if known) along with a listing and discussion of any relevant data issues and concerns (e.g. racial misclassification, undercounting, etc.). Consider tailoring the representation of data to reflect any issues related to numeracy, the ability of your target audience to reason with numbers and other mathematical concepts.

2. **Module Two – What is Cancer?** Describing the disease cancer can be particularly challenging due to cultural variations surrounding language and lack of existing words for this disease among populations. Consider tailoring information within this module to reflect the *meaning* of the word “cancer” to the target population. Including information about relevant cultural beliefs and perceptions may be helpful in expanding the definition/terminology about cancer.

3. **Module Three – Cancer Risk Factors and Risk Reduction:** Population specific risk factor data varies or may be unknown. Consider addition of relevant information about how cancer risk has evolved over time for the target population. For example,
how have changes in lifestyle and the environment influenced cancer risk? Are there certain forms of cancer that have a disproportionate effect on the target population?

4. **Module 4 – Role of Genes in Cancer:** Consider adding a story about someone from the target population/community with a strong family history of breast or colorectal cancer. For example, develop a scenario that describes someone’s experience learning about their family history and exploring the option of genetic testing to learn more about their own risk.

5. **Module 5 - Cancer Screening and Early Detection:** Consider adding relevant information about barriers to participating in early detection and screening practices specific to the target population. For example, what are the health seeking behaviors or illness belief systems that influence timely participation in cancer screening?

6. **Module 6 – Cancer Diagnosis and Staging:** Consider adding information that provides a description of the diagnosis and staging process that someone from the target population/community would be subject to based on healthcare facility access, etc. For example, develop a scenario that is cancer site specific and describes someone’s experience from first sign/symptom through diagnosis and staging process.

7. **Module 7 – Basics of Cancer Treatment:** In addition to the various conventional (Western, mainstream) methods used to treat cancer described within this module, consider adding descriptions, as appropriate, of any alternative and/or traditional pathways for healing utilized by the target population. Because beliefs surrounding illness, wellness, and healing vary greatly among populations, alternative and/or complementary forms of medicine may be considered as part of getting well again.

8. **Module 8 – Biospecimens and Biobanking:** Discussing biospecimens and biobanking can be particularly challenging in some communities due to past cases such as Henrietta Lacks and the Havasupai Indian case. Consider tailoring information within this module to reflect history (or lack thereof) around biospecimens within the target population as well as potential benefits in advancing cancer detection and treatment. Including information about relevant cultural beliefs and perceptions may be helpful in generating discussion around this topic.

9. **Module 9 – Chronic Conditions and Cancer:** Population specific data around chronic conditions may vary or may be unknown. Consider addition of relevant information about how chronic conditions and cancer have evolved over time for the target population. For example, how have changes in lifestyle and the environment influenced chronic condition risk? Are there certain forms of chronic conditions that have a disproportionate effect on the target population?
10. Module 10 – Support for Patients and Caregivers: Cultural variations may also have an influence on the recovery or healing pathway following cancer treatment. Add information, as appropriate, that describes cultural considerations in addressing the psychological, emotional, spiritual impact and healing related to cancer.

**STEP THREE:** Employ methods to ensure the adaptation is relevant to the target population and the content is accurate.

1. Determine the type of evaluation needed according to the type of objectives (process, educational/learning, behavioral and environmental, and program). Although it may be time-intensive to develop four types of objectives, it is important for getting a complete picture of what is happening and why. Much of the literature recommends developing objectives that are specific, measurable, achievable, realistic, and time-framed (SMART)\(^4\).

   a. **Process Objectives:** The process objectives are what you do to accomplish all other levels of objectives. Think of them as inputs and process components needed to carry out the program. For a very comprehensive process evaluation, you may choose to create specific objectives that will track all possible components, which could include:
      - Program resources (materials, funds, space)
      - Type and appropriateness of activities
      - Target audience exposure and attendance

   b. **Educational/Learning Objectives:** The educational/learning objectives follow a hierarchy. If the intent is for the target audience to adopt and maintain a behavior, participants must 1) be aware of the need or value, 2) expand their knowledge of available and appropriate resources, 3) adopt and maintain beliefs in the effectiveness of these resources and their own ability to use them, and 4) possess the actual skills to obtain information efficiently.
      - The results may be change in awareness, knowledge, attitudes, beliefs, skills, and practices.
      - Evaluation of educational/learning objectives helps determine if the desired change in awareness, knowledge, attitudes, beliefs, skills, and practices has occurred.

   c. **Behavioral and Environmental Objectives:** The behavioral and environmental objectives
      - The results from behavioral objectives may be to seek changes in behavior that resolve health information needs - such as becoming information seekers.

• Environmental objectives can be loosely defined as those that remove physical and social barriers to enacting behavioral changes.

d. Program Objectives: Program objectives are the ultimate objectives of a program, expressed as the outcomes of individual and community change in using or providing health information.

2. Pilot Test
• You may want to do a pilot test in order to evaluate the effect of your program. Do a practice run using a small group that is similar to your target audience\(^5\). This allows you to\(^6\):
  1. Assess comprehensibility (does the target audience understand the content?)
  2. Identify strong and weak points (what parts of the adaptation are and aren’t doing their job?)
  3. Determine personal relevance (does the target audience identify with the adaptation?)
  4. Gauge confusing, sensitive, or controversial elements (do particular topics make the target audience uncomfortable?)

   • Provides an opportunity to see if there are any major problems.
   • Gives an idea of possible evaluation results.
   • Can use pilot test results/feedback to fine-tune the adaptation.

3. Evaluation: The evaluation process should be sensitive to the history of research-related issues and concerns with diverse populations. For example, members of diverse communities may be skeptical or mistrustful of the evaluation process because their experience has been that scientists enter their communities and collect data, but frequently fail to share their findings or take visible and beneficial action.

a. It is important to build confidence in the purpose and benefits of evaluation results for the community\(^7\):

   • Try to involve respected community members and leaders in evaluation planning (e.g. to review a questionnaire and data collection strategy).
   • Ask their cooperation in helping you to recruit participation.
   • Directly involve members of the community in data collection efforts.
   • Be sure to share your findings, if possible as early as the draft state, for their review and comment.

b. When trying to measure effectiveness to determine if the objectives were achieved, you may consider using one or more of the following methods. Keep in mind that each one has advantages and disadvantages:\(^8,^9,^10\):

- Questionnaires (pre-test/assessment, post test/assessment, surveys, oral test)
- Interviews
- Observation (skills test, vignettes)
- Records (activity logs, attendance sheets, diaries, medical/social service records)
- Focus groups (meetings, talking circles, etc.)
- Case study


**ADDITIONAL RESOURCES** (Disclaimer: Links to non-Federal organizations are provided solely as a resource. These links do not constitute an endorsement of these organizations or their programs by the NCI or the Federal Government, and none should be inferred. The NCI is not responsible for the content of the individual organization Web pages found at these links.)

1. Culture
   d. **Curricula Enhancement Module Series**, National Center for Cultural Competence [www.nccccurricula.info](http://www.nccccurricula.info)
   g. **Ethnomed**, University of Washington – Harborview Medical Center [http://ethnomed.org/](http://ethnomed.org/)
   i. **The Community Toolbox**, Work Group for Community Health & Development at the University of Kansas [http://ctb.ku.edu](http://ctb.ku.edu)

2. Health Literacy
e. Health Literacy Style Manual, Covering Kids & Families
http://coveringkidsandfamilies.org/resources/docs/stylemanual.pdf
f. Teaching Patients with Low Literacy Skills, Second Edition
   Authored by: Cecelia C. Doak, Leonard G. Doak, & Jane H. Root
   http://www.hsph.harvard.edu/healthliteracy/resources/doak-book/

3. Materials/Curriculum Review and Analysis
   a. Health Education Curriculum Analysis Tool (HECAT), Centers for Disease
   b. Materials Health Literacy Scoring Sheet (SAM + Comprehensibility)
      UNM Health Evaluation & Research Office - Jane Cotner

ACKNOWLEDGEMENTS
These Adaptation Guidelines are designed as a tool for those working to adapt Cancer
101: A Cancer Education and Training Program for American Indians and Alaska
Natives for other audiences.

The following individuals have provided their time, effort and expertise in the
development of these guidelines:

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Service

Cynthia Seaborn, DrPHc, MPA, Program Manager – Office of Minority Health, Florida
Department of Health, Tallahassee, FL

Madeline R. LaPorta, MS, Associate Director of the Office of Partnerships and
Dissemination Initiatives at the National Cancer Institute served as a Project Advisor on
this document.
Section 2

Training Tips

PREPARING FOR A TRAINING:

Tip #1 - Prepare for the training session: In order to implement a Cancer 101 training, you will need the training curriculum Cancer 101: A Cancer Education and Training Program for American Indians and Alaska Natives as well as the accompanying PowerPoint slides. You should print out handouts for each participant to use during the training.

Tip #2 - Review the curriculum before implementing the training. Read ahead to see what is included in subsequent modules. This curriculum has been designed to be straightforward and easy to follow. However, in order to ensure a successful and seamless session, it is beneficial to familiarize yourself with the slides, talking points, and information in the modules. During this review, you will be able to identify information that may to be highlighted with your group. You will need equipment to access and display PowerPoint slides. This means a computer or laptop as well as an LCD projector. By reading ahead to following modules, you will know what is to come. You will be able to reference the future modules during discussions. Also, participants may have a tendency to jump ahead. In turn, reading ahead will help you to keep the session on track by reassuring participants that their concerns/questions will be addressed soon.

Tip #3 - Review case studies in the modules: Most of the modules include a case study, which takes participants through content being learned in the module. This help participants get a better understanding of the material. You may choose to develop your own case study for the training with a topic more closely relates to your participants.

Tip #4 - Anticipate questions: This curriculum has been pilot tested to be delivered in 30-40 minutes education sessions for each module. If you find something a little more difficult to follow, anticipate that others will too. Think of ways to explain the concept in terms of your experience. Also, it may be helpful to think of some potential questions to pose to your participants. Therefore, if your participants do not immediately ask questions or are more passive, you can generate discussion or other questions.

Tip #5 - Be realistic about your time: Each module should take 30-40 minutes to deliver. If you cannot plan for this time, you may need to modify activities to shorten the time. The modules can be implemented separately as educational sessions, in a group for a ½ day or one-day training, or in their entirety for a two-day training. You may decide to skip a module due to time limitations or if your participants already demonstrate that they know the information. If you skip a module, you may want to highlight what is covered and the case study for that module (if it has one).
Tip #5 - Share your findings: After you have completed a training, get back to your participants and let them know how it went overall. We also appreciate hearing from you. Please feel free to contact us with any feedback about the training, questions you could not answer about the information provided, an alternative case study that you would like to share, and/or additional resources you think would be beneficial to include in the training. Please email: Kathy Briant at kbriant@fhcrc.org

DELIVERING A TRAINING:

We learn and remember more when we feel comfortable with the learning process. As a trainer, you can create a comfortable place for learning to take place. Learning about cancer can be difficult for many people.

Some issues that may hinder learning:
- Fear of discovering that one has a high risk of cancer;
- Fear of exposing one’s lack of knowledge to others;
- Fear of remembering painful memories of loved ones lost to cancer;
- Differences in learning styles, cultural beliefs and perspectives.

At the beginning of each training, you can reassure the participants that these feelings are normal and will be carefully considered during the training session.

The following highlights some basic trainer qualities and communications skills that may help you. For more information about training, please use the NCI’s Trainer’s Guide for Cancer Education that can be ordered through the NCI Publications Ordering Service https://cissecure.nci.nih.gov/ncipubs/home.aspx.

Some Qualities of Effective Trainers:
- Understands the impact that her/his own behavior can have on the learners;
- Encourages learners;
- Patience and respect for the needs of learners;
- Gives information in a clear manner and allows plenty of time for questions/discussion;
- Uses audio-visual aids (flipcharts, videos, slides, etc.) to keep learners engaged;
- Culturally sensitive and open to different ways of thinking about things;
- Adapts the training to meet the needs of the learners;
- Responds to sensitive and confidential issues appropriately.
Communication Skills:

Voice:
- Speak so that everyone can hear you.
- Use expression in your voice.
- Emphasize key words so that the audience understands the main points of the lesson.

Eye Contact:
- Look around the entire room when you speak.
- Look to specific individuals through the room when you speak.
- For large audiences, look to general areas to establish contact.

Posture:
- Use a relaxed posture.
- Walk around and use the entire area during your presentation.
- If sitting, rest your arms comfortably in front of you; don’t slouch forward.

Gestures:
- Use gestures that feel natural to you.
- Keep your hands empty so you don’t distract the audience by clicking a pen, for example.

Pacing:
- Speak at a comfortable pace.
- Do not use “um”, “OK”, or “uh huh” to fill the place of silence.
- Use pauses or a faster speaking pace to emphasize key points.

Adapted from: Using What Works: Adapting Evidence-Based Programs to you’re your Needs Trainer Materials; Trainer’s Guide for Cancer Education, National Cancer Institute; Training Design and Delivery: A Capacity-Building Workshop for CIS Trainers, National Cancer Institute; and Effective Training Techniques, Fred Hutchinson Cancer Research Center.
Dear Trainer,
We need your help! As a Cancer 101 user, you are part of a very important educational initiative to educate American Indian and Alaska Native people about cancer. A strong feedback loop between our office and the users of the Cancer 101 curriculum is critical to the ongoing success of the program. This feedback loop will provide you with the opportunity to let us know how you are using the materials and how the curriculum can be strengthened. Your suggestions will enable us to modify the curriculum to suit the needs of your audiences, and to provide you with additional resource materials. Thank you in advance for your participation!

After using Cancer 101 for training/education, please complete this form and return it to Kathy Briant at kbriant@fhcrc.org.

**Trainer Name:** ________________________________

**Trainer Telephone:** ________________________________

**Trainer E-mail:** ________________________________

**Tribe/Organization/Group:** ________________________________

**Date of training/activity:** ________________________________

**Training/Activity location:** ________________________________

**Number of participants:** ________________________________

**Type of Activity:**
- [ ] Tribal Staff Training
- [ ] Patient/family education session
- [ ] Community Health Representative Training
- [ ] Group Presentation
  - [ ] Support Group
  - [ ] Women’s Group
  - [ ] Men’s Group
  - [ ] Other (please indicate): ________________________________
Materials Used for My Training/Activity:

- Module 1
- Module 2
- Module 3
- Module 4
- Module 5
- Module 6
- Module 7
- Module 8
- Module 9
- Module 10
- Healthy Change Checklist

If you did not use the pre/post self assessment, why didn’t you, or did you use them in some other way, i.e. as a discussion guide? ____________________________________
______________________________________________________________________
______________________________________________________________________

This is optional, but it will strengthen our evaluation of the Cancer 101 curriculum if you are able to send a summary of completed pre/post assessments, healthy changes checklist, or other evaluation tool(s) used to measure the impact of your training or activity. If you are able to share this information, it can be sent to Kathy Briant (contact information below).

If you have any questions, or would like to discuss the use of the curriculum, please feel free to contact Kathy Briant.

Kathy Briant
Community Health Educator
Center for Community Health Promotion
Fred Hutchinson Cancer Research Center
1100 Fairview Ave. N., M3-B232
Seattle, WA 98109

Email: k briant@fhcrc.org
Telephone: 206-667-1137
Fax: 206-667-5977

THANK YOU!!
Healthy Changes Checklist

After this workshop using the Cancer 101 curriculum, some health changes I intend to make are:

- Use this information my own knowledge and awareness.
- Share information about cancer issues in Native communities with my family and friends.
- Talk about cancer prevention with family and friends.
- Share what I’ve learned about cancer and information about some of the treatments for cancer.
- Share information about support services available for people who are dealing with cancer.
- Offer my support to people who are dealing with cancer.
- Talk with family members to learn my family health history.
- Get regular physical exams that include screening for cancer.
- Pay attention to changes in my body that last more than two weeks (such as a lump in the breast or a cough that doesn’t go away), and seek medical attention.
- Get 30 minutes of physical activity at least five times a week.
- Eat a healthy diet that includes a variety of fruits and vegetables and is lower in fat.
- Stop smoking, or encourage a loved one to stop smoking, and reserve the use of tobacco for traditional purposes.
- Limit alcohol consumption to no more than one daily drink for women and two daily drinks for men.
- Protect myself from sun exposure.
- Protect myself and my partner from sexually transmitted diseases.
- Other health changes I would like to make: ______________________________
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Workshop Evaluation

The purpose of these questions is to help us know if Cancer 101 was useful to you. Please answer each question as best you can. You don’t have to answer any questions you don’t want to.

1. Have you previously attended a cancer presentation, workshop or training?
   - O Yes
   - O No
   - O Don’t know/Don’t remember

2. What was your primary reason for attending this training? Choose only one answer.
   - O Learn basic information about cancer
   - O Network with others
   - O Learn about cancer resources for patients and caregivers
   - O Learn about cancer resources for healthcare providers/professionals
   - O Understand cancer issues and concerns for American Indians and Alaska Natives
   - O Opportunity to ask questions, discuss cancer issues and concerns with others
   - O Learn about community-based cancer projects
   - O Develop knowledge and skills to educate others
   - O Develop knowledge and skills to participate in cancer control activities
   - O Other____________________________

Please rate by filling in one answer for each of the statements below.

<table>
<thead>
<tr>
<th>Please rate by filling in one answer for each of the statements below.</th>
<th>Extremely Poor</th>
<th>Below Average</th>
<th>Average</th>
<th>Above Average</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. how well the training met the stated goal(s) and objective(s)</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>4. how understandable the information was</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>5. how valuable the training was for your self, work, and/or community service</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>6. how well the training has prepared you to plan and implement Cancer 101 events/programs in your community</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>7. your comfort level in sharing information about cancer with others in your community after this training</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>

Evaluation continues on next page
Please rate by filling in one answer for each of the statements below.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Extremely Poor</th>
<th>Below Average</th>
<th>Average</th>
<th>Above Average</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. The value of learning about cancer resources</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>9. How well the training met your expectations</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>10. How well the training was organized</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>11. The length of the training session</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>12. The length of time for discussion</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>

13. What aspects of the training were **most** helpful?

14. What aspects of the training were **least** helpful?

15. What are your plans for use of the materials, or curriculum, when you get back to your community?

16. Any other comments or suggestions?

Thank you!
**Section 1**

**Organizational Resources**

The following is an alphabetical list of some organizations that offer cancer-related services to people with cancer and their families. Numerous organizations provide services to people with cancer, and this is by no means a comprehensive list. These listings are meant to provide a starting point. For a more extensive list, visit the National Cancer Institute’s website at: https://cissecure.nci.nih.gov/factsheet/FactSheetSearch8_1.aspx

- **American Cancer Society:** The American Cancer Society (ACS) is a nationwide, community-based voluntary health organization. The ACS offers a variety of services and programs for patients and their families. The ACS also supports research, provides printed materials, and conducts educational programs. Staff can accept calls and distribute publications in Spanish.
  
  **Telephone:** 1-800-227-2345 (Responds to call in English and Spanish)
  
  **Web site:** http://www.cancer.org

- **AVONCares Program:** CancerCare, in partnership with the Avon Foundation, operates the AVONCares Program for Medically Underserved Women. This program provides financial assistance to low-income, under- and uninsured, underserved women throughout the country who need supportive services (transportation, childcare, or home care) related to the treatment of breast and gynecological cancers (cervical, endometrial, ovarian, uterine, vaginal, vulvar). To apply for funds from the AVONCares Program, download an application form online or contact CancerCare to receive the application.

  **Telephone:** 1-800-813-4673 (Responds to call in English and Spanish)
  
  **Web site:** http://www.cancercare.org
- **Cancer Legal Resource Center**: The Cancer Legal Resource Center (CLRC) is a joint program of the Disability Rights Legal Center Loyola Law School, Los Angeles. The CLRC provides free information and resources on cancer-related legal issues to people with cancer, survivors, caregivers, employers, health care professionals, and others coping with cancer. The CLRC has a national toll-free line where callers can receive information about relevant laws and resources for their particular situation. The CLRC volunteer panel of attorneys and other professionals provides more in-depth information and counsel to CLRC callers. Extensive resources are available on a broad range of cancer-related legal issues, including health insurance, employment, government benefits, estate planning, advance health care directives, family law, and consumer assistance. CLRC provides services in Spanish and has bilingual staff who are able to assist people on the toll-free line. Some publications are also available in Spanish.
  
  **Telephone**: 1-866-843-2572 (Responds to call in English and Spanish)
  
  **Web site**: [http://www.cancerlegalresourcecenter.org](http://www.cancerlegalresourcecenter.org)

- **Cancer Care**: CancerCare provides free professional support services to anyone affected by cancer (people with cancer, caregivers, children, loved ones, and the bereaved). CancerCare programs include counseling and support groups, education, financial assistance, and practical help. Counseling is provided by oncology social workers and is available on the telephone and face-to-face (available at offices in New York City, Long Island, New Jersey, and Connecticut). Support groups are offered online, via telephone, and in face-to-face groups. Connect® Education Workshops are available via the telephone or via live streaming through the Internet. In the workshops, leading experts in oncology provide the most current information. CancerCare also provides free publications, some in Spanish. Limited grants are available to eligible families for cancer-related costs like transportation and childcare. A section of the CancerCare Web site is available in Spanish.
  
  **Telephone**: 1-866-843-2572 (Responds to call in English and Spanish)
  
  **Web site**: [http://www.cancerlegalresourcecenter.org](http://www.cancerlegalresourcecenter.org)

- **Indian Health Service**: The Indian Health Service (IHS) is responsible for providing federal health services to American Indians and Alaska Natives. The IHS’s mission is to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level by assuring that comprehensive, culturally acceptable personal and public health services are available and accessible to American Indian and Alaska Native people. You can access information on current projects, training opportunities, and resources related to cancer through their web site.
  
**Leukemia and Lymphoma Society:** The Leukemia and Lymphoma Society (LLS) is dedicated to funding blood cancer research, public and professional education, advocacy and community services. Services include family support groups led by health care professionals and First Connection (Peer-to-Peer) Program that links patients and their families with a trained volunteer who has experienced a similar situation. Numerous other resources are available for patients and caregivers and include education programs, online support programs, and information about home-care services. The LLS provides a limited amount of financial assistance ($150) to help patients offset expenses. To apply, a patient must be a U.S. resident and be in active treatment or ongoing medical follow-up for leukemia, lymphoma, myeloma, myelodysplastic syndromes or another blood cancer. LLS’s headquarters is located in New York and chapter offices are located across the United States.  
*Telephone:* 1-800-955-4572 (Responds to call in English and Spanish)  

**National Cancer Institute’s Cancer Information Service:**  
The National Cancer Institute’s (NCI’s) Cancer Information Service (CIS) is a federally funded program that was established in 1975 as an essential part of NCI's cancer education and information efforts. NCI’s CIS provides free scientifically based, unbiased information to patients, their families and friends, physicians and other health professionals, and the general public about all aspects of cancer. Information Specialists are trained to answer questions by telephone, instant messaging, and email.  
*Telephone:* 1-800-422-6273 (Responds to call in English and Spanish)  

**National Coalition for Cancer Survivorship:** The National Coalition for Cancer Survivorship (NCCS) is a survivor-led cancer advocacy organization. NCCS’s primary goal is to advocate for quality cancer care for all Americans and empower cancer survivors. Resources provided include the Cancer Survival Toolbox® (free, self-learning audio program), NCCS publications, Surviving with Confidence program (dispels misconceptions about chemotherapy), Cancer Care Planning, and Journey Forward (program that promotes clear steps for care and monitoring after active cancer treatment). NCCS also provides a Resource Guide, a database of organizations that can be searched based on cancer type, treatment issues, side effects, cancer-related information (e.g., long-term survival clinics), and state.  
*Telephone:* 1-888-650-9127 (Responds to call in English only)  
*Web site:* [http://www.canceradvocacy.org](http://www.canceradvocacy.org)
- **National Patient Travel Center:** The National Patient Travel Center (NPTC) provides the National Patient Travel Helpline, a telephone service that facilitates patient access to charitable medical air transportation resources in the United States. The Helpline conducts an initial screening of patient need to determine the most suitable means of travel, and then refers callers to the most appropriate charitable medical air transportation program.
  
  **Telephone:** 1-800-296-1217 (Responds to call in English only)
  **Web site:** [http://www.patienttravel.org](http://www.patienttravel.org)

- **Native American Cancer Research:** Native American Cancer Research (NACR) is an American Indian operated, community-based non-profit organization. The mission is to reduce cancer incidence and increase survival among Native Americans. NACR’s priority is to implement cancer research projects involving prevention, health screening, education, training, control, treatment options, and support.
  
  **Telephone:** 1-800-537-8295 (Responds to call in English only)
  **Web site:** [http://natamcancer.org](http://natamcancer.org)

- **Native CIRCLE:** The American Indian/Alaska Native Cancer Information Resource Center and Learning Exchange (Native CIRCLE) exists to stimulate, develop, maintain, and disseminate culturally appropriate cancer information materials for American Indian/Alaska Native educators, healthcare leaders, and students. Native CIRCLE is housed within the Mayo Clinic Comprehensive Cancer Center.
  
  **Telephone:** 1-877-372-1617 (Responds to call in English only)
  **Web site:** [http://nativeamericanprograms.org/index-circle.html](http://nativeamericanprograms.org/index-circle.html)

- **Patient Advocate Foundation:** The Patient Advocate Foundation (PAF) provides professional case management services to Americans with chronic, life-threatening, and debilitating illnesses. PAF case managers (assisted by doctors and health care attorneys) serve as liaisons between the patient and their insurer, employer, and/or creditors to resolve insurance, job retention, and/or debt crisis matters as they relate to the patient's diagnosis. The PAF seeks to safeguard patients through effective mediation to ensure access to care, maintenance of employment, and preservation of financial stability. PAF publications on health-related topics are available online and in hard copy. PAF has a Scholarship for Survivors program and awards scholarships to individuals under the age of 25 that are or have been diagnosed with cancer or a critical or life-threatening disease.
  
  **Telephone:** 1-800-532-5274 (Responds to call in English only)
  **Web site:** [http://www.patientadvocate.org](http://www.patientadvocate.org)
The National Cancer Institute offers free publications. Orders may be placed online through the NCI Publications Locator web site https://cissecure.nci.nih.gov/ncipubs/home.aspx. Orders may also be placed by calling the Publications Ordering Service toll-free (1-800-422-6237).

NCI’s publications are free, and for orders up to 20 items are shipped at no charge. Bulk orders of greater than 20 items incur a shipping and handling charge of 15 cents per copy with a minimum charge of $8.

Depending on your audience, and the focus of the training, the following is a list of some NCI publications that may be helpful to include either at a resource table at a training, or with participant handouts/materials:

**GENERAL CANCER INFORMATION:**
- What You Need To Know About™ Series:
  - Cancer (*available in Spanish*)
  - Breast Cancer (*available in Spanish*)
  - Cancer of the Colon and Rectum (*available in Spanish*)
  - Cervical Cancer (*available in Spanish*)
  - Lung Cancer (*available in Spanish*)
  - Prostate Cancer (*available in Spanish*)

**CANCER TREATMENT:**
- Cancer Staging Fact Sheet (*available in Spanish*)
- Tumor Grade Fact Sheet (*available in Spanish*)
- Chemotherapy and You: Support for People With Cancer (*available in Spanish*)
- Chemotherapy Side Effect Fact Sheet Series (*available in Spanish*)
- Radiation Therapy and You: Support for People With Cancer (*available in Spanish*)
- Radiation Therapy Side Effect Fact Sheet Series (*available in Spanish*)
- Eating Hints: Before, During and After Cancer Treatment (*available in Spanish*)
- Thinking About Complementary and Alternative Medicine: A Guide for People With Cancer

**CLINICAL TRIALS:**
- Taking Part in Cancer Treatment Research Studies
- If You Want To Find Ways to Prevent Cancer…Learn About Prevention Clinical Trials (*also available in Spanish*)
COPING WITH CANCER:
- Taking Time: Support for People With Cancer
- Pain Control: Support for People With Cancer (available in Spanish)
- Coping with Advanced Cancer: Support for People With Cancer
- When Cancer Returns: Support for People With Cancer
- When Someone You Love Is Being Treated for Cancer: Support for Caregivers
- Caring for the Caregiver: Support for Cancer Caregivers (available in Spanish)
- When Someone You Love Has Advanced Cancer: Support for Caregivers

SURVIVORSHIP:
- Facing Forward: Life After Cancer Treatment (available in Spanish)
- Facing Forward: Making a Difference in Cancer
- Facing Forward: When Someone You Love Has Completed Cancer Treatment

CANCER PREVENTION & EARLY DETECTION:
- BREAST:
  - Common Breast Changes: Things to Know (available in Spanish)
  - Understanding Breast Changes: A Health Guide for Women

- CERVIX:
  - Understanding Cervical Changes: A Health Guide for Women
  - Pap Tests: Things To Know
  - Cervical Cancer: What You Can Do To Protect Yourself (available in Spanish)
  - Human Papilloma Viruses and Cancer Fact Sheet (available in Spanish)

- COLON & RECTUM:
  - Colorectal Cancer Screening Fact Sheet (available in Spanish)

- PROSTATE:
  - Understanding Prostate Changes: A Health Guide for Men
  - Prostate Specific Antigen (PSA) Test Fact Sheet (available in Spanish)

- SKIN:
  - Anyone Can Get Skin Cancer (available in Spanish)
The following materials have been adapted for AI/AN from National Cancer Institute publications. Contact Native C.I.R.C.L.E. at 1-877-372-1617 (toll-free) or order online at http://nativeamericanprograms.org/index-circle.html.

- The Journey Forward: A Guide for Cancer Survivors
- Important Things for You to Know About Cancer
- Pocket Glossary of Cancer Language
- Video: Cancer In The Great Land
- Video: AI/AN Clinical Trials and Native People-A Gift For Our Children
- Native C.I.R.C.L.E. brochure

The following materials have been created for Alaska Natives. For more information, or to order copies, please visit the Alaska Community Health Aide Program web site at: http://www.akchap.org/CancerCME.cfm.

- Awakening Choices: Colon Health – Our Stories
- Help Yourself to Health
- Staying Strong, Staying Health: Alaska Native Men Speak Out About Cancer
- Understanding: Stepping into the Light
- Weaving Breast Health Into Our Lives