Guide for Patient Navigators

A Supplement to the Oncology Patient Navigator Training: The Fundamentals
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**Tip:** Viewing this PDF in Google Chrome? Use “Ctrl+Click” on links to open them in a new tab.

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The George Washington University (GW) Cancer Center is committed to advancing patient navigation and cancer survivorship efforts locally and nationally through training, research, policy analysis, outreach, and education. One of our goals is to equip patient navigators with the skills and resources needed to address barriers to care that patients experience across the care continuum.

We are excited to offer our Oncology Patient Navigator Training: The Fundamentals at no cost to patient navigators. In 2013 we started an 18-month process to create the first-ever competencies for non-clinical Oncology Patient Navigators. In 2015 we launched a free, competency-based training through a cooperative agreement with the Centers for Disease Control and Prevention. We included the foundational knowledge that patient navigators need as well as a comprehensive Guide for Patient Navigators. This guide has been updated with free resources and tools you can put into practice immediately.

Our vision is to help support Oncology Patient Navigators in their important work and build a qualified workforce to increase cancer patients’ access to care. Competency-driven training can help standardize core duties of the navigation profession, so patients and other health care professionals know what to expect when working with a patient navigator. Training can also help to sustain the profession by helping patient navigators demonstrate their value to administrators and other stakeholders. Local training is also critical to support patients in your specific context. Please note that in 2022, we made downloadable slides available to you in the event you have limited internet bandwidth or want to use content to customize to your location or context.

We hope that you find the training and this updated Guide for Patient Navigators beneficial in your role as a patient navigator as you seek to improve the lives of those affected by cancer.

Sincerely,

Mandi Pratt-Chapman, MA, Ph.D., Hon-OPN-CG
Associate Professor, Department of Medicine, School of Medicine and Health Sciences
Associate Professor, Prevention and Community Health, Milken Institute School of Public Health
Associate Center Director, Patient-Centered Initiatives & Health Equity, GW Cancer Center
Acknowledgements

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Competency Development Steering Committee

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Competency Reviewers

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Training Reviewers

We thank the training reviewers: Andrea Dwyer, MSW, Kathleen Garrett, Elizabeth Glidden, MPH, Lillie Shockney, RN, BS, MAS, Patricia Valverde, Ph.D., MPH, Beverly Wasserman, RN.

About GW Cancer Center

The George Washington University (GW) Cancer Center is a collaboration of the George Washington University, the GW Hospital and the GW Medical Faculty Associates to expand GW's efforts in the fight against cancer. The GW Cancer Center also incorporates all existing cancer-related activities at GW, with a vision to create a cancer-free world through groundbreaking research, innovative education and equitable care for all. Learn more about the GW Cancer Center at gwcancercenter.org.
An Overview of the Training

This training course is comprised of seven modules.

Each module contains:

- Pre-Assessment*
- Interactive Presentations*
- A Brief Quiz
- Post-Assessment*
- Guide for Patient Navigators - Tools and resources to complement the video and further learning

Each module is self-paced. You can pause the modules at any point and come back to the presentation. Each module contains additional resources that are relevant to patient navigators.

* The pre-assessment, presentations, quizzes, and post-assessment are required elements within each lesson and are necessary before moving on to the next module. You must pass each quiz with a score of 70% or better to move to the next lesson. Reviewing the additional information and activities is optional but strongly recommended.

Navigating the Training

Each module includes a section called Resources and a section called Activities. The content in the Resources section is optional and complements materials in the Activities section. The content in the Activities section is required. In the Activities section, you will complete a pre-assessment for each lesson, view an interactive presentation and complete a brief quiz and post-assessment before moving on to the next lesson. When these activities are completed for each lesson, you are able to move to the next module.
# MODULE 2: An Overview of Patient Navigation and Competencies

## LESSON 1: An Overview of Patient Navigation and Competencies

### Learning Objectives

- Describe social determinants of health and health disparities
- Define patient navigation
- Discuss the history and evolution of patient navigation
- Explain models of patient navigation
- Discuss the process for developing the Core Competencies for Patient Navigators

### Key Takeaways

- Social determinants of health can lead to cancer health disparities
- Patient navigation is an intervention created that addresses health disparities
- The field of patient navigation has quickly grown since the first program in Harlem in 1990
- Patient navigation programs vary in their structure, and patient navigators can come from different backgrounds
- The GW Cancer Center created the first-ever consensus-based competencies for oncology patient navigators who do not have a clinical license (e.g. licensed navigators may be social workers or nurses)
- The GW Cancer Center created this training based on those competencies

According to the US Department of Health and Human Services, “Social determinants of health are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.”

---

1. [1-24]
Five key factors have been identified that can impact a person’s health: economic stability, education, social and community context, health and health care, and neighborhood and built environment.¹

**Principles of Patient Navigation**

Patient navigation is patient-centric with a goal of virtually integrating a fragmented health care system for the individual patient. The “core function of patient navigation” is “the elimination of barriers to timely care across all segments of the health care continuum.”² Patient navigation should focus on a clear part of the cancer continuum with a clear scope of practice and clear beginning and end point. Navigators should provide services that align with their skill level and should be supported by training.²

**Oncology Patient Navigator Core Competencies**

The Oncology Patient Navigation Training: The Fundamentals, and this guide, are built on the Core Competencies for Non-Clinically Licensed Patient Navigators that were developed by Dr. Mandi Pratt-Chapman at the GW Cancer Center through a collaborative, multi-phase process. Learning objectives for all modules align with one or more of these competencies. Appendix A includes the full list of competencies.

**Oncology Nursing Society Oncology Nurse Navigator Core Competencies**

In 2013, the Oncology Nursing Society published its Oncology Nurse Navigator Core Competencies based on a rigorous process. The competencies cover:

- Professional Role
- Education
- Coordination of Care
- Communication

**Resources for Patient Navigators**

- [Center for Health Progress](#) (CHP): Offers information for health care professionals who work with the underserved populations.
- [Intercultural Cancer Council](#) (ICC): Offers a series of [Cancer Fact Sheets](#) on a variety of medically underserved populations.
- National Cancer Institute’s [Center to Reduce Cancer Health Disparities](#) (CRCHD): Initiates, integrates, and engages in collaborative research studies with NCI
divisions and NIH institutes and centers to promote research and training in cancer health disparities, and to identify new and innovative scientific opportunities to improve cancer outcomes in communities experiencing an excess burden of cancer.

- Office of Minority Health’s Think Cultural Health Website: This site, sponsored by the Department of Health and Human Service’s Office of Minority Health, offers the latest resources and tools to promote cultural and linguistic competency in health care. You may access free and accredited continuing education programs as well as tools to help you and your organization provide respectful, understandable, and effective services.
LESSON 1: Medical Terminology

Learning Objectives

- Define basic medical terms using prefixes, root words, and suffixes
- Describe common words used in oncology
- Identify resources on basic medical terms

Key Takeaways

- Most medical and scientific terms come from Greek or Latin words
- Medical terms are often made up of a prefix, root word, and suffix, so knowing the meaning of these word parts can help you understand medical terms
- Online dictionaries and guides, flashcards, and courses can help you improve your understanding of medical terminology

Prefixes, Roots, and Suffixes

Most medical and scientific terms include three parts. They appear complex but can be broken down into parts to give you a basic idea of their meaning. Each word has a prefix, root, or suffix to help determine the term’s meaning.

Figure 1. Differences between the prefix, root, and suffix
PREFIX
This part of the word will usually help you figure out size, color, shape as well as location, direction, and amount.

Location: Near, Towards, Upon, Within, Around
Direction: Away From, Beneath, Above, Between, Before, After
Amount: Lack Of, Without, Excessive, Difficult

ROOT
This part of the word will usually help you determine which part of the body it relates to.

SUFFIX$^{25,26}$
This part can also help describe size, shape, or color but, more importantly, can tell you what the problem actually is.

A list of common prefixes is below. Remember that a prefix will usually help you determine size, color, shape as well as location, direction, and amount. Review these prefixes so words become easier for you to recognize and define. Pre means “before.” Prefixes are typically found at the beginning of the word.

Table 1. Examples and descriptions of prefixes

<table>
<thead>
<tr>
<th>PREFIX</th>
<th>WHAT IT DESCRIBES</th>
<th>EXAMPLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>AN-, A-</td>
<td>without/lack of</td>
<td>anemia = lack of red blood cells</td>
</tr>
<tr>
<td>AB-</td>
<td>away from</td>
<td>abnormal = away from the normal</td>
</tr>
<tr>
<td>AD-</td>
<td>near/toward</td>
<td>adren al gland = gland near to the kidney</td>
</tr>
<tr>
<td>BI-</td>
<td>two/both</td>
<td>bilateral Wilm’s = tumor in both kidneys</td>
</tr>
<tr>
<td>DYS-</td>
<td>difficult/painful</td>
<td>dysfunction = not working properly</td>
</tr>
<tr>
<td>ECTO-</td>
<td>outside</td>
<td>ectopic pregnancy = outside the uterine cavity</td>
</tr>
<tr>
<td>ENDO-</td>
<td>inside</td>
<td>endoscopy = an instrument to look inside the body cavities or organs</td>
</tr>
<tr>
<td>EPI-</td>
<td>upon</td>
<td>epi dermis = the outer layer of skin</td>
</tr>
<tr>
<td>HYPER-</td>
<td>excessive/above</td>
<td>hyperglycemia = excessive blood sugar levels</td>
</tr>
<tr>
<td>HYPO-</td>
<td>beneath/below</td>
<td>hypodermic = injection below the skin</td>
</tr>
<tr>
<td>INTER-</td>
<td>between</td>
<td>intercostal = between the ribs</td>
</tr>
<tr>
<td>INTRA-</td>
<td>within/inside</td>
<td>intravenous = into a vein</td>
</tr>
<tr>
<td>PARA-</td>
<td>beside/about/near</td>
<td>parathyroid = beside the thyroid gland</td>
</tr>
</tbody>
</table>
Prefix Example #1
WORD: Anemia
- The prefix “a-” describes a lack of
- The root “-nemia” describes blood
- The combination of this prefix and root yields, (a-)(-nemia), a word that means a lack of red blood cells.

Prefix Example #2
WORD: Intercostal
- The prefix “inter-” means between
- The root “-costal” describes ribs
- The combination of this prefix and root yields, (inter-)(-costal), a word that means a in between the ribs.

Prefix Example #3
WORD: Syndrome
- The prefix “syn-” means together
- The root “-drome” is a from the Greek word meaning “run”
- The combination of this prefix and root yields, (syn-)(-drome), a word that means a group of symptoms “running” together.

Table 2. Summary of prefixes that describe size, direction, and location

<table>
<thead>
<tr>
<th>SIZE</th>
<th>DIRECTION AND LOCATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Macro (large)</td>
<td>Hyper (fast, elevated, overproducing, energetic)</td>
</tr>
<tr>
<td>Micro (small)</td>
<td>Hypo (slow, low, under-producing, low energy)</td>
</tr>
<tr>
<td>Megalo or Megaly (abnormally large)</td>
<td>Tachy (rapid)</td>
</tr>
<tr>
<td></td>
<td>Brady (slow)</td>
</tr>
<tr>
<td></td>
<td>Extra (outside, excess, beyond)</td>
</tr>
<tr>
<td></td>
<td>Endo (within)</td>
</tr>
</tbody>
</table>
### Table 3. Examples and descriptions of roots

<table>
<thead>
<tr>
<th>ROOT</th>
<th>WHAT IT DESCRIBES</th>
<th>EXAMPLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>BLAST-</td>
<td>germ, immature cell</td>
<td>blastoma = cancer made of immature cells</td>
</tr>
<tr>
<td>CARCINO-</td>
<td>cancer</td>
<td>carcino</td>
</tr>
<tr>
<td>CARDIO-</td>
<td>heart</td>
<td>cardioxicity = toxicity to the heart</td>
</tr>
<tr>
<td>CYTO-</td>
<td>cell</td>
<td>cytoxic = toxic to the cell</td>
</tr>
<tr>
<td>DERMA-</td>
<td>skin</td>
<td>derma</td>
</tr>
<tr>
<td>HISTO-</td>
<td>tissue</td>
<td>histology = study of tissue</td>
</tr>
<tr>
<td>HEPATI-</td>
<td>liver</td>
<td>hepatoblastoma = liver cancer</td>
</tr>
<tr>
<td>MALIGN-</td>
<td>bad/harmful</td>
<td>malignant = growing, spreading</td>
</tr>
<tr>
<td>NEPHRO-</td>
<td>kidney</td>
<td>nephroxic = harmful to the kidneys</td>
</tr>
<tr>
<td>NEURO-</td>
<td>nerves</td>
<td>neuroblast = an immature nerve cell</td>
</tr>
<tr>
<td>ONCO-</td>
<td>mass/tumor</td>
<td>oncology = the study of cancer</td>
</tr>
<tr>
<td>OSTEO-</td>
<td>bone/bony tissue</td>
<td>osteosarcoma = bone cancer</td>
</tr>
<tr>
<td>PAED-</td>
<td>child</td>
<td>pediatric oncology = study of childhood cancer</td>
</tr>
<tr>
<td>SARCO-</td>
<td>tissue</td>
<td>sarcoma = tumor of bone, muscle, or connective tissue</td>
</tr>
<tr>
<td>TOXO-</td>
<td>poison</td>
<td>toxicology = study of poisons</td>
</tr>
</tbody>
</table>

**Root Word Example #1**

**WORD**: Dermatitis
- No prefix
- The root “DERMA” means skin
- The suffix “-itis” describes inflammation
- The combination of this root and suffix yields, (Derma-)t(-itis), a word that means *inflammation of the skin*.
Root Word Example #2

**WORD**: Nephrotoxic
- The prefix/root “nephron” means dealing with the kidney
- The root “-tox” describes poison
- The combination of this prefix and root yields, (nephro-)(-tox), a word that means toxic to the kidneys.

Root Word Example #3

**WORD**: Osteosarcoma
- The prefix/root “osteo-” means bone
- The root “-sarco” means tumor of bone, muscle, or connective tissue
- The combination of this prefix and root yields, (osteo-)(-sarco)ma, a word that means cancer of the bones.

The suffix is the third and last component of a word. It can also help describe size, shape, or color but, more importantly, can tell you what the problem actually is.

### Table 4. Examples and descriptions of suffixes

<table>
<thead>
<tr>
<th>SUFFIX</th>
<th>WHAT IT DESCRIBES</th>
<th>EXAMPLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>-AEMIA</td>
<td>condition of blood</td>
<td>leukemia = cancer of blood cells</td>
</tr>
<tr>
<td>-ECTOMY</td>
<td>excision/removal</td>
<td>nephrectomy = excision of a kidney</td>
</tr>
<tr>
<td>-ITIS</td>
<td>inflammation</td>
<td>hepatitis = inflammation of the liver</td>
</tr>
<tr>
<td>-OLOGY</td>
<td>study/science of</td>
<td>cytology = the study of cells</td>
</tr>
<tr>
<td>-OMA</td>
<td>tumor</td>
<td>retinoblastoma = tumor of the eye</td>
</tr>
<tr>
<td>-PATHY</td>
<td>disease</td>
<td>neuropathy = disease of the nervous system</td>
</tr>
<tr>
<td>-OSIS</td>
<td>disease/condition</td>
<td>necrosis = dying cells</td>
</tr>
</tbody>
</table>

Suffix Example #1

**WORD**: Nephrectomy
- The root “Nephro-” means kidney
- The suffix “-ectomy” means excision or removal
- The combination of this root and suffix yields, (nephr-)(-ectomy), a word that means excision or removal of a kidney.
Suffix Example #2  
**WORD**: Retinoblastoma  
- The prefix/root “-retin” describes the eye  
- The root “-blast” describes an immature cell  
- The suffix “-oma” describes a tumor  
- The combination of these roots and the suffix yields, (retino-)(-blast-)(-oma), a word that means *tumor of the eye*.

### Table 5. Summary of common roots and suffixes that are used to describe common tests and procedures

<table>
<thead>
<tr>
<th>ROOT</th>
<th>WHAT IT DESCRIBES</th>
<th>EXAMPLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>ECHO-</td>
<td>Using ultrasonic waves</td>
<td><strong>Echo</strong>cardiogram = use of sound waves to create a picture of the heart</td>
</tr>
<tr>
<td>ELECTRO-</td>
<td>Using electricity</td>
<td><strong>Electro</strong>cardiogram = records the electrical activity of the heart</td>
</tr>
<tr>
<td>SUFFIX</td>
<td>WHAT IT DESCRIBES</td>
<td>EXAMPLE</td>
</tr>
<tr>
<td>-ECTOMY</td>
<td>Surgical removal of</td>
<td>Append<strong>ectomy</strong> = removal of the appendix</td>
</tr>
<tr>
<td>-GRAM</td>
<td>Written or drawn, a picture or record</td>
<td><strong>Angio</strong>gram = procedure that uses an x-ray image and dye to see the flow of blood in the blood vessels</td>
</tr>
<tr>
<td>-GRAPH(Y)</td>
<td>Process of making an image or instrument for recording</td>
<td><strong>Angio</strong>graphy = medical imaging technique to visualize the inside of blood vessels or organs of the body</td>
</tr>
<tr>
<td>-OTOMY</td>
<td>Making a cut in</td>
<td>Lob<strong>otomy</strong> = making a cut in connections in the prefrontal lobe of the brain</td>
</tr>
<tr>
<td>-SCOPY</td>
<td>Using an instrument for viewing</td>
<td>Endo<strong>scopy</strong> = procedure to examine the digestive tract using an endoscope</td>
</tr>
<tr>
<td>-STOMY</td>
<td>Create an opening</td>
<td>Colo<strong>stomy</strong> = an opening made in the colon</td>
</tr>
</tbody>
</table>

### Common Words Used in Cancer

Osteosarcoma: “osteo” describes the bone or bony tissue, and “sarcoma” is defined as any type of “malignant,” which means harmful, “tumor.” Sarcomas specifically refer to a malignant tumor of the connective tissue. So, osteosarcoma describes *bone cancer*. 
Another example: Carcinogenic. “Carcino” describes cancer, and remember that cancer means the uncontrolled growth of abnormal cells. Genic can be defined as “producing or causing.” So, when you put all the words and meanings together, you find that carcinogenic describes something that causes cancer.

Table 6. Summary of various roots and their meanings

<table>
<thead>
<tr>
<th>ROOT</th>
<th>MEANING</th>
</tr>
</thead>
<tbody>
<tr>
<td>OSTEO</td>
<td>bone</td>
</tr>
<tr>
<td>MYO</td>
<td>muscle tissue</td>
</tr>
<tr>
<td>NEURO</td>
<td>nerves</td>
</tr>
<tr>
<td>DERM</td>
<td>skin</td>
</tr>
<tr>
<td>ANGIO</td>
<td>blood vessels</td>
</tr>
<tr>
<td>VENO/PHLEBO</td>
<td>veins</td>
</tr>
<tr>
<td>CARDIO</td>
<td>heart</td>
</tr>
<tr>
<td>RHINO</td>
<td>nose</td>
</tr>
<tr>
<td>NEPH</td>
<td>kidney</td>
</tr>
<tr>
<td>CRANIO</td>
<td>skull</td>
</tr>
<tr>
<td>OPTHALMO/OCULO</td>
<td>eye or eyeball</td>
</tr>
<tr>
<td>OTO</td>
<td>ear</td>
</tr>
<tr>
<td>THROMBO</td>
<td>blood blot</td>
</tr>
<tr>
<td>HEPATO</td>
<td>liver</td>
</tr>
<tr>
<td>MAMMO</td>
<td>breast</td>
</tr>
<tr>
<td>COLO</td>
<td>colon or large intestine</td>
</tr>
<tr>
<td>GASTRO</td>
<td>stomach</td>
</tr>
<tr>
<td>ILEO</td>
<td>small intestine</td>
</tr>
<tr>
<td>THORACO</td>
<td>thorax</td>
</tr>
<tr>
<td>PNEUMO/PLEURO</td>
<td>lungs or respiratory functions</td>
</tr>
</tbody>
</table>

Medical Terminology Cheat Sheet

Table 7. Summary of examples and descriptions of prefixes, roots, and suffixes

<table>
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<td>adrenal gland = gland near to the kidney</td>
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<td>two/both</td>
<td>bilateral Wilm’s = tumor in both kidneys</td>
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<td>PREFIX</td>
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<td>EXAMPLE</td>
</tr>
<tr>
<td>--------</td>
<td>------------------</td>
<td>---------</td>
</tr>
<tr>
<td>DYS-</td>
<td>difficult/painful</td>
<td>dysfunction = not working properly</td>
</tr>
<tr>
<td>ECTO-</td>
<td>outside</td>
<td>ectopic pregnancy = outside the uterine cavity</td>
</tr>
<tr>
<td>ENDO-</td>
<td>inside</td>
<td>endoscope = an instrument to look inside the body cavities or organs</td>
</tr>
<tr>
<td>EPI-</td>
<td>upon</td>
<td>epidermis = the outer layer of skin</td>
</tr>
<tr>
<td>HYPER-</td>
<td>excessive/above</td>
<td>hyperglycemia = excessive blood sugar levels</td>
</tr>
<tr>
<td>HYPO-</td>
<td>beneath/below</td>
<td>hypodermic = injection below the skin</td>
</tr>
<tr>
<td>INTER-</td>
<td>between</td>
<td>intercostal = between the ribs</td>
</tr>
<tr>
<td>INTRA-</td>
<td>within/inside</td>
<td>intravenous = into a vein</td>
</tr>
<tr>
<td>PARA-</td>
<td>beside/about/near</td>
<td>parathyroid = beside the thyroid gland</td>
</tr>
<tr>
<td>PERI-</td>
<td>around</td>
<td>pericardium = membrane around the heart</td>
</tr>
<tr>
<td>PRE-</td>
<td>before</td>
<td>prenatal = before birth</td>
</tr>
<tr>
<td>POST-</td>
<td>after</td>
<td>post-surgical stage = stage after surgery</td>
</tr>
<tr>
<td>SUB-</td>
<td>under/below</td>
<td>submucosa = tissue below mucus membrane</td>
</tr>
<tr>
<td>SYN-</td>
<td>together with</td>
<td>syndrome = group of symptoms occurring together</td>
</tr>
<tr>
<td>ROOT</td>
<td>WHAT IT DESCRIBES</td>
<td>EXAMPLE</td>
</tr>
<tr>
<td>BLAST-</td>
<td>germ, immature cell</td>
<td>blastoma = a cancer made of immature cells</td>
</tr>
<tr>
<td>CARCINO-</td>
<td>cancer</td>
<td>carcinogenic = cancer causing</td>
</tr>
<tr>
<td>CARDIO-</td>
<td>heart</td>
<td>cardiotoxicity = toxicity to the heart</td>
</tr>
<tr>
<td>CYTO-</td>
<td>cell</td>
<td>cytotoxic = toxic to the cell</td>
</tr>
<tr>
<td>DERMA-</td>
<td>skin</td>
<td>dermatitis = inflammation of the skin</td>
</tr>
<tr>
<td>HISTO-</td>
<td>tissue</td>
<td>histology = study of tissue</td>
</tr>
<tr>
<td>HEPATI-</td>
<td>liver</td>
<td>hepatoblastoma = liver cancer</td>
</tr>
<tr>
<td>MALIGN-</td>
<td>bad/harmful</td>
<td>malignant = growing, spreading</td>
</tr>
<tr>
<td>NEPHRO-</td>
<td>kidney</td>
<td>nephrotoxic = harmful to the kidneys</td>
</tr>
<tr>
<td>NEURO-</td>
<td>nerves</td>
<td>neuroblast = an immature nerve cell</td>
</tr>
<tr>
<td>ONCO-</td>
<td>mass/tumor</td>
<td>oncology = the study of cancer</td>
</tr>
<tr>
<td>OSTEO-</td>
<td>bone/bony tissue</td>
<td>osteosarcoma = bone cancer</td>
</tr>
<tr>
<td>PAED-</td>
<td>child</td>
<td>pediatric oncology = study of childhood cancer</td>
</tr>
<tr>
<td>SARCO-</td>
<td>tissue</td>
<td>sarcoma = tumor of bone, muscle, or connective tissue</td>
</tr>
<tr>
<td>TOXO-</td>
<td>poison</td>
<td>toxicology = study of poisons</td>
</tr>
</tbody>
</table>
### SUFFIX | WHAT IT DESCRIBES | EXAMPLE
--- | --- | ---
-AEMIA | condition of blood | leukemia = cancer of blood cells
-ECTOMY | excision/removal | nephrectomy = excision of a kidney
-ITIS | inflammation | hepatitis = inflammation of the liver
-LOGY | study/science of | cytology = the study of cells
-OMA | tumor | retinoblastoma = tumor of the eye
-PATHY | disease | neuropathy = disease of the nervous system
-OSIS | disease/condition | necrosis = dying cells

**Resources for Patient Navigators**

- American Cancer Society’s [Guide to Treatment Types](https://www.cancer.org/treatment/treatments-and-side-effects/treatment-options/service-treatment-options.html): Consider using this resource to become familiar with the names of common drug and treatment options for cancer patients.
- National Cancer Institute’s [Dictionary of Cancer Terms](https://www.cancer.gov Dictionary of Cancer Terms): This resource has more than 7,000 terms related to cancer and medicine.
- **Quizlet**: You can study anything for free on Quizlet, including medical terminology. The flash card tool is a great way to make learning fun and engaging.
- University of Minnesota’s [WebAnatomy](https://webanatomy.org): This series of self-test questions can help you practice your knowledge of roots, prefixes, and suffixes.
MODULE 3: The Basics of Health Care

LESSON 2: Cancer Basics

Learning Objectives

- Demonstrate a basic understanding of cancer
- Demonstrate a basic understanding of cancer screening and testing to detect cancer
- Summarize basic cancer treatment options
- Identify supportive care services and options that are generally available
- Identify and use professional resources

Key Takeaways

- Cancer is the uncontrolled growth of abnormal cells that divide and invade others within a person’s body
- Different kinds of cancers include carcinomas, sarcomas, lymphomas, and leukemias
- Cancers are named based on where they start in the body
- There are many risk factors for cancer, and there are ways to reduce the risk for cancer
- Avoiding or quitting tobacco is the single most effective lifestyle decision any person can make to prevent cancer
- People with cancer may or may not experience symptoms
- Cancer can be detected or diagnosed with biopsies, blood tests, urine tests, colonoscopies or sigmoidoscopies, x-rays, ultrasounds, bone scans, CT scans, MRI, or surgery, or using several of these methods
- Screening is important in the early diagnosis of several types of cancers: cervical, breast, prostate, colorectal, and lung
- A biopsy is done to collect a sample of tissue to look at it under a microscope and see if it is cancerous
- The TNM staging system is used for most cancers which ranges cancers from Stage 0 to Stage IV
- Cancer treatment depends on the cancer type and stage and can include: surgery, radiation, chemotherapy, targeted therapy, and palliative treatment
- Complementary, alternative, and integrative approaches may be used but the patient's doctor should know to make sure there are no risks to the patient

**Defining Cancer**

Cancer is the uncontrolled growth of abnormal cells that divide and invade others within a person’s body. Everyone has trillions of cells in their body that grow and divide to make new cells and die in a controlled way. Cancer happens when cells become abnormal and start to grow out of control. This might mean that cells that are supposed to die do not die when the cells are no longer needed. Or it could mean that abnormal cells replicate too rapidly and grow into other tissues. Growing out of control and growing into other tissues make cells cancerous.

**Classifying Cancer**

Sometimes normal-looking cells multiply abnormally. This is called hyperplasia. Dysplasia occurs when cells appear abnormal. Cells that have undergone hyperplasia or dysplasia may or may not progress to cancer.

<table>
<thead>
<tr>
<th>Table 8. Difference between normal cells and tumors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NORMAL CELLS</strong></td>
</tr>
<tr>
<td>Can undergo hyperplasia or dysplasia and become cancerous</td>
</tr>
</tbody>
</table>

A tumor is an abnormal mass, or group, of cells. Tumors are benign -- or non-cancerous -- if they do not grow into other tissue. Benign tumors can still cause problems by putting pressure on other organs if they grow large, so even benign tumors may need to be removed surgically in some cases. Tumors are malignant—or cancerous— if they are...
made up of abnormal cells, invade tissue, and/or spread to other places in the body. Cancer spread is known as metastasis.

Table 9. Difference between benign and malignant tumors

<table>
<thead>
<tr>
<th>BENIGN</th>
<th>MALIGNANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Non-cancerous</td>
<td>• Cancerous</td>
</tr>
<tr>
<td>• Do not grow into other tissue</td>
<td>• Invade tissue or spread</td>
</tr>
</tbody>
</table>

There are several different kinds of cancers. Cancer is the name for a group of more than 100 diseases that can all be classified by the following categories.

Figure 2. Cancer categories

Carcinomas
- Start in the cells that cover external and internal organs or glands
- The most common type of cancer
- Common types in the United States include lung, breast, prostate, and colorectal cancer

Sarcomas
- Start in cells in the supporting tissues of the body, such as bone, cartilage, fat, connective tissue, and muscle

Lymphomas
- Start in the lymph nodes and tissues of the body’s immune system

Leukemias
- The immature blood cells that grow in the bone marrow bloodstream and tend to accumulate or gather in large numbers in the bloodstream

Cancer can start almost anywhere in the body. Scientists use a variety of names to distinguish the different types of carcinomas, sarcomas, lymphomas, and leukemias. As you learned in Lesson 1 of Module 3, many of these names use different Latin and Greek prefixes that stand for the location where cancer began. For example, the prefix “osteо” means bone, so cancer starting in bone is called an osteosarcoma. Similarly, the prefix “adeno” means gland, so cancer of gland cells is called adenocarcinoma--for example, a breast adenocarcinoma.
### Table 10. Summary of most commonly used prefixes describing cancer types

<table>
<thead>
<tr>
<th>PREFIX</th>
<th>MEANING</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADENO-</td>
<td>gland</td>
</tr>
<tr>
<td>CHONDRO-</td>
<td>cartilage</td>
</tr>
<tr>
<td>ERYTHRO-</td>
<td>red blood cell</td>
</tr>
<tr>
<td>HEMANGIO-</td>
<td>blood vessels</td>
</tr>
<tr>
<td>HEPATO-</td>
<td>liver</td>
</tr>
<tr>
<td>LIPO-</td>
<td>fat</td>
</tr>
<tr>
<td>LYMPHO-</td>
<td>lymphocyte</td>
</tr>
<tr>
<td>MELANO-</td>
<td>pigment cell</td>
</tr>
<tr>
<td>MYELO-</td>
<td>bone marrow</td>
</tr>
<tr>
<td>MYO-</td>
<td>muscle</td>
</tr>
<tr>
<td>OSTEO-</td>
<td>bone</td>
</tr>
</tbody>
</table>

Cancer may spread through the body in two ways: invasion or metastasis. In invasion, cancer cells directly invade neighboring tissues. With metastasis, the cancer cells use the lymphatic system or bloodstream to travel throughout the body to invade normal tissue located elsewhere.

**Cancer Risk Factors and Prevention**

Cancer risk factors increase a person’s risk of developing cancer. Some risk factors are controllable through environmental, dietary, or lifestyle changes. These risk factors are called modifiable risk factors. Smoking is an example of a modifiable risk factor for some cancers. However, many other risk factors, such as your genes, are not changeable or avoidable.

Factors known to increase risk of cancer include:
- Older in age
- History of cancer (family or personal)
- Tobacco use
- Viral infections, such as human papillomavirus
- Radiation exposure, including the sun’s ultraviolet radiation
- Immunosuppressive medications
- Diet high in red & processed meats
- Alcohol
- Obesity
- Exposure to certain chemicals or substances
- Diabetes (particularly type 2 diabetes)
- Estrogen
Genetic Risk Factors

There are several known genetic risk factors for cancer, and we continue to learn more about genetic risk factors. As of 2022, the following are some common risk factors that you may hear of when navigating patients and resources for more information:

- Mutations on the BRCA1 and BRCA2 genes can increase the risk of developing inherited breast, ovarian, prostate and pancreatic cancers, as well as melanoma. The National Cancer Institute has a [fact sheet on BRCA1 and BRCA2](https://www.cancer.gov/about-cancer/causes-prevention/risk/brca/factsheet).
- Lynch Syndrome, also known as hereditary non-polyposis colorectal cancer (HNPCC). Lynch Syndrome is a type of inherited cancer of the digestive tract. Cancer.net has [information about Lynch Syndrome](https://www.cancer.net/cancer-types/lynch-syndrome).
- TP53 or p53 are common gene mutations known to increase the risk of developing several different types of cancer.
- While not known to be inherited, oncogenes, including HER2 and the RAS family of genes, turn healthy cells into cancerous cells.

Genetic counseling and testing may be needed to determine family risk, non-inherited gene mutations, and/or how to tailor treatment for a specific cancer. Given frequent advancements in the field, monitor reliable sources, such as the National Cancer Institute or ASCO, for up-to-date cancer genetic risk information.

Screening and Testing to Detect Cancers

The following organizations provide comprehensive guidelines and recommendations for screening; the recommendations are not always the same across organizations and are routinely updated. Stay updated on current recommendations by frequently visiting these sites.

- **US Preventive Services Task Force (USPSTF):** The USPSTF is an independent panel of experts in primary care and prevention who systematically review the evidence and develop recommendations for clinical preventive services. [As of 2022, recommendations are available](https://www.uspreventiveservicestaskforce.org/) for bladder, breast, cervical, colorectal, lung, oral, ovarian, pancreatic, prostate, skin, testicular, and thyroid cancers. Importantly, the USPSTF has recently changed how they will assess evidence and provide recommendations to be more inclusive of all genders.
• American College of Obstetricians and Gynecologists (ACOG): ACOG offers patient information on cervical cancer screening guidelines.
• The University of California, San Francisco offers consensus-based guidelines for transgender primary care, including cancer screening guidelines for breast, cervical, prostate and ovarian cancers.

Table 11 summarizes common cancer screening tests and resources for more information. The screenings listed below were updated in the 2022 revision of this guide. Refer to the organizations listed above for the most up-to-date guidelines and recommendations. Cancer screening guidelines are routinely updated based on the most current research findings.

Table 11. Summary of common cancer screening tests and resources for more information

<table>
<thead>
<tr>
<th>CANCER TYPE</th>
<th>SCREENING TEST</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>BREAST</td>
<td>Mammogram</td>
<td>A mammogram takes an x-ray of the breast and aims to detect breast cancer in the early stages. Biennial mammograms are most beneficial for women undergoing menopause and those ages 50-74. Patients with a family history of breast cancer should discuss screening at an earlier age with their physician. If a mammogram detects a possible, abnormal tissue mass, additional tests are required to determine whether breast cancer is present.</td>
</tr>
<tr>
<td></td>
<td>Fact sheet (USPSTF)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fact sheet (ACS)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Breast cancer screening in transgender men (UCSF)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Breast cancer screening in transgender women (UCSF)</td>
<td></td>
</tr>
<tr>
<td>CERVICAL</td>
<td>HPV/Pap co-testing</td>
<td>Cervical cancer screening is recommended in individuals with a cervix between the ages of 21-65 years. Recommendations vary by age, organization guideline, and one’s health history. A conversation with a physician can help</td>
</tr>
<tr>
<td>Procedure</td>
<td>Details</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Pap test (or Pap smear)</td>
<td>A Pap test or Pap smear is used for early detection of cervical cancer. During the screening test, a doctor collects a small sample of cells from the cervix and upper vagina using a small brush or scraper. The cervical cells are then sent to a laboratory and examined under a microscope for abnormalities. If testing only by Pap smear, screening is recommended every 3 years.</td>
<td></td>
</tr>
<tr>
<td>Human Papilloma Virus (HPV) testing</td>
<td>Human Papilloma Virus (HPV) testing can find HPV before it visibly changes the cervical cells. Additional tests or procedures may be needed if the Pap test results are abnormal.</td>
<td></td>
</tr>
</tbody>
</table>

**Fact sheet (USPSTF)**

**Fact sheet (ACS)**

**Screening for cervical cancer in transgender men (UCSF)**

---

**COLORECTAL (COLON/RECTUM)**

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fecal Occult Blood Test (FOBT)</td>
<td>. . . .</td>
</tr>
<tr>
<td>Test Type</td>
<td>Description</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Fecal Immunochemical Test (FIT)</td>
<td>A test that can be done at home detects small amounts of blood in stool through the use of antibodies. A FIT test should be conducted annually, unless a previous test reveals abnormal results.</td>
</tr>
<tr>
<td>DNA Stool Test with a FIT component (sDNA-FIT)</td>
<td>A DNA stool test with a FIT component that can be done at home. sDNA-FIT should be conducted annually, unless a previous test reveals abnormal results.</td>
</tr>
<tr>
<td>Sigmoidoscopy</td>
<td>A test done by a specialist that uses a flexible tube with a light and camera to examine in the rectum and lower colon. A sigmoidoscopy should be done every five years, unless a previous test reveals abnormal results.</td>
</tr>
<tr>
<td>Colonoscopy</td>
<td>A test done by a specialist that uses a lighted instrument with a camera to examine the entire colon. A colonoscopy should be done every ten years, unless a previous test reveals abnormal results.</td>
</tr>
<tr>
<td>CT Colonography</td>
<td>A type of CT scan of the colon and rectum. A CT colonography should be done every five years, unless a previous test reveals abnormal results.</td>
</tr>
</tbody>
</table>

**LUNG**

<table>
<thead>
<tr>
<th>Test Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>LDCT or low-dose CT scan</td>
<td>Screening with low-dose computed tomography can help to detect lung cancer. Screening is recommended for adults in fairly good health between 50 to 80 years old who currently smoke or smoked within the last 15 years, and have a 20 pack-year smoking history. A 20 pack-year may mean someone who smoked 1 pack per day for 20 years OR someone who smoked 2 packs per day for 10 years. During this test, an x-</td>
</tr>
</tbody>
</table>
Prostate-Specific Antigen test (PSA) | ray machine scans the patient’s body and makes detailed pictures of the lungs using low doses of radiation.

Fact sheet (USPSTF)
Fact sheet (ACS)

Digital Rectal Exam (DRE) | Prostate-specific antigen, or PSA, is a protein produced by cells of the prostate gland. The PSA test measures the level of PSA in a man’s blood. In a DRE, the doctor puts a gloved, lubricated finger into the rectum to feel for lumps or abnormalities. Together, these tests can help doctors detect prostate cancer in men who have no symptoms of the disease.

Guidelines recommend that individuals with a prostate between the age of 50 to 69 and their physicians talk about the risk and benefits of PSA and DRE to screen for prostate cancer. African American individuals or individuals with a family history of prostate cancer should talk with their physician about getting tested for prostate cancer starting at age 45. Most transgender women retain a prostate and have a lower baseline PSA level, however, transgender women can still get prostate cancer.

Fact sheet (USPSTF)
Fact sheet (ACS)
Prostate and testicular cancer in transgender women (UCSF)

Please note that biopsy might occur if cancer is suspected based on findings from screening results.
Cancer Staging\textsuperscript{51}

**Table 12. TNM cancer staging system**

<table>
<thead>
<tr>
<th>T</th>
<th>Amount of tumor</th>
</tr>
</thead>
<tbody>
<tr>
<td>• TX: Tumor cannot be evaluated</td>
<td></td>
</tr>
<tr>
<td>• T0: No evidence of tumor</td>
<td></td>
</tr>
<tr>
<td>• Tis: Carcinoma in situ</td>
<td></td>
</tr>
<tr>
<td>• T1-T4: Size/extent of tumor</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>N</th>
<th>Lymph nodes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• NX: Lymph nodes cannot be evaluated</td>
<td></td>
</tr>
<tr>
<td>• N0: No lymph node involvement</td>
<td></td>
</tr>
<tr>
<td>• N1-N3: Degree of regional lymph node involvement</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>M</th>
<th>Metastasis (spread)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• MX: Metastasis cannot be evaluated</td>
<td></td>
</tr>
<tr>
<td>• M0: No metastasis</td>
<td></td>
</tr>
<tr>
<td>• M1: Metastasis is present</td>
<td></td>
</tr>
</tbody>
</table>

**Figure 3. Cancer staging system**

- **Stage 0**
  - Carcinoma in situ

- **Stage I, Stage II, Stage III**
  - Higher numbers mean the disease is more extensive, such as larger tumor size and/or spread

- **Stage IV**
  - Spread to distant tissues/organs

**Cancer Treatment\textsuperscript{36,78}**

Common cancer treatments include surgery, radiation, chemotherapy, targeted therapy, hormone therapy, and other treatments that may be provided alone or in combination. Treatment recommendations are based on cancer type and stage. Treatment may be used to shrink, remove or cure cancer, or to reduce symptoms or suffering (palliative treatment). This table summarizes common cancer treatment options.\textsuperscript{78}
Table 13. Summary of cancer treatments

<table>
<thead>
<tr>
<th>TREATMENT</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery</td>
<td>Physically removes a tumor through an operation.</td>
</tr>
<tr>
<td>Radiation</td>
<td>Radiation therapy is used to shrink tumors and kill cancer cells. Therapy may be provided by aiming radiation at the cancer using a machine. Some radiation therapies can be swallowed, injected, or placed in the body near the tumor (a radioactive “seed”). Side effects of radiation may include damage to normal cells, swelling, skin changes, or fatigue.</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>In chemotherapy, drugs are used to slow or stop cancer cell growth or to kill cancer cells. There are many forms of chemotherapy, including pills or liquids taken by mouth, injections, skin creams, or given through a vein or artery. Side effects of chemotherapy depend on the person, type, and amount of the drug used. Side effects may include fatigue, nausea, vomiting, hair loss, and mouth sores/pain.</td>
</tr>
<tr>
<td>Neo-adjuvant (Given before)</td>
<td>Neo-adjuvant treatment is treatment given BEFORE a patient’s main treatment with the goal of shrinking a tumor before surgery. Neo-adjuvant treatments could include chemotherapy, radiation therapy, and hormone therapy.</td>
</tr>
<tr>
<td>Adjuvant (Given after)</td>
<td>Adjuvant treatment is defined as an additional cancer treatment to lower the risk that cancer will come back, and it is given AFTER the primary treatment, usually surgery. Adjuvant therapy may also include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy, which helps the immune system fight cancer or lessen the side effects of other cancer treatments.</td>
</tr>
<tr>
<td>Targeted Therapy</td>
<td>Targeted therapy is often done in combination with chemotherapy. Using precision medicines, this therapy targets the proteins and genes involved in the cancer cells.</td>
</tr>
<tr>
<td>Immunotherapy</td>
<td>Immunotherapies boost the immune system to attach or slow the spread of cancer cells.</td>
</tr>
<tr>
<td>Hormone Therapy</td>
<td>Hormone therapy uses drugs to block the body’s natural hormones to slow or stop the growth of cancer.</td>
</tr>
</tbody>
</table>
### Palliative Medicine

Palliative medicine provides patients with relief from their symptoms. Palliative care is used throughout the cancer experience, not just at the end of life. A patient can receive palliative care at the same time as treatment.

### Complementary and Integrative Health Approaches

Complementary health approaches are defined by NIH’s National Center for Complementary Integrative Health (also known as NCCIH) as a group of diverse practices and products that are not generally considered to be part of conventional medicine. Conventional medicine is sometimes referred to as mainstream medicine or the type of medicine practiced here in the United States. NCCIH uses the term integrative health to describe incorporating complementary approaches into mainstream health care.

Complementary medicine is used together with conventional medicine. An example is the use of acupuncture for pain management while also using medications and physical therapy.

Alternative medicine is used in place of conventional medicine. An example is using traditional medicine from other cultures to treat cancer instead of chemotherapy, radiation, or surgery recommended by a medical doctor. According to NCCIH, the practice of true alternative medicine is less common.

### Treatment Guidelines

Patient navigators that do not have a clinical license should not provide opinions about patients’ clinical care. Nurse navigators may have duties that include symptom management. All navigators should be aware of existing care guidelines:

- **American Society of Clinical Oncology (ASCO) Practice Guidelines**: ASCO publishes clinical practice guidelines as a guide for doctors and outlines appropriate methods of treatment and care.

- **National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology** (NCCN Guidelines®): NCCN publishes guidelines for the treatment of cancer by site, detection, prevention, and risk reduction; supportive care, and age-related recommendations. Patient versions are also available.
Supportive Services and Options

The following are examples of supportive care services and options.

Figure 4. Examples of supportive care services and options

<table>
<thead>
<tr>
<th>Psychosocial support services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rehabilitation (lymphedema, physical, occupational, and speech therapies)</td>
</tr>
<tr>
<td>Spiritual support/chaplaincy services</td>
</tr>
<tr>
<td>Hospice</td>
</tr>
</tbody>
</table>

Tips for Selecting a Complementary Health Practitioner

The NIH NCCIH offers six tips for patients looking for a complementary health practitioner.

- Ask your doctor or health care provider for the names of complementary health practitioners near you
- Learn about your potential practitioner, including their education, training, licenses, and certifications
- Check whether the practitioner and your existing health care provider are willing to work together
- Discuss your health conditions with the practitioner and whether they have training/experience working with other people with those conditions
- Look into whether your health insurance will cover the complementary health practitioner’s services
- Inform all your health care providers about the complementary practitioners, approaches, and treatments you are using
Resources for Patient Navigators

- **American Cancer Society's Cancer Information**: Information about cancer in more than ten languages.
- CDC’s **US Cancer Statistics Data Visualization Tool**: Current data on cancer risk factors and outcomes.
- **ESMO - Interactive Guidelines** webpage: Recommendations for helping patients with the best care options.
- **ICISG – Cancer Information in Other Languages**: Cancer organizations with information in more than 20 languages.
- National Cancer Institute: **What is Cancer?**: The webpage provides information about what cancer is, how it spreads, and types of cancer.
- National Cancer Institute: **Cancer Treatment**: The webpage provides links to information on cancer treatment methods, specific anticancer drugs, and drug development and approval. Research updates, cancer treatment facilities, and other topics are also covered.
- The NIH **Center for Complementary and Integrative Health**: NCCIH conducts and supports research and provides information about complementary health products and practices.
- Patient Navigator Training Collaborative’s **Preventive Healthcare 101**: In this course, you will learn about preventive health care, staying healthy, and risk factors that may cause disease. You will also learn how to encourage clients to form healthy habits and avoid habits that may be harmful. Client stories and videos with quiz questions will apply what you learn.
- US Preventive Services Task Force **Information for Health Professionals**: The tools available here can help a variety of audiences better understand what clinical preventive services are and how they can be implemented in the real world.
- WHO – **Screening Programmes: A Short Guide**: Provides international screening-specific guidance.
Resources for Patients

- American Cancer Society’s Questions to Ask My Doctor About My Cancer: This resource provides a list of questions when you are told you have cancer when deciding on a treatment plan, before treatment, during treatment, and after treatment.
- National Coalition for Cancer Survivorship’s Teamwork: The Cancer Patient’s Guide To Talking With Your Doctor: This book covers tips for understanding how to talk with your doctor, background information and staging, coping with a diagnosis, treatment options, cost, and insurance issues, treatment planning, transitioning off treatment, when treatment options are limited, and living with loss.
- US Preventive Services Task Force’s Information for Consumers: On this page, you will find easy-to-understand information on the Task Force and on health topics for which the Task Force has released a recommendation. These materials include guides, fact sheets, slideshows, and videos available for view and download.
LESSON 3: Clinical Trials

**Learning Objectives**

- Describe clinical trials
- Identify the risks and benefits of clinical trials
- Discuss strategies for helping patients understand clinical trials
- Identify resources for patients on how to learn more about clinical trials

**Key Takeaways**

- The goal of a clinical trial is to find better and safer ways to prevent, screen for, diagnose, treat disease or improve patients’ quality of life
- There are four phases of clinical trials (Phase I-Phase IV)
- Few adults participate in clinical trials
- Participation in clinical trials is voluntary
- Patients can leave a clinical trial at any time
- Federal laws protect the rights of research participants
- Clinical trials are not right for everyone
- There are risks and benefits to participating in clinical trials, and patients should be made aware of both
- Patient navigators help patients understand clinical trials in general and do not provide information about specific trials and eligibility or recommendations about participating
- Patient navigators should inform patients about clinical trials and advise them to speak with their doctor about eligibility
Common patient concerns about clinical trials are related to the quality of care, new treatment not working as well as standard treatment, mistrust of medical research and being used as a “guinea pig,” and the misbelief they will receive a placebo instead of getting the “experimental treatment”

- Note: Placebos are never given to patients. If patients do not receive the treatment being researched they will be given the standard treatment, not a placebo.

Frequently Asked Questions (FAQs) About Clinical Trials84-86

WHY ARE CLINICAL TRIALS IMPORTANT?

Clinical trials advance medicine. Today’s medical treatments were once studied in clinical trials. After being found to be safe and effective, they were introduced into medical practice.

WHO ARE INVOLVED IN A CLINICAL TRIAL?

Clinical trials require a team of different people and professionals. Researchers collect, analyze, and report data. Clinicians such as doctors, nurses, and pharmacists and other health care team members are also involved.

WHAT DO CLINICAL TRIALS STUDY?

There are a variety of clinical trials that study different areas of health and disease. Clinical trials may look to prevent, find, diagnose, or treat different health conditions.

- **Prevention Trials**: Look to stop diseases from developing or from coming back; could include medicine, vitamins, vaccines, diet, exercise, or other lifestyle changes
- **Screening Trials**: Try to find the best ways to identify health conditions
- **Diagnostic Trials**: Look for better ways to diagnose health conditions through new or improved tests and procedures
- **Treatment Trials**: Test new drugs, surgeries, treatments, or combinations of treatments to improve health outcomes
- **Quality of Life Trials**: Look to improve comfort of patients
WHO PAYS FOR A CLINICAL TRIAL?

It depends on the study. Every study is different, so be sure to check who covers the costs of a specific clinical trial. The costs of a clinical trial could be covered by the:

- **The Sponsor of the study**: Some clinical trial costs are paid for by the sponsor, which is the group doing the study. This could be the government, a drug maker, or a medical technology company. They may pay for the treatment, special tests, or extra doctor visits.

- **The Insurance company**: Some clinical trial costs may be covered by the patient’s insurance company. These include routine care costs for care patients would receive whether or not they were on a clinical trial.

- **Medicare**: Medicare will pay for routine care costs for many clinical trials, including all trials funded by the National Institutes of Health, the Centers for Disease Control and Prevention, and the Veterans Affairs Medical system. Routine care costs are costs of care patients would receive whether or not they are on a clinical trial.

- **The Patient**: Patients may need to pay some costs not covered by the sponsor or the insurance company, but the Affordable Care Act now requires commercial health insurance plans and the Federal Employee Health Benefits Plan to cover routine care costs for many clinical trials.

CAN A PATIENT GET PAID TO BE IN A CLINICAL TRIAL?

Sometimes. Paying patients to be in a study might be unethical. It depends on what is being studied. Some clinical trials pay small amounts of money for costs related to the clinical trial, such as travel or daycare expenses. Increasingly, funders are appreciating that compensating for time of patients may be important as long as it is not coercive or sways a patient to participate in a trial they otherwise would not participate in.

DO PATIENTS IN A CLINICAL TRIAL STILL SEE THEIR OWN DOCTOR?

Generally, the answer is yes. The patient’s primary care doctor or specialist will likely follow their care closely. Patients will have regular appointments with their doctor to see how the new treatment is working and to make sure that it does not conflict with other medicines or treatments.
CAN A PATIENT LEAVE A CLINICAL TRIAL AFTER IT STARTS?

Yes. A patient can leave a clinical trial at any time. If a patient decides to leave a clinical trial, it is important that they talk to their doctor first. The doctor needs to know so they can:

- Make sure there are no harmful effects of stopping treatment
- Help the patient choose a different treatment
- Let researchers know about any problems with the treatment
- Monitor the patient’s treatment (some medications have harmful effects if a patient suddenly stops taking them)

CAN SOME PATIENTS GET A PLACEBO OR “SUGAR PILL” INSTEAD OF REAL TREATMENT?

No. If patients do not receive the experimental treatment they will still receive the best standard of care treatment.

Experimental treatments are always testing what researchers think will be an improvement to the standard of care.

IF A PATIENT CHOOSES NOT TO PARTICIPATE IN A CLINICAL TRIAL, WILL HE OR SHE BE TREATED DIFFERENTLY?

No. It is entirely the patient’s choice to participate in a trial or not. The patient should not be treated any differently by his or her health care providers.

Key facts about clinical trial participation:

- Participation is voluntary
- The patient may stop participation in the trial at any time
- Research participant rights are protected by federal laws
- Clinical trials are not right for every patient
- Patient navigators should inform patients about clinical trials and advise them to speak with their doctor about eligibility
WHICH PATIENTS CAN JOIN A CLINICAL TRIAL?

Every clinical trial is different. Each clinical trial has strict requirements for which patients can participate in the trial. Trials may enroll only certain patients based on age, gender, disease, or treatment history. Eligible patients meet all the requirements for that specific clinical trial. Importantly, clinical trials also try to include a diverse set of patients.

WHY DO CLINICAL TRIALS NEED A VARIETY OF PEOPLE TO PARTICIPATE?

Researchers want to know if their treatment works on people of different ages, genders, races/ethnicities, and medical histories. Testing a treatment on only one group will only tell researchers if the treatment works in that group but does not help researchers know if it will work on others. For example, if a clinical trial includes only young, cisgender, Asian women, we can learn how well a medication works for this group. However, we still don’t know how it works in other groups, including patients of different ages, races, or genders. Therefore, it is important for trials to include a diverse group of people.

WHY IS IT IMPORTANT TO INCLUDE PATIENTS THAT ARE PLACED AT HIGHER RISK IN CLINICAL TRIALS?

Patients who may be at higher risk for poorer outcomes should be included in clinical trials to help researchers know whether the treatment under study will work in those patients. Examples of patients placed at higher risk include minoritized racial or ethnic groups, minoritized sexual and gender groups, individuals experiencing low socioeconomic conditions, older adults, those who live in rural areas, or those who have more than one disease. Historically, patients of minoritized backgrounds did not always receive full information about trials, or were studied without their consent. More recently, trials have reflected mostly White and more affluent people. This may be partly due to fear of minoritized groups based on historical abuses in research. This may also be partly due to bias in how research is conducted.

WHY ARE NAVIGATORS IMPORTANT TO UNDERSERVED PATIENTS?

Patients that are underserved may not always meet the requirements to join or stay in a clinical trial. Clinical trialists often require health insurance, addresses, and phone numbers from their patients. These are examples of how research can be set up for biased results from the start. Patient navigators play an important role in addressing these barriers to help patients both start and continue participating in a clinical trial.
RISKS

- New treatments are not always better or may not work as well as treatments already being used
- New treatments may have unexpected or worse side effects than current treatments
- Patients in a clinical trial may have more doctor visits, procedures, or tests
- Some costs may not be covered by health insurance or the study’s sponsor - but the Affordable Care Act requires coverage for many of these costs by many insurers, so be sure to double-check if costs can be covered

BENEFITS

- New treatments may be more effective or safer than the current treatments
- Patients in a clinical trial may be the first to benefit from new treatments before they are widely available
- Patients get high-quality care and are closely followed by doctors and other health professionals
- Patients can help others by being part of medical research

Clinical trials are required to take patient safety and protections seriously. All clinical trials go through an ethical review process before the clinical trial is approved and begins. There are laws that require certain protections and information for patients in research studies. These guidelines and laws were created to stop people from being forced into harmful research studies or not provided with important treatments or information about their illness. Ethical review aims to ensure that unfair research practices and abuses do not happen in the future.

Patient Protections

Patients are protected from unethical or abusive treatment in clinical trials by several procedures and laws. Protections include:

1. **MEDICAL ETHICS**: In the past, some research studies were unfair or abusive. As a result, government and medical groups developed three medical ethics principles that are described in what’s called the Belmont Report.
   - **RESPECT FOR PERSONS**: Participants should be treated with courtesy and respect
• **BENEFICENCE:** Researchers should seek to maximize benefits and minimize risks to participants
• **JUSTICE:** Researchers should ensure that research is fair and benefits the participants

2. **SCIENTIFIC REVIEW:** Every clinical trial is reviewed by a group called an Institutional Review Board, or IRB, before the study begins. IRB review is required by federal law for all research involving humans. The IRB is made up of researchers, doctors, and other professionals. There are strict rules about who can be a member of the IRB and how the IRB is run. The purpose of the scientific review is to protect patient safety by determining whether the study is safe, ethical, and well-designed. The IRB reviews and approves the clinical trial and performs periodic checks-in on the clinical trial. Some institutions have additional review committees that must also approve a study.

3. **STRICT RESEARCH PROTOCOLS:** Every clinical trial must follow strict rules. The researchers must spell out these rules in a research protocol, which details all the plans and activities the researchers and doctors will do as part of the study. Research protocols are reviewed by the IRB.

4. **INFORMED CONSENT:** Every patient must give “informed consent” before taking part in a clinical trial. Providing informed consent means the patient acknowledges that they were provided information about the study’s procedure, risks, and benefits, and after receiving this information, agree, or “consent,” to participate. Informed consent is required by federal law to participate in a clinical trial. Sometimes patients give verbal informed consent to participate in a study if the primary risk to the patient is disclosure of their identity. Usually, a patient gives informed consent by signing a document that states that they understand:

- The purpose of the clinical trial
- What will happen during the clinical trial
- Benefits and risks
- Patient’s rights as a member of the clinical trial and contact information for a group or individual that can respond to patient questions or reports if they feel mistreated.

Informed consent forms must be in writing, so that the patient can go back to information about the trial if they have questions later. The form should help patients understand the clinical trial, its purpose, procedures, risks, and benefits.
Informed consent forms follow strict guidance. If a patient does not speak English, an informed consent form written in their language must be provided together with an interpreter who is fluent in English and the language that a patient speaks.

**The Navigator Role in Clinical Trials**

Patient navigators play an important role in the success of clinical trials by helping the patient to understand what they are and what questions they might want to ask their doctor. It is important to understand what is and what is not the patient navigator’s role in clinical trials.

**Table 14. Summary of what is (not) patient navigator’s role in clinical trials**

<table>
<thead>
<tr>
<th>YES</th>
<th>MAYBE</th>
<th>NO</th>
</tr>
</thead>
</table>
| • Increase patient interest  
• Reduce barriers | • Explain clinical trials (yes if general information; no if clinical information or information about a specific trial) | • Encourage patients to join clinical trial  
• Decide if a patient can join a clinical trial  
• Provide details about a specific trial |

Patient navigators should keep up-to-date about the clinical trials in their own clinic, so they can connect patients to the trial coordinators, help arrange appointments, and keep patients on track with their care.

**Helping Patients Understand Clinical Trials**

**Table 15. Tips on helping patients to understand clinical trials**

**VERBAL INFORMATION**
• Take notes  
• Check understanding  
• Teach back “Tell me what you know about this trial”  
• Open-ended questions “How do you feel about joining”  
• Connect patients to clinical coordinator

**WRITTEN INFORMATION**
• Consult with a clinical coordinator for answers  
• Review written materials with patients  
• Write down medical term definitions
Some fears or concerns related to patients’ hesitancy to enroll in a clinical trial might be the following:

- Quality of care
- New treatment not working as well as standard treatment
- Mistrust of medical research and being used as a “guinea pig”
- Mistakenly believing they will receive a placebo (sugar pill) instead of “real treatment”

Possible Questions to Ask Patients Regarding Clinical Trials

- What concerns you about this clinical trial?
- How could this clinical trial be good for you?
- What do you think are the risks?
- What about this clinical trial may stop you from enrolling?
- What do you hear about clinical trials that worries you?
- What do you need to know to feel more comfortable about enrolling in this clinical trial?

How to Find Clinical Trials

The National Cancer Institute offers a 6-step guide on How to Find a Cancer Treatment Trial. It goes into detail on the following steps:

- Step 1: Gather Details about Your Cancer
- Step 2: Find Clinical Trials
- Step 3: Take a Closer Look at the Trials that Interest You
- Step 4: Contact the Team Running the Trial
- Step 5: Ask Questions
- Step 6: Make an Appointment

Other resources for finding clinical trials include:

- Searching the National Cancer Institute clinical trials database or 800-4-CANCER to speak with someone who can help.
- Searching clinical trials through the National Institutes of Health clinical trials database at Clinicaltrials.gov.
Resources for Patient Navigators

- Medicare’s [Coverage Issues Manual - Clinical Trials](#): This section of the manual reviews Medicare’s clinical trials coverage.
- Patient Navigator Training Collaborative’s [Clinical Trials and Patient Navigation](#): This course addresses the role that patient navigators play in clinical trials. Navigators help patients understand how clinical trials work, support patients as they decide whether or not to join a clinical trial, then help patients address barriers that may keep them from joining a clinical trial.
- [Systematic Review and Meta-Analysis of the Magnitude of Structural, Clinical, and Physician and Patient Barriers to Cancer Clinical Trial Participation](#): Current clinical trial participation rates.

Resources for Patients

- Cancer.net’s [Getting Treatment in a Clinical Trial](#): This webpage has information about the risks and benefits of participating, patient stories, and a video on clinical trials as a treatment option.
- Cancer.net’s [PRE-ACT](#): PRE-ACT (Preparatory Education About Clinical Trials) is an educational program designed to provide general information about clinical trials.
- [EORTC - Clinical Trials Database](#): Search portal for ongoing and future cancer clinical trials.
- National Cancer Institute’s [Clinical Trials Information for Patients and Caregivers](#): The National Cancer Institute offers a variety of information on clinical trials and enables users to find a clinical trial and clinical trials results.
- National Cancer Institute’s [Paying for Clinical Trials](#): This section of the website provides information about insurance coverage, working with insurance plans, and federal government programs related to clinical trials.
- OncoLink’s [Clinical Research Trials: The Basics](#): This webpage provides basic information about clinical trials.
- [WHO – International Clinical Trials Registry Platform](#) webpage: Search portal for clinical trials in 10 languages.
LEsson 4: Impact of Cancer

Learning Objectives

- Describe the potential physical, psychological, social, and spiritual impacts of cancer

Key Takeaways

- Cancer patients face many physical, psychological, social, and spiritual impacts from cancer and its treatment
- Adolescents and young adults, aged 15-40, face unique challenges during and after treatment
- People living with advanced cancer also face unique challenges
- Cancer can impact people even after treatment ends
- Survivorship Care Plans are tools to help cancer survivors and their providers after treatment, including a treatment summary and a plan for follow-up care
- Many patients will have end-of-life needs, which vary from patient to patient

Physical, Psychosocial, Practical, and Spiritual Impacts

Cancer impacts patients in many ways. Each patient is different and will experience treatment differently, even if given the same treatment regimen.

Table 16. Summary of various types of cancer impacts on patients

<table>
<thead>
<tr>
<th>PHYSICAL IMPACTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
</tr>
<tr>
<td>Fatigue</td>
</tr>
<tr>
<td>Anemia</td>
</tr>
<tr>
<td>Weight gain/loss</td>
</tr>
<tr>
<td>Nausea/vomiting</td>
</tr>
<tr>
<td>Self-care and mobility issues</td>
</tr>
</tbody>
</table>
• Other treatment side effects
• Life-threatening medical emergencies

**PSYCHOSOCIAL IMPACTS**
• Body image issues
• Anxiety and depression
• Changes in relationships and roles in the family
• Caregiver burden and support needs
• Stigma, fear, social isolation
• Mental health

**PRACTICAL IMPACTS**
• Financial
• Ability to work
• Food, housing, utilities
• Legal

**SPIRITUAL IMPACTS**
• Finding meaning in illness
• Changes in belief
• End-of-life

**Issues Unique to Adolescents and Young Adults (aged 15-40)**

**Figure 5. Challenges related to cancer experienced by Adolescents and Young Adults (aged 15-40)**

- Family dynamics
- Disruption to school/work/career
- Managing distress/emotions
- Isolation
- Peer groups
- Sexual relationships/dating
- Fertility

**Issues Unique to Those Living with Advanced Cancer**

According to the American Cancer Society, advanced cancer is a type of cancer that is not curable but can be controlled with treatment. The two types of advanced cancer
include locally advanced and metastatic. Locally advanced cancer refers to cancer that has grown a little bit outside of the body part, whereas metastasis means that cancer has spread to other parts of the body.

**Figure 6. Challenges related to advanced cancer**

- Psychological distress
- Emotional support
- Information
- Decision making and communication
- Relief of symptoms
- Practical concerns

**Post-Treatment Survivorship: Long-term and Late Effects**

Cancer survivors are individuals who have been diagnosed with cancer, regardless of where they are in the course of the disease. Cancer survivors are at risk for long-term and late effects. A long-term effect is something that starts during treatment and lasts even after treatment is over. For example, if a patient has lymphedema after surgery, this might continue even after they are done with all of their treatment. A late effect is something that starts after treatment. Late effects can happen months or even years after treatment.

Adolescents and young adults may have unique needs during and after treatment. They may struggle with relationships and dating, including when and how to tell people that they had cancer. Fertility and sexuality issues might continue as well as employment or school issues. For example, adolescents and young adult survivors experience challenges in job stability as they manage long-term and late effects of cancer, leading to financial hardships for younger people who lack a history of earning income.
Table 17. Summary of long-term and late effects caused by cancer treatment types

<table>
<thead>
<tr>
<th>TREATMENT</th>
<th>LONG-TERM EFFECTS</th>
<th>LATE EFFECTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy</td>
<td>Fatigue, Premature menopause, Sexual dysfunction,</td>
<td>Vision/cataracts, Infertility, Liver problems,</td>
</tr>
<tr>
<td></td>
<td>Neuropathy (tingling in hands/feet), “Chemo brain”,</td>
<td>Lung disease, Osteoporosis (bone weakness),</td>
</tr>
<tr>
<td></td>
<td>Kidney failure</td>
<td>Reduced lung capacity, Second primary cancers</td>
</tr>
<tr>
<td>Radiation</td>
<td>Fatigue, Skin sensitivity, Lymphedema</td>
<td>Cataracts, Cavities and tooth decay, Cardiovascular disease, Hypothyroidism, Infertility, Lung disease, Intestinal problems, Second primary cancers</td>
</tr>
<tr>
<td>Therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>Sexual dysfunction, Incontinence, Pain</td>
<td>Functional disability, Infertility</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Components of Survivorship Care

According to the Lost in Transition Report, survivorship care should include these four components:

- **Prevention and detection** of new cancers and recurrent cancers
- **Surveillance** for recurrence or new primary cancers
- **Interventions** for long-term and late effects
- **Coordination** between specialists and primary care providers

Survivorship Care Plans

Survivorship Care Plans are tools to help cancer survivors and their providers after active treatment.
The American Society of Clinical Oncology (ASCO) offers an example of a Survivorship Care Plan. It suggests including general information about the patient, a brief treatment summary, and a follow-up care plan. The second part of the plan suggests listing surveillance or other tests needed and indicating how often they are needed. It also includes potential long-term and late effects, possible physical, emotional and practical concerns, and recommendations for healthy behaviors to discuss with a doctor or nurse.

The following are free Survivorship Care Plan templates:

- ASCO Cancer Treatment Summaries and Survivorship Care Plans
- Journey Forward
- LIVESTRONG Your Survivorship Care Plan

To learn more about cancer survivorship care, visit the GW Cancer Center’s free Cancer Survivorship E-Learning Series.

End-of-Life Care

Learning that one has advanced cancer is frightening. Helping prepare patients for what may happen at the end-of-life can help their quality of life.

End-of-life care looks different for each patient. Some people stay at home, or some go to a hospital or other facility. Hospice programs provide comprehensive end-of-life care, and these programs can be offered in-home or at a medical facility. Many people think hospice services are only for the last days or weeks of life but they can actually be provided with as much as six months of life expectancy. Hospice care includes medical
care, counseling, and respite care to help support caregivers. Research has shown that patients and families who use hospice services report a higher quality of life than those who do not.

While all hospice care is palliative, not all palliative care is hospice. Navigators can help ensure that patients receive timely pain relief at all phases of cancer and its treatment, not just at end-of-life.

**Resources for Patient Navigators and Patients**

- American Cancer Society’s *Treatment and Side Effects*: This webpage has links to information on types of cancer treatment, clinical trials, dealing with side effects, coping with cancer, and complementary and alternative medicine.
- National Cancer Institute’s *Adolescents and Young Adults with Cancer*: This section of the website includes a variety of information related to adolescent and young adult cancers, including organizations and resources specific to this group.
- National Cancer Institute’s *Coping with Advanced Cancer: Choices for Care Near the End of Life*: This booklet is for people who have been told they have late-stage cancer or that their cancer is not responding to treatment. Family and friends may also want to read this booklet.
- Cancer.net’s *Survivorship*: This webpage has links to a variety of information about life after cancer treatment.
- GW Cancer Center Prepared Patient’s *Making Plans For Your End-Of-Life Care*: This webpage includes information on advance directives.
LEsson 5: U.S. Health Care System

Learning Objectives

- Compare hospital structures (public, non-profit, private)
- Describe how cancer care may be structured and delivered
- Compare inpatient and outpatient care delivery
- Discuss types of care and types of health care professionals involved in different types of care

Key Takeaways

- Cancer care can be delivered in hospital-based programs, academic cancer centers, community cancer centers, and private practices
- Cancer care may be delivered inpatient or outpatient, although most adult cancer care is delivered outpatient
- There are different types of care, such as primary care, specialty care, urgent care, and hospice care
- Oncology specialists include radiologists, pathologists, radiation oncologists, hematologists/oncologists, and surgeons
- Cancer care is a team effort that includes many disciplines, such as doctors, nurses, pharmacists, therapists, and patient navigators

Cancer Care Delivery

Cancer care can be delivered in the following ways:

- **Hospital-based programs**
  Some care, like surgery, can be hospital-based. Children often receive chemotherapy in a hospital, while adults more often receive chemo in an
ambulatory care setting, which may be called a cancer center. Hospitals may be public, non-profit or private.

### Table 18. Descriptions of different types of hospitals

<table>
<thead>
<tr>
<th>Public</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Funded and owned by local, state, or federal governments</td>
</tr>
<tr>
<td>• Receive money from the government</td>
</tr>
<tr>
<td>• Some are associated with medical schools</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Non profit</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Often community hospitals</td>
</tr>
<tr>
<td>• May be linked with a religious denomination</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Private</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Owned by investors, to whom they are accountable</td>
</tr>
</tbody>
</table>

- **Academic cancer center**  
  Academic cancer centers are tied to universities and focus significantly on basic and clinical care, cancer research, education, and training.

- **Community cancer center**  
  Most patients receive care at community cancer centers, which focus mostly on care delivery.

- **Private practice**  
  Patients may be treated by private oncologists, as well, who are not part of a larger cancer center and offer fewer services.

### Inpatient vs. Outpatient Care Delivery\(^{113,114}\)

A patient’s status as inpatient or outpatient affects how much an insurer covers and the patient pays for hospital services. A patient is inpatient if they must be admitted to the hospital for their procedure, regardless of whether they spend the night in the hospital. Outpatient care means that services can be provided outside of a hospital setting.

Patients may also experience different types of care settings, such as:

- **Primary care**  
  Patients should first go to primary care medical care. In primary care, the focus is on preventive services, such as physical exams or screenings, and managing general health through diagnosis and treatment. If a patient’s health condition requires special expertise, a primary care doctor will refer the patient to a specialist.
• **Specialty care**
  Specialty care can be ongoing or preventive care regarding a specific health condition that requires special expertise.

• **Emergency care**
  Emergency care diagnoses and treats life-threatening illnesses or injuries requiring immediate attention. Such care may occur in ambulances, hospital emergency rooms, or intensive care units.

• **Urgent care**
  Urgent care diagnoses and cares for illnesses or injuries that need immediate attention.

• **Long-term care**
  Long-term care provides assistance to individuals to perform daily living activities because of an injury, disability, chronic condition, or dementia. Long-term care consists of medical, nursing, and social care.

• **Hospice care**
  Hospice care aims to reduce illness symptoms toward the end of life through physical, emotional, spiritual, or social support for patients and their families. Hospice care may be provided in a patient’s home or in a hospice care facility.

• **Mental health care**
  Mental health care assists patients suffering from mental illness or an emotional crisis. Mental health treatment may include medication, psychotherapy, or a combination of both.

**Overview of Health Care Specialists**

Cancer care is a team effort. Each health care provider has a specific role. Some team members are doctors or technicians who help diagnose disease. Others are experts who treat disease or care for patients' physical and emotional needs.
Appendix B includes a list of many medical specialties that may also be involved in the care of a patient with a diagnosis of cancer.

**Overview of Oncology Specialists**

Several types of specialties exist within oncology. Although some of these may sound similar, specialists in these fields provide very different services.

- **Radiology** focuses on imaging. Doctors trained in this field are called radiologists. Radiologists provide diagnostic services for patients by taking images of the body, including the detection of cancer.
- **Pathology** focuses on diagnosis. Doctors trained in this field are called pathologists. They look at body fluids to diagnose cancer.
- **Radiation oncology** focuses on treating cancer using radiation. Doctors trained in this field are called radiation oncologists.
- **Hematology/oncology** provides chemotherapy treatment to cancer patients. Doctors who practice in this field are called oncologists or medical oncologists.
- **Surgery** is another specialty that treats cancer patients. Doctors who practice surgery are called surgeons.
### Types of Health Care Professionals involved in Cancer Care Coordination

Table 19. Summary of different types of health care professionals involved in cancer care coordination

<table>
<thead>
<tr>
<th>Type of Health Care Professional</th>
<th>Role in Caring for a Patient with Cancer</th>
</tr>
</thead>
</table>
| Doctors                          | • Primary Care Doctors  
                                     | • Specialists            |
| Advanced Practice Providers      | • Physician Assistants   
                                     | • Nurse Practitioners    
                                     | • Advanced Practice Nurse (APRN) |
| Nurses                           | • Licensed Practical Nurse (LPN)      
                                     | • Registered Nurse (RN)   |
| Mental Health Professionals      | • Psychiatrists            
                                     | • Counselors             
                                     | • Psychologists          
                                     | • Licensed Clinical Social Workers |
| Pharmacists                      | • Provides prescribed medicine |
| Technologists and Technicians    | • Laboratory Technologists   
                                     | • Radiology Technologists  
                                     | • Pharmacy Technicians   |
| Therapists and Rehabilitation Specialists | • Occupational Therapists  
                                            | • Physical Therapists   
                                            | • Respiratory Therapists 
                                            | • Speech Therapists       
                                            | • Sexual Health Therapists |
| Emotional, Social and Spiritual Support | • Mental Health Professionals  
                                          | • Clergy                   |
| Administrative and Clerical Staff | • Administrative Medical Staff  
                                         | • Medical Records Specialists  
                                         | • Medical Billing Specialists  
                                         | • Financial Counselor       
                                         | • Scheduler         |
| Volunteers                       |                                         |
Patient Navigator Roles

- Assist patients in accessing and navigating health care
- Assess barriers to care
- Engage patients in creating solutions
- Identify resources
- Educate patients about what to expect
- Invite patients to communicate
- Support patients in their adherence to care

Resources for Patient Navigators

- Patient Navigation Training Collaborative’s Introduction to the Healthcare System: In this course, you will learn about different types of health care systems, hospitals, clinics, community health agencies, and the role of other health care team members. You will also learn the basics of health insurance and important things you need to know about legal issues related to patient navigation.

Resources for Patients

- Cancer.Net The Oncology Team: Information for patients describing elements of the cancer care team.
- The Commonwealth Fund’s International Health Care System Profiles: Information about health care systems from 20 countries.
LESSON 6: U.S. Health Care Payment and Financing

Learning Objectives

- Understand how health insurance works in the U.S.
- Define key insurance terms
- Describe public and private health insurance options, including eligibility

Key Takeaways

- The financing of health care, or how it is paid for, centers around two streams of money: the collection of money for health care, or money going in, and the reimbursement of health service providers for health care, or money going out
- Common insurance terms include copay, co-insurance, deductible, and premium
- Health insurance can be public (Medicaid and Medicare, CHIP, and the VA/TRICARE) or private (through employers or through the health insurance marketplace)
- Health plans can be health maintenance organizations, preferred provider organizations, point of sale, fee for service, or high deductible
- Medicare is a federal program that covers individuals aged 65 and over and some disabled individuals
- Medicaid is a federal program that covers very poor pregnant women, children, elderly, disabled, and sometimes parents/caretaker relatives and varies by state
- The Patient Protection and Affordability Act (ACA) or Obamacare, created health insurance marketplaces, established the ten essential health benefits, increased insurance options, protected patients with pre-existing conditions, and mandated that information be easy to understand
A Dictionary of Common Insurance Terms (Alphabetical)123,135,136

- **Allowable charge**—sometimes known as the "allowed amount," "maximum allowable," and "usual, customary, and reasonable (UCR)" charge. This is the dollar amount considered by a health insurance company to be a reasonable charge for medical services or supplies based on the rates in your area.
- **Benefit**—the amount payable by the insurance company to a plan member for medical costs.
- **Benefit level**—the maximum amount that a health insurance company has agreed to pay for a covered benefit.
- **Benefit year**—the 12-month period for which health insurance benefits are calculated, not necessarily coinciding with the calendar year. Health insurance companies may update plan benefits and rates at the beginning of the benefit year.
- **Claim**—a request by a plan member, or a plan member's health care provider, for the insurance company to pay for medical services.
- **Coinsurance**—the amount you pay to share the cost of covered services after your deductible has been paid. The coinsurance rate is usually a percentage. For example, if the insurance company pays 80% of the claim, you pay 20%.
- **Coordination of benefits**—a system used in group health plans to eliminate duplication of benefits when you are covered under more than one group plan. Benefits under the two plans are usually limited to no more than 100% of the claim.
- **Copayment**—one of the ways you share in your medical costs. You pay a flat fee for certain medical expenses (e.g., $10 for every visit to the doctor), while your insurance company pays the rest.
- **Deductible**—amount patient owes before health insurance coverage begins to cost-share services.
- **Dependent**—any individual, either legal partner, spouse, or child, that is covered by the primary insured member’s plan.
- **Drug formulary**—a list of prescription medications covered by your plan.
- **Effective date**—the date on which a policyholder’s coverage begins.
- **Exclusion or limitation**—any specific situation, condition, or treatment that a health insurance plan does not cover.
- **Explanation of benefits**—the health insurance company’s written explanation of how a medical claim was paid. It contains detailed information about what the company paid and what portion of the costs you are responsible for.
• **Group health insurance**—a coverage plan offered by an employer or other organization that covers the individuals in that group and their dependents under a single policy.

• **Health maintenance organization (HMO)**—a health care financing and delivery system that provides comprehensive health care services for enrollees in a particular geographic area. HMOs require the use of specific, in-network plan providers.

• **Health savings account (HSA)**—a personal savings account that allows participants to pay for medical expenses with pre-tax dollars. HSAs are designed to complement a special type of health insurance called an HSA-qualified high-deductible health plan (HDHP). HDHPs typically offer lower monthly premiums than traditional health plans. With a HSA-qualified HDHP, members can take the money they save on premiums and invest it in the HSA to pay for future qualified medical expenses.

• **In-network provider**—a health care professional, hospital, or pharmacy that is part of a health plan’s network of preferred providers. You will generally pay less for services received from in-network providers because they have negotiated a discount for their services in exchange for the insurance company sending more patients their way.

• **Individual health insurance**—health insurance plans purchased by individuals to cover themselves and their families. Different from group plans, which are offered by employers to cover all their employees.

• **Medicaid**—a health insurance program created in 1965 that provides health benefits to low-income individuals who cannot afford Medicare or other commercial plans. Medicaid is funded by the federal and state governments, and managed by the states.

• **Medicare**—the federal health insurance program that provides health benefits to Americans aged 65 and older. Signed into law on July 30, 1965, the program was first available to beneficiaries on July 1, 1966, and later expanded to include disabled people under 65 and people with certain medical conditions. Medicare has four parts: Part A, which covers hospital services; Part B, which covers doctor services; Part C, which is Medicare Advantage (this is care managed by Health Maintenance Organizations that administer Medicare benefits to patients and is actually not part of Medicare); and Part D, which covers prescription drugs.

• **Medicare supplement plans**—plans offered by private insurance companies to help fill the “gaps” in Medicare coverage.

• **Network**—the group of doctors, hospitals, and other health care providers that insurance companies contract with to provide services at discounted rates. You
will generally pay less for services received from providers in your network.

- **Out-of-network provider**—a health care professional, hospital, or pharmacy that is not part of a health plan’s network of preferred providers. You will generally pay more for services received from out-of-network providers.

- **Out-of-pocket maximum**—the most money you will pay during a year for coverage. It includes deductibles, copayments, and coinsurance, but is in addition to your regular premiums. Beyond this amount, the insurance company will pay all expenses for the remainder of the year.

- **Payer**—the health insurance company whose plan pays to help cover the cost of your care. Also known as a carrier.

- **Pre-existing condition**—a health problem that has been diagnosed, or for which you have been treated, before buying a health insurance plan.

- **Preferred provider organization (PPO)**—a health insurance plan that offers greater freedom of choice than HMO (health maintenance organization) plans. Members of PPOs are free to receive care from both in-network or out-of-network (non-preferred) providers but will receive the highest level of benefits when they use providers inside the network.

- **Premium**—the amount you or your employer pays each month in exchange for insurance coverage.

- **Provider**—any person (i.e., doctor, nurse, dentist) or institution (i.e., hospital or clinic) that provides medical care.

- **Rider**—coverage options that enable you to expand your basic insurance plan for an additional premium. A common example is a maternity rider.

- **Underwriting**—the process by which health insurance companies determine whether to extend coverage to an applicant and/or set the policy’s premium.

- **Waiting period**—period of time that an employer makes a new employee wait before he or she becomes eligible for coverage under the company’s health plan.

**Types of Health Insurance and Eligibility**

The following table shows different types of insurance, eligibility criteria, and resources for each.
<table>
<thead>
<tr>
<th>INSURANCE TYPE</th>
<th>ELIGIBILITY</th>
<th>RESOURCES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaid</td>
<td>Covers pregnant women, children, and elderly, and disabled individuals under a certain income level</td>
<td>Medicaid.gov</td>
</tr>
<tr>
<td>Medicare</td>
<td>Covers individuals aged 65 and over and some individuals with disabilities</td>
<td>Medicare.gov</td>
</tr>
<tr>
<td>CHIP</td>
<td>Covers children whose families make too much money to qualify for Medicaid but make too little to purchase private health insurance</td>
<td>InsureKidsNow.gov</td>
</tr>
<tr>
<td>Veterans Affairs (VA)</td>
<td>Offers affordable care to veterans</td>
<td>VA.gov</td>
</tr>
<tr>
<td>Employers</td>
<td>Employers are not required to offer health benefits, but larger employers face penalties for not providing affordable coverage</td>
<td>Kaiser Family Foundation</td>
</tr>
<tr>
<td>State-based Health Insurance Marketplaces or Exchanges</td>
<td>Marketplaces run by some states</td>
<td>CMS.gov Healthcare.gov</td>
</tr>
<tr>
<td>National Health Insurance Marketplace or Exchange</td>
<td>National marketplace for residents of states that do not have a state-run exchange</td>
<td>Healthcare.gov CuidadoDeSalud.gov Other Languages</td>
</tr>
</tbody>
</table>

**Federal Poverty Guidelines (Except Alaska and Hawaii)**

Eligibility for many public health insurance programs is calculated by determining a patient’s income in relation to the federal poverty level (FPL) or a percentage of the FPL. The FPL is the same for all states except Alaska and Hawaii. As a patient navigator, you should become familiar with these poverty levels or have them readily accessible, since many programs and services are eligible for patients based on a percentage of FPL.
Since states do not all have the same eligibility levels based on FPL, it is important to find the criteria for your state. Through the Affordable Care Act, states are encouraged to expand FPL eligibility, but not all states have chosen to do this.

Visit the Federal Register website to stay up-to-date on changes each year.

A detailed list of the Federal Poverty Level Guidelines is available online through the Centers for Medicare & Medicaid Services.

**Health Plan Type Comparison**

**Table 21. Summary of different health insurance types**

<table>
<thead>
<tr>
<th>HEALTH PLAN TYPE</th>
<th>DETAILS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Maintenance Organization (HMO)</td>
<td>• Comprehensive services available</td>
</tr>
<tr>
<td></td>
<td>• Patients can only see HMO doctors and hospitals</td>
</tr>
<tr>
<td></td>
<td>• No deductible</td>
</tr>
<tr>
<td></td>
<td>• Small copay</td>
</tr>
<tr>
<td></td>
<td>• Must have a primary care provider</td>
</tr>
<tr>
<td></td>
<td>• Must get a referral for specialty care</td>
</tr>
<tr>
<td></td>
<td>• Cannot use out-of-network providers</td>
</tr>
<tr>
<td>Preferred Provider Organization (PPO)</td>
<td>• A “network” of providers agrees to charge a certain amount for care</td>
</tr>
<tr>
<td></td>
<td>• Patients can see other providers but will pay more</td>
</tr>
<tr>
<td></td>
<td>• Copay and deductible are expected</td>
</tr>
<tr>
<td></td>
<td>• Referrals are not required</td>
</tr>
<tr>
<td></td>
<td>• Some networks have more providers than others</td>
</tr>
<tr>
<td>Point of Service (POS)</td>
<td>• Patient can see providers outside of the network but will pay more</td>
</tr>
<tr>
<td></td>
<td>• Copays and deductibles are low</td>
</tr>
<tr>
<td></td>
<td>• Referral required to see a specialist</td>
</tr>
<tr>
<td>Fee for Service (FFS)</td>
<td>• Refers to reimbursing a clinician for a specific service</td>
</tr>
<tr>
<td></td>
<td>• Patient can choose any doctor or hospital</td>
</tr>
<tr>
<td></td>
<td>• Fewer services may be covered</td>
</tr>
<tr>
<td></td>
<td>• May cost more</td>
</tr>
<tr>
<td>High Deductible Health Plan</td>
<td>• Low premiums but high deductibles</td>
</tr>
<tr>
<td></td>
<td>• Patients can see any doctor or hospital</td>
</tr>
<tr>
<td></td>
<td>• Insurance pays for coverage after a deductible is met</td>
</tr>
</tbody>
</table>
The Affordable Care Act (ACA)\textsuperscript{122}

The law provides more coverage; makes coverage more affordable and accessible; and mandates that insurance information be easier to understand. The law includes many components, such as:

- Setting essential benefits that must be included in all health plans sold in the marketplaces
- Providing free screenings and other preventive care to people in new plans, Medicare, or those who are newly eligible for Medicaid
- Reducing the Medicare Part D “donut hole”
- Providing coverage for routine patient costs for clinical trials
- Removing lifetime dollar limits on coverage and benefits and limiting out of pocket and deductibles costs
- Banning health plans from charging sick people more
- Allowing children to stay on their parent’s health insurance until the age of 26
- Banning health plans from rescinding or stopping coverage when someone gets sick
- Creating national and state-based marketplaces exchanges
- Allowing states to expand Medicaid coverage
- Making health plan information more accessible

This list is not comprehensive. For more information, see the Resources for Patient Navigators section or Healthcare.gov.

One of the key components of the Affordable Care Act is the creation of Health Marketplaces or Exchanges. Every state must have Marketplace plans for those individuals who may not be covered by an employer’s plan or who prefer to get coverage on their own. The Insurance Marketplace or “exchange” is described on Healthcare.gov as a place where people without health coverage enroll in a high-quality plan online, by phone, or with a paper application.
Resources for Patient Navigators

- Patient Navigation Training Collaborative’s *Introduction to the Healthcare System*: In this course, you will learn about different types of health care systems, hospitals, clinics, community health agencies, and the role of other health care team members. You will also learn the basics of health insurance and important things you need to know about legal issues related to patient navigation.
- Healthcare.gov’s *The “Metal” Categories: Bronze, Silver, Gold & Platinum*: This webpage highlights the differences between bronze, silver, gold, platinum, and catastrophic health insurance plans.
- American Cancer Society’s *Health Insurance Laws*: This easy-to-read guide explains how the Affordable Care and other acts help cancer patients and their families.
- US Department of Health and Human Services (HHS) *About the Affordable Care Act*: The full text of the Affordable Care Act is available from HHS.
- Henry J. Kaiser Family Foundation: Offers topic pages on health reform and has a lot of information regarding the ACA and health reform in general. Facts and figures related to the ACA, as well as perspectives from a variety of individuals, are included on the site.

Resources for Patients

- Verywellhealth.com’s *HMO, PPO, EPO, POS—What’s the Difference & Which Is Best?*: Compares six ways that health plans differ.
- American Cancer Society’s *Health Insurance Laws*.
- Center for Health Guidance’s *The Health Care Law and You*: Covers health insurance and how the Affordable Care Act impacts patients.
- National Coalition for Cancer Survivorship’s *What Cancer Survivors Need to Know About Health Insurance*: Discusses several aspects of health insurance that are relevant to cancer patients along the care continuum.
- US Office of Personnel Management’s *Health Insurance Fact Sheet*: Compares different types of health plans, including features and tradeoffs.
LESSON 1: The Role of the Patient Navigator

Learning Objectives

• Describe the role of the patient navigator
• Compare and contrast roles across patient navigator types

Key Takeaways

• All navigators address barriers to care.
• Barriers to care may be practical, personal, systems-based, provider-based, or psychosocial

The Patient Navigator’s Role

Patient navigator duties vary, but their main role is to address barriers to care by helping patients identify and overcome challenges to getting medical care. The navigator can directly remove barriers for patients, but often helps the patients remove barriers themselves. General categories of patient navigator functions include:

- Professional Roles and Responsibilities
- Barriers to Care/Health Disparities
- Patient Empowerment
- Communication
- Community Resources
- Education, Prevention and Health Promotion
- Ethics and Professional Conduct
- Cultural Competency
- Outreach
- Care Coordination
- Psychosocial Support Services/Assessment
- Advocacy
Figure 9. Patient navigator role in the cancer continuum

Primary Prevention: Adoption of healthy lifestyle, disease prevention
Screening/Early Detection: Remove barriers to accessing screening
Treatment: Education, support, coordination of multi disciplinary care, resource referrals
Survivorship: Referrals for wellness/nutrition; stress management; education; survivorship care plans; support groups, retreats and other services

See Appendix C for Navigator Types and Roles and Appendix D for a sample patient navigator job description.

Possible Barriers

Table 22. Possible barriers to care

<table>
<thead>
<tr>
<th>PRACTICAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment costs</td>
</tr>
<tr>
<td>Transportation</td>
</tr>
<tr>
<td>Language barriers</td>
</tr>
<tr>
<td>Work</td>
</tr>
<tr>
<td>Food insecurity</td>
</tr>
<tr>
<td>Insurance problems</td>
</tr>
<tr>
<td>Stable housing</td>
</tr>
<tr>
<td>Immigration status</td>
</tr>
<tr>
<td>Internet access for telemedicine</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PSYCHOSOCIAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety and depression</td>
</tr>
<tr>
<td>Changes in relationships and roles in the family</td>
</tr>
<tr>
<td>Family and social support</td>
</tr>
<tr>
<td>Stigma, fear, social isolation</td>
</tr>
<tr>
<td>Mental health</td>
</tr>
</tbody>
</table>
• Biases in medical recommendations
• Poor communication with patients with low literacy
• Poor communication with limited English-proficient patients
• Cultural dissonance

• Lack of interpreters
• Long wait times
• Lack of appropriate providers
• Inconvenient appointment times

• Lack of knowledge
• Health myths
• Mistrust of providers
• Low priority placed on health

Patient Navigator Duties

Another way of thinking about patient navigation duties is to think about what actions, or “tasks” you take to help patients, and what ways you interact with others, or how you “network.”

Navigator Tasks

Table 23. Patient navigator tasks managed along the cancer continuum

<table>
<thead>
<tr>
<th>Navigating</th>
<th>Facilitating</th>
<th>Maintaining Systems</th>
<th>Documenting Activities</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Coaching</td>
<td>• Finding patients</td>
<td>• Identifying potential</td>
<td>• Charting to track navigation activities in patient’s record or through navigation software or tools</td>
<td>• Administrative duties to support research</td>
</tr>
<tr>
<td>• Explaining</td>
<td>• Coordinating team communication</td>
<td>• Building networks and</td>
<td></td>
<td>• Filing papers</td>
</tr>
<tr>
<td>• Active</td>
<td>• Integrating information through</td>
<td>referral routines</td>
<td></td>
<td>• Collaborating with nurse navigators (if applicable)</td>
</tr>
<tr>
<td>listening</td>
<td>documentation and sharing with team</td>
<td>• Reviewing cases</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Asking</td>
<td>• Collaborating</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>questions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Navigation Network Duties\textsuperscript{137}

Figure 10. List of primary navigation network duties

<table>
<thead>
<tr>
<th>Patient interactions</th>
<th>Provider interactions</th>
<th>Non-clinical staff</th>
<th>Supportive services</th>
<th>Paper or electronic medical records</th>
</tr>
</thead>
</table>

A Day in the Life of a Patient Navigator

The table below summarizes a typical day for a patient navigator who works with breast cancer patients.

Table 24. Example day for a patient navigator

<table>
<thead>
<tr>
<th>BARRIER/EVENT</th>
<th>ACTION/NEXT STEPS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Call from a patient who has surgery in 2 days. The patient would like to</td>
<td>Mail patient information on a camisole, including a prescription and a list of places to get it; ask the doctor to task anesthesiologist to call the</td>
</tr>
<tr>
<td>speak with the anesthesiologist about nerve block. The patient also needs</td>
<td>patient before the procedure.</td>
</tr>
<tr>
<td>information about bras/garments they should wear after the surgery.</td>
<td></td>
</tr>
<tr>
<td>Newly diagnosed patient (older woman, came alone).</td>
<td>Complete distress screening, assess barriers to care, help patient identify support; next step: Breast-Specific Gamma Imaging (BSGI) (refer to nurse to explain procedure).</td>
</tr>
<tr>
<td>A patient has concerns about 6-month follow-up screening plan given to them</td>
<td>Ask physician to clarify screening plan with a patient; supply patient with correct order if needed and tell her how to schedule procedure(s).</td>
</tr>
<tr>
<td>by the doctor. They are supposed to have a mammogram, but one of their</td>
<td></td>
</tr>
<tr>
<td>cancers was not visible on mammography.</td>
<td></td>
</tr>
<tr>
<td>Scenario</td>
<td>Action</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>A patient calls with questions about radiation (has not been in for a consult yet).</td>
<td>Assist patient with scheduling the appointment and give general information.</td>
</tr>
<tr>
<td>Newly diagnosed patient (mid-30s, has young children) comes in for first appointment.</td>
<td>Complete distress screening, assess barriers to care, help identify support; assist in finding oncologist close to patient’s home; give basic information about breast cancer and chemotherapy; refer to nurse to explain Mediport and tests needed before starting treatment.</td>
</tr>
<tr>
<td>A patient beginning chemo needs her doctor to speak with surgeon as soon as possible regarding recommendations. Other doctor is going on vacation tomorrow.</td>
<td>Get doctor’s direct phone number, track down surgeon, ask her to call doctor.</td>
</tr>
<tr>
<td>A patient applying for disability and Medicaid, needs referral to infectious disease, psychiatry. Needs PET/CT scans.</td>
<td>Fax Medical Examination Report form to PCP’s office; task infectious disease administrative staff to call patient with appointment time; give patient number to schedule PET/CT; follow up on psychiatry referral.</td>
</tr>
<tr>
<td>A patient is planning mastectomy surgery, would like to speak with former patient who had the same procedure.</td>
<td>Work with surgeon to identify former patient; contact former patient and ask if she would like to participate; contact current patient with former patient’s contact information.</td>
</tr>
<tr>
<td>A patient lives far away and would like a consult with radiation on the same day as her appointment with surgeon.</td>
<td>Assist patient with scheduling appointment; call patient back with information.</td>
</tr>
<tr>
<td>Referral from the medical oncologist for patient to see dietitian.</td>
<td>Call patient and set up time to meet with dietitian; add patient to dietitian’s schedule.</td>
</tr>
<tr>
<td>A patient needs appointment with physical therapist.</td>
<td>Discuss role of rehabilitation clinic; schedule patient appointments.</td>
</tr>
</tbody>
</table>
Resources for Patient Navigators

- **Academy of Oncology Nurse and Patient Navigators** (AONN+): AONN+ is the largest professional society for oncology nurse and patient navigators.

- **Association of Community Cancer Centers’ (ACCC) Patient Navigation Tools**: This section of the ACCC website offers a program pre-assessment tool, description of patient navigator responsibilities and core functions, sample job descriptions, sample program policies and standard operating procedures (SOPs), sample assessment and tracking forms, sample patient satisfaction surveys, and an outcomes measurement tool.

- **Kansas Cancer Partnership’s Cancer Patient Navigation Program Toolkit**: This guide provides a variety of patient navigator tools, including a sample patient navigator position description, sample intake forms and tracking tools, sample flyers, a sample patient satisfaction survey, and more.

- **The Boston Medical Center Patient Navigation Toolkit**: This toolkit provides tools for determining your navigation tasks, sample interview questions, patient navigator introduction tips, patient navigator protocols, and other useful tools.
LESSON 2: Patient Assessment

Learning Objectives

- Determine a patient’s barriers
- Assess patient’s strengths and ability to remove barriers
- Describe strategies to remain neutral and non-judgmental
- Determine and prioritize challenges to accessing care with a patient
- Use problem-solving strategies to develop a plan with the patient
- Assess a patient’s ability to cope with their diagnosis and treatment
- Describe and apply strategies for helping patients cope

Key Takeaways

- The 5A’s can be used to help patients: Ask, Assess, Advise, Assist, Arrange
- Building rapport with patients is critical
- A strengths-based approach can help you as you work with patients to address barriers
- Patient navigators must remain neutral and non-judgmental
- A helpful strategy to guide your communication is Elicit-Provide-Elicit
- The patient, not the patient navigator, should determine the priority of needs by helping the patient think about which barriers have the most impact
- The Problem-Solving Cycle can be used when working with patients
- Help the patient create an action plan, documenting with the patient what tasks will be done, who will do them, and the deadline
- Cancer patients have many emotional needs
• A patient navigator should NEVER provide any clinical information, such as diagnosis or prognosis, to patient or family; diagnose mental illness or counsel patients; or be the sole source of patient’s social support
• There are many ways patients may cope with stressors
• Over-refer to mental health specialists as each patient has different ways of expressing emotions, coping, and communicating

**The 5 A’s**

The 5 A’s is a model developed by the National Cancer Institute to help people quit smoking. You can use it for navigating patients, too. We have adapted it here for patient navigation.

**Figure 11. The 5 A’s model**

- **ASK** the patient questions to understand what challenges they are facing and their perceptions
- **ADDRESS** the patient’s needs, goals, and abilities
- **ARRANGE** to follow up with the patient
- **ASSIST** patients in removing barriers and implementing the plan
- **ADVISE** the patient on developing a plan

For a sample intake form, see Appendix E. I Want You to Know.
Barriers Assessment Tool: Barriers Checklist

Patients may experience a variety of barriers. Below are some examples. For a case management tool to track barriers and their solutions, see the Patient Navigation Barriers and Outcomes Tool™ (PN-BOT™). PN-BOT™ is only available for PCs. We do not currently have a version that works for Macs.

**Financial and Insurance:**
- Difficulty meeting copays
- Financial planning
- Low financial literacy
- Non-medical financial needs
- Uninsured
- Underinsured

**Cultural, spiritual, and distress:**
- Beliefs conflict with treatment
- Difficulty coping with diagnosis
- Difficulty coping with treatment
- Difficulty coping with survivorship
- End of life concerns
- Lack of support
- Negative perceptions of medical team/care
- Mental health comorbidity
- Spiritual crisis
- Stigma/discrimination
- Treatment-related depression or anxiety

**Logistical:**
- Clothing
- Dependent Care

**Care coordination:**
- Appointment making
- Home health care
- Incorrect referrals or orders
- Needs referral
- Next stage of care
- Physical comorbidity
- Rx or medical supplies

**Employment:**
- Ability to work through treatment
- Family member’s employment
- Needs job accommodations
- Stigma/discrimination
- Unemployed

**Communication:**
- Cultural barriers to communication
- Health literacy
- Language barrier
- Literacy
**Tips for Building Rapport**

Before you can help a patient with barriers, you need to build trust and rapport. Caregivers often need your help, too. Patients and caregivers sometimes underestimate the amount of help that is available to them, while helpers often underestimate how uncomfortable patients feel in asking for help. As a navigator, your role is to make sure these issues don’t stop patients from getting help from you.

- Clarify your role and how you can help
- Show interest
- Anticipate patient and caregiver feelings
- Normalize the need to ask for help
- Anticipate patient and caregiver needs
- Use non-threatening language
- Listen to what the other person is saying and use open-ended questions
- Be aware of our body language and other non-verbal signals you are sending
- Be empathetic

**Tips for Asking and Assessing**

Asking and assessing are starting points for helping patients. The navigator should not follow the same generic script and offer the same assistance to all patients because each patient is starting with different strengths, levels of knowledge, and personal gaps and barriers. To provide effective, relevant, and tailored assistance, start by assessing the patient’s knowledge, attitudes, beliefs, and readiness.

- What does the patient know already?
- What are the patient’s attitudes and beliefs?
- How ready is the patient?

Other tips include:

- Listen: patient expresses worries, fear, concern, anger
- Look: expression of doubt or anger, disinterest
- Clarify: you sound worried that you will not be able to…
- Ask: what may make it difficult to attend your appointment?
**A Strengths-Based Approach**

Identifying the strengths of a patient helps them be more effective in solving problems that come up later. Strengths can be:

- Personal, such as the ability to cope
- Within the family and social network, such as having a son who has high health literacy
- Within the patient’s community, such as a support group at the patient’s existing place of worship

**Figure 12. Example of patient’s strengths**

<table>
<thead>
<tr>
<th>Previous experience</th>
<th>Knowledge of self</th>
<th>Knowledge of condition</th>
<th>Coping skills</th>
<th>Personal strength</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Persistence</td>
<td>Self-efficacy</td>
<td>Readiness for medical care</td>
<td>Spirituality</td>
<td>Practical skills</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Questions you could ask to help you assess a patient’s strengths:**

- Tell me how you have coped with difficult situations in the past
- How has your support system (family, friends, etc.) helped you during past crises?
- Tell me about your ability to cope with difficulties?
- Who did you rely on?
- What worked, what didn’t in that situation?
- What do you do to make your symptom or situation better?
- What makes brings you purpose in your life?
- Who is important in your life?
- What is going well in your life now?
- What do you do to enjoy yourself?

**Conversation Tips**

Ambivalence means having mixed feelings about something. Some patients may be ambivalent about their illness and are uncertain about how much information they want or can handle. The navigator’s goal is to explore further and help resolve ambivalence before moving on. You can address ambivalence by:

- Exploring the pros and cons of knowing details and not knowing
• Acknowledging the difficulty of the patient’s situation
• Naming the ambivalence (“It sounds like you have some reasons you want to know and reasons you don’t. Do I have this right?”)
• Naming emotions to clarify feelings and discuss openly

It is also important to remain neutral and non-judgmental by:
• Not taking sides
• Active listening
• Not assigning value

**Figure 13. Elicit-Provide-Elicit strategy**

The Problem-Solving Cycle can help your patients solve their own issues. Please see Appendix F for Problem-Solving Cycle steps.

**Barriers and Actions**

**Table 25. List of potential barriers and actions to overcome them**

<table>
<thead>
<tr>
<th>BARRIER</th>
<th>POSSIBLE ACTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment costs</td>
<td>- Identify free drug programs based on eligibility</td>
</tr>
<tr>
<td></td>
<td>- Identify co-pay and financial assistance programs and work with patients to complete paperwork</td>
</tr>
<tr>
<td></td>
<td>- Refer to financial navigator, financial counselor, or billing specialist</td>
</tr>
</tbody>
</table>
- Create a financial tumor board and review treatment options with the multi-disciplinary team to reduce financial toxicity for patients

| Lack of transportation | - Discuss potential solutions, such as asking a friend  
- Provide sources of transportation assistance  
- Work with patient to complete paperwork for transportation assistance  
- Set up an Uber Health program at your center |

| Language barrier | - Schedule a medical interpreter to attend next appointment  
- Provide educational materials in patient’s preferred language  
- Identify providers that speak the same language as the patient |

| Insurance problem | - Identify possible sources of insurance (if uninsured or underinsured)  
- Prepare patient to call insurance company  
- Call insurance company with patient’s permission  
- Understand patient coverage  
- Assist with claim denial appeals |

| Anxiety | - Refer to social worker or other mental health professional |

| Need support | - Refer to support group or peer / buddy program  
- Refer to counseling  
- Identify patient sources of social support |

| Lack of understanding | - Assist patient with developing a list of questions  
- Provide resources/resource recommendations  
- Sit in on appointments  
- Encourage patient to bring a notetaker |
Figure 14. Different types of support that could be provided to a patient

**Emotional support needs**
- Remind patients to spend time with family and friends for pleasure-related activities
- Model and help patients practice direct communication of feelings and needs with members of their present support network
- Help the patient find new avenues of sharing and support such as: support groups, therapy or counseling, journaling or pets

**Informational support needs**
- Find out what a patient already knows about their disease or treatment and provide information or resources for the gaps
- Let patients know where they can find credible sources of information
- Remind patients to always check with their doctor or other relevant professional to confirm information they have heard or read

**Tangible support needs**
- Remind patients to speak with their supervisor and HR department if they need work accommodations, such as qualifying for accommodations through the American Disabilities Act
- For patients with small children, sharing child care with others can allow for ‘days off’ following difficult treatment
- Churches, community organizations, and senior centers can be good sources of support for things such as rides to a doctor appointment, bringing in meals, or helping with chores

**Assessing Emotional Needs**

The emotional challenges of cancer can be significant. Patients should work with trained clinicians to address these impacts.

**Table 26. What is and is not the role of a patient navigator**

<table>
<thead>
<tr>
<th>Patient Navigator’s Role</th>
<th>NOT A Patient Navigator’s Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Assess how much information a patient wishes to know about their illness</td>
<td>• Provide any clinical information, such as diagnosis or prognosis to patient or family</td>
</tr>
<tr>
<td>• Be aware of signs and symptoms of mental illness</td>
<td>• Diagnose mental illness or counsel patients</td>
</tr>
<tr>
<td>• Know when to refer to a mental health specialist</td>
<td>• Be the sole source of patient’s social support</td>
</tr>
</tbody>
</table>

The GW Cancer
There are many ways that patients cope with their stressors, depending on whether or not the stressor is controllable. Controllable stressors can be impacted by a person’s actions. Controllable stressors usually call for a problem-focused coping strategy. Strategies can also be either active or passive.

Active strategies mean a person is actually doing something, whereas passive strategies mean a person is not doing something directly to address the stressor. Uncontrollable stressors usually call for choosing healthy, emotion-focused coping strategies. If the patient recognizes that they have no control over a situation, they can begin the process of accepting the situation and finding emotional support. Note that not all emotion-focused strategies are positive for the patient’s health and wellbeing! For example, drinking and drugs, denial, and even distraction can be harmful. Navigators can help patients identify productive emotion-focused strategies. Generally, active coping is healthier than passive coping strategies.
Figure 16. Summary of controllable and uncontrollable stressors with coping strategies

<table>
<thead>
<tr>
<th>Controllable Stressors</th>
<th>Passive Problem Focused Strategies</th>
<th>Active Problem Focused Strategies</th>
<th>Uncontrollable Stressors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active Emotion Focused Strategies</td>
<td>Seek information</td>
<td>Behavioral avoidance (not doing anything about stressor)</td>
<td>Smoking, over or under eating, heavy drinking, substance abuse</td>
</tr>
<tr>
<td>Passive Emotion Focused Strategies</td>
<td>Set goals</td>
<td>Cognitive avoidance (denial, ignoring stressor)</td>
<td>Not caring for self (missing meds, doctor appointments, low hygiene)</td>
</tr>
<tr>
<td>Active</td>
<td>Make decisions</td>
<td>Reappraise the situation (reframe thoughts)</td>
<td>Keeping feelings inside</td>
</tr>
<tr>
<td></td>
<td>Resolve conflicts</td>
<td>Exercise, massage, walks, meditation, relaxation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Request help</td>
<td>Accept negative emotions</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Talk with support persons</td>
<td></td>
</tr>
</tbody>
</table>

Signs and Symptoms of Mental Illness\textsuperscript{144,145}

You need to be able to recognize the signs and symptoms of mental distress. You are NOT expected to diagnose a patient or provide counseling. If you see the signs of generalized anxiety disorder or depression in a patient, you should refer them to their clinical oncology team or an organization or program to see a mental health specialist, such as a licensed counselor, psychologist, or psychiatrist.
### Table 27. Common symptoms of depression and generalized anxiety disorder

<table>
<thead>
<tr>
<th>Generalized Anxiety Disorder</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excessive or out of control worry that hinders daily function (6+ months)</td>
<td>Severe symptoms that interfere with the ability to work, sleep, study, eat, and enjoy life</td>
</tr>
<tr>
<td>• Cannot relax</td>
<td>• Feeling:</td>
</tr>
<tr>
<td>• Startle easily</td>
<td>- Sad, anxious, or “empty”</td>
</tr>
<tr>
<td>• Poor concentration</td>
<td>- Hopeless or pessimistic</td>
</tr>
<tr>
<td>• Irritability</td>
<td>- Guilty, worthless, or helpless</td>
</tr>
<tr>
<td>• Muscle fatigue, tension, ache</td>
<td>- Irritable or restless</td>
</tr>
<tr>
<td>• Headaches</td>
<td>• Losing interest in activities or hobbies once pleasurable, including sex</td>
</tr>
<tr>
<td>• Sleep disturbances</td>
<td>• Lacking energy, fatigued</td>
</tr>
<tr>
<td>• Sweaty palms</td>
<td>• Problems with concentration, memory, and decision-making</td>
</tr>
<tr>
<td>• Dry mouth, difficulty swallowing</td>
<td>• Sleep issues (insomnia, waking early, excessive sleeping)</td>
</tr>
<tr>
<td>• Trembling, twitching</td>
<td>• Changes in appetite (overeating, loss of appetite)</td>
</tr>
<tr>
<td>• Nausea, lightheadedness</td>
<td>• Suicidal thoughts or attempts</td>
</tr>
<tr>
<td>• Shortness of breath</td>
<td>• Persistent aches, pains, headaches, cramps, or digestive problems that do not respond to treatment</td>
</tr>
<tr>
<td>• Frequent trips to the bathroom</td>
<td></td>
</tr>
<tr>
<td>• Hot flushes</td>
<td></td>
</tr>
</tbody>
</table>

### When to Refer to a Mental Health Specialist

Each patient will have a different way of expressing emotions, coping, and communicating. It is difficult to know exactly when to refer a patient to a mental health specialist, but here are some general guidelines. As a rule of thumb, it is better to over-refer than under-refer. The chart below indicates times when it is important you refer the patient to a mental health specialist.
Figure 17. Summary of symptoms indicating the need for referral

- Exhibits or reports symptoms consistent with anxiety, depression or other mental illness
- Exhibits or reports significant distress, difficulty or inability to make medical decisions or take action regarding the illness or in other areas of life, difficulty in significant relationships (family, couple, etc.)
- Displays sudden changes in behavior or acts out aggressively
- Becomes impulsive in actions or decision making
- Engages in risky or self destructive behavior, drug or alcohol abuse, risky or compulsive sexual behavior, illegal activities or abuse of others
- Expresses a desire to hurt him or herself or others

Check out Tips for Assessing Patient Support Networks in Appendix G.

Resources for Patient Navigators

- Association of Community Cancer Centers’ (ACCC) Patient Navigation Tools: This section of the ACCC website offers a program pre-assessment tool, description of patient navigator responsibilities and core functions, sample job descriptions, sample program policies, and standard operating procedures (SOPs), sample assessment and tracking forms, sample patient satisfaction surveys, and an outcomes measurement tool.
The Boston Medical Center Patient Navigation Toolkit.

**Resources for Patients**

- **CancerCare**: CancerCare provides telephone, online, and face-to-face counseling, support groups, educational workshops, publications, and financial and co-payment assistance. Professional oncology social workers offer personalized care, and all of the services are free of charge.
- **Cancer Support Community**: Cancer Support Community provides resources, information, and support for people affected by cancer. The organization has more than 30 alliances and coalitions across the country that provide in-person services.
MODULE 4: The Basics of Patient Navigation

LEsson 3: Shared Decision-Making

Learning Objectives

• Encourage active participation by the patient in decision-making and explain choices or rights to the patient in a patient-centered manner
• Assess patient desire and capacity to be involved in decision-making
• Determine patient preferences and priorities for treatment
• Identify strategies to assist patients in discussing preferences and priorities
• Support the patient in the decision-making process in alignment with the desired level of engagement
• Describe a treatment plan
• Assess barriers to patient adherence to the plan
• Develop a plan with the patient for addressing adherence challenges
• Identify self-management and health promotion resources

Key Takeaways

• Patient participation in decision-making can improve patient knowledge, adherence to treatment, outcomes, and patient satisfaction with care
• Health literacy, language, physical condition, and environment and learning style impact a patient’s capacity for decision-making responsibility
• Patient navigators should support patients in the decision-making process
• Clinicians should always be made aware of patient challenges following their treatment plan
• Patients can help self-manage their disease, and patient navigators can provide support to patients, being careful to never provide clinical information to patients
Shared Decision-Making

Shared decision-making, as defined by the United States Preventative Services Task Force, is “a process in which patients are involved as active partners with the clinician in clarifying acceptable medical options and in choosing a preferred course of clinical care.”

Certain elements must be in place to encourage patients’ active participation in care, including:

- Belief in right/responsibility to participate
- Awareness of choice
- Time with physician
- Patient knowledge
- Physician encouragement

Patient navigators can encourage patient participation in shared decision-making using the following general patient-centered strategies:

**Figure 18. General patient-centered strategies**

- Encourage the patient and build a partnership
- Set the agenda together
- Practice active listening
- Ensure the patient understands information
- Display warmth and empathy verbally and non-verbally

**Treatment Preferences and Priorities**

Patient navigators can use different approaches to help patients discuss treatment preferences and priorities, making sure patients understand and have their questions answered. The patient navigator facilitates this process rather than answering questions or making recommendations:

- Understand what patients need to make informed decisions
- Coordinate with clinicians
- Use decision aids and tailored information
- Communicate effectively
- Return to the 5A’s (Ask, Assess, Advise, Assist, Arrange)
Starting a Conversation with a Patient

Here are questions a navigator might ask to start a conversation with a patient about their preferences. These questions can help you better understand the patient’s needs and advocate on their behalf, if necessary.

- Do you have any religious beliefs? If so, how do those impact your care?
- What about spiritual beliefs?
- How do you like to learn new information? (Give examples of visual, auditory, and kinetic learning styles)
- How much information would you like to have about your particular disease or treatment?
- What is the best way to communicate with you?
- Is there anyone else you would like to be involved in your care, like a friend, family member, or religious/spiritual advisor?
- What do you do to take care of yourself? How can our team support you in taking care of yourself?

Assessing Desire for Shared Decision-Making

The most common source of patient dissatisfaction is feeling uninformed and uninvolved in care and treatment decisions. Assessing the patient’s capacity and desire to participate in their health management involves many factors. Considerations in assessing desire for shared decision-making should include:

- Culture: Patient navigators must be culturally humble when working with patients and their families. Everyone has bias. Navigators should recognize and confront their cultural biases, generalizations, and values that may differ from the patients they are working with. Navigators should take into consideration the impact that culture may have on shared decision-making. For example, some patients may not want to be involved in shared decision-making as their culture dictates that the provider is always correct. Or there may be generational differences within a family when it comes to how involved to be in decision-making.
- Personal preference: Not all patients want to engage in decision-making, while some patients want to be involved in every decision. The navigator should work with the patient to clarify his or her preferences, keeping in mind factors that could impact desire and ability to participate, as well as changes in preferences and priorities over time.
Assessing Capacity for Shared Decision-Making\textsuperscript{156-161}

Considerations in assessing capacity for shared decision-making should include:

\textbf{Figure 19. Capacity for decision-making responsibility model}

![Diagram of Capacity for Decision Making Responsibility Model]

\textbf{Using Plain Language\textsuperscript{162,163}}

Using plain language as a strategy can be effective in addressing low health literacy. Communicating in plain language means that the individual will understand what they hear or read the first time. Here is a strategy for providing information in plain language:

- Organize the language with the most important information presented first
- Divide the messages into chunks to make complex information easier to understand
- Speak or write using simple words and provide definitions of any technical terms
- Use active voice

Low or limited literacy is not the same as limited English proficiency (LEP). Individuals with LEP may be literate in their primary language but struggle to communicate in English. In these instances, translation services are necessary.
Understanding Health Literacy

Literacy, health literacy, and limited English proficiency are related yet different concepts.

Table 28. The distinction between low literacy, low health literacy, and limited English proficiency concepts

<table>
<thead>
<tr>
<th>Low Literacy</th>
<th>Low Health Literacy</th>
<th>Limited English Proficiency</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Cannot read or write, so:</td>
<td>• Have difficulties with reading, writing, speaking or computing to solve problems, so:</td>
<td>• May be literate in their primary language but struggle to communicate in English, so:</td>
</tr>
<tr>
<td>- Set realistic objectives</td>
<td>- Spend more time making sure they understand</td>
<td>- Arrange interpreter services</td>
</tr>
<tr>
<td>- Focus on behaviors and skills</td>
<td>- Adapt your interaction style to better fit their ability, for example you could pause more often to ask the patient to tell you what they heard</td>
<td></td>
</tr>
<tr>
<td>- Present the context first, then give new information</td>
<td>- Select more appropriate resources that are tailored to their ability</td>
<td></td>
</tr>
<tr>
<td>- Break up into smaller parts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Make educational sessions interactive</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Checklists can be used to help patient navigators identify patients experiencing low or limited literacy. For a Health Literacy Checklist and Tips, see Appendix H.

Summary of Learning Styles

Patient navigators can assess their patient’s learning styles to determine the best method for sharing information. It is important to remember that learning styles are not weaknesses but just personal preferences for obtaining information. Your patient may have several learning styles, in which case presenting information in more than one format may be most effective. The Fleming and Mills VARK learning theory describes the styles of learning, Visual, Auditory, Read or Write, and Kinesthetic, as they relate to patient education.
Strategies for Patient Navigators\textsuperscript{156,160,165-167} 

Strategies that patient navigators can use to support patients:
- Provide information in a user-friendly way
- Provide verbal support of patient's ability to make decisions
- Understand patients' decisions and preferences may change
- Facilitate open dialogue between patient and physician to identify shared goals
- Provide ongoing support and encouragement
- Refer to community-based organizations and encourage patients to use them

Treatment Plans and Adherence

**Treatment Plan**: A document that describes the path of cancer care and can be given to the patient, family, or other members of the care team in order to inform everyone about the path of care and who is responsible for each portion of that care. A treatment plan includes:
Figure 21. Summary of treatment plans

| Specific tissue diagnosis and stage, including relevant biomarkers | Initial treatment plan and proposed duration | Expected common and rare toxicities during treatment and their management | Expected long-term effects of treatment |
| Who will take responsibility for specific aspects of treatment and their side effects | Psychosocial and supportive care plans | Vocational, disability, or financial concerns and their management | Advance care directives and preferences |

Barriers to Treatment Plan Adherence

Patients may have trouble following their treatment plan. For example, they may:

- Fail to fill prescriptions because they
  - Feel that the medication isn’t necessary
  - Are unable to afford the medication
  - Do not want to take the medication
  - Do not believe the medication will be effective
- Not want to change their behavior
- Want to avoid the side effects of treatment
- Have disbelief about the severity of their condition
- Feel too busy or too stressed to follow the treatment plan
- Feel incapable of changing their behavior
- Be uninvolved in treatment plan creation

Addressing Challenges to Adhering to the Treatment Plan

Regardless of the challenge, there are steps that can be taken to address barriers and help patients adhere to their treatment plan. Always make sure the doctor is aware of any adherence issues.
Figure 22. Steps for treatment plan adherence

- Agree on what the patient’s challenge is to treatment adherence
- Determine appropriate goal to overcome the challenge
- Talk to the patient about their options
- Help the patient choose the option that makes the most sense to them
- Have the patient summarize what was just discussed
- Follow up with questions
- Be nonjudgmental when following up on treatment plan adherence

Self-Management\textsuperscript{171, 172}

Encourage patients to self-manage their care.

Self-management is taking the actions necessary to live well and manage chronic conditions. Patients comfortable with self-management coordinate the various aspects of their care.

Figure 23. Example of typical self-management tasks

**Typical Self-Management Tasks**

- Tracking symptoms
- Determining what to do when symptoms cause problems
- Adopting healthy behaviors
- Taking medications as prescribed
- Scheduling doctors’ appointments and lab visits
## Self-Management Resources for Patients

### Table 29. Self-management resources and examples

<table>
<thead>
<tr>
<th>SELF-MANAGEMENT RESOURCES</th>
<th>EXAMPLES (RESOURCES, TOOLS, ORGANIZATIONS, SERVICES, PROGRAMS, MOBILE APPS)</th>
</tr>
</thead>
</table>
| **Exercise**              | - **LIVESTRONG** at the YMCA  
- American Cancer Society *Nutrition and Physical Activity During and After Cancer Treatment: Answers to Common Questions*  
- MD Anderson Cancer Center *Nutrition and Exercise for Cancer Survivors*  
- General fitness trackers/apps: SuperTracker, My Fitness Pal, Runkeeper, Fitocracy |
| **Coping**                | - Cancer Support Community  
- CancerCare  
- Cancer Hope Network |
| **Stress Management**     | - Mindfulness-Based Stress Reduction Information  
- Relaxation Techniques for Health: What You Need to Know |
| **Quitting Tobacco**      | - Smoke Free.Gov website  
- American Lung Association: *Getting Help to Quit Smoking*  
- American Cancer Society: *Guide to Quitting Smoking* (also available in Spanish) |
| **Health Care Team**      | Provide contact information for relevant health care team members for patients. For example, contact information for the medical oncologist, surgeon, radiation oncologist and what number to call for after-hours concerns. |
| **Hospital Facility/Resources** | Provide information on support groups and other resources at your facility such as chaplaincy services, pain management, physical therapy/rehabilitation, palliative care, exercise classes, and dietitian services. |
| **Community Resources**   | Provide information on local resources relevant to patients such as local chapters of national organizations (such as **Sisters Network® Inc.**, American Cancer Society, Cancer Support Community), community support groups, cooking classes, local organizations that provide free or low-cost services to cancer patients or local funds providing financial assistance. |
## Cancer Organizations

### Table 30. Cancer organizations

<table>
<thead>
<tr>
<th>RESOURCES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>National General Cancer Resources</strong></td>
</tr>
<tr>
<td>ASCO Cancer Foundation</td>
</tr>
<tr>
<td>American Cancer Society</td>
</tr>
<tr>
<td>Cancer Support Community</td>
</tr>
<tr>
<td>LIVESTRONG</td>
</tr>
<tr>
<td>National Cancer Institute</td>
</tr>
<tr>
<td>National Coalition for Cancer Survivorship</td>
</tr>
<tr>
<td><strong>Support Group Organizations by Cancer Type</strong></td>
</tr>
<tr>
<td><strong>Bladder</strong></td>
</tr>
<tr>
<td>Bladder Cancer Advocacy Network</td>
</tr>
<tr>
<td><strong>Brain</strong></td>
</tr>
<tr>
<td>American Brain Tumor Association</td>
</tr>
<tr>
<td>National Brain Tumor Society</td>
</tr>
<tr>
<td>The Brain Tumor Foundation</td>
</tr>
<tr>
<td><strong>Breast</strong></td>
</tr>
<tr>
<td>Susan G. Komen Foundation</td>
</tr>
<tr>
<td>Breastcancer.org</td>
</tr>
<tr>
<td>Avon Foundation for Women</td>
</tr>
<tr>
<td><strong>Carcinoid</strong></td>
</tr>
<tr>
<td>Neuroendocrine Tumor Research Foundation</td>
</tr>
<tr>
<td>The Carcinoid Cancer Foundation</td>
</tr>
<tr>
<td><strong>Cervical</strong></td>
</tr>
<tr>
<td>National Cervical Cancer Coalition</td>
</tr>
<tr>
<td><strong>Colorectal</strong></td>
</tr>
<tr>
<td>Fight Colorectal Cancer</td>
</tr>
<tr>
<td><strong>Gastric</strong></td>
</tr>
<tr>
<td>Gastric Cancer Foundation</td>
</tr>
<tr>
<td><strong>GIST (gastrointestinal stromal tumors)</strong></td>
</tr>
<tr>
<td>GIST Support International</td>
</tr>
<tr>
<td><strong>Head and Neck, Esophageal</strong></td>
</tr>
<tr>
<td>Head and Neck Cancer Alliance</td>
</tr>
<tr>
<td><strong>Lung</strong></td>
</tr>
<tr>
<td>Foundation for Lung Cancer</td>
</tr>
<tr>
<td>Tissue</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>American Lung Association</td>
</tr>
<tr>
<td>Leukemia and Lymphoma</td>
</tr>
<tr>
<td>Leukemia and Lymphoma Society</td>
</tr>
<tr>
<td>Liver</td>
</tr>
<tr>
<td>American Liver Foundation</td>
</tr>
<tr>
<td>Melanoma</td>
</tr>
<tr>
<td>American Melanoma Foundation</td>
</tr>
<tr>
<td>Melanoma Research Foundation</td>
</tr>
<tr>
<td>Oral</td>
</tr>
<tr>
<td>Support for People with Oral and Head and Neck</td>
</tr>
<tr>
<td>Ovarian</td>
</tr>
<tr>
<td>Ovarian Cancer Research Alliance</td>
</tr>
<tr>
<td>Rhonda’s Club</td>
</tr>
<tr>
<td>The National Ovarian Cancer Coalition</td>
</tr>
<tr>
<td>The Ovarian Cancer Institute</td>
</tr>
<tr>
<td>Pancreatic</td>
</tr>
<tr>
<td>Pancreatic Cancer Action Network</td>
</tr>
<tr>
<td>Prostate</td>
</tr>
<tr>
<td>Prostate Cancer Research Institute</td>
</tr>
<tr>
<td>Us Too Prostate Cancer</td>
</tr>
<tr>
<td>Renal</td>
</tr>
<tr>
<td>Kidney Cancer Association</td>
</tr>
<tr>
<td>Sarcoma</td>
</tr>
<tr>
<td>Sarcoma Foundation of America</td>
</tr>
<tr>
<td>Sarcoma Alliance</td>
</tr>
<tr>
<td>Testicular</td>
</tr>
<tr>
<td>Testicular Cancer Society</td>
</tr>
<tr>
<td>Thyroid</td>
</tr>
<tr>
<td>Thyroid Cancer Survivors’ Association, Inc.</td>
</tr>
<tr>
<td>Uterine, Vulvar</td>
</tr>
<tr>
<td>Foundation for Women’s Cancer</td>
</tr>
</tbody>
</table>
Resources for Patient Navigators

- **Introduction to VARK** (learning styles): This website provides information about different learning styles.
- National Comprehensive Cancer Network’s (NCCN) **Distress Thermometer and Problem List for Patients**: The NCCN Distress Thermometer and Problem List are easy tools to use to assess patient distress.
- Agency for Health Care Research and Quality’s **Health Literacy Measurement Tools**: This webpage includes tools in English and Spanish to assess health literacy.
- Centers for Disease Control and Prevention’s **Health Literacy Section**: This website provides information and tools to improve health literacy and public health. These resources are for all organizations that interact and communicate with people about health.
- Stanford School of Medicine’s **Working with Professional Interpreters**: This 18-minute video provides an overview of working with professional interpreters.

Resources for Patients

- **The VARK Questionnaire**: This questionnaire helps people figure out their learning styles.
- **Ottawa Personal Decision Guides**: These guides can help with any health-related or social decisions.
- LIVESTRONG Foundation’s **Developing Your Treatment Plan**: This website provides guidance on working with a health care provider to create a treatment plan.
- Agency for Health Care Research and Quality’s **Question Builder App**: This tool lets patients build questions to ask their health care team.
- American Cancer Society’s **Questions to Ask My Doctor About Your Cancer**.
- National Coalition for Cancer Survivorship’s **Teamwork: The Cancer Patient’s Guide To Talking With Your Doctor**.
LEsson 4: Identifying Resources

Learning Objectives

- Create a list of patient resources, which are both internal and external
- Evaluate resources for appropriateness for patient
- Acquire resources for patients as appropriate
- Indicate situations in which clinical referral is required

Key Takeaways

- Asset mapping helps you identify resources that can be helpful to your patients, such as friends, families, or other individuals in a patient’s support network
- A resource directory can help you organize information about resources and systematically capture the same information about each
- It’s important to make sure a resource is a good fit for the patient
- It’s also important to assess the credibility or resources
- Health on the Net Foundation, or HON, is an international organization that promotes and guides users to websites that provide reliable and useful information
- Try to prepare before contacting organizations, and make sure you maintain professional relationships with them
- Given resources are limited and many patients need help, patient navigators need to be good stewards of resources by prioritizing resources for the neediest patients
- Always refer to a clinician for emergencies, medical advice or consultation, and counseling
Asset Mapping

An asset is a useful thing, person, or quality. Asset mapping helps you identify resources that can be helpful to your patients. Assets can be:

- A person
- A community organization or institution
- A physical structure or place
- A service

Figure 24. Summary of resources patients need

Resources by Level

Table 31. Summary of different levels of resources

<table>
<thead>
<tr>
<th>Level</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual</td>
<td>Patient strengths and assets</td>
</tr>
<tr>
<td>Network</td>
<td>Emotional support</td>
</tr>
<tr>
<td></td>
<td>Practical support</td>
</tr>
<tr>
<td></td>
<td>Knowledge and expertise</td>
</tr>
<tr>
<td>Local community</td>
<td>Cancer organizations</td>
</tr>
<tr>
<td></td>
<td>Schools, libraries, religious organizations</td>
</tr>
<tr>
<td>State, regional, or national</td>
<td>Government agencies</td>
</tr>
<tr>
<td></td>
<td>Non-profit organizations</td>
</tr>
</tbody>
</table>

A resource directory is a collection of items that may be helpful when addressing patient needs. See Appendix I for a sample resource directory template.

Tips for Making Your Resource Directory

Figure 25. Tips for creating a resource directory

- Identify personal, network, and community assets
- Interview individuals from formal and informal organizations
- Look for resources at Local, State, and National levels
- Include resources to meet basic needs in addition to disease specific resources
- Complete the resource directory form(s)
- Compile in a notebook or enter in database and use existing resource directories
Making an Inventory of Local Organizations

You can collect resources and make an inventory of local informal organizations by examining the following:

1. Printed materials:
   - Newspapers
   - Community directories (2-1-1)
2. Contact local institutions:
   - Schools
   - Churches
   - Parks and recreation
3. Contact opinion leaders and individuals
4. FindHelp.org (formerly Aunt Bertha)

Evaluating Resources

Figure 26. Criteria for resource assessment

<table>
<thead>
<tr>
<th>Sponsorship</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The sponsor of the website and its' mission should be easily identifiable</td>
</tr>
<tr>
<td>• Determine if there is any potential bias that the organization could bring to the information provided on their site?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Currency</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The website should be up-to-date. Usually, the date of the latest update is provided at the bottom of the page</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The information on the website should be verifiable from a primary information source such as professional literature or other websites</td>
</tr>
<tr>
<td>• If information is represented as an opinion, it should be clearly stated, and the source should be identified as a qualified professional or organization</td>
</tr>
<tr>
<td>• Information should serve as a supportive tool instead of replacing the doctor-patient relationship</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Audience</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The website should state the intended audience (consumer vs health professional)</td>
</tr>
<tr>
<td>• The website design should have clear sections for the audience to use</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Privacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The privacy of personal data provided on the website should be respected, ensuring the privacy and confidentiality</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Financial Disclosure</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The website should indicate the funding sources</td>
</tr>
</tbody>
</table>
Resources that have the HON Code logo have been deemed reliable by the Health on the Net Foundation, or HON.

Health On the Net Foundation provides the [Honcode extension](#) for the Chrome browser.

Once you know a resource is credible, you need to assess whether it is a good fit for your patient. You can ask yourself the following questions:

**Figure 27. Questions for assessing if the resource is a good fit for a patient**

- Does your patient **want** the resource?
- Is your patient **eligible** to receive the resource?
- Is your patient the **intended audience** for the resource?
- Can your patient **feasibly access** the resource?

**Calling Organizations**

Once you have identified potential sources of assistance, begin accessing the resources for your patient. Before contacting an organization, it is important that you are prepared to appear professional and avoid unnecessary additional calls or follow-ups.

**Figure 28. Tips for preparing for your conversation with different organizations**

- Know what you are asking for
  - What assistance does the patient need?
  - What is the patient's time frame?
  - What information will the patient need to know?

- Know who you are calling
  - What do you know about the organization?
  - What information will the organization want to know about the patient or situation?

- Be persistent!
Once you have prepared to contact the organization, you can use the following steps:

**Figure 29. Steps for managing the conversation with different organizations**

- Introduce yourself
- Concisely state the need
- Make sure you are talking to the right person
- Elaborate on details if needed
- Ask key questions

**Maintaining Relationships with Organizations**

- Reduce the burden on their staff
- Be respectful and courteous
- Have a positive attitude
- Convey thanks and appreciation
- Maintain professionalism
- Give back and provide support
- Formalize relationships with certain organizations

**When You Cannot Find Resources**

- Be honest and explain that you have not been able to find anything else
- Offer to provide phone numbers or explain where you already looked
- The client may have additional ideas

**Tips for Stewarding Resources**

Given resources are limited and many patients need help, patient navigators need to be good stewards of resources. This means that you must prioritize resources for the neediest patients.
Figure 30. Tips for stewarding resources

Stewardship

- Prioritize resources across patients
- Do not overuse resources
- Ensure patients get most relevant and helpful resources
- Update resources

Resources for Patient Navigators

- Health On the Net Foundation (HON): HON promotes and guides the deployment of useful and reliable online health information and its appropriate and efficient use.
- 211.org: This website includes a searchable list of 211 directory services across the country.
- The Community Toolbox’s Identifying Community Assets and Resources: This section of the site includes information on asset mapping as well as free tools to help you create an asset map.
- Agency for Health Care Research and Quality’s The Patient Education Materials Assessment Tool (PEMAT) and User’s Guide: AHRQ’s PEMAT and User’s Guide outlines a systematic way to assess patient education materials and ensure they are understandable, accessible, and actionable for people with differing levels of health literacy. Using materials that score better on the PEMAT increases confidence that the target audience will be able to identify, understand, and explain the key messages and actions presented, regardless of their health literacy level.

Resources for Patients

- National Coalition for Cancer Survivorship’s Cancer Survival Toolbox.
- The Joint Commission’s Patient 101: How to Find Reliable Health Information: This guide helps people find reliable, trusted sources of health care information on the internet.
LESSON 1: Communicating with Patients

Learning Objectives

- Identify common barriers and solutions to effective communication
- Identify and use strategies to improve communication
- Describe tips to help patients improve communication
- Identify and implement conflict resolution strategies
- Describe strategies for handling difficult conversations

Key Takeaways

- In a health care setting, good communication is essential, and poor communication can have negative impacts on patient outcomes
- There are many common barriers to communication as well as effective solutions to those barriers
- Active or reflective listening, open-ended questions, affirmations, and summarizing are strategies that can improve your communication with patients
- Everyone has to deal with conflict at one point or another, so good conflict resolution skills are important
- Patient navigators may have difficult conversations with patients and should use strategies to do so respectfully and clearly

Patient-Centered Communication Framework

The National Cancer Institute’s Patient-Centered Communication Framework consists of six core functions that overlap and interact, leading to communication that can improve outcomes. Many of the skills necessary to implement the NCI patient-centered communication framework are covered in Module 4.
Figure 31. Patient-Centered Communication Framework

1. Fostering healing relationships, which includes building trust and rapport with the patient
2. Exchanging information about cancer and its treatment
3. Responding to emotions by recognizing a patient’s emotional state and asking appropriate questions to understand emotions
4. Managing uncertainty, which is particularly relevant for cancer patients who often have complex illness
5. Making decisions
6. Enabling self-management

Importance of Communication

Benefits of Good Communication:
- Builds trust between patient and navigator
- May help the patient disclose information
- May lead to more satisfied patients
- Engages the patient in decision-making about their health
- Helps patients to make informed health decisions
- Results in more realistic expectations
- Improves practice effectiveness
- Reduces the risk of errors and mishaps

Risks of Poor Communication:
- Decreases confidence and trust in medical care
- Patient deterred from revealing important information
- Patient distress
- Patient failing to seek further medical care
- Misunderstandings
- Misinterpretations of health care advice
- Patient complaints
Effective Communication

General information:
- Communication includes verbal and non-verbal messages:
  - Spoken words
  - Written words
  - Body language
  - Listening, not interrupting
- Communication is affected by the physical environment, the people involved, their culture, and individual characteristics
- Effective communication happens when a message is shared and easily understood by the patient

Common Communication Barriers and Solutions

Good communication is not always easy. Below you will find some common communication barriers as well as possible solutions to those barriers.

Figure 32. Common communication barriers and solutions

<table>
<thead>
<tr>
<th>Common Barriers</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical environment</td>
<td>Quiet, private, non-distracting location</td>
</tr>
<tr>
<td>Not listening to the patient:</td>
<td>Effective listening</td>
</tr>
<tr>
<td>- Being distracted</td>
<td>- Stop, look, listen</td>
</tr>
<tr>
<td>- Judging the patient</td>
<td>- Be empathetic</td>
</tr>
<tr>
<td>- Information overload</td>
<td>- Ask questions</td>
</tr>
<tr>
<td>- Focusing on a personal agenda</td>
<td></td>
</tr>
<tr>
<td>Misperception of patient’s meaning:</td>
<td>Improved perception</td>
</tr>
<tr>
<td>- Stereotyping and generalizing</td>
<td>- Analyze your own perceptions</td>
</tr>
<tr>
<td>- Rushing</td>
<td>- Work to improve them</td>
</tr>
<tr>
<td>- Distorted focus</td>
<td>- Focus on others</td>
</tr>
<tr>
<td>- Making assumptions</td>
<td></td>
</tr>
<tr>
<td>- Getting mixed signals</td>
<td></td>
</tr>
<tr>
<td>Poor verbal communication by navigator:</td>
<td>Improved verbal communication</td>
</tr>
<tr>
<td>- Lacking clarity</td>
<td>- Focus on the issue, not the person</td>
</tr>
<tr>
<td>- Using stereotypes and generalizations</td>
<td>- Be genuine rather than manipulative</td>
</tr>
<tr>
<td>- Jumping to conclusions</td>
<td>- Empathize rather than remain detached</td>
</tr>
<tr>
<td>- Dysfunctional responses</td>
<td>- Be flexible towards others</td>
</tr>
<tr>
<td>- Lacking confidence</td>
<td>- Value yourself and your own experiences</td>
</tr>
<tr>
<td></td>
<td>- Present yourself as an equal rather than a superior</td>
</tr>
<tr>
<td></td>
<td>- Use affirming responses</td>
</tr>
</tbody>
</table>
Strategies for Improving Communication\textsuperscript{78,153,179}

Figure 33. Summary of strategies for communication improvement

**Active/Reflective Listening**
- Appropriate eye contact early in the interaction
- Attending to verbal and non-verbal cues
- Clarifying the information provided by the patient
- Clarifying the patient’s understanding of the information provided by the doctor

**Open ended Questions**
- Cannot be answered with “yes” or “no”
- Allow for a fuller, richer discussion
- Are non judgmental
- Let the patients you work with think out loud
- Allow them to do most of the talking, using their own words

**Affirmations**
- Statements or gestures that come in the form of compliments, appreciation or understanding that validate the patient’s experiences, build rapport, reinforce exploration, and build patient confidence

**Summarizing**
- Restates the key parts of the conversation, including thoughts, concerns, plans or reflections

Other tips for conversation include:

Figure 34. Additional tips for improving communication

- Ask open ended questions
- Allow patient to answer
- Reflect back
- Wait for patient to say more
- Ask more questions
- Summarize to make sure you understood

Supporting Open Communication between Patient and Provider\textsuperscript{181}

Patient navigators can support open, honest, and meaningful interactions between patients and providers in a number of ways:

- Build a trusting relationship.
- Share information, preferences, and priorities for treatment and care with the health care team to facilitate dialogue.
- Discuss patients’ feelings and concerns about their care to determine the best course of action, referring to clinical staff when necessary.
- Be aware of factors that may have an impact on patients’ communication with the providers, such as age, race, ethnicity, socioeconomic status, language, culture, family, stage of treatment, and other lived experiences.
Communication Tips for Patients

Below are some communication tips for patients. These tips come from the National Coalition for Cancer Survivorship’s Cancer Survival Toolbox®, which is an audio program for patients and teaches people communication skills and other important skills.

Figure 35. Communication tips for patients

[Table]

- Be assertive
- Use “I” messages
- Listen actively
- Match what you say in words with what you “say” without words
- Express your feelings

Primary Strategies

To resolve conflicts, it is important to recognize the three primary strategies used to deal with conflict.

Table 32. Flight-fight-unite strategies

<table>
<thead>
<tr>
<th>Flight</th>
<th>Fight</th>
<th>Unite</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Avoiding conflict and hoping that it will go away</td>
<td>• Using authority, rights or force to attempt to prevail over others</td>
<td>• Talking with other people to develop solutions that will satisfy mutual interests, some result that they all can “live with”</td>
</tr>
</tbody>
</table>

Conflict Resolution Strategies

Everyone has to deal with conflict at one point or another. Here are some tips to resolve conflict.
### Figure 36. Conflict resolution strategies

<table>
<thead>
<tr>
<th><strong>Talk about the issues</strong></th>
<th><strong>Recognize the value of the conflict</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Avoidance does not stop the conflict. People may need to back away for a moment but the parties should discuss the conflict.</td>
<td>• Conflict is natural, and can even be a source of improved relations and a good solution. It can help set expectations, move a relationship to another level, and identify a problem.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Recognize conflict is a spiral but you can change the direction of the spiral</strong></th>
<th><strong>Emphasize common goals</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• There is a constructive and destructive direction. We match our tone of voice and our body posture to the other, which can be used productively. For example, you can lower your tone of voice to bring down the emotional level.</td>
<td>• Figure out which goals you have in common. Once you show where the goals are compatible, you no longer have conflict. You can use lead ins that will frame the problem as a joint problem: “How can we…,” “What can be done to…,” “What time frame is acceptable to…”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Check perceptions</strong></th>
<th><strong>Use competent communication techniques</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Think about the questions, “What resources do you actually have? Is anything getting in the way?”</td>
<td>• Such as actively listening, asking questions and providing feedback to check your perceptions.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Agree to disagree</strong></th>
<th><strong>Attack the problem, not the person</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Some conflict just can’t be solved or isn’t important enough to try too hard to resolve.</td>
<td>• The other person is a human being with hopes and dreams too, so you need to make sure you respect the person and focus on the problem and how it can be resolved.</td>
</tr>
</tbody>
</table>

### Breaking Bad News

In health care settings, the term “difficult conversation” often refers to telling a patient that treatment is not working. As a patient navigator, it is not your role to tell patients about the results of their treatment. However, difficult conversations may occur when working with highly emotional patients, family member confrontations, or when telling a patient disappointing information, such as denial of financial aid. The SPIKES protocol is used for breaking bad news.
Figure 37. SPIKES protocol

**SETTING up the interview**
- Privacy
- Family/Friends
- Sit
- Connect with the patient

**PERCEPTION**
What is the patient’s understanding of the situation?

**INVITATION**
Assess patient preference for information

**KNOWLEDGE**
- Give and information to the patient
- Use plain, non-technical language
- Avoid excessive bluntness
- Give information in small chunks, and check for understanding periodically

**Assess EMOTIONS with EMPATHIC Responses**
- Observe the patient's reaction
- Allow for silence
- Use empathic statements (“I know this isn't what you wanted to hear. I wish the news were better.”)

**STRATEGY and SUMMARY**
- Check for understanding
- Make an action plan

**Resources for Patient Navigators**

- National Cancer Institute's Patient-Centered Communication in Cancer Care: This book provides information for health care professionals related to communication and cancer care.
- National Cancer Institute's Communication in Cancer Care PDQ®: This webpage has information about the importance of good communication in cancer care.

**Resources for Patients**

- National Coalition for Cancer Survivorship’s Cancer Survival Toolbox.
- CancerCare’s Communicating With Your Healthcare Team: This module walks patients through how to communicate with the health care team.
LESSON 2: Patient Advocacy

Learning Objectives

• Describe the terms advocacy and self-advocacy
• Implement strategies for advocating for your patient
• Describe components of self-advocacy
• Assess patient capacity to advocate for her or himself
• Support patient empowerment to advocate for themselves
• Identify self-advocacy tools to support patient
• Identify strategies to support the patient’s ability to advocate for him or herself and communicate with the medical team
• Describe strategies for advocating for quality patient care and optimal patient systems

Key Takeaways

• Patient-provider communication should be patient-centered and allow patients to express their wants, needs, and preferences
• Patient navigators play a key role in advocating on behalf of patients and in teaching patients to self-advocate
• To support self-advocacy, patient navigators can help patients seek information, engage providers, talk to family and caregivers, organize preferences and priorities, and use resources
• Self-advocacy tools to support patients include checklists of questions for providers, checklists of items and documents to take to appointments, lists of local resources, and information packets
The National Coalition for Cancer Survivorship’s Cancer Survival Toolbox® is a free, self-learning audio program to help people develop skills to better meet and understand the challenges of cancer.

Patient navigators are uniquely positioned to identify common barriers many patients face and advocate on behalf of all patients and individual patients.

**Advocacy Overview**

Advocacy can be defined as:

- “The act of pleading for supporting or recommending”
  - Dictionary.com
- “The act or process of supporting a cause or proposal”
  - Merriam-Webster

The National Cancer Institute’s definition of a patient advocate is:

“A person who helps a patient work with others who have an effect on the patient’s health, including doctors, insurance companies, employers, case managers, and lawyers. A patient advocate helps resolve issues about health care, medical bills, and job discrimination related to a patient’s medical condition.”

Advocating, or speaking up when a problem goes unnoticed, is a key responsibility for assisting patients. Patient navigators may have to advocate for patients to their doctor, family, or spouse. Tips for advocating on behalf of patients include:

- Know your patient’s needs
  - Help the patient learn more about medical and treatment options
  - Help the patient’s family come to an agreement on decisions that need to be made for a loved one
  - Find legal assistance
- Determine when to advocate
- Balance assertiveness and aggressiveness

**Self-Advocacy Overview**

Self-advocacy has been defined as:

“An assertiveness and willingness to represent one’s own interests when managing a life-threatening disease.” - Hagan et al., 2013
Remember that self-advocates stand up for their needs. Patient navigators equip patients with the skills and confidence to do so. There are three basic elements that patients need to advocate for themselves:

**Figure 38. Basic elements of patient’s advocacy**

<table>
<thead>
<tr>
<th>Thoughts/Cognitions</th>
<th>Actions</th>
<th>Use Of Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accepting that cancer is a part of their life</td>
<td>Take command of care through assertion</td>
<td>Seek individual and group support for cancer care</td>
</tr>
<tr>
<td>Prioritization of needs and wants throughout the cancer continuum</td>
<td>See themselves as members of their health care team</td>
<td>Identify with the larger cancer community</td>
</tr>
<tr>
<td>Sense of empowerment</td>
<td>Make informed decisions about whether to adhere to or modify treatment</td>
<td>Contribute to cancer awareness, policy and advocacy, research</td>
</tr>
</tbody>
</table>

A patient’s ability to self-advocate can be influenced by:
- Personal characteristics:
  - Learned skills
  - Attainability of support

To know if the patient is capable of self-advocating, use an assessment.

**Figure 39. Questions for assessing patient’s ability to self-advocate**

- Does the patient accept cancer as part of their life? Do they feel empowered?
- Is the patient assertive and engaged in shared decision-making?
- Does the patient use available resources?
- Does the patient have personal characteristics to help them advocate?
- Does the patient have the skills needed?
- Does the patient have access to support?
Outcomes of Self-Advocacy

For patients, self-advocacy is thought to result in:

Figure 40. Outcomes for self-advocacy

- Improved self-concept
- Increased control over one’s own care
- Strengthened sense of autonomy
- Improved symptom management
- Improved adherence
- Increased satisfaction with care
- Improved quality of life
- Decreased health care use

Barriers to Self-Advocacy

Possible barriers to self-advocacy include a fragmented health care system and an overwhelming amount of information:

Table 33. Barriers to self-advocacy

<table>
<thead>
<tr>
<th>Fragmented health care system</th>
<th>Overwhelming amount of information</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Need to improve access to care</td>
<td>• Need to decide what information and resources should be used</td>
</tr>
<tr>
<td>• Need to support patient empowerment to advocate for themselves</td>
<td>• Need to know how to incorporate information into conversations with health care providers</td>
</tr>
</tbody>
</table>

Supporting Patient Empowerment

As a patient navigator, you can support patient empowerment.

Table 34. Summary of ways to support patient empowerment

<table>
<thead>
<tr>
<th>Knowledge</th>
<th>Skills</th>
<th>Attitudes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Providing information and resources</td>
<td>• Ability to self-care</td>
<td>• Encouraging assertiveness</td>
</tr>
<tr>
<td>• Discussing options</td>
<td>• Ability to cope</td>
<td></td>
</tr>
<tr>
<td>• Helping with decision-making</td>
<td>• Ability to actively communicate</td>
<td></td>
</tr>
</tbody>
</table>
Figure 41. Examples of self-advocacy tools

- Checklist of questions to ask providers
- Checklist of items and documents to take to appointments
- List of local resources
- Information packets

Strategies to Support the Patient's Ability to Advocate

To support self-advocacy, patient navigators can help patients to:
- Seek information
- Engage providers
- Talk to family and caretakers
- Organize preferences and priorities
- Use resources

Learning About the Patient

The best way to help support patient empowerment is by learning about the patient first. Each patient has different needs, priorities, and strengths.

Figure 42. Summary of how learning about a patient can support their empowerment
Helping Patients Contact Organizations

Patients share the responsibility of finding and using resources. Patients may also need to directly contact organizations. You can help patients by giving them information about the organization and process to request resources so that they feel prepared.

Helping Patients with Limited English Proficiency

When your patient’s primary language is not English, it is best to connect them with services in their preferred language.

- Find language-concordant services when possible
- Work with interpreter services if available
- If you are a bilingual navigator, provide assistance in the patient’s preferred language
- Enlist family members, friends, and neighbors to make calls in English and provide other support
- Practice asking for a person who speaks the language of the patient
- Identify agencies that the patient can visit in person

Supporting Patients

Additional strategies for patient support:

- Draw from knowledge of medical terms
- Remain empathic, encouraging, positive, and reassuring
- Focus on working with the patient
- Gently confront the patient when necessary
- Encourage the patient to speak up and ask questions and to make sure she understands all of the treatment options

Maintain Communication with the Patient

While helping patients get resources, it is important to use open and clear communication with them:

- Do not promise or guarantee anything that you cannot provide yourself
- Always keep your word and follow-through
- Be open and honest with the patient about realistic outcomes
- Keep the patient updated
**System Advocacy**

As a patient navigator, you will be in a unique role to see system issues for patients. Here are some examples of system advocacy:

- Speak up at tumor boards
- Talk with the health care team about common issues you see
- Join a committee or workgroup
- Contact local organizations
- Call state or national representatives

**Engagement Behavior Framework**

The Engagement Behavior Framework was created to describe the behaviors individuals can take to be engaged in their health care.

**Figure 43. Engagement Behavior Framework**

- Find good health care
- Communicate with health care professionals
- Organize health care
- Pay for health care
- Make good treatment decisions
- Participate in treatment
- Promote health
- Get preventive health care
- Plan for end of life
- Seek health knowledge

Learn more about the [Engagement Behavior Framework](#).
Resources for Patient Navigators

- National Coalition for Cancer Survivorship's What is Advocacy?: This section of the website reviews different types of advocacy.

Resources for Patients

- Agency for Health Care Research and Quality's Question Builder.
- Susan G. Komen's Questions to Ask Your Doctor: This resource includes many lists of questions patients can ask related to clinical trials, treatment choices, radiation therapy, lymphedema, and much more.
- American Cancer Society’s Questions to Ask My Doctor About My Cancer.
- National Coalition for Cancer Survivorship’s Self-Advocacy: A Cancer Survivor’s Handbook: This booklet helps patients advocate for themselves.
- Mayo Clinic’s Being Assertive: Reduce Stress, Communicate Better: This article talks about the need to be assertive, distinguishes between being assertive and aggressive, and provides tips for being assertive.
LESSON 3: Culturally Competent Communication

Learning Objectives

- Define cultural competency and adopt cultural humility
- Describe how personal, cultural, ethnic, and spiritual beliefs shape an individual's interpretation and experience of his or her own disease and its treatment
- Compare ways in which diverse stakeholders are similar to and different from you
- Understand your own potential unconscious biases
- Describe strategies for dealing with your own biases
- Identify and implement strategies for communicating with empathy
- Describe methods to enhance cross-cultural communication
- Describe and apply Culturally & Linguistically Appropriate Services (CLAS) standards
- Demonstrate sensitivity in one’s approach to interacting with patients and others

Key Takeaways

- As a patient navigator, you will see patients from a variety of backgrounds and cultures, so it is important to help make sure the care they receive suits their preferences and needs, which is sometimes called cultural competency
- As a culturally humble navigator, to guide your interactions you must acknowledge and understand how personal, cultural, ethnic, and spiritual beliefs, can significantly impact a person’s life and future to
- It is important to understand your biases, so you can minimize them
• You also have a responsibility to speak out when you observe bias and inequity
• Other stakeholders, such as patients and other health care professionals, have needs that may be similar or different from yours
• Communicating with empathy is essential for patient navigators
• The RESPECT Model of Cross-Cultural Communication and the LEARN Model can help you work with diverse patients
• The CLAS standards were developed by the U.S. Department of Health and Human Services Office of Minority Health and are guidelines to support culturally and linguistically appropriate health services
• Patient navigators can seek to support CLAS standards at their institutions in many ways

Cultural Competency and Bias

As a patient navigator, you will see patients from a variety of backgrounds and cultures, so it is important to be sensitive to this, not only to support the delivery of quality care but also to help make sure they get the care that best suits their preferences and needs. This sensitivity is sometimes called cultural competency.

A culturally competent health care system acknowledges and incorporates the importance of culture, assessment of cross-cultural relations, vigilance toward the dynamics that result from cultural differences, expansion of cultural knowledge and adaptation of services to meet culturally unique needs. Cultural competency is always something to be sought through humility; it is not something ever acquired.

- Betancourt et al., 2003.

Keep in mind that cultural competence is not something that you acquire or have permanently. Cultural competence happens along a continuum, starting with cultural sensitivity and knowledge of your own perceptions and biases, then growing with experience and an openness to learn and actively listen to your patients. We advocate for cultural humility, which is a lifelong learning approach.
Each person has their own experience and style, so it is important to reduce misperceptions, misinterpretations, and misjudgment. Patient navigators must be aware of how they approach interactions and minimize any biases.

Bias is “the negative evaluation of one group and its members relative to another.” --Blair et al., 2011.

- **Explicit bias** implies that a person is aware of their negative evaluation of a group.
- The actions of **implicit bias** are unintentional or unconscious.

**Linking Communication to Health Outcomes**

Provider-patient communication is linked to satisfaction, adherence, and outcomes. Cultural and linguistic barriers can negatively impact communication and trust, which then leads to worse satisfaction, adherence, and outcomes. Failing to think about social and cultural factors can lead to stereotyping, which impacts provider behavior and decision-making, and maybe even leads to biased or discriminatory treatment.

**Figure 44. The connection between communication and health outcomes**

**Stakeholder Perspectives**

Different stakeholders may have some shared and some different perspectives in terms of what they most value. Understanding these perspectives can help navigators better work with each stakeholder group.
Figure 45. Summary of what stakeholders’ value

<table>
<thead>
<tr>
<th>Patient/Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Help patient meet health care needs</td>
</tr>
<tr>
<td>• Feel heard &amp; respected</td>
</tr>
<tr>
<td>• Receive medical services and available resources</td>
</tr>
<tr>
<td>• Determine decision making role (active or passive)</td>
</tr>
<tr>
<td>• Understand expectations financial costs, time, level of engagement</td>
</tr>
<tr>
<td>• Confidentiality and privacy respected</td>
</tr>
<tr>
<td>• Access to medical services (no barriers)</td>
</tr>
<tr>
<td>• Good communication with and among service providers regarding care</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient Navigator</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Help patient access care through system</td>
</tr>
<tr>
<td>• Share responsibilities for patient care with patient and family and other care team</td>
</tr>
<tr>
<td>• Patient engagement</td>
</tr>
<tr>
<td>• Coordination among health care team so roles and responsibilities are respected and patient receives needed care</td>
</tr>
<tr>
<td>• Good communication with patient and support system</td>
</tr>
<tr>
<td>• Good communication with other members of care team</td>
</tr>
<tr>
<td>• Ability to access resources to meet patient needs</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patient and family centered, team based activity to assess and meet needs of patients</td>
</tr>
<tr>
<td>• Clinical coordination determines where to send patient, what info is important to share, how accountability and responsibility for patient is managed</td>
</tr>
<tr>
<td>• Patient adherence to treatment recommendation</td>
</tr>
<tr>
<td>• Patient ability to conduct self care management practices</td>
</tr>
<tr>
<td>• Ability to provide high quality care without barriers (i.e. insurance, financial issues)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health Systems</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Integrate personnel, info and other needed resources to carry out all patient care activities between and among participants</td>
</tr>
<tr>
<td>• Facilitation of appropriate and efficient delivery of health care services within and across systems</td>
</tr>
<tr>
<td>• Access payor sources for medical services rendered</td>
</tr>
<tr>
<td>• High level of patient satisfaction</td>
</tr>
<tr>
<td>• High quality services</td>
</tr>
<tr>
<td>• Positive reputation</td>
</tr>
<tr>
<td>• Clear roles among service delivery (no duplication of services)</td>
</tr>
</tbody>
</table>

Steps for Gaining Cultural Knowledge[^190]

Understanding a patient’s “world view” can help the professional to understand how the patient views their illness and their thoughts and actions as a result.
Figure 46. Steps for gaining cultural knowledge

Stage 1
- Unconscious incompetence (unaware of lack of knowledge)

Stage 2
- Conscious incompetence (aware that knowledge is lacking; do not know how to apply knowledge of various cultures to practice)

Stage 3
- Conscious competence (intentional learning and practicing cultural sensitivity)

Stage 4
- Unconscious competence (provide culturally competent care without thinking about it)

Assessing Your Bias\textsuperscript{78,191-196,202}

Figure 47. Summary of self-awareness assessment

<table>
<thead>
<tr>
<th>Awareness</th>
<th>• Am I aware of my personal biases and prejudices towards cultural groups different than mine?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skill</td>
<td>• Do I have the skill to perform a culturally-based needs and strengths assessment in a sensitive manner?</td>
</tr>
<tr>
<td>Knowledge</td>
<td>• Do I have knowledge of the patient’s world view? Do I have knowledge of the ways biology, culture, society, and language interrelate to impact people?</td>
</tr>
<tr>
<td>Encounters</td>
<td>• How many face-to-face encounters have I had with patients from diverse cultural backgrounds?</td>
</tr>
<tr>
<td>Desire</td>
<td>• What is my genuine desire to “want to be” culturally competent?</td>
</tr>
</tbody>
</table>

Here are some strategies for identifying your biases:

- Keep a journal
- Role-play difficult situations with colleagues
- Record and critically review your encounters with patients
- Observe how colleagues work with similar patients
**Figure 48. Summary of strategies to reduce bias**

**Stereotype replacement**
- Recognize and acknowledge that your response has its basis in a stereotype. Reflect on why that response has occurred. Then think about how to avoid future responses based on stereotypes and what would be an unbiased response.

**Counter stereotypic imaging**
- Use detail imagery of counter-stereotypes which directly contradict or disconfirm the individual or group stereotypes. These images can be abstract such as a professional or celebrity (e.g., high-level government authority), or a regular person (e.g., a personal friend).

**Individuation**
- Prevent stereotypes by learning about individual group members.

**Perspective taking**
- “Walk in the other person’s shoes.” Take on and actively consider the group member’s experiences.

**Increasing opportunities for contact**
- Seek opportunity for engagement in positive interactions between different groups of people.

**Strategies for Improved Communication**

Good communication is critical for maintaining cultural sensitivity. Empathy is an important part of communication. Think of empathy as a form of professional interaction rather than an emotional experience or personality trait. To simplify, empathy can be thought of as a set of skills or competencies. Empathy involves an ability to:

- Understand the patient’s situation, perspective, and feelings
- Communicate that understanding and check its accuracy
- Act on that understanding with the patient in a helpful way
- Be willing to be wrong

Non-verbal communication can help you with empathy.

**Figure 49. Non-verbal communication and empathy**

<table>
<thead>
<tr>
<th>E.M.P.A.T.H.Y.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eye contact</td>
</tr>
<tr>
<td>Muscle of facial expression</td>
</tr>
<tr>
<td>Posture</td>
</tr>
<tr>
<td>Affect</td>
</tr>
<tr>
<td>Tone of voice</td>
</tr>
<tr>
<td>Hearing the whole patient</td>
</tr>
<tr>
<td>Your response</td>
</tr>
</tbody>
</table>
Strategies for Cross-Cultural Communication\textsuperscript{199,200}

There are several strategies and models you can use to improve cross-cultural communication.

**Figure 50. Strategies for cross-cultural communication**

- Slow down and speak clearly
- Encourage patients
- Do not use slang, idioms, and sayings
- Avoid humor
- Avoid asking negative questions
- Consider writing down something if you are unsure that it has been made clear
- Take turns in your conversation, being sure to listen fully to responses
- Summarize and repeat what has been said
- Avoid asking two questions at once; both questions may not have been comprehended

Two models may also help you with cross-cultural communication: L.E.A.R.N. and R.E.S.P.E.C.T.

**Figure 51. L.E.A.R.N. model**

- **L** - Listen to the patient, encourage the patient to talk with you, be open and non-judgmental.
- **E** - Explain to the patient your perception of the problem.
- **A** - Acknowledge differences AND similarities in your perception and the patient’s perception.
- **R** - Recommend solutions to the problem that involve the patient.
- **N** - Negotiate the action plan that accounts for the patient’s cultural needs and preferences.
Figure 52. R.E.S.P.E.C.T. model

**Rapport**
- Attempt to connect on a personal level
- Ask questions to get the person’s point of view
- Make a conscious effort to suspend judgment
- Realize when you are making assumptions and stop

**Empathy**
- Know that it is difficult for someone to ask for help
- Ask questions to understand the patient’s reasons for behaviors or illness
- Verbalize acknowledgement and legitimize the patient's feelings

**Support**
- Identify and reduce barriers to care
- Involve family members as desired
- Reassure the patient that your role is to provide assistance

**Partnership**
- Be flexible with regard to issues of control
- Negotiate roles when necessary
- Stress that you will be working collaboratively to address medical problems

**Explanations**
- Assess and enhance comprehension and use appropriate language for linguistic preference and literacy level

**Cultural Competence (Humility)**
- Demonstrate respect for person’s culture and cultural health beliefs
- Realize that the patient’s view of you may be identified by ethnic or cultural stereotypes
- Become aware of your own biases and preconceptions
- Know your limitations in addressing issues across cultures and seek out others who can help you
- Understand your personal style and recognize when it may not be working with a given patient

**Trust**
- Take the necessary time and consciously work to establish trust
### Figure 53. The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (the National CLAS Standards)

<table>
<thead>
<tr>
<th><strong>Principal Standard</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Provide patient-centered equitable and respectful quality care, taking into account patients' different cultural backgrounds, languages, and level of health literacy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Governance, Leadership, and Workforce</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Ensure sustainability of organizational governance and leadership involved in CLAS and health equity promotion through policy, practices, and allocated resources</td>
</tr>
<tr>
<td>• Recruit, promote, and support a culturally and linguistically diverse governance, leadership, and workforce that are involved in the population care in the service area</td>
</tr>
<tr>
<td>• Provide continuous education in culturally and linguistically appropriate policies and practices for governance, leadership, and workforce</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Communication and Language Assistance</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Provide free language interpreters assistance to those patients who have limited English proficiency or require any other communication assistance</td>
</tr>
<tr>
<td>• Inform patients about available language assistance services in their preferred language in writing and verbally</td>
</tr>
<tr>
<td>• Verify the expertise of language interpreters, making sure that untrained individuals and/or minors are not involved in language assistance for patients</td>
</tr>
<tr>
<td>• Provide printed and multimedia materials that are easily understood, using the languages that are commonly used by the populations in the service area</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Engagement, Continuous Improvement, and Accountability</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Create culturally and linguistically appropriate goals, policies, and management accountability and use them throughout the organization’s planning and operations</td>
</tr>
<tr>
<td>• Continuously assess organization’s CLAS-related activities and utilize CLAS-related measures in measurement and quality improvement activities</td>
</tr>
<tr>
<td>• Collect accurate and and reliable demographic data in order to assess the impact of CLAS on health equity and outcomes</td>
</tr>
<tr>
<td>• Routinely conduct community health and needs assessments to plan and implement services, paying close attention to the cultural and linguistic diversity of populations in the service area</td>
</tr>
<tr>
<td>• Collaborate with the community to design, implement, and evaluate policies, practices, and services to ensure cultural and linguistic appropriateness</td>
</tr>
<tr>
<td>• Create culturally and linguistically appropriate standards for conflicts/complaints, grievance, and resolution</td>
</tr>
<tr>
<td>• Provide updates on organization’s progress of implementation and sustainability of CLASS to the stakeholders, constituents, and the general public</td>
</tr>
</tbody>
</table>
Figure 54. Summary of ways patient navigators could support CLAS standards

- Making others aware of CLAS Standards
- Providing effective, equitable, respectful care and services
- Being responsive to diverse cultural beliefs and practices
- Supporting provision of services in the patient’s preferred language
- Assessing and supporting health literacy
- Communicating effectively and compassionately

Resources for Patient Navigators

- Harvard’s [Implicit Bias Test](#): This questionnaire helps you find out your implicit associations about race, gender, sexual orientation, and other topics.
- **National CLAS Standards**: The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (the National CLAS Standards) are intended to advance health equity, improve quality, and help eliminate health care disparities by providing a blueprint for individuals and health and health care organizations to implement culturally and linguistically appropriate services. Adoption of these Standards will help advance better health and health care in the United States.
- **National Center for Cultural Competence (NCCC)**: The mission of the NCCC is to increase the capacity of health care and mental health care programs to design, implement, and evaluate culturally and linguistically competent service delivery systems to address growing diversity, persistent disparities and to promote health and mental health equity.
- Stanford School of Medicine’s [Working with Professional Interpreters](#): This 18-minute video provides an overview of working with professional interpreters.
MODULE 6: Professionalism

LESSON 1: Scope of Practice

Learning Objectives

- Compare the roles of different health care professionals
- Describe professional boundaries
- Identify and implement strategies for acting within professional boundaries
- Define conflicts of interest
- Identify potential conflicts of interest between personal and professional responsibilities
- Identify and apply strategies for managing conflicts of interest

Key Takeaways

- It is essential that patient navigators know what they can and cannot do
- There is no current standard of practice used by all patient navigators, but we are one step closer to standardizing the role through the Oncology Patient Navigator Core Competencies
- Acting outside of your scope of practice can have serious implications
- Boundaries are important to make sure that you stay within your scope of practice and distinguish a professional relationship from a social or personal relationship
- Dual relationships, relationships formed in settings where you are seen as a professional but want to participate as a peer, should be avoided
- Being a navigator is different from being a patient’s friend
- Conflicts of interest, instances when the needs or interests of a navigator impact the navigator’s abilities to act professionally and focus on the needs of the patient, can be avoided and managed
Roles of Different Health Care Professionals

Table 35. Scope of practice for clinical professionals

- **Physicians/Physician Assistants/Nurse Practitioners**
  - Diagnose and treat disease; manage symptoms

- **Nurses**
  - Work closely with patients to provide care; administer treatment

- **Clinical Social Workers**
  - Counsel and treat mental health needs

- **Allied Health Professionals**
  - Technologists, technicians, therapists, or rehabilitation specialists

Table 36. Scope of practice for other professionals

- **Direct Service Social Workers**
  - Coordinate services to help patients cope with emotional, physical, and financial issues

- **Community Health Workers**
  - Promote risk reduction and screening

- **Patient Advocates**
  - Support resolving medical bills, job discrimination, and health care issues

- **Case Managers**
  - Help patients achieve “optimal wellness, self-management, and functional capability”

Patient navigators play a unique role in addressing non-clinical barriers to care for patients. Although there is not yet a defined scope of practice for the profession, it is essential that patient navigators do not provide health care services or offer opinions and judgements.

Table 37. Services, opinions, and judgements that patient navigators should not provide to patients

- **Do NOT provide health care services such as:**
  - “Hands-on” patient care
  - Physical assessments, diagnoses or treatment
  - Counseling
  - Interpretation, unless you are a certified medical interpreter

- **Do NOT offer opinions or judgments about:**
  - The quality of physicians or medical care
  - Diagnosis or treatment options
  - Any aspect of health care
** Scope of Practice for Patient Navigators without a clinical license **

There is no current standard of practice used by all patient navigators, which may make maintaining professional boundaries difficult. However, we have come one step closer to standardizing the role through the [Oncology Patient Navigator Core Competencies](#).

Patient navigators may assist individual patients at a particular point in the continuum, or they may help individual patients across the continuum.

**Figure 55. Patient navigators’ roles along cancer continuum**

**Medical Liability and its Implications**

Acting outside of your scope of practice can have serious implications. These consequences depend on the issue, your institution, and state laws.

**Figure 56. Implications due to acting out of practice**
Table 38. Examples of behaviors that blur boundaries and keep patient navigators in boundaries while talking to a patient

<table>
<thead>
<tr>
<th>BEHAVIOR THAT BLURS BOUNDARIES</th>
<th>TIPS FOR STAYING IN BOUNDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing Personal Information/Self-Disclosure/ Too Much Information</td>
<td>• Use caution when talking to a patient about your personal life&lt;br&gt;• Stay outwardly focused&lt;br&gt;• Therapeutic, not social relationship</td>
</tr>
<tr>
<td>Gifts/Favors (Giving and Receiving)</td>
<td>• Check the gifts policy&lt;br&gt;• Practice saying no graciously&lt;br&gt;• Explain that you are not allowed to accept gifts, tips&lt;br&gt;• To protect yourself, report offers of unusual or large gifts to your supervisor</td>
</tr>
<tr>
<td>Over Involvement (Developing Friendships)</td>
<td>• Focus on patient needs, not personalities&lt;br&gt;• Don’t confuse patient needs with your own&lt;br&gt;• Maintain a helpful relationship, treating each patient with the same quality of care and attention, regardless of your emotional reaction to the patient&lt;br&gt;• Ask yourself if you are becoming overly involved with the patient’s personal life. If so, discuss your feelings with your supervisor&lt;br&gt;• Be self-aware</td>
</tr>
<tr>
<td>Physical Contact/Touch</td>
<td>• Sexual or romantic contact with a patient or family member is never permitted&lt;br&gt;• Touch initiated by the patient navigator is strongly discouraged&lt;br&gt;• Allow the patient to initiate touch only if you are comfortable&lt;br&gt;• Use touch only when it will serve a good purpose for the patient&lt;br&gt;• Ask your patient if he/she is comfortable with your touch&lt;br&gt;• Be aware that a patient may react differently to touch than you intend</td>
</tr>
<tr>
<td>Overall/Other Blurring Boundaries</td>
<td>Overall/Other Blurring Boundaries</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>• When using touch, be sure that it is serving the patient’s needs and not your own</td>
<td>• Focus on what the patient needs</td>
</tr>
<tr>
<td>• Discourage flirting behavior by your patient</td>
<td>• Be self-aware</td>
</tr>
<tr>
<td>• Be self-aware</td>
<td>• Be self-aware about body language and non-verbal cues</td>
</tr>
<tr>
<td></td>
<td>• Do not touch the patient</td>
</tr>
<tr>
<td></td>
<td>• Do not give advice or attempt to counsel the patient; refer to an appropriately trained team member</td>
</tr>
</tbody>
</table>

**Maintaining Boundaries with Other Professionals**

Strategies to maintain boundaries with other professionals include:

- Remain firm
- Explain that the task is outside your scope of practice and makes you uncomfortable
- Remain focused on assisting the doctor with the patient and offer to assist with a solution

**Understanding Professional Boundaries with Patients**

Boundaries distinguish a professional relationship from a personal one. Establishing clear limitations help to:

- Maintain focus on your goals & your patient’s goals for your relationship
- Ensure confidentiality
- Prevent inappropriate or dual relationships

**Being a Navigator is Different from Being a Friend**

As a representative of this profession, it is important to behave in a way that is consistent with the role as defined by the profession and your facility or agency’s application of this service. Your role is to:

- Use institutional and community resources to provide support to patients
- Give that support effectively
- Establish a relationship with patients that is temporary
Navigators are not acting as individuals, with their own set of rules to govern the helping relationship. They are expected to demonstrate appropriate boundaries for the profession and the organization that they represent.

**A Caring Relationship**

In a “caring relationship” the professional, whose emotional predisposition is that of caring, connects with the emotions of the patient; that is called empathy. The relationship is reciprocal and leads to connectivity between the patient and the navigator, helping the patient to trust in the professional.\(^{208}\)

However, there is no reciprocity in the focus of the relationship. The goal of the encounter is to address the personal needs of the patient, not the needs of the professional. The patient is appropriately focused on how the patient navigator can help them. The patient should remain self-oriented, while the professional should be other-oriented, focusing on the patient. You must actively listen to what the patient feels and needs instead of imposing personal views on the patient.

**Evaluating Your Behavior\(^{78,205}\)**

To remain within your professional boundaries, you should continuously evaluate your behavior. Before acting, remember your patients see you as a representative of your profession and organization. Navigators need to recognize when emotions or experiences cause the focus or perspective to switch. Patients trust us to keep their best interests in mind.

**Conflicts of Interest\(^{206}\)**

Conflicts of interest are instances when the needs or interests of a navigator impact the navigator’s abilities to act professionally and focus on the needs of the patient. Such instances can lead to a lapse in professional objectivity and make it harder to maintain professional judgment. Patient navigators can use various strategies to avoid and manage conflicts of interest. First and foremost, consult your supervisor and research any policies and procedures your organization may have in place. Organizations often have their own definition of conflicts of interest and specific steps employees should follow to prevent and address conflicts. If you have a conflict of interest, you can resolve it with various strategies.
Dual Relationships

Patients identify you by both your professional and nonprofessional roles. Dual relationships can occur before, during, or after the navigator-patient relationship. Examples of dual relationships include:

- Settings where you are seen as a professional but want to participate as a peer, such as a support group
- Social relationships, such as friendships or intimate relationships
- Business-related relationships
- Financial relationships

The Ethical Dilemma of Dual Relationships

Dual relationships pose an ethical dilemma to the navigator, and they may:

- Impact your patient’s progress
- Impact your ability to competently perform your duties
- Could violate your patient’s confidentiality
- Could lead to unrealistic expectations for the navigator or the patient
How to Address Dual Relationships

Figure 58. Strategies to address dual relationships

Avoid dual relationships
Seek help from a supervisor
Seek help to work through memories triggered by patients

Resources for Patient Navigators

- National Association of Social Workers’ Setting and Maintaining Professional Boundaries: Although developed for social workers, this short document provides tips for setting and maintaining professional boundaries that are applicable to patient navigators.
- Minnesota State University’s Ethics and Boundaries: This presentation provides an overview of ethical challenges and professional boundaries.
- University of Iowa Hospitals & Clinics Conflict of Interest: The Policy: This webpage is an example of a conflict of interest policy.
LEsson 2: Ethics and Patient Rights

Learning Objectives

- Define ethical standards as it relates to the health care system
- Describe a process for ethical decision-making
- Discuss how to build ethical relationships with patients
- Describe the Patient's Bill of Rights
- Identify opportunities to support patient rights
- Identify ethical principles related to compliance with laws, policies, and regulations

Key Takeaways

- Ethics is a process of navigating and negotiating values in order to act with integrity as an individual, organization, or society
- The Framework for Ethical Decision-Making can be used when you are faced with making difficult decisions
- Part of building trust and a successful career includes maintaining professional boundaries and looking out for your own well-being but as you work with patients to address barriers and find them services, the line between a professional and personal relationship can become unclear
- Anyone who works with patients or medical records needs to know about the Patient Bill of Rights and patient responsibilities, HIPAA, and informed consent
- Some health care professionals have legal obligations which often vary by state, and patient navigators need to be aware of any legal obligations that may apply to them
Overview of Ethics

Ethics is a process of navigating and negotiating values in order to act with integrity as an individual, organization, or society. Whenever we experience values that are competing or conflicting, we are involved in the work of ethics. When we are thinking about what is “ethical,” we are not simply choosing what the right thing to do is. Ethics is about working through value conflicts.

To better understand the term ethics, it is important to talk about what ethics does NOT mean.

- **Ethics does not equal emotions.** Our emotions may discourage us from doing what is right if it is hard to do.
- **Ethics does not equal religion.** Many people are not religious, but ethics is not based on religion. Ethics applies to everyone.
- **Ethics does not equal law.** The law may not uphold what is considered ethical.
- **Ethics does not equal culture.** Although an act may be considered a societal norm, it may not take into consideration ethical standards.
- **Ethics does not equal science.** Science and ethics are not the same. Science describes human behavior, but ethics provide a reason behind how people should behave.

Sources of Ethical Standards

Five sources for ethical standards can help determine how to approach complex situations. These sources are not a one-size-fits-all approach, as people disagree about what a human right or a civil right is, what “the common good” is, or what is good and harmful. Each approach does not define ethics in the same way. These approaches may often, however, lead to similar solutions to ethical dilemmas.
### Figure 59. Sources of ethical standards

<table>
<thead>
<tr>
<th><strong>Utilitarian Approach</strong></th>
<th>The Utilitarian Approach focuses on consequences. Think about which possible action provides the least amount of harm and the most good.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rights Approach</strong></td>
<td>The Rights Approach assumes that we have a duty to respect the rights of others.</td>
</tr>
<tr>
<td><strong>Fairness or Justice Approach</strong></td>
<td>The Fairness or Justice Approach focuses on treating all people equally. If any human being is to be treated unequally, there must be some solid reason.</td>
</tr>
<tr>
<td><strong>Common Good Approach</strong></td>
<td>The Common Good Approach is based on the connections of all people. With this approach all people should live in community and have respect and compassion for others, particularly for those who are considered to be vulnerable.</td>
</tr>
<tr>
<td><strong>Virtue Approach</strong></td>
<td>Finally the Virtue Approach, assumes that actions should be based on universal ideals, or virtues. Examples include honesty, courage, fairness, compassion and prudence.</td>
</tr>
</tbody>
</table>

### Framework for Ethical Decision-Making

The Framework for Ethical Decision-Making can be used to guide your ethical decision-making. The steps for adopting this framework can be found in Appendix J.

### Standards for Ethical Health Care Systems

There are standards that an ethical health care system upholds. The entire health care team, including the patient navigator, should strive to approach care delivery with the following standards in mind. Here, we summarize the standards for ethics in health care.

### Building Strong Ethical Relationships with Patients

Working closely with patients can be emotionally rewarding yet challenging. Part of building trust and a successful career includes maintaining professional boundaries and looking out for your own well-being.
Figure 60. Strategies to build strong ethical relationships with patients

**Going above the call of duty is not always a good idea**

- Be clear about your role upfront
- Keep patient information private
- Be patient with patients

**Communicate like a professional**

- Active, reflective listening
- Focusing on the patient
- Providing accurate information

**Patient Bill of Rights**

In 1997, President Clinton established the Advisory Commission on Consumer Protection and Quality in the Health Care Industry to report on changes in the health care system and recommend ways to improve. The Commission drafted the Consumer Bill of Rights and Responsibilities to protect patients, ensure quality health care, and establish trust between patients and health care providers. It also protects health care workers and gives way for patients to address problems with the health care system. Many health care systems have adopted or adapted the general principles of the Consumer Bill of Rights and Responsibilities. Check to see if your organization has its own.

**Table 39. Components of the Patient Bill of Rights**

<table>
<thead>
<tr>
<th>Patient Rights</th>
<th>Patient Responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>See their health care records /</td>
<td>Patients are responsible for their own health</td>
</tr>
<tr>
<td>Accurate and easy to understand information</td>
<td></td>
</tr>
<tr>
<td>Choose their health care providers and plans</td>
<td>Patients must disclose information</td>
</tr>
<tr>
<td>Access emergency services</td>
<td>Patients must be financially and administratively responsible</td>
</tr>
<tr>
<td>Be part of treatment decisions</td>
<td>Patients must be respectful of others</td>
</tr>
<tr>
<td>Be treated with respect and without</td>
<td></td>
</tr>
<tr>
<td>discrimination</td>
<td></td>
</tr>
<tr>
<td>Have their health information kept private</td>
<td></td>
</tr>
<tr>
<td>Complain about their health care</td>
<td></td>
</tr>
</tbody>
</table>
You will often have opportunities to support patients’ rights, including:

- Supporting patient understanding of his or her condition and treatment
- Supporting patient decision-making
- Supporting access to a second opinion
- Providing resources
- Helping patients make lists of questions
- Helping patients figure out what their needs are and helping them advocate for themselves

**Informed Consent**

Federal laws require that patients give their informed consent to participate in a clinical trial. However, patients typically sign informed consent for any treatment, not just clinical trials. This means that they are informed of the study’s or treatment’s procedures, risks, and benefits, and they agree, or give consent, to participate.

**Figure 61. Components of the informed consent form**

<table>
<thead>
<tr>
<th>The purpose of the treatment/clinical trial</th>
</tr>
</thead>
<tbody>
<tr>
<td>What will happen during the treatment/clinical trial</td>
</tr>
<tr>
<td>Benefits and risks of participating in treatment/the clinical trial</td>
</tr>
<tr>
<td>Patient’s rights</td>
</tr>
<tr>
<td>Who to contact if the patient has questions or feels they have been mistreated</td>
</tr>
</tbody>
</table>

**Health Insurance Portability and Accountability Act (HIPAA)**

Because private information about patients can be in many places, it is important to have a way to protect health information and keep it private. The Health Insurance Portability and Accountability Act (HIPAA) is a law to protect patient privacy. HIPAA Privacy Rules:
Figure 62. HIPAA privacy rules

**Set limits on who has the right to use a patient’s written, spoken or electronic health information**

**Describe how health care organizations and insurance providers must protect health information including:**

- How to handle protected health information
- How to share information
- What type of information can be shared
- With whom they can share information

If you break HIPAA rules, you may be subject to fines or prison terms. For up-to-date information on HIPAA violations, go to the HIPAA website.

Table 40. List of main organizations that are subject to HIPAA

<table>
<thead>
<tr>
<th>Health Care Providers</th>
<th>Health Insurers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
<td>Health insurance companies</td>
</tr>
<tr>
<td>Clinics</td>
<td>HMOs</td>
</tr>
<tr>
<td>Hospitals</td>
<td>Company Health Plans</td>
</tr>
<tr>
<td>Psychologists</td>
<td>Government Programs (Medicare and Medicaid)</td>
</tr>
<tr>
<td>Chiropractors</td>
<td></td>
</tr>
<tr>
<td>Nursing Homes</td>
<td></td>
</tr>
<tr>
<td>Pharmacies</td>
<td></td>
</tr>
<tr>
<td>Dentists</td>
<td></td>
</tr>
</tbody>
</table>

Check with your organization to see if you are subject to HIPAA. Many organizations are not subject to HIPAA rules and may follow different rules to protect health information.

**Protected Health Information (PHI)**

Protected Health Information, or PHI, is protected under HIPAA. PHI can take many forms, including written, spoken, or electronic information.
### Table 41. Summary of information that is considered PHI

<table>
<thead>
<tr>
<th>Contact information</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Name</td>
</tr>
<tr>
<td>• Address (all geographic subdivisions smaller than state, including street address, city, county, zip code)</td>
</tr>
<tr>
<td>• Telephone numbers</td>
</tr>
<tr>
<td>• FAX number</td>
</tr>
<tr>
<td>• E-mail address</td>
</tr>
<tr>
<td><strong>Electronic contact information</strong></td>
</tr>
<tr>
<td>• Web URL (web address)</td>
</tr>
<tr>
<td>• Internet Protocol (IP) address numbers</td>
</tr>
<tr>
<td><strong>Dates related to a patient or their care</strong></td>
</tr>
<tr>
<td>• Birth or death date</td>
</tr>
<tr>
<td>• Admission or discharge date</td>
</tr>
<tr>
<td><strong>Identifying numbers</strong></td>
</tr>
<tr>
<td>• Social Security Number</td>
</tr>
<tr>
<td>• Medical record number</td>
</tr>
<tr>
<td>• Health plan beneficiary number</td>
</tr>
<tr>
<td>• Account number</td>
</tr>
<tr>
<td>• Certificate/license number</td>
</tr>
<tr>
<td><strong>Device or vehicle numbers</strong></td>
</tr>
<tr>
<td>• Device identifiers or serial numbers</td>
</tr>
<tr>
<td>• Any vehicle or other device serial number</td>
</tr>
</tbody>
</table>

**Pictures, finger prints or voice recordings**

There are other various items that could uniquely identify an individual. Some examples in your work setting might include: clinic notes, lab results, or treatment records in a medical record, voice messages left on a patient's answering machine to confirm an appointment, conversations about patients between doctors or nurses, a doctor's recorded voice transcription of a patient's clinic visit, filled prescription bottles, or pictures of patients on a public website.
**Guideline 1: Use only the minimum information needed to do your job**

Use only the minimum patient information needed to complete your job. Provide others with only the information they need to complete their job.

Example situations in which other individuals may request PHI:

- **Service Providers** – provide only the information these individuals need to complete their service. For example, a transportation service only needs appointment date, time, and location to successfully complete their job.
- **Family Members** – information related to a patient’s care may be provided to family members, friends, or caregivers who ask questions about the patient if the information will benefit the patient. Do not provide information if the patient asks you not to, or if sharing the information would be inappropriate. Sharing medication information with the caregiver of a patient with memory problems is an example of a situation in which it would be okay to share patient information.

**Guideline 2: If in doubt about giving information, get patient authorization**

If you are unsure whether you should provide PHI to a person or organization, have the patient sign an authorizing form. This form gives the provider permission to release certain PHI. Remember to check the patient’s file for existing authorization forms.

**Guideline 3: Keep PHI secure**

Keeping PHI secure means protecting it from being viewed by people who should not see it. Examples of how to keep PHI secure include:

- Ensuring PHI is not accessible to patients or others not authorized to view it
  - Cover or move any PHI left in a place where it can be seen by others
  - Make sure others cannot view your computer screen or desk while you are working with PHI without you knowing they are there
  - Remove PHI from fax or copy machines as soon as possible
  - Leave files or documents with PHI in the office or clinic
- Ensuring others cannot hear you discuss patient PHI
  - Do not discuss patients in public areas
  - Close the door when talking to or about patients
- Ensuring PHI is properly stored
  - Store in a locked office or file cabinet
  - Shred any PHI files that are no longer needed
- Use passwords, anti-virus software, data backups, and encryption to protect electronic PHI*

*Adapted from The Patient Navigator Training Collaborative, Module 4: Ethics and Law, 2011.

**Legal Obligations**

As part of the health team, you too will need to understand the rules and regulations that most health professionals must abide by to protect patient rights and the rights of the public. Check with your supervisor about legal obligations that apply to you.

**Figure 63. Examples of legal obligations**

**Duty to warn**

- Duty to warn as defined by the National Conference of State Legislatures is a mandatory duty for certain professionals to report any suspicion that a patient may pose a danger to themselves or others. This law varies by state and may include certain civil and criminal protections for the professional.

**Abuse reporting rules**

- As with any interaction, once you establish rapport, a person may reveal important information that can arouse suspicion of abuse or neglect. Many professions are required or “mandated” to break patient confidentiality and report any suspicion of abuse or neglect. These include:
  - Human Services Providers such as social workers, mental health professionals, psychologists, therapists and counselors.
  - Health Care Providers such as hospital personnel, registered nurses, physicians, residents, interns, psychiatrist and medical examiners.
  - Child Care Providers such as day care providers, child or foster care workers and residential care takers.
  - Education providers such as teachers, assistant teachers, administrators, preschool staff.
  - Law enforcement such as police officers, peace officers.

**Safety contracting**

- Having a contract for safety was a practice that began in 1973, between a therapist and a patient, that established a patient’s vow to not harm themselves on purpose or accidentally. Today, many doctors continue to use this contract for safety. As a patient navigator and as part of the health care team it is not your role to assess a patient’s intentions to harm themselves. While the assessment is the doctor’s responsibility, should the patient discuss any harmful intentions or express suicidal thoughts it is your responsibility to seek the doctor or your supervisor immediately.
Resources for Patient Navigators

- **Summary of the HIPAA Privacy Rule**: This is a summary of key elements of the Privacy Rule, including who is covered, what information is protected, and how protected health information can be used and disclosed. Because it is an overview of the Privacy Rule, it does not address every detail of each provision.
- **National Center for Ethics in Health Care**: This website includes multimedia ethics education, podcasts, and other resources on ethics in health care.
- Santa Clara University [Markkula Center for Applied Ethics](https://www.markkula.org/): This website includes articles, cases, and links on medical ethics, biotechnology and ethics, clinical ethics, end-of-life decision making, culturally competent health care, and public health policy.
- HHS [Protected Health Information Training](https://www.hhs.gov/): This self-paced slide set covers aspects of protected health information.
- Temple Health’s [A Practical Guide to Informed Consent](https://www.templehealth.org/): This toolkit provides background on informed consent and ways to improve informed consent.
- National Conference of State Legislatures [Mental Health Professionals’ Duty to Warn](https://www.ncsl.org/research/health/mental-health-professionals-duty-to-warn.aspx): This webpage provides information about the duty to warn and summarizes state laws on the topic.
LESSON 1: Practicing Efficiently and Effectively

Learning Objectives

- Describe and implement strategies for building trust
- Explain the importance of performing duties accurately and efficiently
- Describe organizational skills and methods
- Describe time management skills and methods
- Describe problem-solving skills and methods
- Describe critical thinking skills and methods
- Manage workload and apply organizational, time management, problem-solving and critical thinking skills to assist patients efficiently and effectively
- Describe potential information technology tools to increase efficiency

Key Takeaways

- You will need to be able to build trust with your patients and your colleagues, which leads to better communication and ultimately better outcomes
- A key component of trust is responsiveness
- Patient navigators can use the following skills to improve responsiveness: organization, time management, problem-solving, critical thinking, and workload management
- Information technology, such as email, calendars, and spreadsheets, can help you manage your responsibilities and work more efficiently

Strategies for Building Trust

You will need to be able to build trust with your patients and your colleagues. Trust leads to better communication, which leads to better outcomes, as you’ve learned in
Module 5. Patients will trust you to keep their best interests in mind. You will be seen as the gatekeeper for access to the services, and support patients need or want. You will also be seen by your colleagues as a valuable member of the health care team. Some general strategies for building trust include:

**Figure 64. Strategies for building trust**

- Active listening
- Boundaries
- Respecting patient rights
- Responsiveness

**Skills for Being Responsive**

Patient navigators can borrow from the business and management sciences to be responsive to patients’ needs. Customer responsiveness has been described as “accurately and insightfully giving customers what they need, want or don’t yet know they want and doing so more quickly than anyone else.” Patient navigators can apply this concept by assessing patient needs and developing plans to eliminate barriers. Ask: What does the patient need? How can I help the patient meet the need in a timely manner? By getting to know the patient, patient navigators can also anticipate potential barriers during the course of treatment and develop an action plan to address those as needed.

Another way that successful businesses are responsive to customers’ needs is by prioritizing inquiries based on importance and passing along those inquiries to the knowledgeable staff member that can best address them quickly. Patient navigators can prioritize patients’ needs based on severity of the situation and the magnitude of impact of barriers to care. If you can identify the most urgent patient cases, then you can address the most pressing matters, referring as appropriate to members of the health care team to best meet the needs of the patient. In business, by understanding your clients’ challenges, you can better plan to meet their long-term needs. In this same spirit, patient navigators should work to get to know their patients and the challenges they face. By knowing the patient, what’s important to them, and what they perceive to be
barriers to care, navigators can implement steps to meet those needs. Strategies for being a responsive navigator include being highly organized, managing your time well, developing problem-solving and critical-thinking skills, and managing your workload.

It is important to keep in mind what you have already learned about active listening. Be sure that when you are assessing patient needs and that you are responding to what the patient has indicated as needs without making assumptions. While you can and should provide patients with information on resources that are available, ultimately, you should take your lead from the patient on what they need. Also, remember to focus on those barriers that impact a patient’s progress through the cancer continuum. You cannot and should not take on every burden that a patient might have – to best use your time and help most patients get through their cancer experience, focus on only those problems and barriers that impact the patient’s ability to access or receive recommended care.

**Figure 65. Essentials skills for being responsive**

- **Organization**: Avoid multi-tasking, prioritize, delegate, communicate appropriately, be organized, plan your projects
- **Time Management**: Structure your schedule, time activities, commit to downtime, be organized
- **Problem Solving**: Use Problem Solving Cycle: 1) define and clarify the issue, 2) gather and verify facts, 3) identify other key players, 4) brainstorm possible solutions, 5) identify the pros & cons, 6) choose the best option, 7) develop action plan, 8) follow-up
- **Critical Thinking**: Analyzing (what’s the issue?), applying standards (where have I seen this before?), discriminating (what’s the priority?), information seeking (what don’t I know?), logical reasoning (why is this the way it is?), predicting (what’s going to happen?), transforming knowledge (what’s worked before that I could try again?)
- **Workload Management**: Recognize that being actively engaged in a task doesn’t necessarily mean you are being productive. Track progress, plan your workload, use technology to work, schedule tasks that are more difficult to complete during the times you work best, explore your own work style to build on them, take breaks when necessary; leave time for unplanned tasks.
Administrative Duties of the Patient Navigator

Although your focus is on working with patients, navigators also have many administrative duties.

**Figure 66. Administrative duties of the patient navigators**

- Reaching out to patients via mail, phone or in person
- Providing educational information or hosting educational events
- Documenting barriers and actions taken to resolve barriers
- Providing logistical support such as assisting with screening scheduling and arrangement
- Gathering information regarding access to cancer care screenings
- Sending mail communication, screening reminders, information packages and educational materials
- Placing reminders on patients’ medical charts
- Making follow up phone calls

**Example Patient Tracking Tool**

You can use Excel to create a patient tracking tool. See Appendix K for an example of a tool or check out PN-BOT™ (only available for PCs).

**Information Technology**

Several tools are available to help you manage your responsibilities and work efficiently. Here are some examples of information technology that may help you do your work. It’s important to remember to pay attention to protected health information that you may enter in these tools, as discussed in Module 6, and make sure you are following organizational policies when using these tools.
Figure 67. Information technology that could be used by patient navigators

Example Navigation Software Options

Most commonly used navigation software:

- Cordata
- MagView
- Nursenav
- OncoNav
- PN-BOT™
- Social Solutions (ETO)

Resources for Patient Navigators

- LinkedIn Learning.
- Mindtools.com: This website includes professional development articles and tools.
- The Boston Medical Center Patient Navigation Toolkit.
### LESSON 2: Health Care Team Collaboration

#### Learning Objectives

- Work in cooperation with those who receive care, those who provide care, and others who contribute to or support the delivery of prevention and health services to forge interdependent relationships to improve care and advance learning
- Contribute to a positive working atmosphere
- Identify potential barriers to a smooth transition of patients across screening, diagnosis, active treatment, survivorship, and/or end-of-life care, working with the patient’s clinical team
- Describe how culture, background, religious beliefs, and attitudes impact patient care and the working environment
- Solve conflicts and enable a constructive negotiation in a health care team

#### Key Takeaways

- Teamwork is essential in cancer care.
- Effective teams are based on mutual trust, respect, and collaboration. Collaboration in health care means that health care professionals assume complementary roles and cooperate, sharing responsibility for problem-solving and making decisions to make and carry out plans for patient care.
- Collaborative work environments consist of diverse teams that share knowledge, provide high-quality health care that is patient-focused, offer effective clinical care, and seek improved patient outcomes.
- You may not have control of all of the components of successful teamwork, but you can think about which of these you can contribute to, like practicing open communication, engaging in respectful and routine communication, and information sharing.
• Diversity can impact patient care and the workplace in both positive and negative ways.

• As with patients, good conflict resolution skills are needed to work with other health care professionals.

• SBAR and Walk in the Woods are strategies that can be used to resolve conflicts on your health care team and to help your patients communicate with providers.

**Types of Teams**

There are generally two types of teams in health care:

- Interprofessional teams are made up of individuals who identify with different specialties or disciplines who work together and communicate to make well-informed decisions.

- Multidisciplinary teams are also made up of members who come from various disciplines and specialties, but they tend to work independently, conducting assessments and treatment on their own and then sharing the information with the team afterward.

**Characteristics of Effective Teams**

Effective teams are based on mutual trust, respect, and collaboration. Collaboration in health care means that health care professionals assume complementary roles and cooperate, sharing responsibility for problem-solving and making decisions to make and carry out plans for patient care. When health care professionals participate in interprofessional teams, patients benefit from easier communication with a cohesive team, rather than having to interact with individuals without knowledge of what other individuals are doing to manage the patient’s needs.
What Prevents Interprofessional Teamwork in Health Care?\textsuperscript{229}

**Figure 68. Obstacles for interprofessional teamwork in health care**

- Work in silos
- Struggle with communicating with others of different disciplines
- “In-group” and “Out-group”

Impact of Dysfunctional Teams\textsuperscript{229,231}

**Figure 69. Outcomes of dysfunctional teams**

- Low job satisfaction among staff  →  Increased conflicts between health care professionals  →  Waste of resources
- Fragmented or duplicated care  →  Poor outcomes for patients  →  Poor work environment

Components of Successful Teamwork\textsuperscript{230}

**Figure 70. Barriers to successful team collaboration**

- It takes time
- Perceived loss of autonomy
- Lack of trust or confidence in others’ decisions
- Clashing perceptions/approaches
- Territorialism
- Lack of awareness about different professional disciplines
There are numerous components of successful teamwork. Although as a patient navigator, you may not have control of all these factors, think about which of these you can contribute to.

**Figure 71. Elements of successful teamwork**

- Open communication
- Non punitive environment
- Clear direction
- Clear and known roles and tasks
- Respectful atmosphere
- Shared responsibility for team success
- Balance of member participation for the task at hand
- Acknowledgment and processing of conflict
- Clear authority and accountability
- Clear and known decision making procedures
- Routine communication and information sharing
- Enabling environment
- Mechanism to evaluate and adjust accordingly

**Supporting a Smooth Care Transition**

Barriers to team collaboration can extend to impact the smooth transition of patients across the cancer care continuum. As your patients move through different phases of their cancer journey, from screening to diagnosis, active treatment, survivorship, and/or end-of-life care, other providers will likely join the team. As new team members contribute to the patient’s care experience, a continual and concerted effort is needed to foster communication and cooperation among everyone.

**Figure 72. Barriers and solutions for team collaboration**

**Barriers**
- Confusion about who is leading care at a given moment in time
- Team members may be misinformed about next steps
- Patient may feel that the support system is shrinking

**Solutions**
- Identify who gets the handoff
- Ensure that everyone knows about transitions
- Continue to advocate for the patient
Diversity on Health Care Teams

Although conflict and miscommunication can arise on diverse teams due to role and cultural differences, learning about team dynamics and conflict resolution can mitigate these adverse effects. Diverse health care teams can create:

- Better working environments
- Better problem solving
- Bridge the gap between clinical and cultural knowledge
- Informed about patient environment
- Learning about differences can mitigate conflicts from cultural differences

Common Communication Barriers

These are contextual factors that may create conflict between professionals:

- Conflicting personal values and/or expectations
- Personality differences
- Hierarchy
- Disruptive behavior
- Culture and ethnicity
- Generational differences
- Gender
- Historical interprofessional and intraprofessional rivalries
- Differences in language and jargon
- Differences in schedules and professional routines
- Varying levels of professional preparation, qualifications, and status
- Differences in requirements, regulations, and norms of professional education
- Fears of diluted professional identity
- Differences in accountability, payment, and rewards
- Concerns regarding clinical responsibility
- Complexity of care
- Emphasis on rapid decision-making

To mitigate barriers that impact communication, patient navigators should foster a culture of common purpose, intent, trust, respect, and collaboration. You can accomplish this by starting with something in common-like a goal. For example, you and your team members all strive to provide high-quality patient care. As you work with others, you can think about and emphasize this goal to help everyone feel they are
working together. It’s also important to be in tune with yourself: be self-aware of your own personal biases and beliefs. These may play a hand in your contribution to communication issues.

**Solutions for Effective Communication**

- Foster a culture of common purpose, intent, trust, respect, and collaboration
- Start with common goal = high-quality patient care
- Be self-aware of personal biases and beliefs

**Understanding Conflict**

Understanding conflict and conflict resolution strategies can help address issues of ineffective communication on health care teams.

**Conflict Resolution Strategies**

**Figure 73. Conflict resolution strategies**

- Work at talking about the issues
- Recognize the value of the conflict
- Recognize conflict is a spiral and you can change the direction of the spiral
- Emphasize common goals
- Check perceptions
- Use competent communication techniques
- Agree to disagree

There are two tools that may help you: SBAR and Walk in the Woods.
SBAR: Situation, Background, Assessment, and Recommendation

Figure 74. SBAR model

- **Situation**
  - What is going on with the patient?

- **Background**
  - What is the context?

- **Assessment**
  - What do you think the problem is?

- **Recommendation**
  - What would you do to correct the problem?

Figure 75. Walk in the Woods

**STEP 1: Self Interests**

- Define the problem
- Who has a stake in the problem or who has a say and who will be impacted by the outcome?

**STEP 2: Enlarged Interests**

- Identify what everyone agrees on to reframe the problem
- Identify what everyone disagrees on

**STEP 3: Enlightened Interests**

- All parties are to freely brainstorm new and creative ideas to solve the problem
- Rank solutions:
  1. Unanimous agreement
  2. Ambiguity
  3. Clear disagreement

**STEP 4: Aligned Interests**

- Parties share what they “must, want and would like to receive,” and what they are “eager, willing and unwilling to give” in the deal
- Parties discuss what they will and will not commit to, how they will meet their objectives and what are the implications for the proposed deal
- Agreement should be written down
- Each party should gain something out of the deal
Resources for Patient Navigators

- World Health Organization’s [Patient Safety Course Topic: Being an Effective Team Player](#): This handout provides an overview of being an effective team player.
- Institute for Health Care Improvement’s Course [SBAR Training Scenarios and Competency Assessment](#): This website provides possible SBAR training scenarios, competency assessments, and directions on how to use it in the most effective way.
- MedPro Disposal [What is SBAR and Why is It Important?](#): This webpage provides information and resources about SBAR.
- Patient Safety and Quality Health Care’s [Communication: A Critical Healthcare Competency](#): This article provides information about effective communication between providers and patients.
- Mediatecalm.com’s [Conflict Resolution: What Nurses Need to Know](#): This document is relevant to patient navigators and covers conflict and strategies to deal with conflict in health care.
LEsson 3: Program Evaluation and Quality Improvement

Learning Objectives

- Describe the importance of program evaluation
- Describe potential roles for the patient navigator in evaluating programs
- Identify opportunities for quality improvement based on metrics
- Identify and implement strategies for quality improvement
- Describe the value of patient navigation to different stakeholders
- Summarize patient navigation roles and responsibilities to different stakeholders

Key Takeaways

- Program evaluation is important to show others, such as administrators, clinicians, and funders, the impact of your work
- Patient navigators may be involved in program evaluation in different ways, including data collection, data analysis, and data reporting
- Program evaluation includes formative evaluation, process evaluation, and outcomes evaluation
- Even if no one has directly asked you to participate in program evaluation, it is important that you track your activities for your own records
- A Patient Flow or Process map and the PDCA Cycle are tools you can use for quality improvement
- It is important that patient navigators be able to talk about what they do and why other people should find their work valuable.
- An elevator pitch is a concept to think about how you can talk about what you do
When you communicate about the value of patient navigation, your message should be tailored to the type of stakeholder.

**Program Evaluation Overview**

Some important definitions for program evaluation include:

**Figure 76. Definition of essential program evaluation components**

<table>
<thead>
<tr>
<th>Program</th>
<th>Program is a group of resources and activities used together to fulfill one or more purposes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Evaluation</td>
<td>The systematic collection and analysis of information about some or all aspects of a program to guide judgments or decisions</td>
</tr>
<tr>
<td>Stakeholders</td>
<td>Organizations, groups, or individuals with interest in the power to influence a program</td>
</tr>
</tbody>
</table>

**Figure 77. Indicators for effective program evaluation**

- Improve the program
- Say if the program works
- Find additional funding
- Report to funder
- Describe what you do
- Meet accreditation requirements

Evaluation helps you answer:

- Did we reach our program goals?
- Should we continue the program?
- What can be changed to make the program more effective and improve outcomes?

What evidence demonstrates that our administrators, funders, etc., should continue to support and fund the program?
Figure 78. Summary of three different types of evaluation

Table 42. Patient navigator involvement in evaluation

<table>
<thead>
<tr>
<th>Data Collection</th>
<th>Data Analysis (maybe)</th>
<th>Data Reporting (maybe)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Who are your patients?</td>
<td>• What are the trends?</td>
<td>• Reports for stakeholders</td>
</tr>
<tr>
<td>• What services are you providing?</td>
<td>• Where are the areas for improvement?</td>
<td>• Presentations</td>
</tr>
<tr>
<td>• How well are you assisting your patients?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• How long do certain tasks take?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

You will have to think about where you can find the information you need to answer your evaluation questions:

Table 43. Examples of where and how to obtain information for evaluation questions

<table>
<thead>
<tr>
<th>Where can we find the information?</th>
<th>How do we obtain the information?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patient records</td>
<td>• Patient records abstraction</td>
</tr>
<tr>
<td>• Cancer registry database</td>
<td>• Surveys/questionnaires</td>
</tr>
<tr>
<td>• Tracking logs</td>
<td>• Interviews</td>
</tr>
<tr>
<td>• Administrative data</td>
<td>• Review of tracking logs</td>
</tr>
<tr>
<td>• Meeting summaries</td>
<td>• Focus groups</td>
</tr>
<tr>
<td>• Interview transcripts; notes</td>
<td>• Data Analysis: quantitative and/or qualitative</td>
</tr>
<tr>
<td>• Survey results</td>
<td></td>
</tr>
</tbody>
</table>
Formative Evaluation

Questions you can answer with formative evaluation include:

- How great is the need? What is the problem?
- Who would benefit from our program?
- What might work to meet the need?
- How might we deliver the program activities?
- Should we pilot test/refine the program?

Commission on Cancer Community Needs Assessment Standard\textsuperscript{241,242}

The Commission on Cancer, or CoC, accredits about 1,500 cancer programs across the country. Starting in 2016, the CoC added a new standard related to patient navigation that CoC-accredited programs must address. In 2020, the CoC changed this standard to Addressing Barriers to Care. For a step-by-step guide to meeting this standard, see our Implementing the Commission on Cancer Standard 8.1 Addressing Barriers to Care. For the most up-to-date CoC standards, click here.

Figure 79. Summary of components of needs assessment
Data sources for a Community Needs Assessment

Figure 80. Data sources for community needs assessment
- Surveillance, Epidemiology and End Results (SEER)
- CDC/NCI State Cancer Profiles
- Comprehensive Cancer Control Plans
- HealthyPeople 2030
- Your own program evaluation!

Process Evaluation

Questions you can answer with process evaluation include:
- What was done?
- How was the program implemented?
- How well was the program implemented?
- Was the program implemented as planned?
- How satisfied are patients or providers with the program?
- How can we demonstrate program implementation even before outcomes have been attained?

Table 44. Examples of navigation process measures and their possible data sources

<table>
<thead>
<tr>
<th>MEASURE EXAMPLE</th>
<th>DATA SOURCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who provides the services</td>
<td>Descriptive data</td>
</tr>
<tr>
<td>Types of services provided</td>
<td>Tracking log</td>
</tr>
<tr>
<td># of patients navigated</td>
<td>Tracking log</td>
</tr>
<tr>
<td># patient barriers</td>
<td>Tracking log</td>
</tr>
<tr>
<td># barriers resolved</td>
<td>Tracking log</td>
</tr>
<tr>
<td># patients receiving co-pay assistance due to navigation</td>
<td>Tracking log</td>
</tr>
<tr>
<td>Communication between navigator and patients</td>
<td>Patient surveys</td>
</tr>
<tr>
<td>Patient satisfaction</td>
<td>Patient surveys</td>
</tr>
</tbody>
</table>
Outcomes Evaluation

Questions you can answer with outcomes evaluation include:

- Did we reach our program goals?
- How did the program impact the patient?
- What evidence demonstrates that our administrators, funders, etc., should continue to support and fund the program?

Table 45. Sample navigation outcomes evaluation measures and their possible data sources

<table>
<thead>
<tr>
<th>MEASURE EXAMPLE</th>
<th>DATA SOURCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time from screening to diagnostic resolution</td>
<td>Medical record abstraction</td>
</tr>
<tr>
<td></td>
<td>Tracking log</td>
</tr>
<tr>
<td>Time from diagnosis to treatment</td>
<td>Medical record abstraction</td>
</tr>
<tr>
<td></td>
<td>Tracking log</td>
</tr>
<tr>
<td>Patient adherence to scheduled appointments</td>
<td>Medical record abstraction</td>
</tr>
<tr>
<td></td>
<td>Medical Outcomes Study</td>
</tr>
<tr>
<td></td>
<td>Adherence Survey</td>
</tr>
<tr>
<td>Patient satisfaction with navigation</td>
<td>National Cancer Institute</td>
</tr>
<tr>
<td></td>
<td>Patient Experience Survey</td>
</tr>
<tr>
<td>Patient-reported outcomes: fatigue, distress, pain, quality of life, functionality</td>
<td>FACT-C</td>
</tr>
<tr>
<td></td>
<td>PROMIS</td>
</tr>
<tr>
<td>Time from screening to diagnostic resolution</td>
<td>Medical record abstraction</td>
</tr>
<tr>
<td></td>
<td>Tracking log</td>
</tr>
</tbody>
</table>
**Tips for Tracking Data**

**Figure 81. Tips for tracking data**

- Keep your own records
- Use technology
- Track consistently and regularly
- Ensure data accuracy
- Ensure legibility

**Quality Improvement**

Conducting routine quality improvement can help understand problems that may arise.

Patient Flow/Process Map can help:
- How many times is the patient passed from one person to another (hand-off)?
- Where are delays, queues, and waiting built into the process?
- Where are the bottlenecks?
- What are the longest delays?
- What is the approximate time taken for each step (task time)?
- What is the approximate time between each step (wait time)?
- How many steps are there for the patient?
- How many steps add no value for the patient?
- Are there things that are done more than once?
- Where are the problems for the patients?
Making Improvements: The PDCA Cycle

The PDCA Cycle can be used to make improvements:

**Figure 83. PDCA cycle**

- **Plan**
  - Plan a change

- **Do**
  - Test/pilot change

- **Act**
  - Make a decision: expand, alter, abandon

- **Check/Study**
  - Analyze results
Demonstrating Value to Stakeholders

Table 46. Difference between internal and external stakeholders

<table>
<thead>
<tr>
<th>INTERNAL STAKEHOLDERS</th>
<th>EXTERNAL STAKEHOLDERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration</td>
<td>Funders</td>
</tr>
<tr>
<td>Clinicians</td>
<td>Colleagues</td>
</tr>
<tr>
<td>Navigators</td>
<td>Patients</td>
</tr>
</tbody>
</table>

Promoting Patient Navigation

Patient navigators are valuable for many reasons because they:
- May be seen by patients as independent of the health care system
- Build a strong alliance with patients
- Possess solid knowledge of the health care system
- Demonstrate clear intentions to get to know the patient
- Offer patients personalized assistance
- Facilitate care coordination
- Mediate miscommunications between patients and providers

Elevator Speech

An elevator speech can help you describe what you do to different stakeholders. Use the following tips to craft an elevator speech:
- Keep it short and simple
- Generate excitement
- Be compelling
- Include the value added to stakeholder
- Know your audience
- Have an action item at the end
- Practice!
Table 47. Different elements of focus for particular audiences

<table>
<thead>
<tr>
<th>Providers</th>
<th>Patients</th>
<th>Organizations</th>
<th>Funders</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Reduce no-shows/missed appointments</td>
<td>• Provide information</td>
<td>• Reinforce organizational mission, vision and values</td>
<td>• # of patients served</td>
</tr>
<tr>
<td>• Support adherence to treatment</td>
<td>• Connect them to support resources</td>
<td>• Increase patient satisfaction</td>
<td>• # of barriers eliminated</td>
</tr>
<tr>
<td>• Assist with non-clinical issues (administrative, financial and practical)</td>
<td>• Help them troubleshoot barriers that impact access to screening, treatment and supportive care</td>
<td>• Retain patients within the system</td>
<td>• # of uninsured/underserved patients</td>
</tr>
<tr>
<td>• Free up their time to address clinical issues</td>
<td>• Help them navigate the health care system</td>
<td>• Support community outreach goals</td>
<td>• Outputs and outcomes of your services</td>
</tr>
<tr>
<td></td>
<td>• Provide emotional support</td>
<td>• Leverage community resources</td>
<td>• “Reach”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Public health impact</td>
</tr>
</tbody>
</table>

Targeting Your Message

You can walk through the following scenarios and think about how you would tailor your comments in each one:

Table 48. Case scenarios

**CASE SCENARIOS**

Case scenario #1: You are trying to create a relationship with one of the physicians at the Cherry Blossom Cancer Center, where many of your patients are seen. The doctor has 2 minutes in between patients to chat. What do you say about your role as a navigator?

Case scenario #2: Your organization just hired a new Director of Community Programs. You are meeting with your new supervisor to discuss your role in the organization. How would you describe your value and role as a patient navigator?

Case scenario #3: You are at a community health fair promoting your services as a patient navigator. How would you explain to a resident/patient what you do and how you can help them?

Case scenario #4: You are attending a local fundraising event, and one of the organization’s representatives would like to know more about what ‘you do’. How would you describe to a potential funder your role and value as a patient navigator in the community?
Resources for Patient Navigators

- Commission on Cancer’s [2020 Standards and Resources](#): Learn more about the 8.1 Addressing Barriers to Care Standard.
- Centers for Disease Control and Prevention’s [WONDER](#): The Centers for Disease Control and Prevention has many sources of data available at the state and county levels, including Healthy People 2010 data. It is also an excellent access point to other datasets.
- Centers for Disease Control and Prevention’s [Behavioral Risk Factor Surveillance System (BRFSS)](#): BRFSS is the nation’s premier system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services.
- [U.S. Census Bureau](#): The U.S. Census provides information at various levels--National, Regional, State, County, City, Census Tracks, and Blocks.
- National Association of City and County Health Officials’ [Mobilizing for Action through Planning and Partnerships (MAPP)](#): MAPP is a community-driven strategic planning process for improving community health.
- The Community Toolbox’s [Evaluating the Initiative](#): This toolkit aids in developing an evaluation of a community program or initiative.
- Centers for Disease Control and Prevention’s [Introduction to Program Evaluation for Public Health Programs](#): This self-study guide is intended to assist managers and staff of public, private, and community public health programs to plan, design, implement and use comprehensive evaluations in a practical way.
- American Society for Quality’s [Knowledge Center](#): This website includes information about quality improvement tools as well as free templates you can use.
- The George Washington University Cancer Control TAP [Implementing the Commission on Cancer Standard 8.1 Addressing Barriers to Care](#): The purpose of this road map is to guide comprehensive cancer control (CCC) professionals and administrators in identifying and addressing barriers to accessing health and/or psychosocial cancer care for cancer patients.
- The George Washington University Cancer Center’s [Patient Navigation Barriers and Outcomes Tool (PN-BOT™)](#): No-cost tool for your program evaluation.
MODULE 7: Enhancing Practice

LESSON 4: Personal and Professional Development

Learning Objectives

• Identify sources of feedback
• Describe tips for giving and receiving feedback
• Create and implement a plan for improving daily work based on feedback
• Identify opportunities to learn and improve professionally
• Identify sources of new knowledge
• Create professional development goals based on identified areas
• Develop and implement a professional development plan
• Identify and use tools for dealing with ambiguity and uncertainty
• Identify self-care strategies

Key Takeaways

• The purpose of feedback is to encourage the recipient to assess their performance and use the information provided to make changes toward improvement
• Once you receive feedback, you can incorporate it into a plan for improving your daily work
• A professional development plan can serve as a guide for your career, providing a tool to measure your progress and steer your development activities
• The best way to deal with this uncertainty in the work environment is to learn how best to respond and to develop the skills necessary to be adaptable to change
Feedback Overview

The purpose of feedback is to encourage the recipient to assess their performance and use the information provided to make changes toward improvement. Feedback is used in many settings, including clinical, educational, and home settings. It can improve performance and modify or reinforce behavior. Providing feedback is often seen as a process that happens between an employee and their supervisor but in reality, can be bi-directional and lateral, meaning you could give your supervisor feedback, or the feedback could be between peers. However, if feedback is not communicated effectively, it can have negative effects on motivation or worsen performance.

Figure 84. Different sources of feedback

- Teachers
- Clinicians from a variety of health care professions
- Patients and their loved ones
- Peers and colleagues
- The learner (you)
- Others

Figure 85. Summary of potential barriers to giving effective feedback

- Fear of upsetting or damaging the work relationship
- The recipient being resistant or defensive when receiving criticism
- Feedback being too generalized and not related to specific facts or observation
- Inconsistent feedback from multiple sources
- Fear of doing more harm than good
- Poor handling of a reaction to negative feedback can result in feedback being disregarded thereafter
- Feedback not giving guidance on how to rectify behavior
- Lack of respect for the source of feedback
### Principles of Giving Feedback

**Figure 86. Tips for giving feedback**

<table>
<thead>
<tr>
<th>Tip</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>View feedback as a normal part of your role</td>
</tr>
<tr>
<td>2</td>
<td>Be clear about your understanding of your role and what is expected of you</td>
</tr>
<tr>
<td>3</td>
<td>Be specific</td>
</tr>
<tr>
<td>4</td>
<td>Provide feedback in a non judgmental way and as someone that has directly observed the behavior or interaction</td>
</tr>
<tr>
<td>5</td>
<td>Give feedback in a timely manner</td>
</tr>
<tr>
<td>6</td>
<td>Focus on one to two concepts</td>
</tr>
<tr>
<td>7</td>
<td>Have the recipient of the feedback assess their performance and encourage them to routinely do so</td>
</tr>
<tr>
<td>8</td>
<td>Effective feedback results in a change in behavior that is noticeable in practice</td>
</tr>
</tbody>
</table>

### Principles of Receiving Feedback

**Figure 87. Tips for receiving feedback**

<table>
<thead>
<tr>
<th>Tip</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Listen with intent rather than preparing your defense or response</td>
</tr>
<tr>
<td>2</td>
<td>Ask for clarification if needed</td>
</tr>
<tr>
<td>3</td>
<td>Assume positive intent</td>
</tr>
<tr>
<td>4</td>
<td>Allow yourself time to collect your thoughts and communicate a response</td>
</tr>
<tr>
<td>5</td>
<td>Be willing to constructively provide your perspective</td>
</tr>
<tr>
<td>6</td>
<td>Ask for suggestions to modify your behavior</td>
</tr>
<tr>
<td>7</td>
<td>Take time to respectfully thank the person providing the feedback</td>
</tr>
<tr>
<td>8</td>
<td>Clarify that you have received and understand the feedback and will look to improve</td>
</tr>
</tbody>
</table>
You can incorporate feedback into your daily work:

- Take time to write down the suggested areas of improvement identified by you or someone else
- Carefully assess your daily routine and identify areas where you can integrate improvements based on feedback
- Create notes and reminders about areas of focus and how much time you may need to address some of the concerns
- Set aside time to plan for making improvements
- Check-in frequently with your colleagues or supervisor and communicate any changes or progress you have made

**Professional Development Plans**

A professional development plan can serve as a guide for your career, providing a tool to measure your progress and steer your development activities. You can create an individual development plan for your own personal use. Your employer may require you to create a plan as a part of your performance review process and/or formal career advancement process. Goal-setting helps you solidify what you want to achieve to grow professionally. Having concrete goals helps:

- Track the progress of your professional development
- Motivate you to improve professionally by giving you something to work towards
- Increase your confidence as you act and make progress

**Figure 88. Steps for setting professional development goals**

- Decide on what areas you’d like to improve
- Be specific about what you want to accomplish
- Quantify your goals
- Make sure your goals are realistic
- Prioritize your goals so you can focus on what’s most important
- Create small tasks out of your big goals
- Write down your goals in a positive light
Sources of New Knowledge\textsuperscript{253}

As you make your professional development plan, think about different sources of new knowledge related to both patient navigation itself and to professional growth.

Figure 89. Summary of sources to acquire new information

- Conferences
- Local/regional meetings
- Special interest groups
- Listservs and newsletters
- Journal articles
- Professional development websites
- Networking

Figure 90. Steps for creating a professional development plan

1. Write down your professional development goals and tasks
2. Identify resources
3. Keep track of your progress

Table 49. Sample professional development plan

<table>
<thead>
<tr>
<th>GOAL</th>
<th>RESOURCES</th>
<th>PLAN</th>
<th>PROGRESS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Improve Excel skills to help with documentation</td>
<td>Co-workers</td>
<td>Sit down with co-workers by the end of the month to do a brief tutorial</td>
<td>Meeting scheduled</td>
</tr>
<tr>
<td></td>
<td>Free course offered through the library or LinkedIn Learning (subscription required)</td>
<td>Enroll in free course</td>
<td>Registered for course</td>
</tr>
<tr>
<td>2. Stay up to date on patient navigation issues and research</td>
<td>GW Cancer Center listserv</td>
<td>Register for the listserv and AONN+ membership by the end of the month</td>
<td>Assessed cost of AONN+ membership</td>
</tr>
<tr>
<td></td>
<td>AONN+ Journal of</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Dealing with Ambiguity

Ambiguity, or uncertainty, is common in most work environments and settings. We are often asked to make decisions without having all of the available information. Members of your health care team or your patient may need you to decide on the best course of action to address barriers to care without fully knowing what your patient will require. Sometimes you might be asked to do something without being given instructions. The best way to deal with this uncertainty is to learn how best to respond and to develop the skills necessary to be adaptable to change.

Figure 91. Tips to manage the uncertainty*

- Create a visual to understand the problem
- Get organized
- Act incrementally
- Delve into the problem’s cause
- Reflect on your emotions
- Increase your emotional intelligence
- Ask your supervisor or a colleague for guidance or perspective

*This source was adapted from the George Washington University Human Resources, Dealing with Ambiguity, n.d. [no longer published]
Understanding Stress

Stress is how you respond to a situation, good or bad, that is outside of our usual way of coping. Stress can result from:
- Expectations that are too high
- Situations that cause a conflict or workplace challenge

Stress and Self-Care Strategies

Patient navigators need to be able to handle tough situations and still provide support to their patients. Physical symptoms of acute stress include:

Figure 92. Summary of symptoms of stress

- Clumsiness or awkwardness
- Frequently becoming sick or ill
- Engaging in unhealthy behaviors
- A change in sleeping or eating habits
- Crying more

It is important to seek help if you are concerned that you are experiencing these symptoms. A mental health professional can help you to get to the bottom of your issues and provide you with the support you need. You may also want to speak with your supervisor or your human resources department about how to make your work environment less stressful. Friends, family, and mentors may also be good sources of support during very stressful times.

If stress is not managed, you may progress into a state of burnout. Burnout can lead to more severe mental health issues like depression and anxiety. Burnout could also lead to other illnesses. Burnout is the gradual process by which a person detaches from work...
and other significant roles in response to prolonged stress, and it is common among people in helping professions. It is important to try to avoid burnout and to seek help when necessary.

Compassion fatigue is a form of burnout. It is a deep physical, emotional, and spiritual exhaustion accompanied by acute emotional pain.

**Table 50. Summary of compassion fatigue symptoms**

<table>
<thead>
<tr>
<th>Compassion Fatigue Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>• More frequent or misplaced anger</td>
</tr>
<tr>
<td>• Irritability</td>
</tr>
<tr>
<td>• Substance abuse: food, alcohol, or drugs</td>
</tr>
<tr>
<td>• Blaming “them”</td>
</tr>
<tr>
<td>• Being late frequently</td>
</tr>
<tr>
<td>• Depression or feelings of hopelessness</td>
</tr>
<tr>
<td>• Obsessive worry that you aren’t doing enough; irrationally high self-expectation</td>
</tr>
<tr>
<td>• Less joy toward people or activities that usually bring you happiness</td>
</tr>
<tr>
<td>• Lower sense of personal accomplishment</td>
</tr>
<tr>
<td>• Low self-esteem</td>
</tr>
<tr>
<td>• Workaholism</td>
</tr>
<tr>
<td>• Less balance between empathy and objectivity</td>
</tr>
<tr>
<td>• Hypertension</td>
</tr>
<tr>
<td>• Physical or emotional exhaustion</td>
</tr>
<tr>
<td>• Frequent headaches</td>
</tr>
<tr>
<td>• Gastrointestinal problems</td>
</tr>
<tr>
<td>• Insomnia or problems sleeping</td>
</tr>
<tr>
<td>• Frequent vague illnesses</td>
</tr>
</tbody>
</table>

**Self-Care: Taking Action to Minimize Stress**

People who work in helping professions often do not consider their own needs to be as important as those of the people they serve. However, it is important for patient navigators to recognize the signs of burn-out and actively take care of themselves, too.

- Self-care involves taking the steps necessary to maintain your physical, emotional, and social health
- Health care professionals with burnout adapt to their exhaustion by becoming less empathetic and more withdrawn
- Think of yourself as an “emotional bank account,” where the work can be
draining, even on a good day, but it is up to you to “fill it back up”

- Compassion fatigue is a sign you are not getting their needs met
- Signs of compassion fatigue are a call to action

**Tips for Self-Care**

- Find a mentor that you can talk to and learn from
- Make self-care a priority
- Do not neglect your physical or mental well-being
- Pay attention to your emotions, especially as you interact with patients
- Seek mental health services when appropriate
- Create a schedule for yourself; plan out time for work, friends and family, down time, and any other important aspects of your life
- Build and maintain positive relationships
- Become a member of a group that you find interesting
- Stay focused on meeting the goals in your professional development plan
- Do not overexert or overextend yourself; know when you need a break
- Stay positive and maintain a sense of humor
- Take responsibility for yourself
- Stay on task to meet deadlines; do not procrastinate
- Pick your battles before taking on confrontations
- Maintain your energy with proper nutrition, diet, and exercise

**Resources for Patient Navigators**

- Free Management Library’s [How to Give Useful Feedback and Advice](#): This webpage includes tips for giving and receiving feedback as well as links to other resources on the topic.
- [LinkedIn Learning](#).
- [Mindtools.com](#).
- Mayo Clinic’s [Job Burnout: How to Spot it and Take Action](#): This article discusses what burnout looks like and how to address it.
- The State University of New York at Buffalo’s [Self-Care Starter Kit](#): This kit was developed for social work students and professionals and is relevant to patient navigators.
## Appendix A. Core Competencies for Patient Navigators

### Domain 1: Patient Care
Facilitate patient centered care that is compassionate, appropriate, and effective for the treatment of cancer and the promotion of health.

1. **Assist** patients in accessing cancer care and navigating health care systems. Assess barriers to care and engage patients and families in creating potential solutions to financial, practical, and social challenges.

2. **Identify** appropriate and credible resources responsive to patient needs (practical, social, physical, emotional, spiritual), taking into consideration reading level, health literacy, culture, language, and amount of information desired. For physical concerns, emotional needs, or clinical information, refer to licensed clinicians.

3. **Educate** patients and caregivers on the multi-disciplinary nature of cancer treatment, the roles of team members, and what to expect from the health care system. Provide patients and caregivers evidence-based information and refer to clinical staff to answer questions about clinical information, treatment choices, and potential outcomes.

4. **Invite** patients to communicate their preferences and priorities for treatment to their health care team; facilitate shared decision making in the patient’s health care.

5. **Invite** patients to participate in their wellness by providing self-management and health promotion resources and referrals.

6. Follow up with patients to support adherence to agreed-upon treatment plan through continued non-clinical barrier assessment and referrals to supportive resources in collaboration with the clinical team.

### Domain 2: Knowledge for Practice
Demonstrate a basic understanding of cancer, health care systems, and how patients access care and services across the cancer continuum to support and assist patients.

NOTE: This domain refers to foundational knowledge applied across other domains

1. **Demonstrate** basic knowledge of medical and cancer terminology.

2. **Demonstrate** familiarity with and know how to access and reference evidence-based information regarding cancer screening, diagnosis, treatment, and survivorship.

3. **Demonstrate** basic knowledge of cancer, cancer treatment, and supportive care options, including risks and benefits of clinical trials and integrative therapies.
2.4 Demonstrate basic knowledge of health system operations.

2.5 Identify potential physical, psychological, social, and spiritual impacts of cancer and its treatment.

2.6 Demonstrate general understanding of health care payment structure, financing, and where to refer patients for answers regarding insurance coverage, and financial assistance.

**Domain 3: Practice Based Learning and Improvement**

Improve patient navigation process through continual self evaluation and quality improvement. Promote and advance the profession.

3.1 Contribute to patient navigation program development, implementation, and evaluation.

3.2 Use evaluation data (barriers to care, patient encounters, resource provision, population health disparities data, and quality indicators) to collaboratively improve the navigation process and participate in quality improvement.

3.3 Incorporate feedback on performance to improve daily work.

3.4 Use information technology to maximize the efficiency of patient navigator’s time.

3.5 Continually identify, analyze, and use new knowledge to mitigate barriers to care.

3.6 Maintain comprehensive, timely, and legible records capturing ongoing patient barriers, patient interactions, barrier resolution, and other evaluation metrics and report data to show value to administrators and funders.

3.7 Promote navigation role, responsibilities, and value to patients, providers, and the larger community.

**Domain 4: Interpersonal and Communication Skills**

Demonstrate interpersonal and communication skills that result in the effective exchange of information and collaboration with patients, their families, and health professionals.

4.1 Assess patient capacity to self-advocate; Help patients optimize time with their doctors and treatment team (e.g. prioritize questions, clarify information with treatment team).

4.2 Communicate effectively with patients, families, and the public to build trusting relationships across a broad range of socioeconomic and cultural backgrounds.

4.3 Employ active listening and remain solutions-oriented in interactions with patients,
families, and members of the health care team.

4.4 Encourage active communication between patients/families and health care providers to optimize patient outcomes.

4.5 Communicate effectively with navigator colleagues, health professionals, and health-related agencies to promote patient navigation services and leverage community resources to assist patients.

4.6 Demonstrate empathy, integrity, honesty, and compassion in difficult conversations.

4.7 Know and support National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care to advance health equity, improve quality, and reduce health disparities.

4.8 Apply insight and understanding about emotions and human responses to emotions to create and maintain positive interpersonal interactions.

**Domain 5: Professionalism**

Demonstrate a commitment to carrying out professional responsibilities and an adherence to ethical principles.

5.1 Apply knowledge of the difference in roles between clinically licensed and non-licensed professionals and act within professional boundaries.

5.2 Build trust by being accessible, accurate, supportive, and acting within the scope of practice.

5.3 Use organization, time management, problem-solving, and critical thinking to assist patients efficiently and effectively.

5.4 Demonstrate responsiveness to patient needs within scope of practice and professional boundaries.

5.5 Know and support patient rights.

5.6 Demonstrate sensitivity and responsiveness to a diverse patient population, including but not limited to diversity in gender, age, culture, race, religion, abilities, and sexual orientation.

5.7 Demonstrate a commitment to ethical principles pertaining to confidentiality, informed consent, business practices, and compliance with relevant laws, policies, and regulations (e.g. HIPAA, agency abuse reporting rules, Duty to Warn, safety contracting).
<table>
<thead>
<tr>
<th>5.8</th>
<th>Perform administrative duties accurately and efficiently.</th>
</tr>
</thead>
</table>

**Domain 6: Systems Based Practice**

Demonstrate an awareness of and responsiveness to the larger context and system of health care, as well as the ability to call effectively on other resources in the system to provide optimal health care.

- **6.1** Work with a patient’s clinical care team to support a smooth transition across screening, diagnosis, active treatment, survivorship, and/or end-of-life care.
- **6.2** Advocate for quality patient care and optimal patient care systems.
- **6.3** Organize and prioritize resources to optimize access to care across the cancer continuum for the most vulnerable patients.

**Domain 7: Interprofessional Collaboration**

Demonstrate ability to engage in an interprofessional team in a manner that optimizes safe, effective patient and population centered care.

- **7.1** Work with other health professionals to establish and maintain a climate of mutual respect, dignity, diversity, ethical integrity, and trust.
- **7.2** Use knowledge of one’s role and the roles of other health professionals to appropriately assess and address the needs of patients and populations served to optimize health and wellness.
- **7.3** Participate in interprofessional teams to provide patient- and population-centered care that is safe, timely, efficient, effective, and equitable.

**Domain 8: Personal and Professional Development**

Demonstrate qualities required to sustain lifelong personal and professional growth.

- **8.1** Set learning and improvement goals. Identify and perform learning activities that address one's gaps in knowledge, skills, attitudes, and abilities.
- **8.2** Demonstrate healthy coping mechanisms to respond to stress; employ self-care strategies.
- **8.3** Manage possible and actual conflicts between personal and professional responsibilities.
- **8.4** Recognize that ambiguity is part of patient care and respond by utilizing appropriate resources in dealing with uncertainty.
## Appendix B. Medical Specialties Involved in Cancer Care

<table>
<thead>
<tr>
<th>Medical Specialty</th>
<th>Relevance to Cancer Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allergy and Immunology</td>
<td>Specialize in evaluation, diagnosis and management of diseases related to immune system</td>
</tr>
<tr>
<td>Anesthesiology</td>
<td>Provide pain relief during or following the surgery, diagnostic or other procedures</td>
</tr>
<tr>
<td>Colon and Rectal Surgery</td>
<td>Treat intestinal tract, colon, rectum, anal canal, and perianal cancer types</td>
</tr>
<tr>
<td>Dermatology</td>
<td>Identify skin toxicity due to cancer treatment and other skin reactions</td>
</tr>
<tr>
<td>Emergency Medicine</td>
<td>Immediate care for injuries, acute illness, or other life-threatening conditions</td>
</tr>
<tr>
<td>Family Medicine</td>
<td>Manage general conditions of patients, perform screening and evaluation, and care coordination</td>
</tr>
<tr>
<td>Family Practice</td>
<td>General care of patients to optimize total health care</td>
</tr>
<tr>
<td>Internal Medicine</td>
<td>Manage long-term comprehensive care for common and complex illnesses in hospital and office settings</td>
</tr>
<tr>
<td>Internal Medicine-Pediatrics</td>
<td>Manages complex care for pediatric patients</td>
</tr>
<tr>
<td>Medical Genetics</td>
<td>Identify genetic disorders and birth defects</td>
</tr>
<tr>
<td>Neurological Surgery</td>
<td>Specialize in care management for disorders related to different nervous systems</td>
</tr>
<tr>
<td>Neurology</td>
<td>Treat illness or impaired function of the brain, spinal cord, peripheral and autonomic nervous systems</td>
</tr>
<tr>
<td>Nuclear Medicine</td>
<td>Specialize in cancer detection</td>
</tr>
<tr>
<td>Obstetrics and Gynecology</td>
<td>Manage women care before, during, and after the pregnancy; in addition, diagnosis and treatment of disorders related to female reproductive system</td>
</tr>
<tr>
<td>Ophthalmology</td>
<td>Manage treatment of eye tumors</td>
</tr>
<tr>
<td>Orthopedic Surgery</td>
<td>Restore form and functions of various parts of the body, such as extremities, spine, and other conditions</td>
</tr>
<tr>
<td>Otolaryngology</td>
<td>Treat cancers related to head, neck, ear, nose, or throat</td>
</tr>
<tr>
<td>Pathology-Anatomic and Clinical</td>
<td>Identify causes and nature of the disease</td>
</tr>
<tr>
<td>Pediatrics</td>
<td>Specialize in child cancer care</td>
</tr>
<tr>
<td>Physical Medicine and</td>
<td>Improve cancer related symptoms to enhance quality of</td>
</tr>
<tr>
<td>Medical Field</td>
<td>Description</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>life</td>
</tr>
<tr>
<td>Plastic Surgery</td>
<td>Perform reconstructive surgery as cancer treatment and prevention</td>
</tr>
<tr>
<td>Psychiatry</td>
<td>Provide treatment to improve quality of life of cancer patients by reducing distress, anxiety, and other cancer related psychosocial and cognitive effects</td>
</tr>
<tr>
<td>Radiation Oncology</td>
<td>Manage radiation therapy for cancer treatment by reducing the symptoms or preserving organ functions</td>
</tr>
<tr>
<td>Radiology-Diagnostic</td>
<td>Diagnose a wide range of cancer types</td>
</tr>
<tr>
<td>Sleep Medicine</td>
<td>Specialize in treatment of sleep related issues</td>
</tr>
<tr>
<td>Surgery-General</td>
<td>Provide surgical treatment for a broad spectrum of diseases</td>
</tr>
<tr>
<td>Thoracic Surgery</td>
<td>Specialize in treatment of cancers that have originated in the chest area, such as esophagus and lung cancers</td>
</tr>
<tr>
<td>Urology</td>
<td>Manage treatment of cancers related to male genitourinary system, female urinary tract, and the adrenal gland</td>
</tr>
</tbody>
</table>

*The table was adapted from a list created by the Association of American Medical Colleges*
### Appendix C. Navigator Types and Roles

<table>
<thead>
<tr>
<th>FUNCTIONAL AREA</th>
<th>COMMUNITY (Community Health Worker)</th>
<th>COMMUNITY/HEALTH CARE INSTITUTION (Patient Navigator)</th>
<th>HEALTH CARE INSTITUTION (Nurse Navigator/Social Work Navigator)</th>
</tr>
</thead>
</table>
| **Professional Roles and Responsibilities** | - General knowledge base on health issues such as diabetes, obesity, heart disease, stroke, HIV/AIDS, and other chronic diseases  
- Active documentation in the client record  
- Conduct evaluation focused on community needs assessment and health behaviors | - Knowledge of cancer screening, diagnosis, treatment, and survivorship and related physical, psychological, and social issues  
- Active documentation of encounter with a patient, barriers to care, and resources or referrals to resolve barriers, which may be noted in the client record and/or the medical record  
- Conduct evaluation focused on barriers to care, health disparities, and quality indicators | - Knowledge and maintenance of knowledge (e.g., license certification, continuing education) of cancer clinical impacts on patient, caregivers, and families, and ability to intervene (e.g., symptom management, assessment of functional status, and psychosocial health)  
- Active documentation in the medical record  
- Conduct evaluation focused on clinical outcomes and quality indicators |
| **Barriers to Care/Health Disparities** | - Address barriers to accessing the health care system  
- Focus on reduction of general health | - Address structural, cultural, social, emotional, and administrative barriers to care | - Address clinical and service delivery barriers to care  
- Provision of services to at-risk populations,
<table>
<thead>
<tr>
<th>Disparities</th>
<th>Focus on reduction of cancer health disparities in medically underserved patients and timely access to care across the continuum which may be defined by individual need, high acuity, or high volume at the institutional level</th>
</tr>
</thead>
</table>
| **Patient Empowerment** | - Motivate individuals and the community to make positive changes in health behaviors  
- Activate and support empowerment of individuals and communities to self-advocate and make healthy decisions  
- Assist patients with identifying administrative, structural, social, and practical issues to participate in decision-making and solutions  
- Ensure patients know all their available options  
- Invite patients to self-manage their health by assisting with health care access and working with the patient to identify their preferences and priorities  
- Educate patients on their rights and preferences and ensure they are able to participate in the decision-making process throughout their care and into survivorship or end-of-life care  
- Assist patients in decision-making regarding diagnostic testing and treatment options (Nurse Navigators)  
- Provide patients with strategies to cope with the disease, treatment, and stress (Social Work Navigators)  
- Educate patients on their rights and preferences, and ensure they are able to participate in the decision-making process throughout their care and into survivorship or end-of-life care |
| **Communication** | their care and into survivorship or end-of-life care. Work in collaboration with licensed team members | - Promote healthy behaviors  
- Facilitate communication with the community about access and utilization of the health care system | - Assist patient and provider with communicating expectations, needs, and perspectives | - Provide translation and communication of clinical information (Nurse Navigators)  
- Provide counseling through one-on-one communication and serve as a conduit between patients and providers to address the emotional and psychosocial needs of patients (Social Workers) |
| **Community Resources** | - Provide referral to evidence-based health promotion programs  
- Aid with accessing health insurance | - Aid with scheduling appointments and facilitate request and follow-up with specialists or supportive care based on clinical referral  
- Aid with accessing health insurance, copay programs, and financial assistance | - Focus on clinically oriented resources, such as referrals for second opinions, treatment, or testing that may not be offered at the patient’s institution, as well as supportive or specialty referrals within or external to the institution (Nurse Navigators)  
- Aid in identifying community resources |
| **Education, Prevention, and Health Promotion** | - Provide general health promotion at the individual and community level, including:  
  - physical activity  
  - healthy eating habits  
  - stress reduction  
  - sunscreen use  
  - tobacco cessation  
  - reduction of other risky behaviors | - Educate patients on practical concerns and next steps in treatment with regard to what to expect  
  - Identify the educational needs of patients to advocate on their behalf with the care team  
  - Inform patients of the importance and benefit of clinical trials and connect them with additional resources | - Assess the educational needs of patients  
  - Identify the educational needs of patients to advocate on their behalf with the care team  
  - Inform patients of the importance and benefit of clinical trials and connect them with additional resources  
  - Provide clinical education (Nurse Navigators) |
<p>| <strong>Ethics and Professional Conduct</strong> | - Abide by the state-defined scope of practice | - Understand differences in scope of practice between licensed professionals and non-licensed professionals | - Abide by the ethical principles in the profession’s scope of practices and code of conduct according to licensure |
| <strong>Cultural Competency</strong> | - Act as community/cultural liaison and mediator between community and health care system using | - Provide navigation services in a culturally competent manner (e.g., National Culturally and Linguistically) | - Provide clinical care and education materials in a culturally competent manner |</p>
<table>
<thead>
<tr>
<th></th>
<th>culturally appropriate educational materials</th>
<th>Appropriate Services (CLAS) Standards in Health and Health Care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Outreach</strong></td>
<td>- Work with the community to identify education needs and opportunities</td>
<td>- Educate providers to increase their understanding of the community’s history, culture, and needs</td>
</tr>
<tr>
<td></td>
<td>- Educate on cancer-related topics to reduce fears and barriers related to cancer screening</td>
<td>- Effectively link patients referred from the community to resources that can improve care coordination and timeliness to treatment</td>
</tr>
<tr>
<td></td>
<td>- Consult and counsel patients on their unique risks</td>
<td>-</td>
</tr>
<tr>
<td><strong>Psychosocial Support Services/Assessment</strong></td>
<td><strong>- Identify resources in the community for emotional and social support</strong></td>
<td><strong>- Administer distress screening and aid with administrative, practical, or social issues identified</strong></td>
</tr>
<tr>
<td><strong>Advocacy</strong></td>
<td><strong>- Speak up for individual and community needs</strong></td>
<td><strong>- Educate providers on individual preferences of care and needs</strong></td>
</tr>
</tbody>
</table>
Appendix D. Sample Position Description: Patient Navigator

**Basic Function**

The Patient Navigator works in a dynamic health care environment within one or more departments providing one-on-one assistance to patients, navigating them through the health care system to ensure timely screening, diagnosis, treatment, and/or post-treatment cancer care and supportive services. They work with other health care professionals to establish and maintain a climate of mutual respect, dignity, diversity, ethical integrity, and trust and participate in multi-disciplinary teams to provide patient care that is safe, timely, efficient, effective, and equitable. They use knowledge of one’s role and the roles of other health care professionals to appropriately assess and address the needs of patients served to optimize health and wellness. They are expected to set learning and improvement goals; identify and perform learning activities that address one’s gaps in knowledge, skills, attitudes, and abilities; and respond to feedback to improve professional performance and patient care.

**Characteristic Duties**

- Assist patients in accessing cancer care and navigating health care systems.
- Assess barriers to care and engage patients and families in creating potential solutions to financial, practical, and social challenges.
- Identify appropriate and credible resources responsive to patient needs (practical, social, physical, emotional, spiritual), taking into consideration reading level, health literacy, culture, language, and amount of information desired. Refer to licensed clinicians for physical concerns, emotional needs, or clinical education.
- Educate patients and caregivers on the multi-disciplinary nature of cancer treatment, the roles of team members, and what to expect from the health care system. Provide patients and caregivers evidence-based information and refer to clinical staff to answer questions about clinical information, treatment choices, and potential outcomes.
- Invite patients to communicate their preferences and priorities for treatment to their health care team; facilitate shared decision making in the patient’s health care.
- Invite patients to participate in their wellness by providing self-management and health promotion resources and referrals.
• Follow up with patients to support adherence to agreed-upon treatment plan through continued non-clinical barrier assessment and referrals to supportive resources in collaboration with the clinical team. Contribute to patient navigation program development, implementation, and evaluation.
• Assess patient capacity to self-advocate; Help patients optimize time with their doctors and treatment team (e.g. prioritize questions, clarify information with treatment team).
• Encourage active communication between patients/families and health care providers to optimize patient outcomes.

Related Duties

• Performs special project assignments required to support the implementation and evaluation of patient navigation.
• Assists with care coordination of patients.
• Enhances professional knowledge/skills by identifying and participating in continuing education opportunities.
• Performs other non-clinical work-related duties as requested.

Supervision Received

Supervision is received from _______.

Qualifications and Skills Required

Basic understanding of medical terminology, health care systems, and health care financing required. Proficiency with a personal computer is necessary. Demonstrated fluency in English [Insert any language requirements here]. In addition, the patient navigator must be able to:

• Work cooperatively and communicate effectively with a wide range of individuals, including patients and family members from diverse socioeconomic and cultural backgrounds, health care professional colleagues, and external health- and service-focused organizations.
• Employ active listening and remain solutions-oriented in interactions with patients, families, and members of the health care team.
• Demonstrate empathy, integrity, honesty, and compassion in difficult conversations.
• Apply insight and understanding about emotions and human responses to emotions to create and maintain positive interpersonal interactions.
• Apply knowledge of the difference in roles between clinically licensed and non-licensed professionals and act within professional boundaries. Excellent communication, organizational, and interpersonal skills are necessary.

Working Conditions

The incumbent performs job duties in a typical business office environment and/or in a community-based setting exterior to the typical business office environment. Tasks are generally carried out in a sedentary format within the business environment. This involves working while sitting at a desk for extended periods of time; exterior working environments require standing and/or walking for extended periods of time. Typically, the incumbent will not be exposed to adverse weather conditions or physical activities in order to perform the job other than occasionally lifting office supply items that may weigh up to 20 pounds. The incumbent will be required to attend meetings in other offices or deliver and/or retrieve information from other offices around campus and within community-based settings.
Appendix E. I Want You to Know

This “I Want You to Know” printable card can help patients begin a conversation with their provider about their identity and care preferences. Versions of the cards are available in English, Spanish and Chinese (simplified). A GW Cancer Center-branded and blank (no logo) versions are also available.
Appendix F. The Problem-Solving Cycle

Not all people have good problem-solving skills, especially during times of crisis. Your goal is not to solve people’s problems for them. This should be a collaborative process that includes the patient.

1. Define and clarify the issue to make sure you understand the patient’s issue

Questions to ask:
- What is the problem?
- Does the problem need to be broken down into smaller issues? How urgent or important is the problem?
- Does the problem affect the patient’s ability to continue with a test or treatment? Can the patient move ahead with tests or treatment without solving the problem? What will happen if the problem is not solved?
- Will the patient be unable to stay in treatment?
- Will the problem go away when a family member leaves? Can the patient navigator help?

2. Gather and verify facts

Questions to ask:
- What is getting in the way of solving the problem? Consider thoughts, feelings, motivations, and barriers.
3. **Identify Key Players**

Many barriers require the help of other people such as family members, case workers, social workers, or other agencies. Figure out what the key players can and can’t do to help address the problem. Provide feedback to make sure you understand the patient’s issue.

Questions to ask:
- Who can help?
- What is each person able to do?

4. **Brainstorm**

Keep your feedback positive and work in open-ended questions that help you and the patient brainstorm potential solutions.

Questions to ask:
- Who needs to be there?
- When someone is sick, what usually happens at your work?
- If you have to go somewhere or have a special event, how have you asked for the day off? What do you think your coworkers would do in your situation?

5. **Weigh pros and cons**

6. **The patient chooses best option based on the pros and cons**

Based on the pros and cons, the patient should choose the best option. The patient navigator can provide support during this process, but the navigator should not make decisions or provide recommendations to the patient.

7. **Develop an action plan**

The personal action plan should describe who will do what activities with a deadline. Make sure the patient agrees with the plan. Share the plan with the practice team and patient’s social support. The action plan should outline the following key items:
- Specific goals in behavioral terms
- Barriers and strategies to address barriers
- A follow-up plan
8. Follow up to see if the issue is resolved

See if the issue has been resolved and repeat the process as necessary. You may need to repeat the process again if new barriers have come up or revisit other ideas if barriers continue. If there are changes, then the action plan will need to be updated as well.

Not Able to Solve the Problem?

You will not be able to solve every patient's problem or address every barrier. When you are not able to solve a problem with the patient, they may need additional coaching or counseling. You should tell the patient that you want a colleague to help them. With the patient’s permission, bring in a counselor or a social worker to work with the patient.
Appendix G. Tips for Assessing Patient Support Networks

1. Accessibility:
   • Is a geographic, time, or financial constraint caregiver able to help with?

2. Willingness to offer support:
   • Are people enthusiastic about helping?
   • Have they offered their support?

3. Strains with individuals:
   • Are there interpersonal strains or stressors with an individual or within a support network?

4. Relationship patterns:
   • Is the patient closely involved with people in their support network?
   • Would it be awkward to ask some for help because they have a more distant relationship with the patient?

Enhancing Patient Support Networks:

1. Assess patient support needs:
   • Assess patient’s needs
   • Assess patient’s readiness to accept help

2. Assess support network:
   • What can supportive individuals provide?
   • Be practical about available support

3. Match patient’s needs with available support:
   • Maximum benefit when social support matches the patient’s need
Appendix H. Health Literacy Checklists and Tips

**Health Literacy Checklist: Low Literacy**

- Makes Excuses Not to Read on the Spot
- Points to Text While Reading
- Eyes Don’t Find a Central Focus
- Identifies Medications by Size, Color, or Shape
- Gives Incorrect Answers When Asked About What They Have Read
- Incomplete or Poorly Completed Paperwork

**Health Literacy Checklist: Difficulty Comprehending Health Information**

- Has Difficulty with Abstract Concepts
- Poor Medication Adherence
- Missed Appointments
- Nervousness, Confusion, Frustration, or Indifference in Complex Learning Situations
- Provides Incomplete Medical Information
- Withdraws When Complex Information is Presented

To assess health literacy, try asking these questions:

- How happy are you with the way you read?
- When you have to learn something, how do you prefer to learn the information?
- How often do you have problems learning about your medical condition because of difficulty understanding written information?
- How confident are you in filling out medical forms by yourself?
If you can only ask one question, ask about how confident the patient is filling out information by himself or herself.

To address these issues, you may need to:

- Offer to help patients with completing forms and do this confidentially and privately
- Simplify and clarify instructions
- Spend more time making sure the patient understands
- Have the patient repeat information back to you
- Adapt your interaction style to better fit their ability (for example, pause more often to ask the patient to repeat what they heard)
- Select more appropriate resources that are tailored to their literacy abilities
- Use visual aids and provide maps to referral sites
**Appendix I. Sample Resource Directory***

This sample resource directory is also available for download and modification.

<table>
<thead>
<tr>
<th>Organization Profile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
</tr>
<tr>
<td>Contact Information</td>
</tr>
<tr>
<td>Organization Name</td>
</tr>
<tr>
<td>Address City, State, Zip Code</td>
</tr>
<tr>
<td>Email</td>
</tr>
</tbody>
</table>

**Resource Information**

**Type of Organization**
- □ Agency
- □ Business
- □ Community-based organization
- □ School
- □ Informal neighborhood organization
- □ Religious/spiritual organization
- □ Other:

**Services provided for patients typically served by navigator with specific conditions?**
- □ Yes
- □ No

**Type of patients served:**

**Eligibility requirements:**

**Application process**
- □ Applied/Pending
- □ Need to apply
- □ Applied/Approved
- □ Program Name:

**Time for application to be reviewed and approved:**

**Limitation on services:**

**Fees**
- □ Fee for service: $_____________
- □ No Fee for service

**Bilingual**
- □ Bilingual staff available and someone who answers the phone in _______language

**Comments**

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*This source is no longer posted online.*
Appendix J. Framework for Ethical Decision-Making

The following framework can be used to guide your ethical decision-making.

**Step 1: Recognize an Ethical Issue Is Present**
- Is this situation or decision potentially damaging to an individual or group?
- Is the decision a choice between a “good” vs. “bad” alternative? Between two “goods”? Between two “bads”?
- Does the issue go beyond what is legal? Or is it more about what is more efficient? How so?

**Step 2: Gather the Relevant Facts**
- What are the known, relevant facts? What facts are unknown? Is there more to learn about the situation before making a decision? Do you have enough information to make an informed decision?
- Make sure that you collect all the relevant information needed to take action.
- Who has an important stake in the outcome? Which individuals or groups are your “stakeholders”? Are there some concerns that are more important than others, and if so, why?
- As a patient navigator, your primary concern is your patient. Find out the patient’s concerns and how they are impacted by this situation.
- What are your options? Have you consulted with all the relevant stakeholders? Have you considered creative options for action?

**Step 3: Compare and Consider Alternative Actions**
- Utilitarian Approach: Option that does the most good and least harm?
- Rights Approach: Option that best respects the rights of all stakeholders?
- Ep Justice Approach: Option that treats all people equally and proportionately?
- Common Good Approach: Option that best serves the whole community (not just some people)?
- Virtue Approach: Option that empowers you to act as the type of person you’d like to be?
Step 4: Make a Decision and Test It

- After looking at all the options, which is best for this situation?
- Perform a thought exercise: If you shared your choice with someone else (e.g., someone you respect or a television audience), what would they say?

Step 5: Act and Reflect on the Outcome

- How can my decision be implemented with the greatest care and attention to the concerns of all stakeholders?
- How did my decision turn out and what have I learned from this specific situation?

*This information was adapted from the Lee D, Lim JYS, Phoon KF. Foundations for Fintech. Hackensack, NJ: World Scientific; 2021.
Appendix K. Example Patient Tracking Tool

You can use Excel to create patient tracking tool or check out PN-BOT™ (only available for PCs).

<table>
<thead>
<tr>
<th>BARRIER TYPE</th>
<th>DATE ASSESSED</th>
<th>DATE RESOLVED</th>
<th>ACTION TAKEN</th>
<th>TIME TO RESOLVE BARRIER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Logistical Barriers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td></td>
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<tr>
<td>Housing</td>
<td></td>
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<tr>
<td>Utilities</td>
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<tr>
<td>Dependent Care</td>
<td></td>
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<tr>
<td>Food and Nutrition</td>
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<tr>
<td>Clothing</td>
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<tr>
<td>Immigration Status</td>
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<tr>
<td>Insurance Barriers</td>
<td></td>
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<tr>
<td>Uninsured</td>
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<tr>
<td>Underinsured</td>
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<tr>
<td>High Deductible/ Copays</td>
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<tr>
<td>Financial Barriers</td>
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<tr>
<td>Financial Planning</td>
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<tr>
<td>Low Financial Literacy</td>
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<tr>
<td>Other Non-medical Financial Needs</td>
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<tr>
<td>Employment Barriers</td>
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<tr>
<td>Unemployed</td>
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</tr>
<tr>
<td>Job Accommodations</td>
<td></td>
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<tr>
<td>Ability to Work through Treatment</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Family Member's Employment</td>
<td>Communication Barriers</td>
<td>Language Literacy</td>
<td>Health Literacy</td>
<td>Patient Empowerment</td>
</tr>
<tr>
<td>----------------------------</td>
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<td>---------------------</td>
</tr>
<tr>
<td>Care Coordination Barriers</td>
<td>Coordinating Appointments</td>
<td>Coordinating Referrals</td>
<td>Other</td>
<td></td>
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<tr>
<td>Distress Barriers</td>
<td>Difficulty Coping with Diagnosis</td>
<td>Difficulty Coping with Treatment</td>
<td>Difficulty Coping with Survivorship</td>
<td>Difficulty Coping with End of Life</td>
</tr>
<tr>
<td>Cultural and Religious Barriers</td>
<td>Beliefs Conflict with Treatment</td>
<td>Fear or Negative Perceptions</td>
<td>Stigma or Discrimination</td>
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<tr>
<td>TOTAL</td>
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</table>

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