



Guide for Patient Navigators

A Supplement to the Oncology Patient Navigator Training: The Fundamentals

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MODULE 1: Welcome

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

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Competency Development Steering Committee

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Competency Reviewers

We thank the competency reviewers: Amanda Allison, Susan Bowman, RN, OCN, CBCN, MSW, Elizabeth Clark, Ph.D., MPH, MSW, Margaret Darling, Andrea Dwyer, MSW, Ginny Pate, Angela Patterson, Terri Salter, RN, MSN, MBA, Karen Schwaderer, RN, BSN, OCN, Lillie Shockney, RN, BS, MAS, Patricia Valverde, Ph.D., MPH, Etta-Cheri Washington.

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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 Competencies¹⁻²⁴

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

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.

MODULE 3: The Basics of Health Care

LESSON 1: Medical Terminology²⁵⁻³⁴

Learning Objectives

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

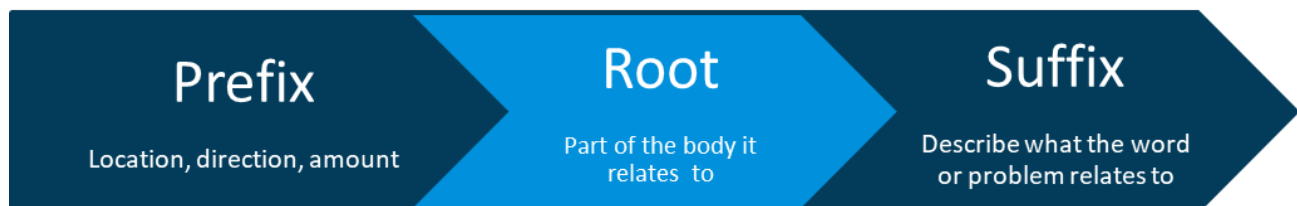
Key Takeaways

- 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

PREFIX	WHAT IT DESCRIBES	EXAMPLE
AN-, A-	without/lack of	anemia = lack of red blood cells
AB-	away from	abnormal = away from the normal
AD-	near/toward	adrenal gland = gland near to the kidney
BI-	two/both	bilateral Wilm's = tumor in both kidneys
DYS-	difficult/painful	dysfunction = not working properly
ECTO-	outside	ectopic pregnancy = outside the uterine cavity
ENDO-	inside	endoscope = an instrument to look inside the body cavities or organs
EPI-	upon	epidermis = the outer layer of skin
HYPER-	excessive/above	hyperglycemia = excessive blood sugar levels
HYPO-	beneath/below	hypodermic = injection below the skin
INTER-	between	intercostal = between the ribs
INTRA-	within/inside	intravenous = into a vein
PARA-	beside/about/near	parathyroid = beside the thyroid gland

PREFIX	WHAT IT DESCRIBES	EXAMPLE
PERI-	around	pericardium = membrane around the heart
PRE-	before	prenatal = before birth
POST-	after	post-surgical stage = stage after surgery
SUB-	under/below	submucosa = tissue below mucus membrane
SYN-	together with	syndrome = group of symptoms occurring together

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

SIZE	DIRECTION AND LOCATION
Macro (large)	Hyper (fast, elevated, overproducing, energetic)
Micro (small)	Hypo (slow, low, under-producing, low energy)
Megalo or Megaly (abnormally large)	Tachy (rapid)
	Brady (slow)
	Extra (outside, excess, beyond)
	Endo (within)

SIZE	DIRECTION AND LOCATION
	Intra (within)
	Inter (between, together, during)
	Peri (about, around, surround)
	Trans (across, beyond, through)

Root words help you know which part of the body a word relates to.

Table 3. Examples and descriptions of roots

ROOT	WHAT IT DESCRIBES	EXAMPLE
BLAST-	germ, immature cell	blastoma = cancer made of immature cells
CARCINO-	cancer	carcinogenic = cancer-causing
CARDIO-	heart	cardiotoxicity = toxicity to the heart
CYTO-	cell	cytotoxic = toxic to the cell
DERMA-	skin	dermatitis = inflammation of the skin
HISTO-	tissue	histology = study of tissue
HEPATI-	liver	hepatoblastoma = liver cancer
MALIGN-	bad/harmful	malignant = growing, spreading
NEPHRO-	kidney	nephrotoxic = harmful to the kidneys
NEURO-	nerves	neuroblast = an immature nerve cell
ONCO-	mass/tumor	oncology = the study of cancer
OSTEO-	bone/bony tissue	osteosarcoma = bone cancer
PAED-	child	pediatric oncology = study of childhood cancer
SARCO-	tissue	sarcoma = tumor of bone, muscle, or connective tissue
TOXO-	poison	toxicology = study of poisons

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

SUFFIX	WHAT IT DESCRIBES	EXAMPLE
-AEMIA	condition of blood	leuk emia = cancer of blood cells
-ECTOMY	excision/removal	neph ectomy = excision of a kidney
-ITIS	inflammation	hepat itis = inflammation of the liver
-OLOGY	study/science of	cyt ology = the study of cells
-OMA	tumor	retinoblast oma = tumor of the eye
-PATHY	disease	neuro pathy = disease of the nervous system
-OSIS	disease/condition	necr osis = dying cells

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, (neph-)(-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

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

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 meanings²⁵

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

Medical Terminology Cheat Sheet^{25,27}

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

PREFIX	WHAT IT DESCRIBES	EXAMPLE
AN-, A-	without/lack of	a nemia = lack of red blood cells
AB-	away from	ab normal = away from the normal
AD-	near/toward	ad renal gland = gland near to the kidney
BI-	two/both	bi lateral Wilm's = tumor in both kidneys

PREFIX	WHAT IT DESCRIBES	EXAMPLE
DYS-	difficult/painful	dys function = not working properly
ECTO-	outside	ecto pic pregnancy = outside the uterine cavity
ENDO-	inside	endo scope = an instrument to look inside the body cavities or organs
EPI-	upon	epi dermis = the outer layer of skin
HYPER-	excessive/above	hyper glycemia = excessive blood sugar levels
HYPO-	beneath/below	hypo dermic = injection below the skin
INTER-	between	inter costal = between the ribs
INTRA-	within/inside	intra venous = into a vein
PARA-	beside/about/near	para thyroid = beside the thyroid gland
PERI-	around	peri cardium = membrane around the heart
PRE-	before	pre natal = before birth
POST-	after	post -surgical stage = stage after surgery
SUB-	under/below	sub mucosa = tissue below mucus membrane
SYN-	together with	syn drome = group of symptoms occurring together
ROOT	WHAT IT DESCRIBES	EXAMPLE
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CARCINO-	cancer	carcino genic = cancer causing
CARDIO-	heart	cardio toxicity = toxicity to the heart
CYTO-	cell	cyto toxic = toxic to the cell
DERMA-	skin	derma titis = inflammation of the skin
HISTO-	tissue	histo logy = study of tissue
HEPATI-	liver	hepat oblastoma = liver cancer
MALIGN-	bad/harmful	malign ant = growing, spreading
NEPHRO-	kidney	nephro toxic = harmful to the kidneys
NEURO-	nerves	neuro blast = an immature nerve cell
ONCO-	mass/tumor	onco logy = the study of cancer
OSTEO-	bone/bony tissue	oste osarcoma = bone cancer
PAED-	child	pedi atric oncology = study of childhood cancer
SARCO-	tissue	sarco ma = tumor of bone, muscle, or connective tissue
TOXO-	poison	toxi cology = study of poisons

SUFFIX	WHAT IT DESCRIBES	EXAMPLE
-AEMIA	condition of blood	leuk emia = cancer of blood cells
-ECTOMY	excision/removal	neph rectomy = excision of a kidney
-ITIS	inflammation	hepat itis = inflammation of the liver
-OLOGY	study/science of	cyt ology = the study of cells
-OMA	tumor	retinoblast oma = tumor of the eye
-PATHY	disease	neurop athy = disease of the nervous system
-OSIS	disease/condition	necr osis = dying cells

Resources for Patient Navigators

- American Cancer Society's [Guide to Treatment Types](#): 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](#): 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](#): 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 Basics³⁵⁻⁸³

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^{35,36,80}

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 8. Difference between normal cells and tumors

NORMAL CELLS	TUMORS
<ul style="list-style-type: none"> • Can undergo hyperplasia or dysplasia and become cancerous 	<ul style="list-style-type: none"> • Can be benign or malignant

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

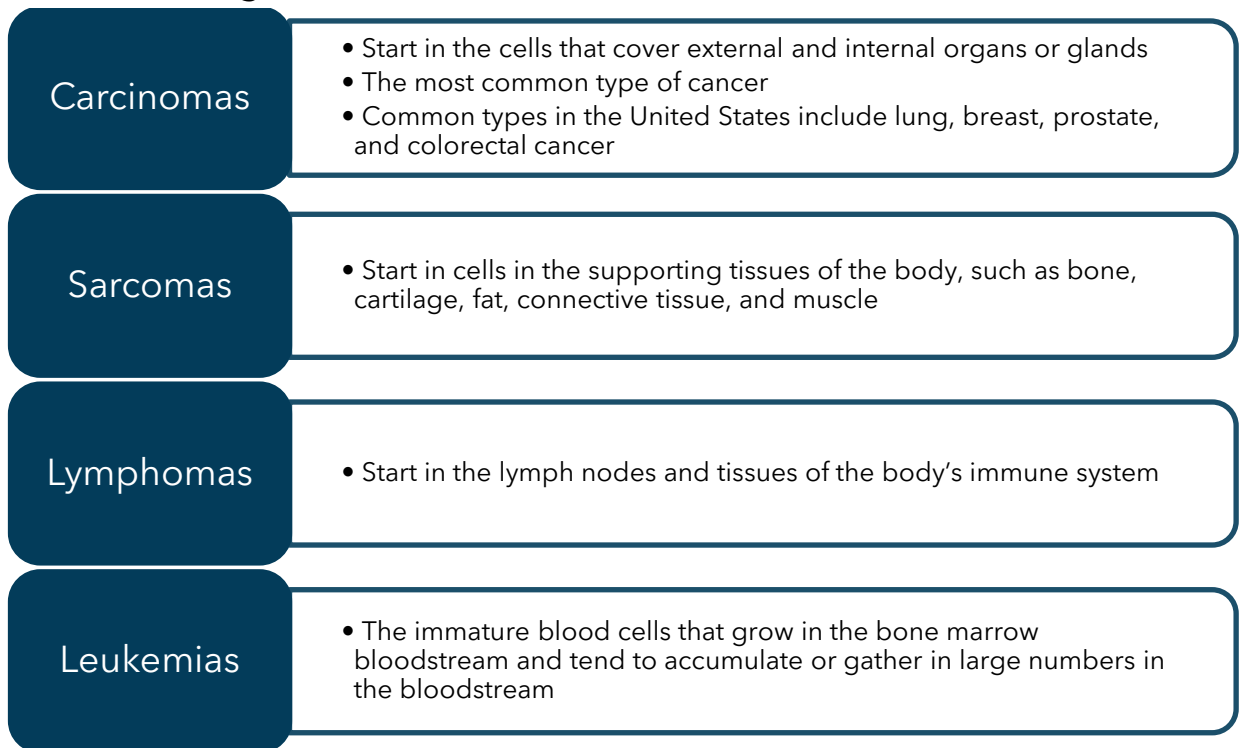
made up of abnormal cells, invade tissue, and/or spread to other places in the body. Cancer spread is known as *metastasis*.

Table 9. Difference between benign and malignant tumors

BENIGN	MALIGNANT
<ul style="list-style-type: none"> • Non-cancerous • Do not grow into other tissue 	<ul style="list-style-type: none"> • Cancerous • Invade tissue or spread

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



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 “osteo” 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

PREFIX	MEANING
ADENO-	gland
CHONDRO-	cartilage
ERYTHRO-	red blood cell
HEMANGIO-	blood vessels
HEPATO-	liver
LIPO-	fat
LYMPHO-	lymphocyte
MELANO-	pigment cell
MYELO-	bone marrow
MYO-	muscle
OSTEO-	bone

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^{37-49,81}

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^{82,83}

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](#)
- 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](#).
- 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^{69,71,75,77,79}

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](#) 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.⁵⁰
- American Cancer Society [Guidelines for the Early Detection of Cancer](#): The American Cancer Society has screening guidelines for breast, colorectal, cervical, endometrial, lung, and prostate cancers.

- 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

CANCER TYPE	SCREENING TEST	DESCRIPTION
BREAST	Mammogram	<p>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.</p> <p>Fact sheet (USPSTF) Fact sheet (ACS) Breast cancer screening in transgender men (UCSF) Breast cancer screening in transgender women (UCSF)</p>
CERVICAL	HPV/Pap co-testing	<p>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</p>

	<p>Pap test (or Pap smear)</p> <p>Human Papilloma Virus (HPV) testing</p>	<p>determine the age to begin and stop testing for cervical cancer. Cervical cancer screening can be done through a Pap test or HPV test, or both tests which is called co-testing. If screening by co-test, co-tests are recommended every 5 years.</p> <p>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.</p> <p>Human Papilloma Virus (HPV) testing can find HPV before it visibly changes the cervical cells.</p> <p>Additional tests or procedures may be needed if the Pap test results are abnormal.</p> <p>Fact sheet (USPSTF) Fact sheet (ACS) Screening for cervical cancer in transgender men (UCSF)</p>
<p>COLORECTAL (COLON/RECTUM)</p>	<p>Fecal Occult Blood Test (FOBT)</p>	

		<p>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.</p> <p>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.</p> <p>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.</p> <p>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.</p> <p>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.</p> <p>Fact sheet (USPSTF) Fact sheet (ACS)</p>
LUNG	LDCT or low-dose CT scan	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-

		<p>ray machine scans the patient’s body and makes detailed pictures of the lungs using low doses of radiation.</p> <p>Fact sheet (USPSTF) Fact sheet (ACS)</p>
PROSTATE	Prostate-Specific Antigen test (PSA)	<p>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.</p>
	Digital Rectal Exam (DRE)	<p>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.</p> <p>Fact sheet (USPSTF) Fact sheet (ACS) Prostate and testicular cancer in transgender women (UCSF)</p>

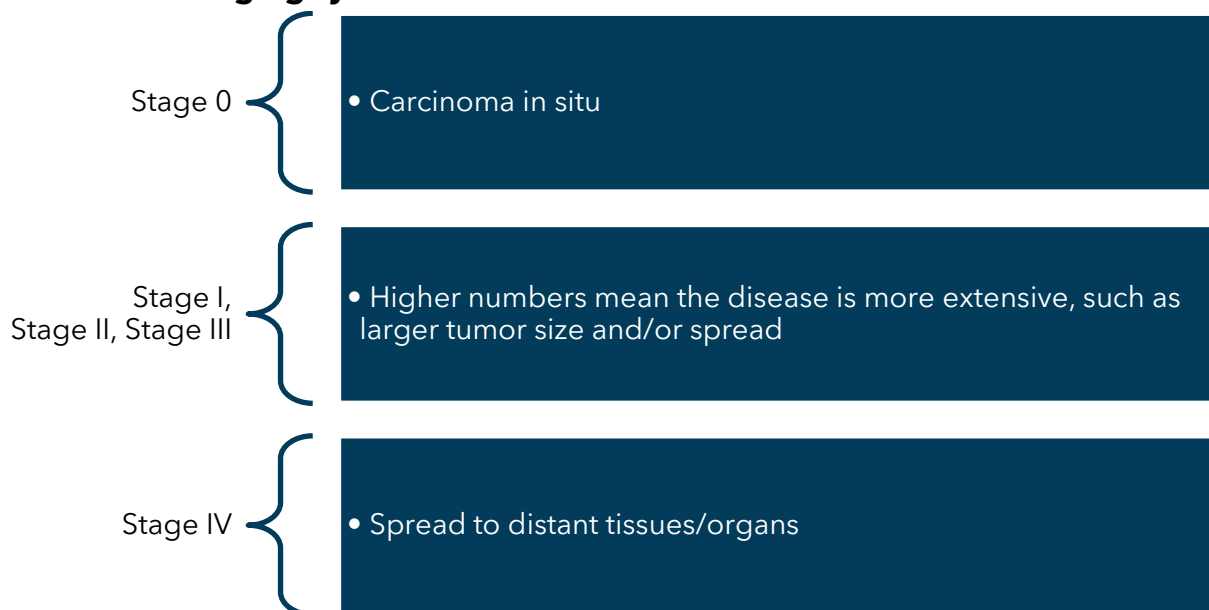
Please note that biopsy might occur if cancer is suspected based on findings from screening results.

Cancer Staging⁵¹

Table 12. TNM cancer staging system

T Amount of tumor	N Lymph nodes	M Metastasis (spread)
<ul style="list-style-type: none"> • TX: Tumor cannot be evaluated • T0: No evidence of tumor • Tis: Carcinoma in situ • T1-T4: Size/extent of tumor 	<ul style="list-style-type: none"> • NX: Lymph nodes cannot be evaluated • N0: No lymph node involvement • N1-N3: Degree of regional lymph node involvement 	<ul style="list-style-type: none"> • MX: Metastasis cannot be evaluated • M0: No metastasis • M1: Metastasis is present

Figure 3. Cancer staging system



Cancer Treatment^{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.⁷⁸

Table 13. Summary of cancer treatments

TREATMENT	DESCRIPTION
Surgery	Physically removes a tumor through an operation.
Radiation	<p>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”).</p> <p>Side effects of radiation may include damage to normal cells, swelling, skin changes, or fatigue.</p>
Chemotherapy	<p>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.</p> <p>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.</p>
Neo-adjuvant (Given before)	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.
Adjuvant (Given after)	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.
Targeted Therapy	Targeted therapy is often done in combination with chemotherapy. Using precision medicines, this therapy targets the proteins and genes involved in the cancer cells.
Immunotherapy	Immunotherapies boost the immune system to attach or slow the spread of cancer cells.
Hormone Therapy	Hormone therapy uses drugs to block the body’s natural hormones to slow or stop the growth of cancer.

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	<p>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.</p> <p>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.</p> <p>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.</p>

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



Tips for Selecting a Complementary Health Practitioner⁵²

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.
- Medicine.net: [Understanding Cancer: Metastasis, Stages of Cancer, and More](#): The article provides a visual overview of cancer.
- 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 - Report on Traditional and Complementary Medicine](#) webpage: National practices, providers, and education.
- [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.

MODULE 3: The Basics of Health Care

LESSON 3: Clinical Trials^{6,84-90}

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

YES	MAYBE	NO
<ul style="list-style-type: none"> • Increase patient interest • Reduce barriers 	<ul style="list-style-type: none"> • Explain clinical trials (yes if general information; no if clinical information or information about a specific trial) 	<ul style="list-style-type: none"> • 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 Trials⁷⁸

Table 15. Tips on helping patients to understand clinical trials

VERBAL INFORMATION
<ul style="list-style-type: none"> • 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
<ul style="list-style-type: none"> • 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.

MODULE 3: The Basics of Health Care

LESSON 4: Impact of Cancer⁹¹⁻¹¹²

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 Impacts⁹¹

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

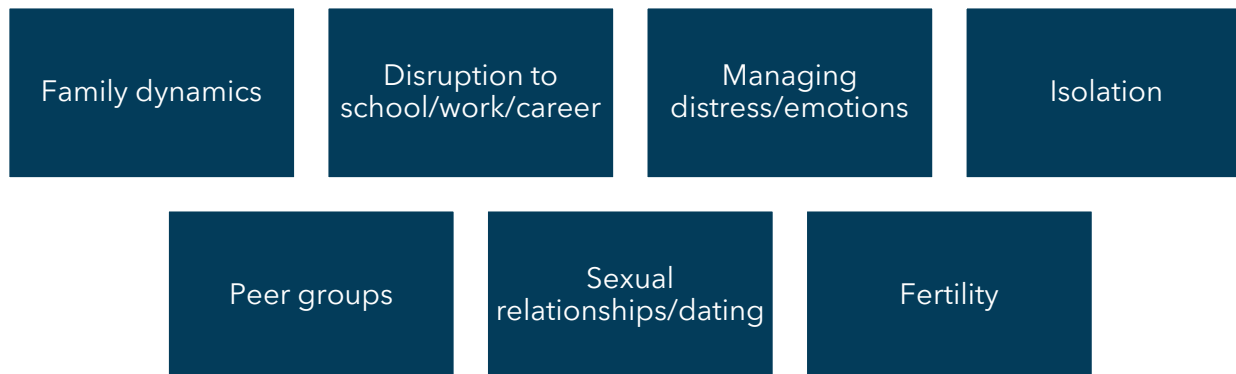
PHYSICAL IMPACTS

- Pain
- Fatigue
- Anemia
- Weight gain/loss
- Nausea/vomiting
- Self-care and mobility issues

<ul style="list-style-type: none"> • Other treatment side effects • Life-threatening medical emergencies
PSYCHOSOCIAL IMPACTS
<ul style="list-style-type: none"> • 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
<ul style="list-style-type: none"> • Financial • Ability to work • Food, housing, utilities • Legal
SPIRITUAL IMPACTS
<ul style="list-style-type: none"> • Finding meaning in illness • Changes in belief • End-of-life

Issues Unique to Adolescents and Young Adults (aged 15-40)⁹²

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



Issues Unique to Those Living with Advanced Cancer⁹³⁻⁹⁵

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



Post-Treatment Survivorship: Long-term and Late Effects⁹⁶⁻⁹⁸

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

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

Components of Survivorship Care

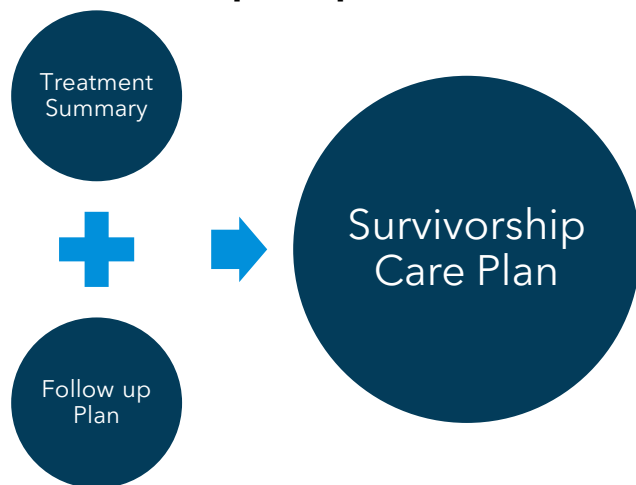
According to the [Lost in Transition Report](#), survivorship care should include these four components:

- **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.

Figure 7. Survivorship care plan structure



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 Care¹⁰⁰

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.

MODULE 3: The Basics of Health Care

LESSON 5: U.S. Health Care System^{21,113-121}

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

Public	Non profit	Private
<ul style="list-style-type: none">• Funded and owned by local, state, or federal governments• Receive money from the government• Some are associated with medical schools	<ul style="list-style-type: none">• Often community hospitals• May be linked with a religious denomination	<ul style="list-style-type: none">• Owned by investors, to whom they are accountable

- **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.

Figure 8. Summary of health care specialists



[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^{21,115}

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

Type of Health Care Professional	Role in Caring for a Patient with Cancer
Doctors	<ul style="list-style-type: none"> • Primary Care Doctors • Specialists
Advanced Practice Providers	<ul style="list-style-type: none"> • Physician Assistants • Nurse Practitioners • Advanced Practice Nurse (APRN)
Nurses	<ul style="list-style-type: none"> • Licensed Practical Nurse (LPN) • Registered Nurse (RN)
Mental Health Professionals	<ul style="list-style-type: none"> • Psychiatrists • Counselors • Psychologists • Licensed Clinical Social Workers
Pharmacists	<ul style="list-style-type: none"> • Provides prescribed medicine
Technologists and Technicians	<ul style="list-style-type: none"> • Laboratory Technologists • Radiology Technologists • Pharmacy Technicians
Therapists and Rehabilitation Specialists	<ul style="list-style-type: none"> • Occupational Therapists • Physical Therapists • Respiratory Therapists • Speech Therapists • Sexual Health Therapists
Emotional, Social and Spiritual Support	<ul style="list-style-type: none"> • Mental Health Professionals • Clergy
Administrative and Clerical Staff	<ul style="list-style-type: none"> • Administrative Medical Staff • Medical Records Specialists • Medical Billing Specialists • Financial Counselor • Scheduler
Volunteers	

Patient Navigator Roles	<ul style="list-style-type: none"> • 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
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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.
- OECD [Country Health Profiles](#): Overview of health and health systems in 2021.

MODULE 3: The Basics of Health Care

LESSON 6: U.S. Health Care Payment and Financing^{22,78,122-136}

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 20. Summary of insurance types, eligibility, and resources

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

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 Comparison¹²³

Table 21. Summary of different health insurance types

HEALTH PLAN TYPE	DETAILS
Health Maintenance Organization (HMO)	<ul style="list-style-type: none"> • Comprehensive services available • Patients can only see HMO doctors and hospitals • No deductible • Small copay • Must have a primary care provider • Must get a referral for specialty care • Cannot use out-of-network providers
Preferred Provider Organization (PPO)	<ul style="list-style-type: none"> • A “network” of providers agrees to charge a certain amount for care • Patients can see other providers but will pay more • Copay and deductible are expected • Referrals are not required • Some networks have more providers than others
Point of Service (POS)	<ul style="list-style-type: none"> • Patient can see providers outside of the network but will pay more • Copays and deductibles are low • Referral required to see a specialist
Fee for Service (FFS)	<ul style="list-style-type: none"> • Refers to reimbursing a clinician for a specific service • Patient can choose any doctor or hospital • Fewer services may be covered • May cost more
High Deductible Health Plan	<ul style="list-style-type: none"> • Low premiums but high deductibles • Patients can see any doctor or hospital • Insurance pays for coverage after a deductible is met

The Affordable Care Act (ACA)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.

MODULE 4: The Basics of Patient Navigation

LESSON 1: The Role of the Patient Navigator^{6,21,22,78,126,127,133,134,137-141}

Learning Objectives

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

Key Takeaways

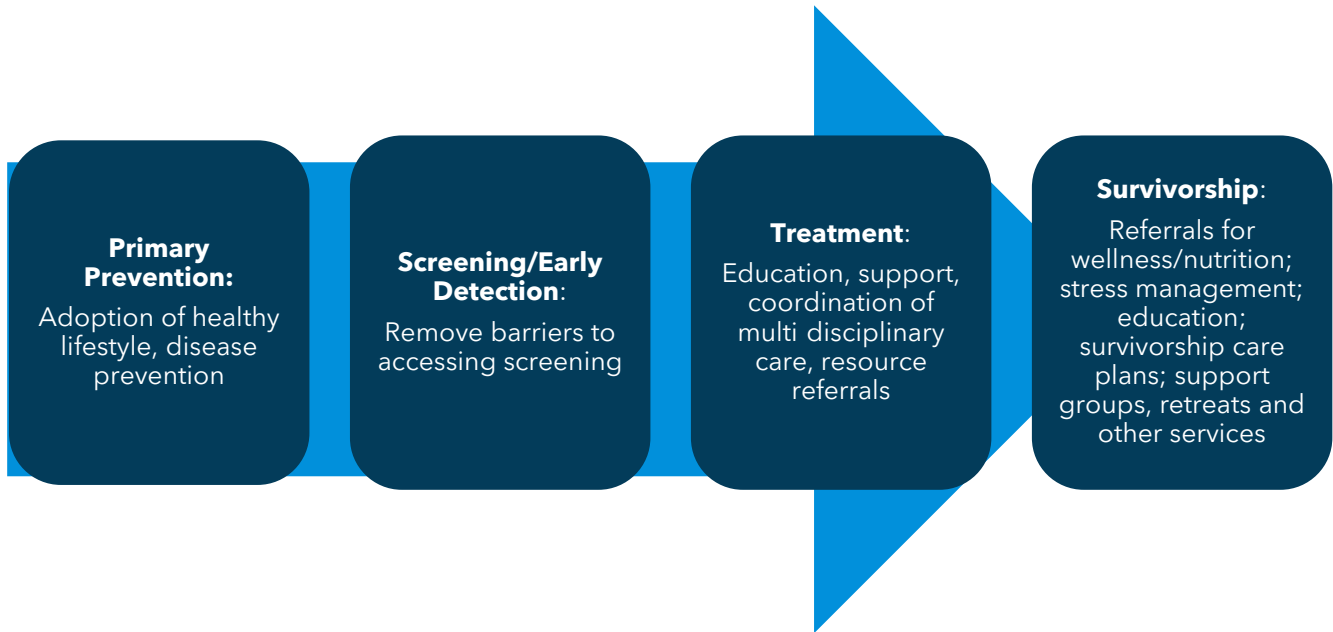
- All navigators address barriers to care.
- Barriers to care may be practical, personal, systems-based, provider-based, or psychosocial

The Patient Navigator's Role⁶

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



See [Appendix C](#) for Navigator Types and Roles and [Appendix D](#) for a sample patient navigator job description.

Possible Barriers⁷⁸

Table 22. Possible barriers to care

PRACTICAL
<ul style="list-style-type: none"> • Treatment costs • Transportation • Language barriers • Work • Food insecurity • Insurance problems • Stable housing • Immigration status • Internet access for telemedicine
PSYCHOSOCIAL
<ul style="list-style-type: none"> • Anxiety and depression • Changes in relationships and roles in the family • Family and social support • Stigma, fear, social isolation • Mental health

<ul style="list-style-type: none"> • Biases in medical recommendations • Poor communication with patients with low literacy • Poor communication with limited English-proficient patients • Cultural dissonance
<ul style="list-style-type: none"> • Lack of interpreters • Long wait times • Lack of appropriate providers • Inconvenient appointment times
<ul style="list-style-type: none"> • 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

Navigating	Facilitating	Maintaining Systems	Documenting Activities	Other
<ul style="list-style-type: none"> • Coaching • Explaining • Active listening • Asking questions 	<ul style="list-style-type: none"> • Finding patients • Coordinating team communication • Integrating information through documentation and sharing with team • Collaborating 	<ul style="list-style-type: none"> • Identifying potential patients • Building networks and referral routines • Reviewing cases 	<ul style="list-style-type: none"> • Charting to track navigation activities in patient’s record or through navigation software or tools 	<ul style="list-style-type: none"> • Administrative duties to support research • Filing papers • Collaborating with nurse navigators (if applicable)

Navigation Network Duties¹³⁷

Figure 10. List of primary navigation network duties



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

BARRIER/EVENT	ACTION/NEXT STEPS
Call from a patient who has surgery in 2 days. The patient would like to speak with the anesthesiologist about nerve block. The patient also needs information about bras/garments they should wear after the surgery.	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 patient before the procedure.
Newly diagnosed patient (older woman, came alone).	Complete distress screening, assess barriers to care, help patient identify support; next step: Breast-Specific Gamma Imaging (BSGI) (refer to nurse to explain procedure).
A patient has concerns about 6-month follow-up screening plan given to them by the doctor. They are supposed to have a mammogram, but one of their cancers was not visible on mammography.	Ask physician to clarify screening plan with a patient; supply patient with correct order if needed and tell her how to schedule procedure(s).

A patient calls with questions about radiation (has not been in for a consult yet).	Assist patient with scheduling the appointment and give general information.
Newly diagnosed patient (mid-30s, has young children) comes in for first appointment.	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.
A patient beginning chemo needs her doctor to speak with surgeon as soon as possible regarding recommendations. Other doctor is going on vacation tomorrow.	Get doctor's direct phone number, track down surgeon, ask her to call doctor.
A patient applying for disability and Medicaid, needs referral to infectious disease, psychiatry. Needs PET/CT scans.	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.
A patient is planning mastectomy surgery, would like to speak with former patient who had the same procedure.	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.
A patient lives far away and would like a consult with radiation on the same day as her appointment with surgeon.	Assist patient with scheduling appointment; call patient back with information.
Referral from the medical oncologist for patient to see dietitian.	Call patient and set up time to meet with dietitian; add patient to dietitian's schedule.
A patient needs appointment with physical therapist.	Discuss role of rehabilitation clinic; schedule patient appointments.

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.

MODULE 4: The Basics of Patient Navigation

LESSON 2: Patient Assessment^{6,21,78,127,128,142-155}

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

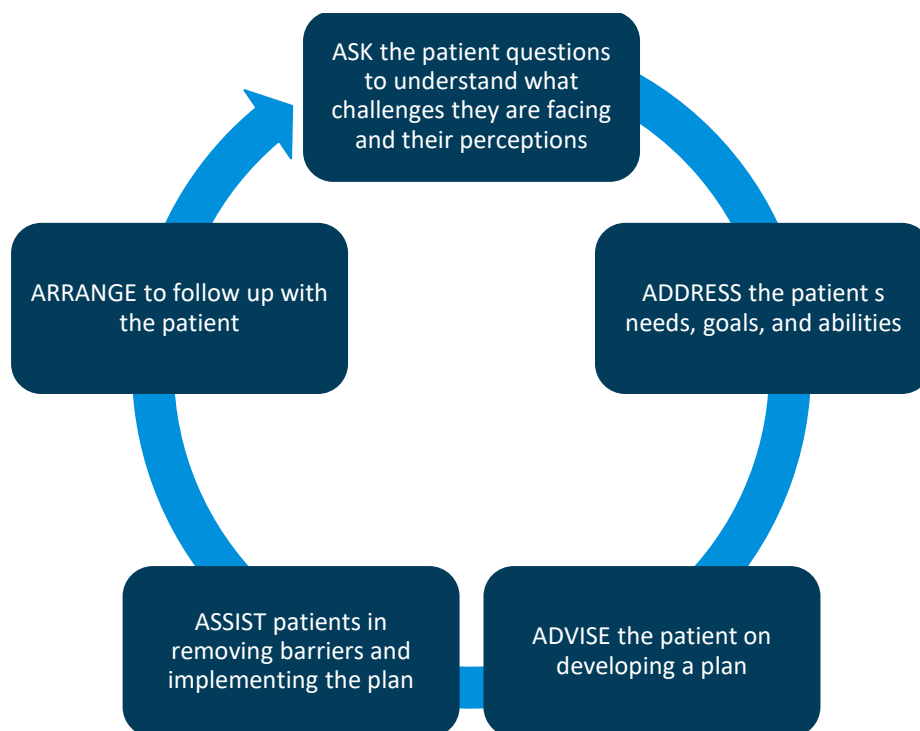
- The 5A's can be used to help patients: Ask, Assess, Advise, Assist, Arrange
- Building rapport with patients is critical
- A strengths-based approach can help you as you work with patients to address barriers
- Patient navigators must remain neutral and non-judgmental
- A helpful strategy to guide 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's¹²⁸

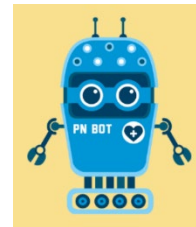
The 5 A's is a model developed by the National Cancer Institute to help people quit smoking. You can use it for navigating patients, too. We have adapted it here for patient navigation.

Figure 11. The 5 A's model



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

- Food
- Housing
- Transportation
- Utilities

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 Assessing⁷⁸

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 Approach⁷⁸

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



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^{78,142,143}

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:

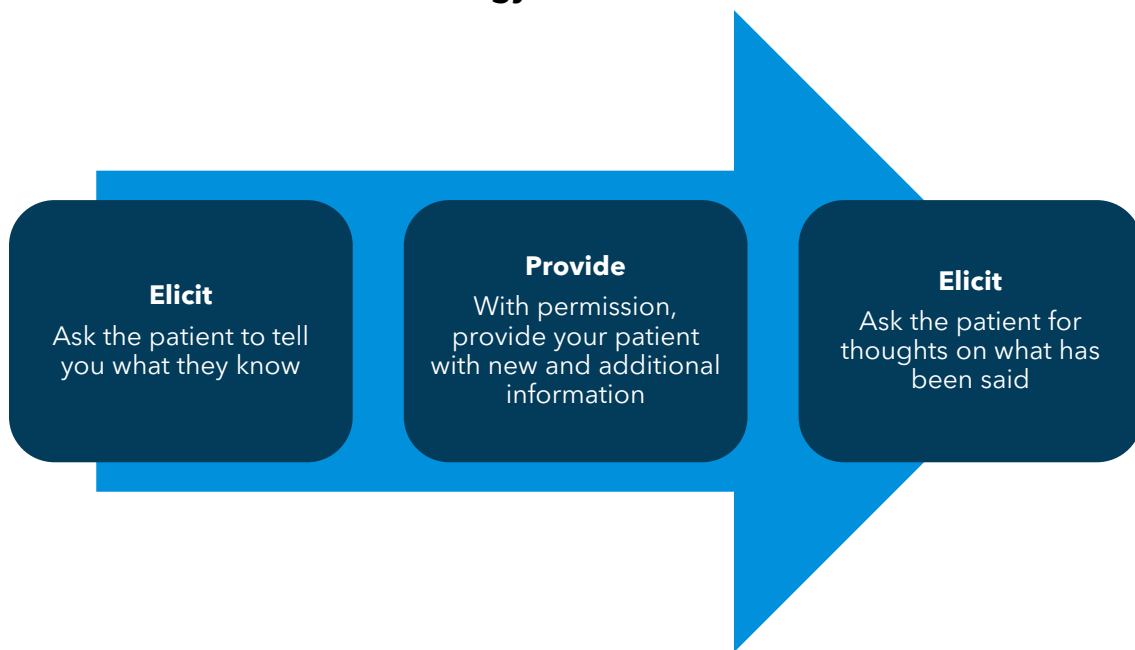
- Exploring the pros and cons of knowing details and not knowing

- 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 Actions⁷⁸

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

BARRIER	POSSIBLE ACTIONS
Treatment costs	<ul style="list-style-type: none"> - Identify free drug programs based on eligibility - Identify co-pay and financial assistance programs and work with patients to complete paperwork - Refer to financial navigator, financial counselor, or billing specialist

	<ul style="list-style-type: none"> - Create a financial tumor board and review treatment options with the multi-disciplinary team to reduce financial toxicity for patients
Lack of transportation	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> - Refer to social worker or other mental health professional
Need support	<ul style="list-style-type: none"> - Refer to support group or peer / buddy program - Refer to counseling - Identify patient sources of social support
Lack of understanding	<ul style="list-style-type: none"> - 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^{78,151}

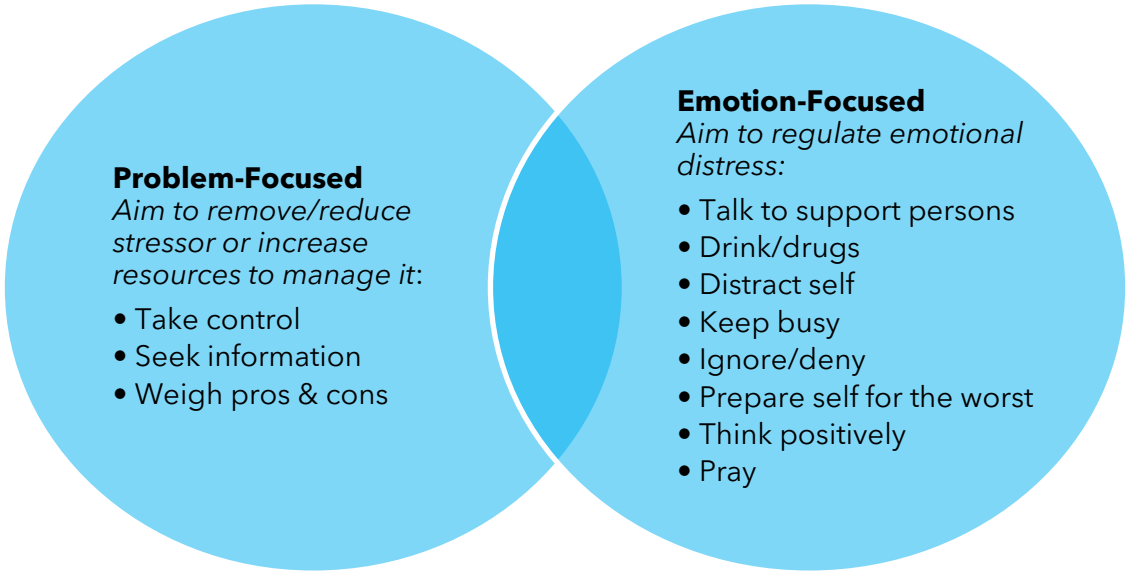
The emotional challenges of cancer can be significant. Patients should work with trained clinicians to address these impacts.

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

Patient Navigator's Role	NOT A Patient Navigator's Role
<ul style="list-style-type: none"> • Assess how much information a patient wishes to know about their illness • Be aware of signs and symptoms of mental illness • Know when to refer to a mental health specialist 	<ul style="list-style-type: none"> • Provide any clinical information, such as diagnosis or prognosis to patient or family • Diagnose mental illness or counsel patients • Be the sole source of patient's social support

<ul style="list-style-type: none"> • Build patient awareness of coping strategies and match stressors with strategies • Assess patient support system and help enhance it 	
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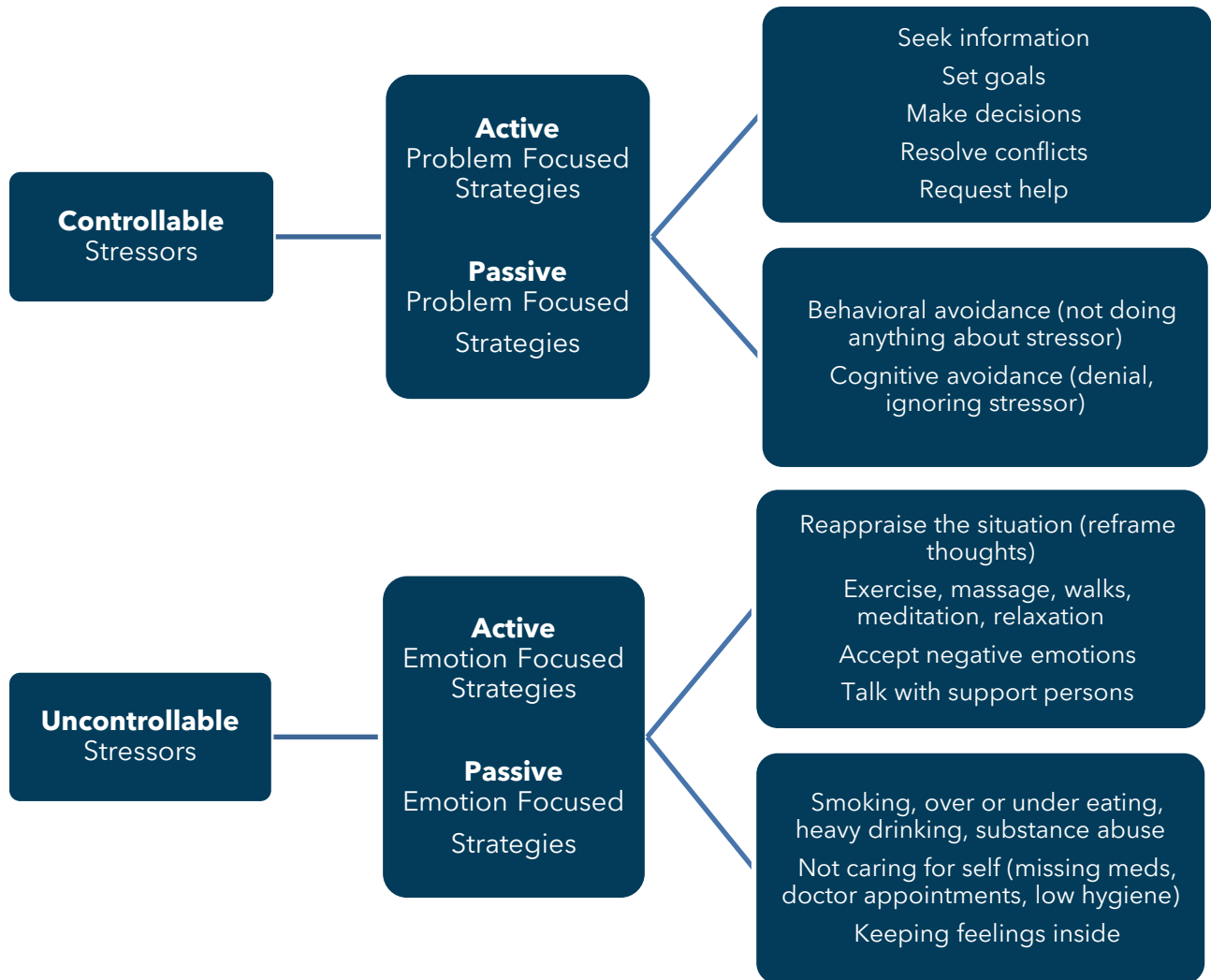
Figure 15. Differences between problem-focused and emotion-focused coping strategies



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 has 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



Signs and Symptoms of Mental Illness^{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.

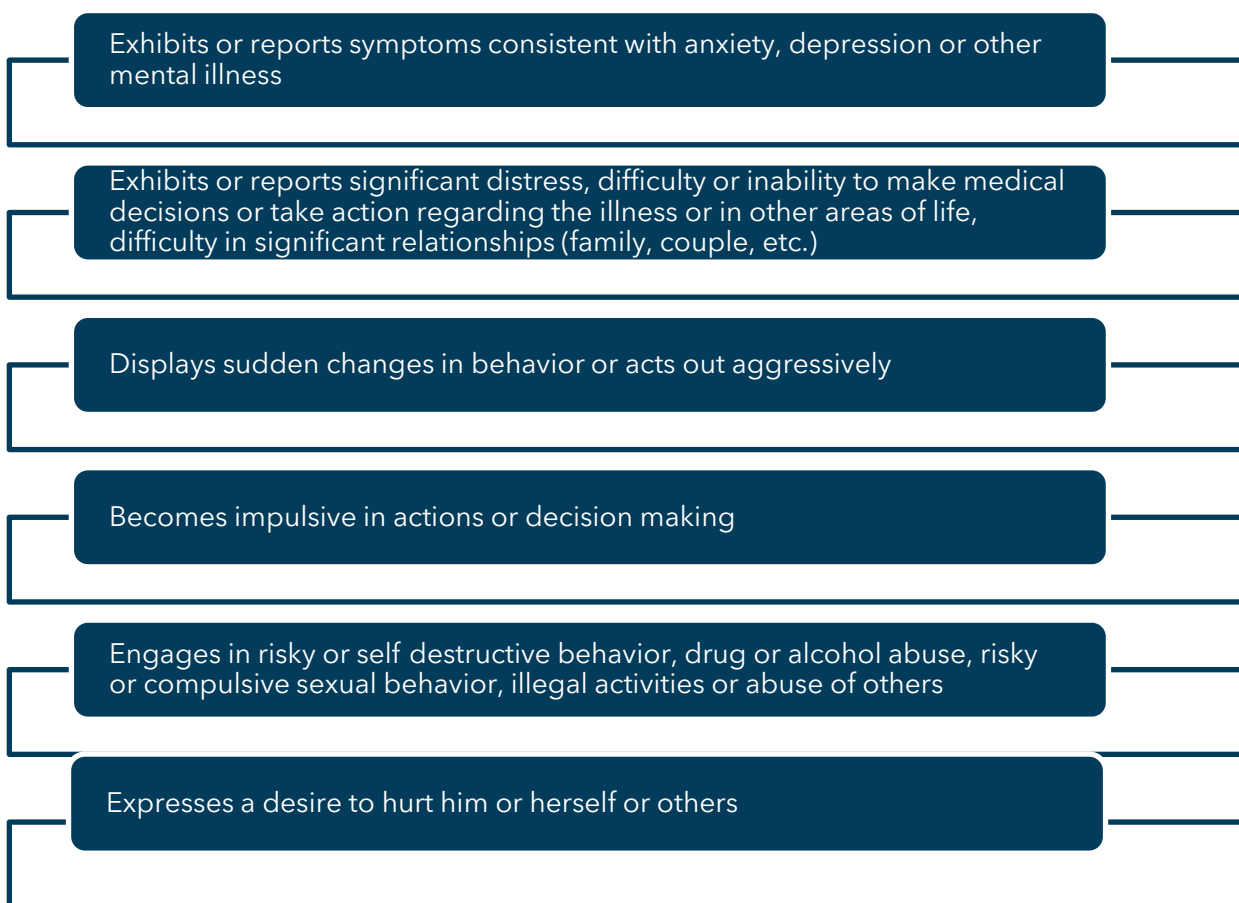
Table 27. Common symptoms of depression and generalized anxiety disorder

Generalized Anxiety Disorder Excessive or out of control worry that hinders daily function (6+ months)	Depression Severe symptoms that interfere with the ability to work, sleep, study, eat, and enjoy life
<ul style="list-style-type: none"> • Cannot relax • Startle easily • Poor concentration • Irritability • Muscle fatigue, tension, ache • Headaches • Sleep disturbances • Sweaty palms • Dry mouth, difficulty swallowing • Trembling, twitching • Nausea, lightheadedness • Shortness of breath • Frequent trips to the bathroom • Hot flashes 	<ul style="list-style-type: none"> • Feeling: <ul style="list-style-type: none"> - Sad, anxious, or “empty” - Hopeless or pessimistic - Guilty, worthless, or helpless - Irritable or restless • Losing interest in activities or hobbies once pleasurable, including sex • Lacking energy, fatigued • Problems with concentration, memory, and decision-making • Sleep issues (insomnia, waking early, excessive sleeping) • Changes in appetite (overeating, loss of appetite) • Suicidal thoughts or attempts • Persistent aches, pains, headaches, cramps, or digestive problems that do not respond to treatment

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



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.
- Kansas Cancer Partnership's [Cancer Patient Navigation Program Toolkit](#).
- National Association of Community Health Centers' [PRAPARE: Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences](#): Patient assessment tools in multiple languages.

- 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-Making¹⁵⁶⁻¹⁷⁶

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-Making¹⁷⁵

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.”¹⁷⁵

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



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

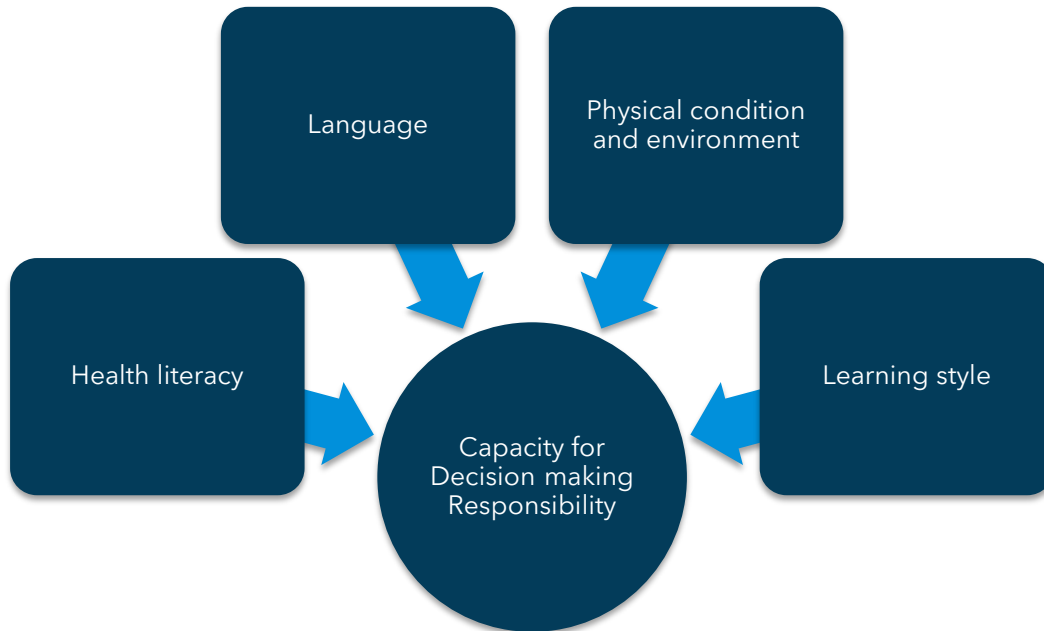
The most common source of patient dissatisfaction is feeling uninformed and uninvolved in care and treatment decisions. Assessing the patient's capacity and desire to participate in their health management involves many factors. Considerations in assessing desire for shared decision-making should include:

- 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-Making¹⁵⁶⁻¹⁶¹

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

Figure 19. Capacity for decision-making responsibility model



Using Plain Language^{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 Literacy¹⁶²

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

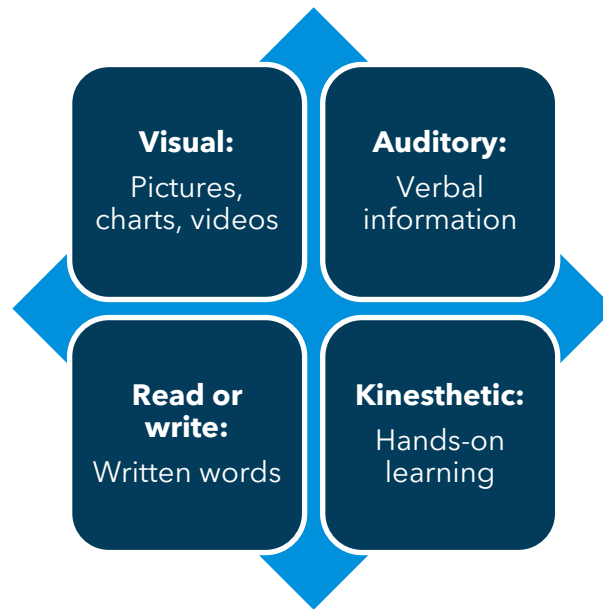
Low Literacy	Low Health Literacy	Limited English Proficiency
<ul style="list-style-type: none">• Cannot read or write, so:<ul style="list-style-type: none">- Set realistic objectives- Focus on behaviors and skills- Present the context first, then give new information- Break up into smaller parts- Make educational sessions interactive	<ul style="list-style-type: none">• Have difficulties with reading, writing, speaking or computing to solve problems, so:<ul style="list-style-type: none">- Spend more time making sure they understand- 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- Select more appropriate resources that are tailored to their ability	<ul style="list-style-type: none">• May be literate in their primary language but struggle to communicate in English, so:<ul style="list-style-type: none">- Arrange interpreter services

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.

Figure 20. Summary of learning styles



Strategies for Patient Navigators^{156,160,165-167}

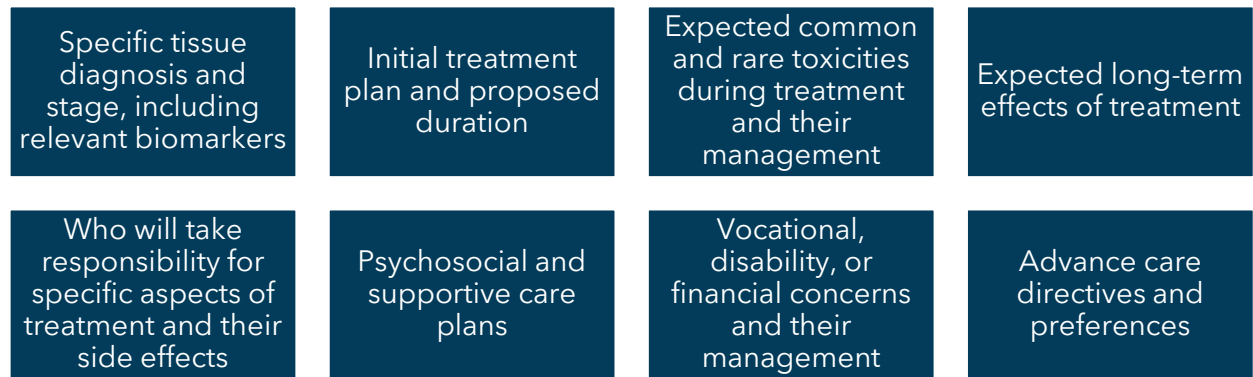
Strategies that patient navigators can use to support patients:

- 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



Barriers to Treatment Plan Adherence

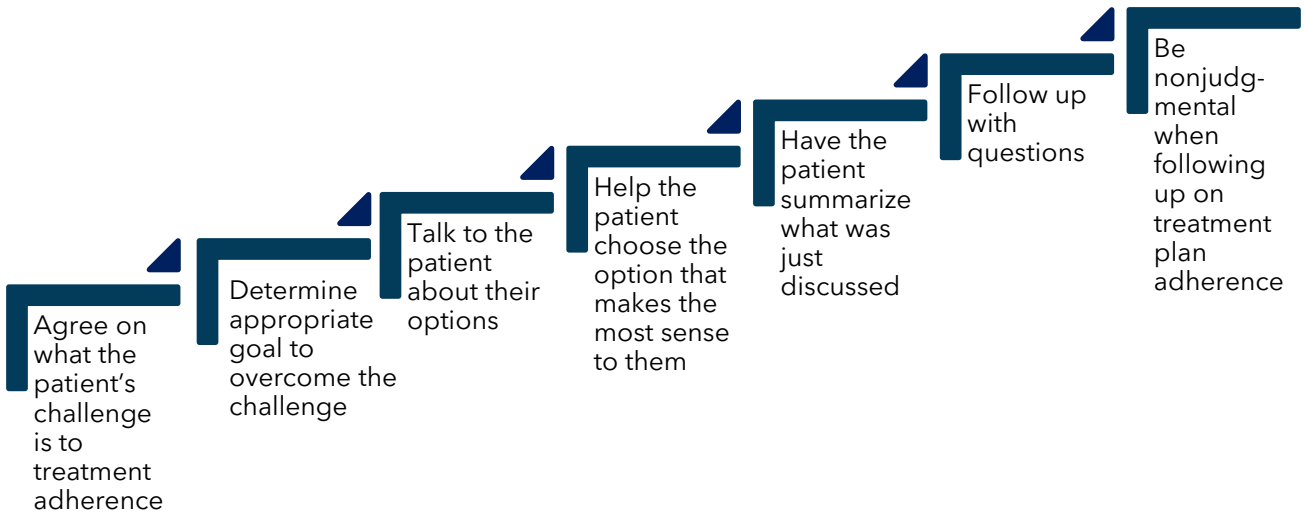
Patients may have trouble following their treatment plan. For example, they may:

- 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 Plan¹⁶⁸⁻¹⁷⁰

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



Self-Management^{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



Self-Management Resources for Patients

Table 29. Self-management resources and examples

SELF-MANAGEMENT RESOURCES	EXAMPLES (RESOURCES, TOOLS, ORGANIZATIONS, SERVICES, PROGRAMS, MOBILE APPS)
Exercise	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> - Cancer Support Community - CancerCare - Cancer Hope Network
Stress Management	<ul style="list-style-type: none"> - Mindfulness-Based Stress Reduction Information - Relaxation Techniques for Health: What You Need to Know
Quitting Tobacco Consumption	<ul style="list-style-type: none"> - 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	<p>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.</p>
Hospital Facility/ Resources	<p>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.</p>
Community Resources	<p>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.</p>

Cancer Organizations

Table 30. Cancer organizations

RESOURCES
National General Cancer Resources
ASCO Cancer Foundation
American Cancer Society
Cancer Support Community
LIVESTRONG
National Cancer Institute
National Coalition for Cancer Survivorship
Support Group Organizations by Cancer Type
Bladder
Bladder Cancer Advocacy Network
Brain
American Brain Tumor Association
National Brain Tumor Society
The Brain Tumor Foundation
Breast
Susan G. Komen Foundation
Breastcancer.org
Avon Foundation for Women
Carcinoid
Neuroendocrine Tumor Research Foundation
The Carcinoid Cancer Foundation
Cervical
National Cervical Cancer Coalition
Colorectal
Fight Colorectal Cancer
Gastric
Gastric Cancer Foundation
GIST (gastrointestinal stromal tumors)
GIST Support International
Head and Neck, Esophageal
Head and Neck Cancer Alliance
Lung
Foundation for Lung Cancer

American Lung Association
Leukemia and Lymphoma
Leukemia and Lymphoma Society
Liver
American Liver Foundation
Melanoma
American Melanoma Foundation
Melanoma Research Foundation
Oral
Support for People with Oral and Head and Neck
Ovarian
Ovarian Cancer Research Alliance
Rhonda's Club
The National Ovarian Cancer Coalition
The Ovarian Cancer Institute
Pancreatic
Pancreatic Cancer Action Network
Prostate
Prostate Cancer Research Institute
Us Too Prostate Cancer
Renal
Kidney Cancer Association
Sarcoma
Sarcoma Foundation of America
Sarcoma Alliance
Testicular
Testicular Cancer Society
Thyroid
Thyroid Cancer Survivors' Association, Inc.
Uterine, Vulvar
Foundation for Women's Cancer

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.
- LIVE**STRONG** 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](#).

MODULE 4: The Basics of Patient Navigation

LESSON 4: Identifying Resources^{21,78,149,162,177-179}

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

Figure 24. Summary of resources patients need



Resources by Level⁷⁸

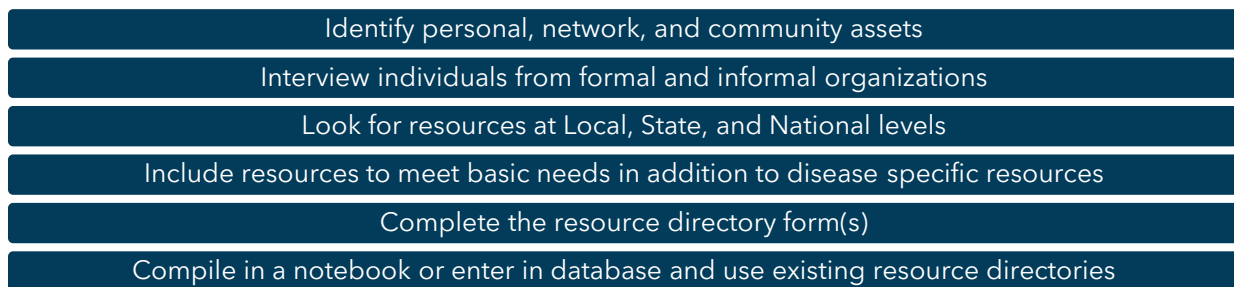
Table 31. Summary of different levels of resources

Individual	Network	Local community	State, regional, or national
<ul style="list-style-type: none">• Patient strengths and assets	<ul style="list-style-type: none">• Emotional support• Practical support• Knowledge and expertise	<ul style="list-style-type: none">• Cancer organizations• Schools, libraries, religious organizations	<ul style="list-style-type: none">• Government agencies• Non-profit organizations

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 Directory⁷⁸

Figure 25. Tips for creating a resource directory



Making an Inventory of Local Organizations⁷⁸

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^{78,177}

Figure 26. Criteria for resource assessment

Sponsorship	<ul style="list-style-type: none">• The sponsor of the website and its' mission should be easily identifiable• Determine if there is any potential bias that the organization could bring to the information provided on their site?
Currency	<ul style="list-style-type: none">• The website should be up-to-date. Usually, the date of the latest update is provided at the bottom of the page
Information	<ul style="list-style-type: none">• The information on the website should be verifiable from a primary information source such as professional literature or other websites• If information is represented as an opinion, it should be clearly stated, and the source should be identified as a qualified professional or organization• Information should serve as a supportive tool instead of replacing the doctor-patient relationship
Audience	<ul style="list-style-type: none">• The website should state the intended audience (consumer vs health professional)• The website design should have clear sections for the audience to use
Privacy	<ul style="list-style-type: none">• The privacy of personal data provided on the website should be respected, ensuring the privacy and confidentiality
Financial Disclosure	<ul style="list-style-type: none">• The website should indicate the funding sources



HONcode

HONcode certification:
Improving the quality of
online health information

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:

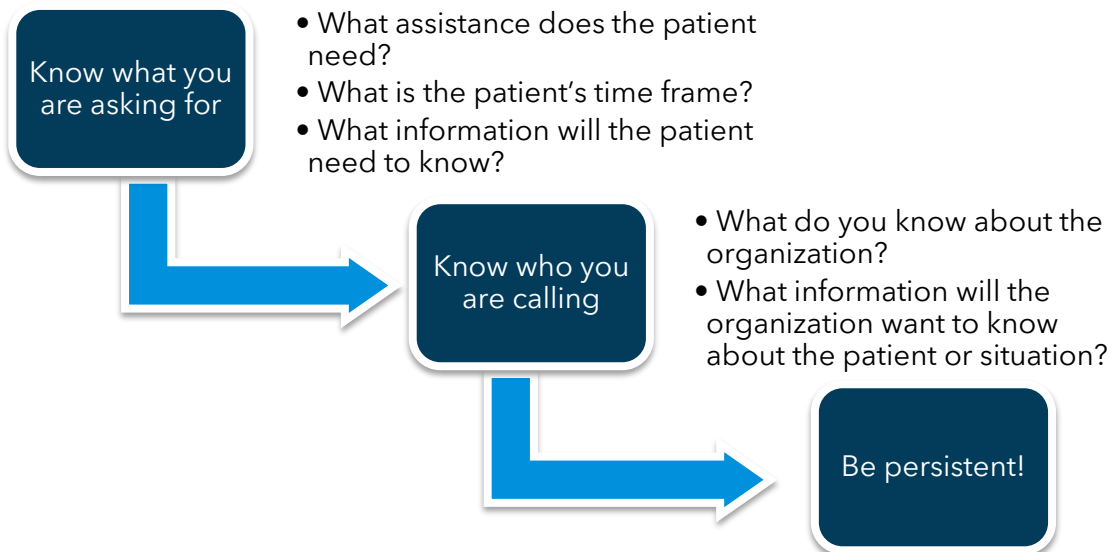
Figure 27. Questions for assessing if the resource is a good fit for a patient

- 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 Organizations⁷⁸

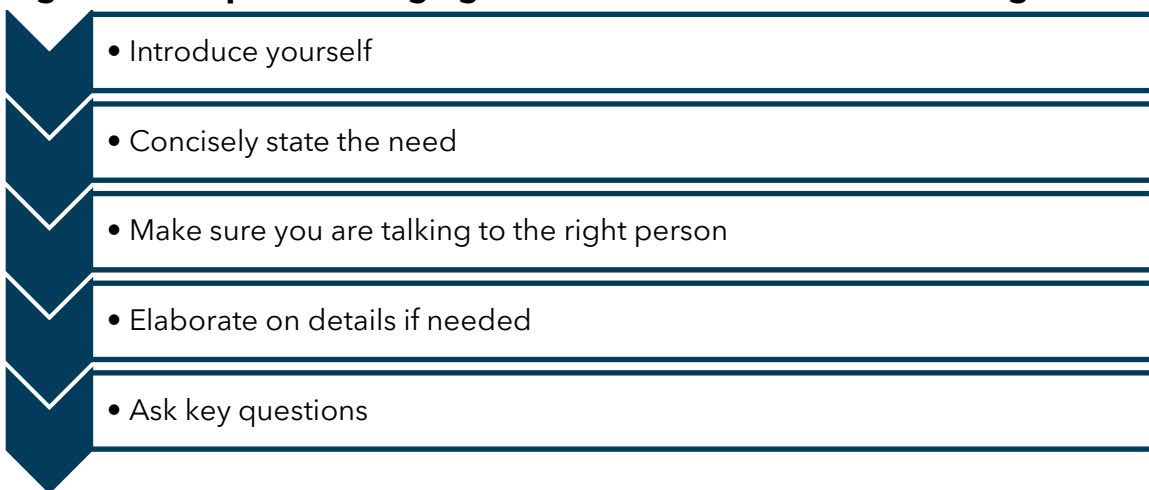
Once you have identified potential sources of assistance, begin accessing the resources for your patient. Before contacting an organization, it is important that you are prepared to appear professional and avoid unnecessary additional calls or follow-ups.

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



Once you have prepared to contact the organization, you can use the following steps:

Figure 29. Steps for managing the conversation with different organizations



Maintaining Relationships with Organizations⁷⁸

- 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 Resources⁷⁸

- 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



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](#): AHRO’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.

MODULE 5: Enhancing Communication

LESSON 1: Communicating with Patients^{78,149,153,157,179-182}

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

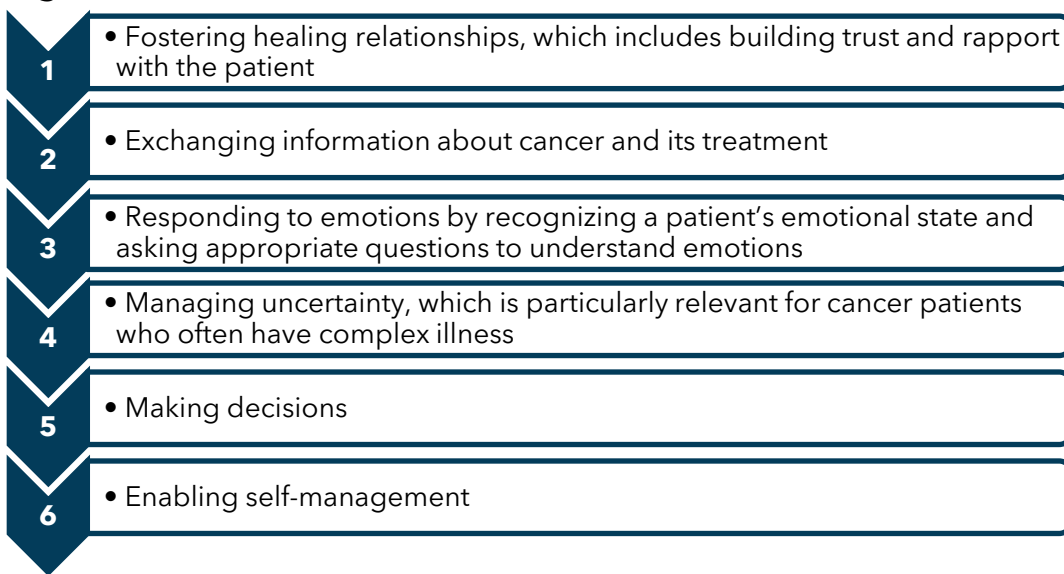
Key Takeaways

- 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 Framework¹⁵⁷

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



Importance of Communication¹⁷⁹

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 Communication⁷⁸

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 Solutions¹⁸⁰

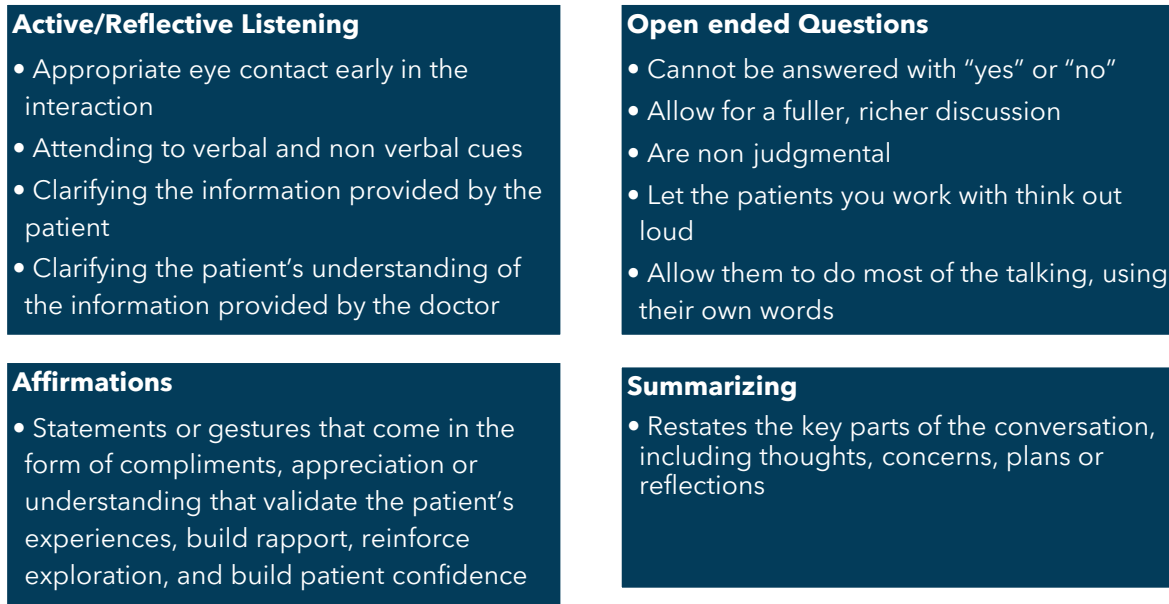
Good communication is not always easy. Below you will find some common communication barriers as well as possible solutions to those barriers.

Figure 32. Common communication barriers and solutions

Common Barriers	Solutions
Physical environment	Quiet, private, non-distracting location
Not listening to the patient: <ul style="list-style-type: none">- Being distracted- Judging the patient- Information overload- Focusing on a personal agenda	Effective listening <ul style="list-style-type: none">- Stop, look, listen- Be empathetic- Ask questions
Misperception of patient's meaning: <ul style="list-style-type: none">- Stereotyping and generalizing- Rushing- Distorted focus- Making assumptions- Getting mixed signals	Improved perception <ul style="list-style-type: none">- Analyze your own perceptions- Work to improve them- Focus on others
Poor verbal communication by navigator: <ul style="list-style-type: none">- Lacking clarity- Using stereotypes and generalizations- Jumping to conclusions- Dysfunctional responses- Lacking confidence	Improved verbal communication <ul style="list-style-type: none">- Focus on the issue, not the person- Be genuine rather than manipulative- Empathize rather than remain detached- Be flexible towards others- Value yourself and your own experiences- Present yourself as an equal rather than a superior- Use affirming responses

Strategies for Improving Communication^{78,153,179}

Figure 33. Summary of strategies for communication improvement



Other tips for conversation include:

Figure 34. Additional tips for improving communication



Supporting Open Communication between Patient and Provider¹⁸¹

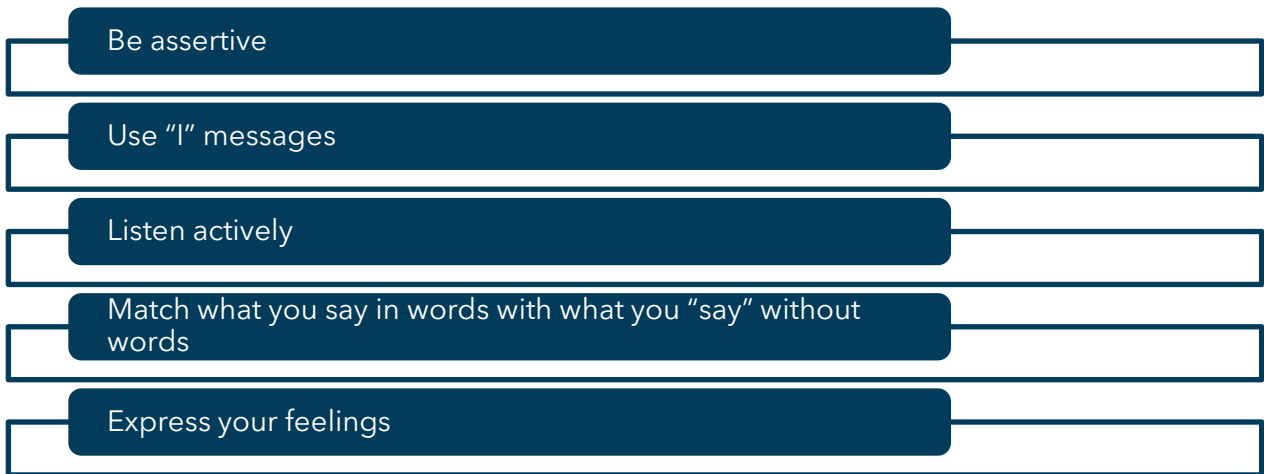
Patient navigators can support open, honest, and meaningful interactions between patients and providers in a number of ways:

- 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 Patients¹⁴⁹

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



Primary Strategies⁷⁸

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

Table 32. Flight-fight-unite strategies

Flight	Fight	Unite
<ul style="list-style-type: none">•Avoiding conflict and hoping that it will go away	<ul style="list-style-type: none">•Using authority, rights or force to attempt to prevail over others	<ul style="list-style-type: none">•Talking with other people to develop solutions that will satisfy mutual interests, some result that they all can "live with"

Conflict Resolution Strategies⁷⁸

Everyone has to deal with conflict at one point or another. Here are some tips to resolve conflict.

Figure 36. Conflict resolution strategies

Talk about the issues

- Avoidance does not stop the conflict. People may need to back away for a moment but the parties should discuss the conflict.

Recognize the value of the conflict

- 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.

Recognize conflict is a spiral but you can change the direction of the spiral

- 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.

Emphasize common goals

- 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..."

Check perceptions

- Think about the questions, "What resources do you actually have? Is anything getting in the way?"

Use competent communication techniques

- Such as actively listening, asking questions and providing feedback to check your perceptions.

Agree to disagree

- Some conflict just can't be solved or isn't important enough to try too hard to resolve.

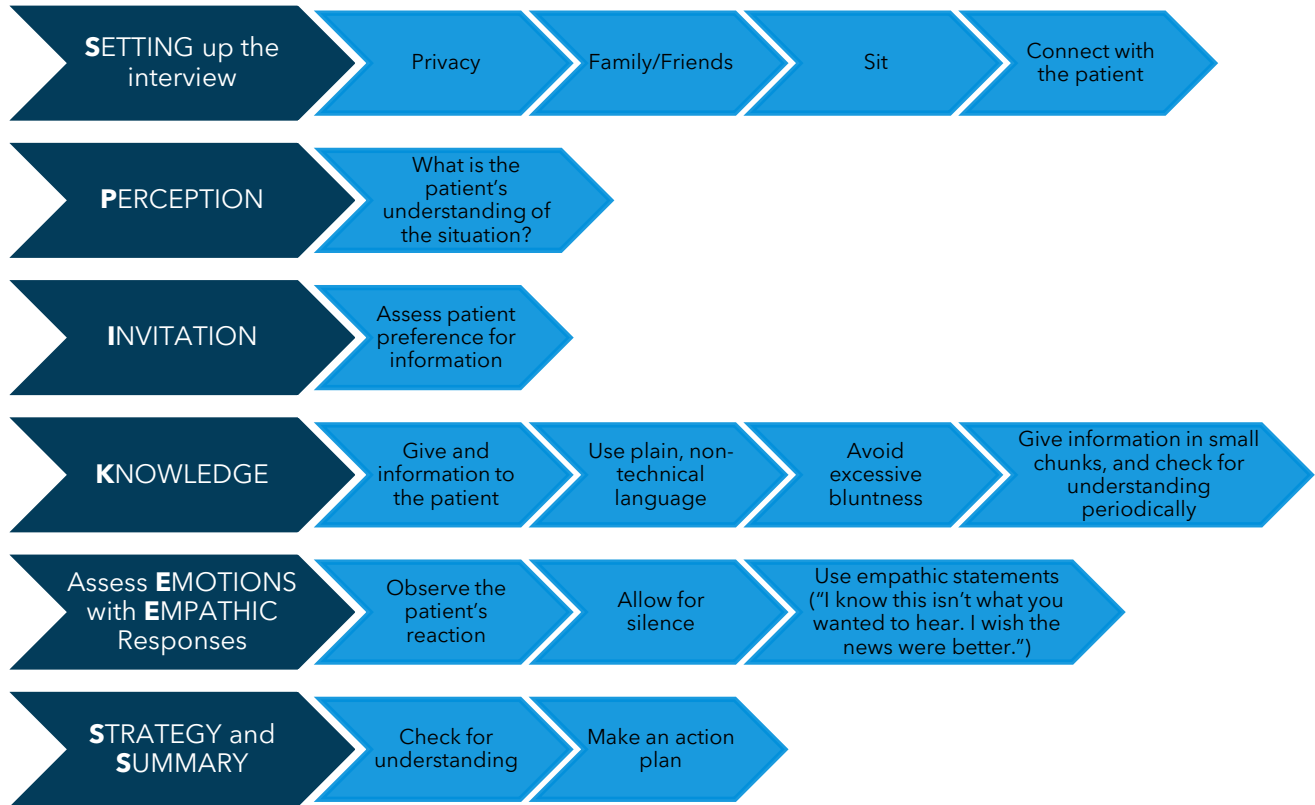
Attack the problem, not the person

- 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.

Breaking Bad News¹⁸²

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



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](#).
- National Coalition for Cancer Survivorship's [Teamwork: The Cancer Patient's Guide To Talking With Your Doctor](#).
- CancerCare's [Communicating With Your Healthcare Team](#): This module walks patients through how to communicate with the health care team.

MODULE 5: Enhancing Communication

LESSON 2: Patient Advocacy^{29,78,128,149,183-186}

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^{29,128,183,184}

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

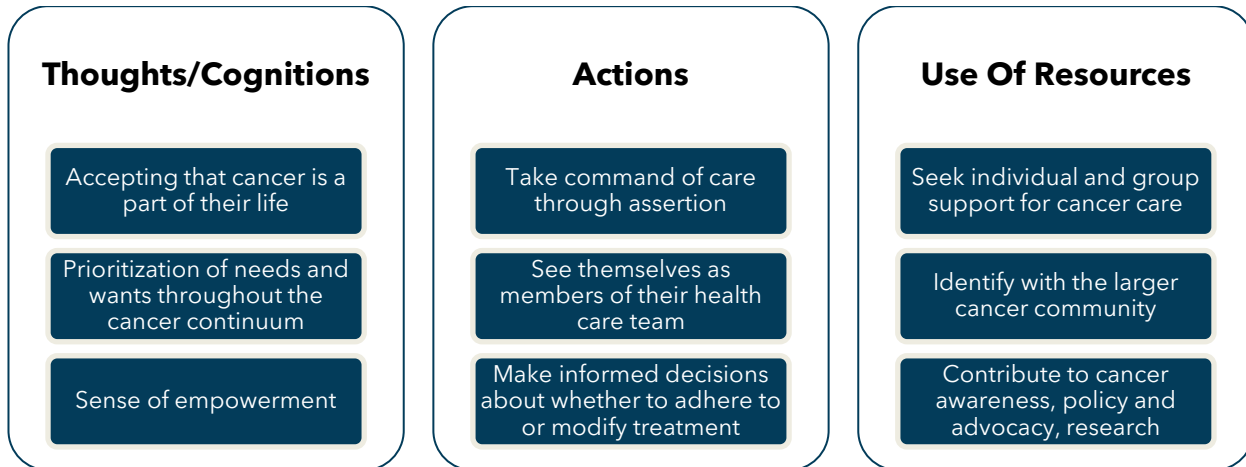
Self-Advocacy Overview¹⁸⁴

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

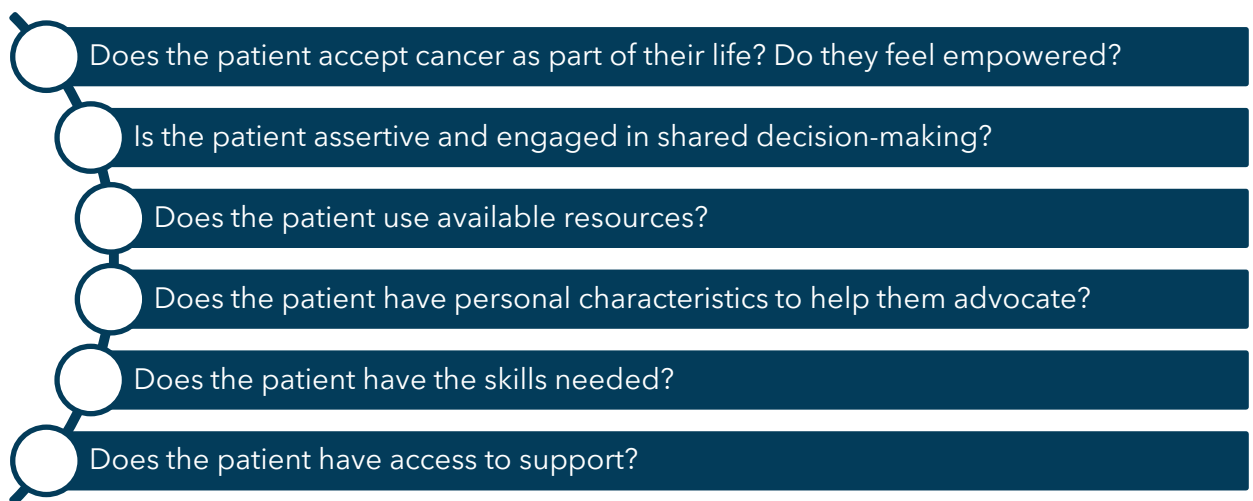


A patient's ability to self-advocate can be influenced by:

- 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



Outcomes of Self-Advocacy¹⁸⁴

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

Figure 40. Outcomes for self-advocacy



Barriers to Self-Advocacy¹⁸⁴

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

Table 33. Barriers to self-advocacy

Fragmented health care system	Overwhelming amount of information
<ul style="list-style-type: none">• Need to improve access to care• Need to support patient empowerment to advocate for themselves	<ul style="list-style-type: none">• Need to decide what information and resources should be used• Need to know how to incorporate information into conversations with health care providers

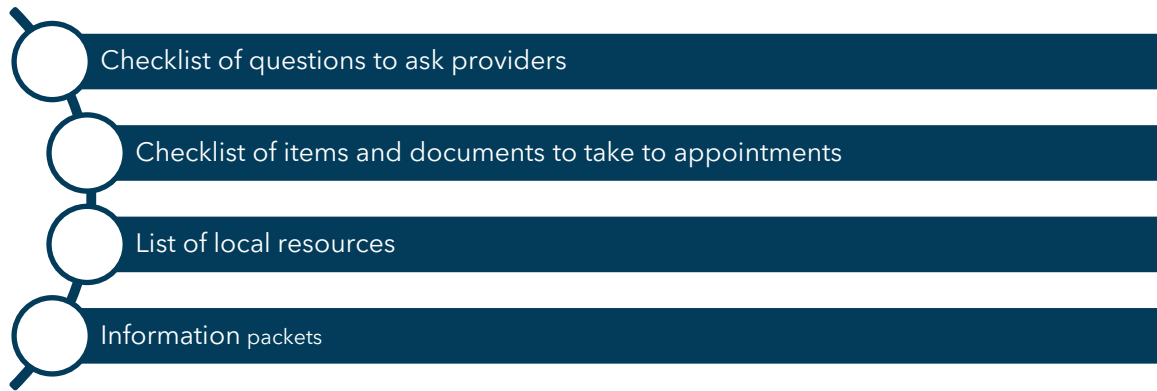
Supporting Patient Empowerment⁷⁸

As a patient navigator, you can support patient empowerment.

Table 34. Summary of ways to support patient empowerment

Knowledge	Skills	Attitudes
<ul style="list-style-type: none">• Providing information and resources• Discussing options• Helping with decision-making	<ul style="list-style-type: none">• Ability to self-care• Ability to cope• Ability to actively communicate	<ul style="list-style-type: none">• Encouraging assertiveness

Figure 41. Examples of self-advocacy tools



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 Patient⁷⁸

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 Organizations⁷⁸

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 Proficiency⁷⁸

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

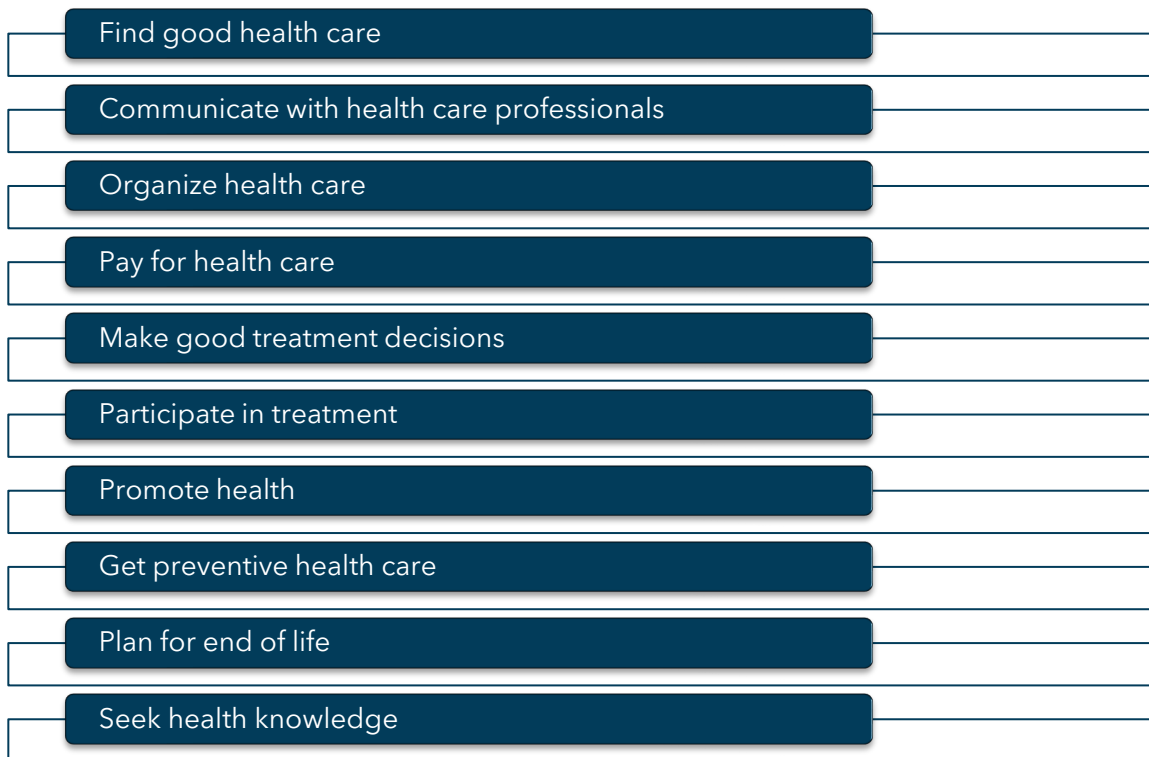
As a patient navigator, you will be in a unique role to see system issues for patients. Here are some examples of system advocacy:

- 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



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.
- National Coalition for Cancer Survivorship's [Teamwork: The Cancer Patient's Guide to Talking with Your Doctor](#).
- 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.

MODULE 5: Enhancing Communication

LESSON 3: Culturally Competent Communication^{78,149,187-203}

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 Bias¹⁸⁷⁻¹⁸⁹

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.

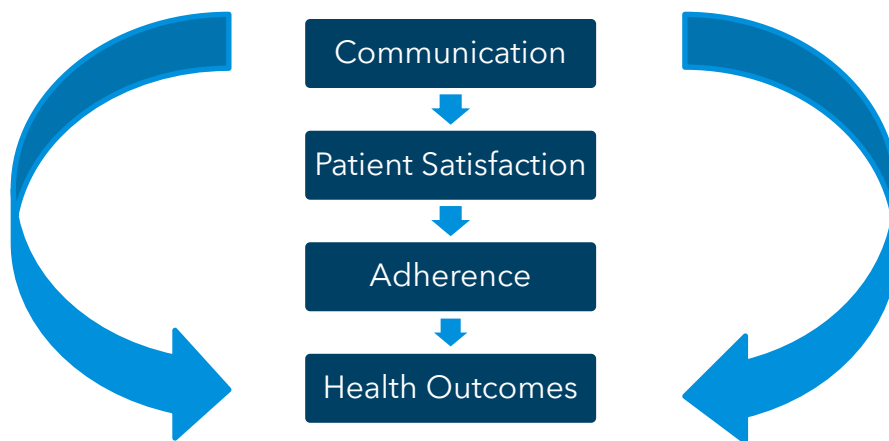
Bias is “the negative evaluation of one group and its members relative to another.” --Blair et al., 2011.

- **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.

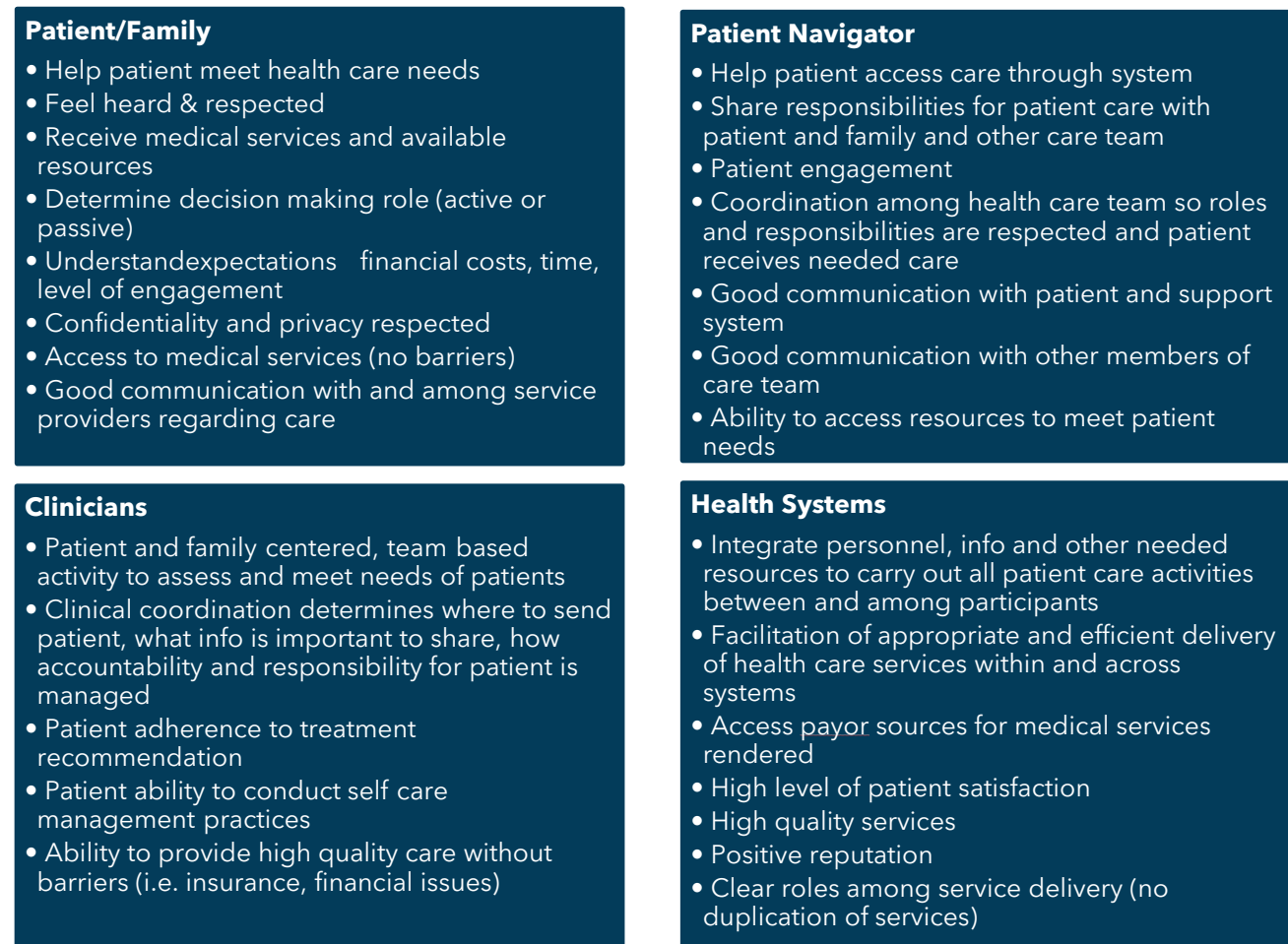
Figure 44. The connection between communication and health outcomes



Stakeholder Perspectives⁷⁸

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.

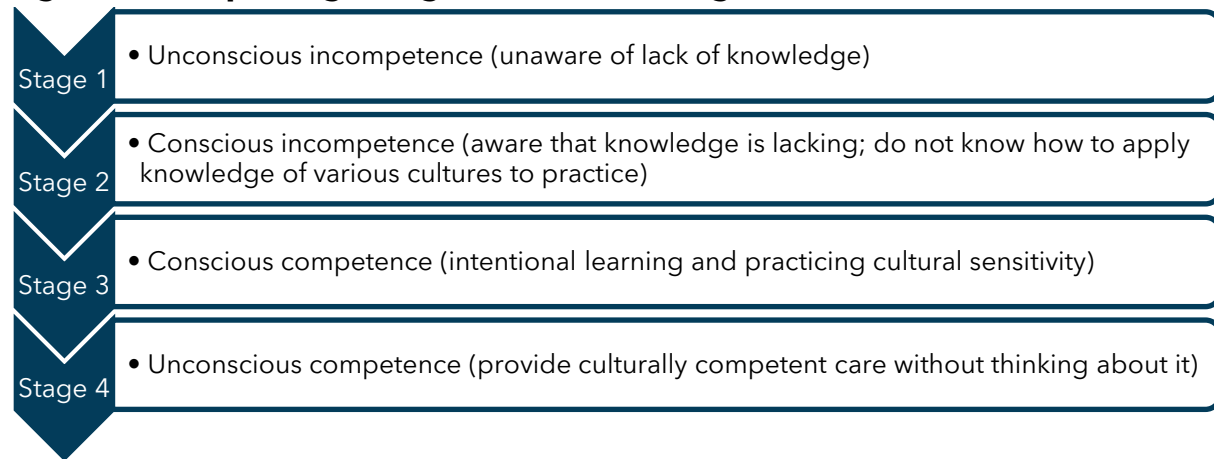
Figure 45. Summary of what stakeholders' value



Steps for Gaining Cultural Knowledge¹⁹⁰

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



Assessing Your Bias^{78,191-196,202}

Figure 47. Summary of self-awareness assessment

Awareness	• Am I aware of my personal biases and prejudices towards cultural groups different than mine?
Skill	• Do I have the skill to perform a culturally-based needs and strengths assessment in a sensitive manner?
Knowledge	• 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?
Encounters	• How many face-to-face encounters have I had with patients from diverse cultural backgrounds?
Desire	• What is my genuine desire to "want to be" culturally competent?"

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

<p>Stereotype replacement</p> <ul style="list-style-type: none"> 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.
<p>Counter stereotypic imaging</p> <ul style="list-style-type: none"> 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).
<p>Individuation</p> <ul style="list-style-type: none"> Prevent stereotypes by learning about individual group members.
<p>Perspective taking</p> <ul style="list-style-type: none"> “Walk in the other person’s shoes.” Take on and actively consider the group member’s experiences.
<p>Increasing opportunities for contact</p> <ul style="list-style-type: none"> Seek opportunity for engagement in positive interactions between different groups of people.

Strategies for Improved Communication^{197,198}

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.

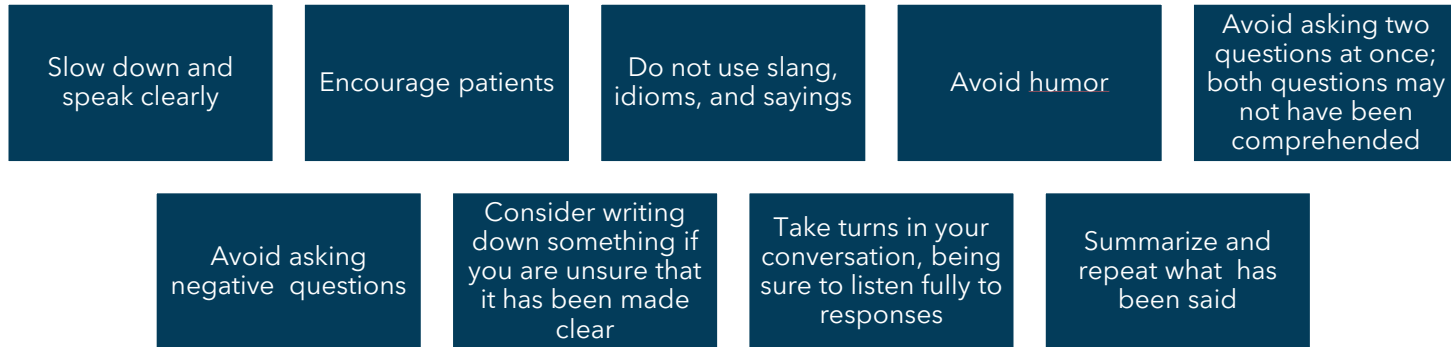
Figure 49. Non-verbal communication and empathy

E.M.P.A.T.H.Y.						
E Eye contact	M Muscle of facial expression	P Posture	A Affect	T Tone of voice	H Hearing the whole patient	Y Your response

Strategies for Cross-Cultural Communication^{199,200}

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

Figure 50. Strategies for cross-cultural communication



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

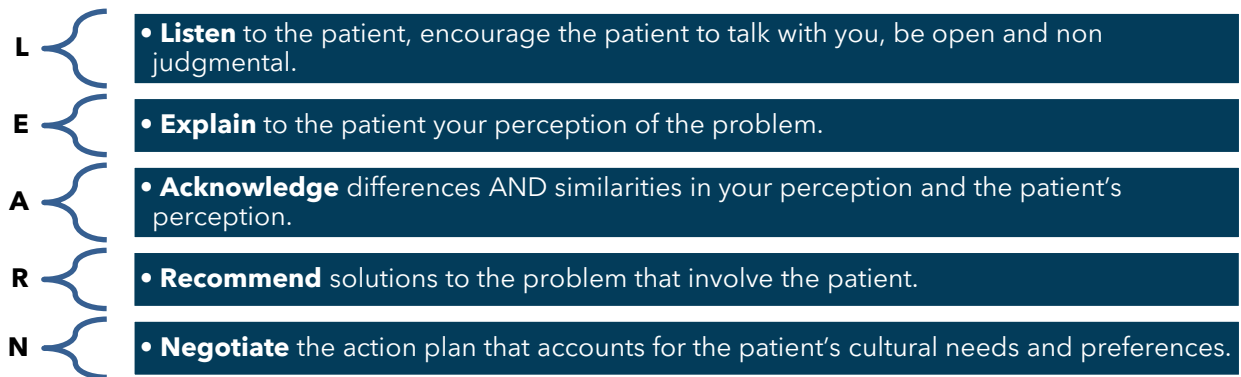


Figure 52. R.E.S.P.E.C.T. model

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)²⁰¹

Principal Standard

- Provide patient-centered equitable and respectful quality care, taking into account patients' different cultural backgrounds, languages, and level of health literacy

Governance, Leadership, and Workforce

- Ensure sustainability of organizational governance and leadership involved in CLAS and health equity promotion through policy, practices, and allocated resources
- Recruit, promote, and support a culturally and linguistically diverse governance, leadership, and workforce that are involved in the population care in the service area
- Provide continuous education in culturally and linguistically appropriate policies and practices for governance, leadership, and workforce

Communication and Language Assistance

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

Engagement, Continuous Improvement, and Accountability

- Create culturally and linguistically appropriate goals, policies, and management accountability and use them throughout the organization's planning and operations
- Continuously assess organization's CLAS-related activities and utilize CLAS-related measures in measurement and quality improvement activities
- Collect accurate and reliable demographic data in order to assess the impact of CLAS on health equity and outcomes
- 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
- Collaborate with the community to design, implement, and evaluate policies, practices, and services to ensure cultural and linguistic appropriateness
- Create culturally and linguistically appropriate standards for conflicts/complaints, grievance, and resolution
- Provide updates on organization's progress of implementation and sustainability of CLASS to the stakeholders, constituents, and the general public

Figure 54. Summary of ways patient navigators could support CLAS standards



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^{4,21,23,78,191,204-207}

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^{23,78,204}

Table 35. Scope of practice for clinical professionals

Physicians/ Physician Assistants/ Nurse Practitioners	Nurses	Clinical Social Workers	Allied Health Professionals
<ul style="list-style-type: none"> • Diagnose and treat disease; manage symptoms 	<ul style="list-style-type: none"> • Work closely with patients to provide care; administer treatment 	<ul style="list-style-type: none"> • Counsel and treat mental health needs 	<ul style="list-style-type: none"> • Technologists, technicians, therapists, or rehabilitation specialists

Table 36. Scope of practice for other professionals

Direct Service Social Workers	Community Health Workers	Patient Advocates	Case Managers
<ul style="list-style-type: none"> • Coordinate services to help patients cope with emotional, physical, and financial issues 	<ul style="list-style-type: none"> • Promote risk reduction and screening 	<ul style="list-style-type: none"> • Support resolving medical bills, job discrimination, and health care issues 	<ul style="list-style-type: none"> • 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

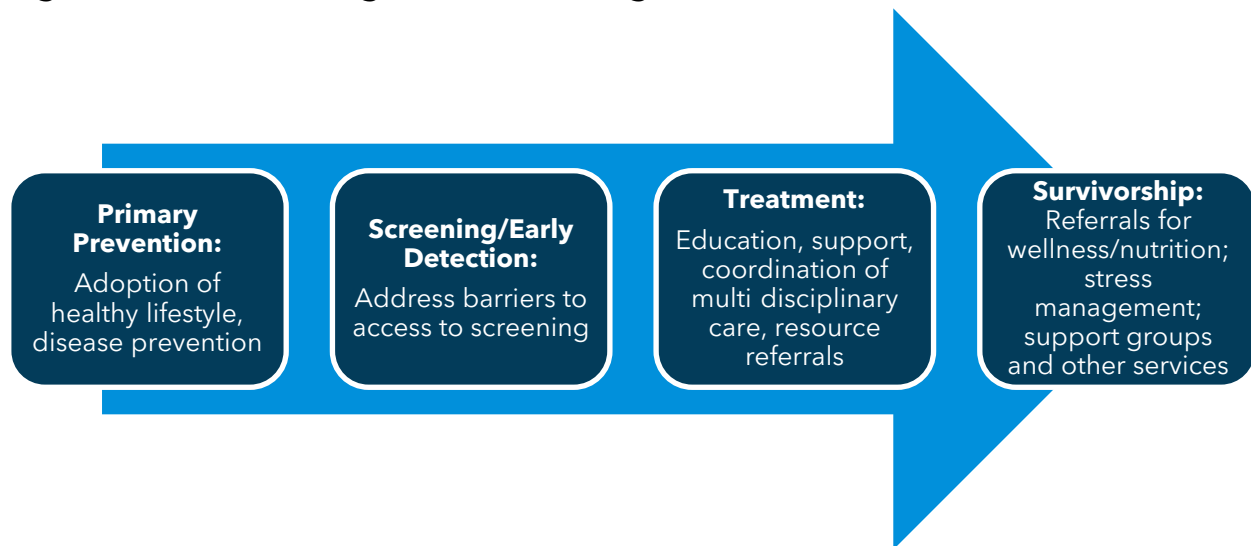
Do NOT provide health care services such as:	Do NOT offer opinions or judgments about:
<ul style="list-style-type: none"> • “Hands-on” patient care • Physical assessments, diagnoses or treatment • Counseling • Interpretation, unless you are a certified medical interpreter 	<ul style="list-style-type: none"> • 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



Tips for Staying In Bounds⁷⁸

Table 38. Examples of behaviors that blur boundaries and keep patient navigators in boundaries while talking to a patient

BEHAVIOR THAT BLURS BOUNDARIES	TIPS FOR STAYING IN BOUNDS
Sharing Personal Information/Self-Disclosure/ Too Much Information	<ul style="list-style-type: none"> • Use caution when talking to a patient about your personal life • Stay outwardly focused • Therapeutic, not social relationship
Gifts/Favors (Giving and Receiving)	<ul style="list-style-type: none"> • Check the gifts policy • Practice saying no graciously • Explain that you are not allowed to accept gifts, tips • To protect yourself, report offers of unusual or large gifts to your supervisor
Over Involvement (Developing Friendships)	<ul style="list-style-type: none"> • Focus on patient needs, not personalities • Don't confuse patient needs with your own • Maintain a helpful relationship, treating each patient with the same quality of care and attention, regardless of your emotional reaction to the patient • Ask yourself if you are becoming overly involved with the patient's personal life. If so, discuss your feelings with your supervisor • Be self-aware
Physical Contact/Touch	<ul style="list-style-type: none"> • Sexual or romantic contact with a patient or family member is never permitted • Touch initiated by the patient navigator is strongly discouraged • Allow the patient to initiate touch only if you are comfortable • Use touch only when it will serve a good purpose for the patient • Ask your patient if he/she is comfortable with your touch • Be aware that a patient may react differently to touch than you intend

	<ul style="list-style-type: none"> • When using touch, be sure that it is serving the patient’s needs and not your own • Discourage flirting behavior by your patient • Be self-aware
Overall/Other Blurring Boundaries	<ul style="list-style-type: none"> • Focus on what the patient needs • Be self-aware about body language and non-verbal cues • Do not touch the patient • Do not give advice or attempt to counsel the patient; refer to an appropriately trained team member

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 Patients¹⁹¹

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 Friend⁷⁸

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 Interest²⁰⁶

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.

Figure 57. Summary of strategies to resolve conflict of interest

Follow your organization's policies for reporting a conflict of interest

Resolve the issue in a way that is in the best interests of your patients

End any dual relationships

Return any gifts or money

End the navigation relationship

Address any issues with employer policies conflicting with patient needs

Dual Relationships¹⁹¹

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 Relationships¹⁹¹

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 Relationships¹⁹¹

Figure 58. Strategies to address dual relationships



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.

MODULE 6: Professionalism

LESSON 2: Ethics and Patient Rights^{23,78,191,209-217}

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^{78,209}

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 Standards²⁰⁹

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

Utilitarian Approach

- The Utilitarian Approach focuses on consequences. Think about which possible action provides the least amount of harm and the most good.

Rights Approach

- The Rights Approach assumes that we have a duty to respect the rights of others.

Fairness or Justice Approach

- 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.

Common Good Approach

- 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.

Virtue Approach

- Finally the Virtue Approach, assumes that actions should be based on universal ideals, or virtues. Examples include honesty, courage, fairness, compassion and prudence.

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 Systems²³

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 Patients⁷⁸

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^{78,210}

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

Patient Rights	Patient Responsibilities
See their health care records / Accurate and easy to understand information	Patients are responsible for their own health
Choose their health care providers and plans	Patients must disclose information
Access emergency services	Patients must be financially and administratively responsible
Be part of treatment decisions	Patients must be respectful of others
Be treated with respect and without discrimination	
Have their health information kept private	
Complain about their health care	

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 Consent⁷⁸

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

- The purpose of the treatment/clinical trial
- What will happen during the treatment/clinical trial
- Benefits and risks of participating in treatment/the clinical trial
- Patient's rights
- Who to contact if the patient has questions or feels they have been mistreated

Health Insurance Portability and Accountability Act (HIPAA)²¹¹

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

Health Care Providers	Health Insurers
<ul style="list-style-type: none">• Doctors• Clinics• Hospitals• Psychologists• Chiropractors• Nursing Homes• Pharmacies• Dentists	<ul style="list-style-type: none">• Health insurance companies• HMOs• Company Health Plans• Government Programs (Medicare and Medicaid)

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)^{78,211,217}

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

Contact information
<ul style="list-style-type: none">• Name• Address (all geographic subdivisions smaller than state, including street address, city, county, zip code)• Telephone numbers• FAX number• E-mail address
Electronic contact information
<ul style="list-style-type: none">• Web URL (web address)• Internet Protocol (IP) address numbers
Dates related to a patient or their care
<ul style="list-style-type: none">• Birth or death date• Admission or discharge date
Identifying numbers
<ul style="list-style-type: none">• Social Security Number• Medical record number• Health plan beneficiary number• Account number• Certificate/license number
Device or vehicle numbers
<ul style="list-style-type: none">• Device identifiers or serial numbers• Any vehicle or other device serial number
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 services 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 Obligations²¹²⁻²¹⁴

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](#): 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](#): This self-paced slide set covers aspects of protected health information.
- Temple Health's [A Practical Guide to Informed Consent](#): This toolkit provides background on informed consent and ways to improve informed consent.
- National Conference of State Legislatures [Mental Health Professionals' Duty to Warn](#): This webpage provides information about the duty to warn and summarizes state laws on the topic.
- National Conference of State Legislatures' [Mandatory Reporting of Child Abuse and Neglect State Statute Overview](#): This webpage summarizes state laws on mandatory reporting requirements.

MODULE 7: Enhancing Practice

LESSON 1: Practicing Efficiently and Effectively^{3,78,157,191,218-228}

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 Trust⁷⁸

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



Skills for Being Responsive^{78,191,218-223}

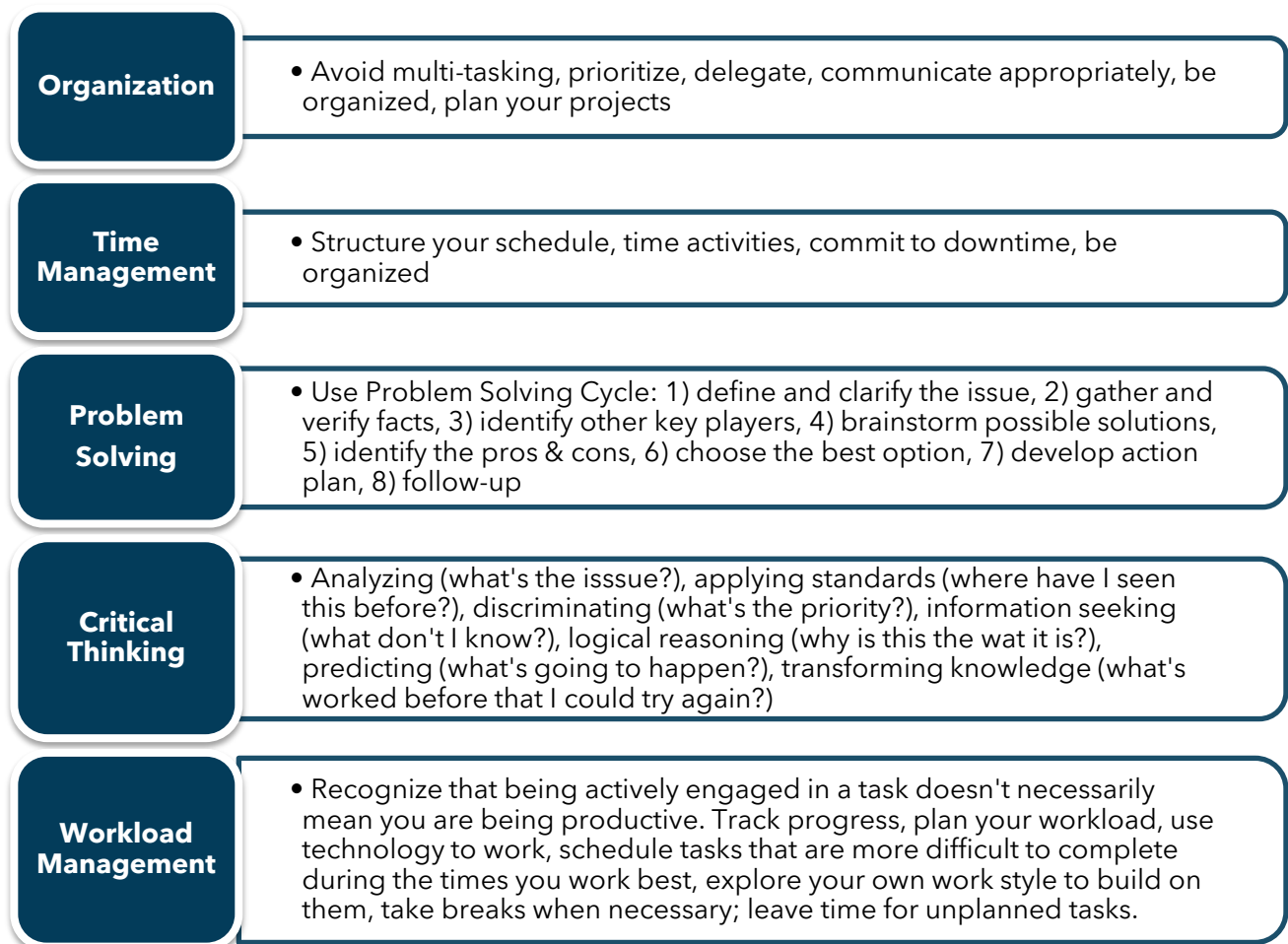
Patient navigators can borrow from the business and management sciences to be responsive to patients' needs. Customer responsiveness has been described as "accurately and insightfully giving customers what they need, want or don't yet know they want and doing so more quickly than anyone else." Patient 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



Administrative Duties of the Patient Navigator²²⁰

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

Figure 66. Administrative duties of the patient navigators



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.
- Kansas Cancer Partnership's [Cancer Patient Navigation Program Toolkit.](#)
- The Boston Medical Center [Patient Navigation Toolkit.](#)

MODULE 7: Enhancing Practice

LESSON 2: Health Care Team Collaboration^{21,78,157,229-239}

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 Teams²²⁹

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 Teams²³⁰

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?²²⁹

Figure 68. Obstacles for interprofessional teamwork in health care



Impact of Dysfunctional Teams^{229,231}

Figure 69. Outcomes of dysfunctional teams



Components of Successful Teamwork²³⁰

Figure 70. Barriers to successful team collaboration



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.

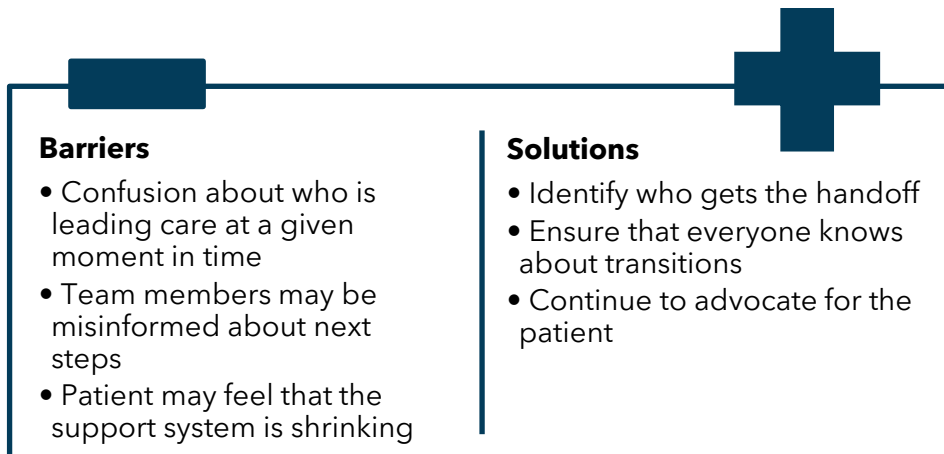
Figure 71. Elements of successful teamwork



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



Diversity on Health Care Teams²³²⁻²³⁴

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 Barriers²³⁰

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 Communication²³⁰

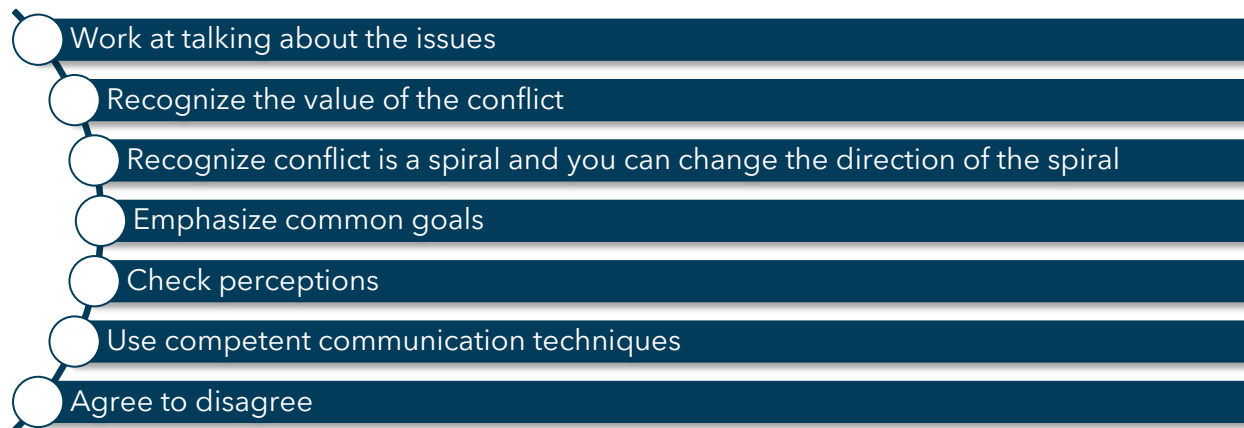
- Foster a culture of common purpose, intent, trust, respect, and collaboration
- Start with common goal = high-quality patient care
- Be self-aware of personal biases and beliefs

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



There are two tools that may help you: SBAR and Walk in the Woods.

SBAR: Situation, Background, Assessment, and Recommendation^{78,230,235}

Figure 74. SBAR model

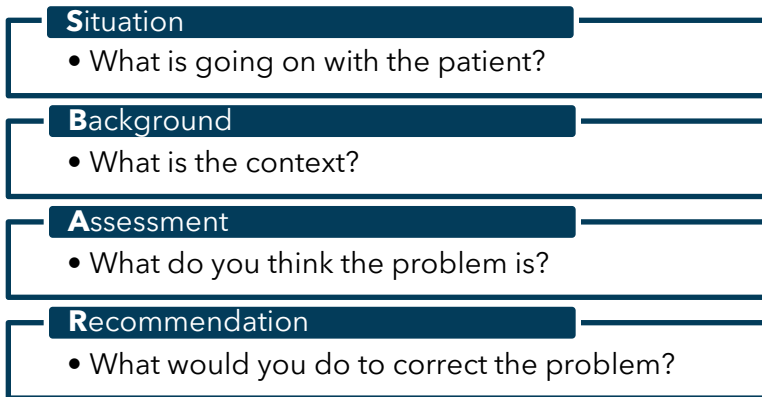
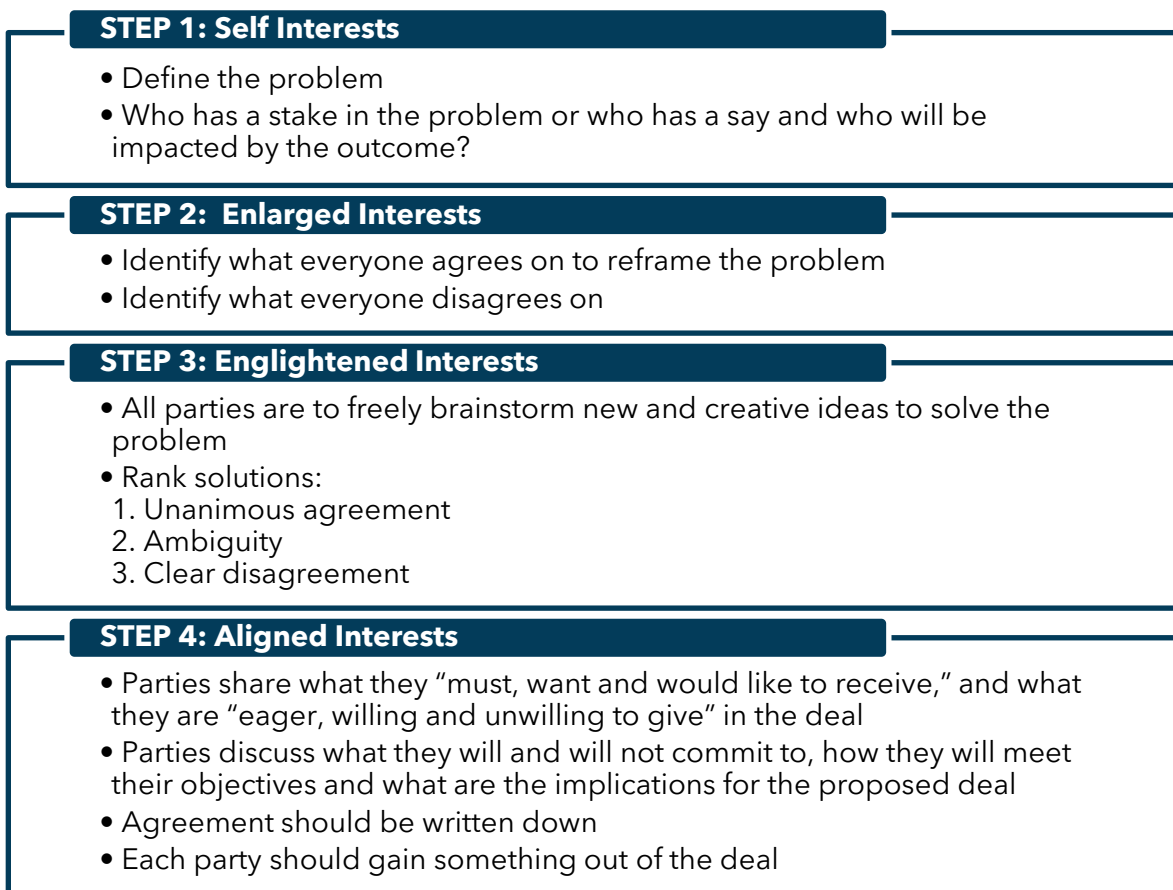


Figure 75. Walk in the Woods



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.

MODULE 7: Enhancing Practice

LESSON 3: Program Evaluation and Quality Improvement^{3,21,78,179,240-250}

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^{78,240}

Some important definitions for program evaluation include:

Figure 76. Definition of essential program evaluation components

Program	<ul style="list-style-type: none"> • A program is a group of resources and activities used together to fulfill one or more purposes
Program Evaluation	<ul style="list-style-type: none"> • The systematic collection and analysis of information about some or all aspects of a program to guide judgments or decisions
Stakeholders	<ul style="list-style-type: none"> • Organizations, groups, or individuals with interest in the power to influence a program

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

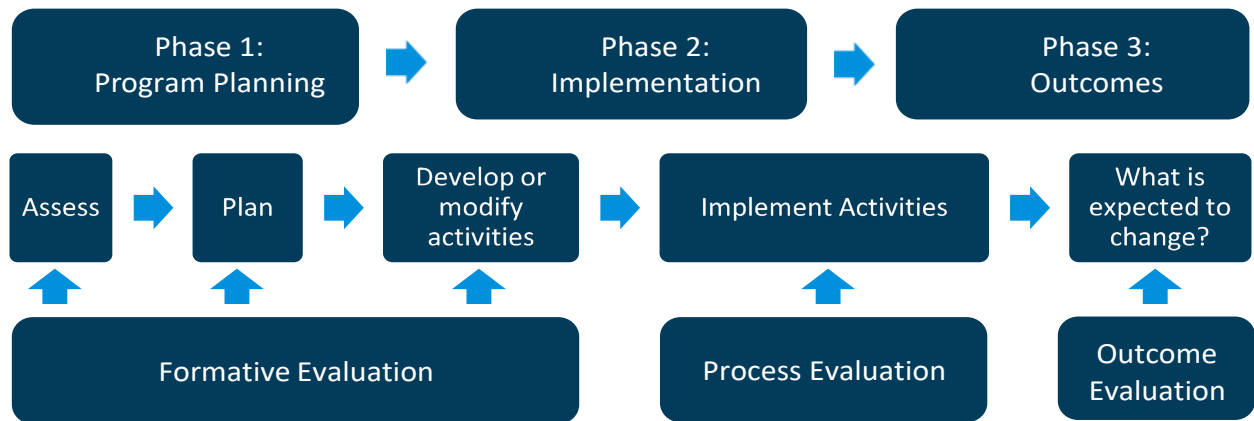


Table 42. Patient navigator involvement in evaluation

Data Collection	Data Analysis (maybe)	Data Reporting (maybe)
<ul style="list-style-type: none"> • Who are your patients? • What services are you providing? • How well are you assisting your patients? • How long do certain tasks take? 	<ul style="list-style-type: none"> • What are the trends? • Where are the areas for improvement? 	<ul style="list-style-type: none"> • Reports for stakeholders • Presentations

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

<u>Where can we find the information?</u>	<u>How do we obtain the information?</u>
<ul style="list-style-type: none"> • Patient records • Cancer registry database • Tracking logs • Administrative data • Meeting summaries • Interview transcripts; notes • Survey results 	<ul style="list-style-type: none"> • Patient records abstraction • Surveys/questionnaires • Interviews • Review of tracking logs • Focus groups • Data Analysis: quantitative and/or qualitative

Formative Evaluation

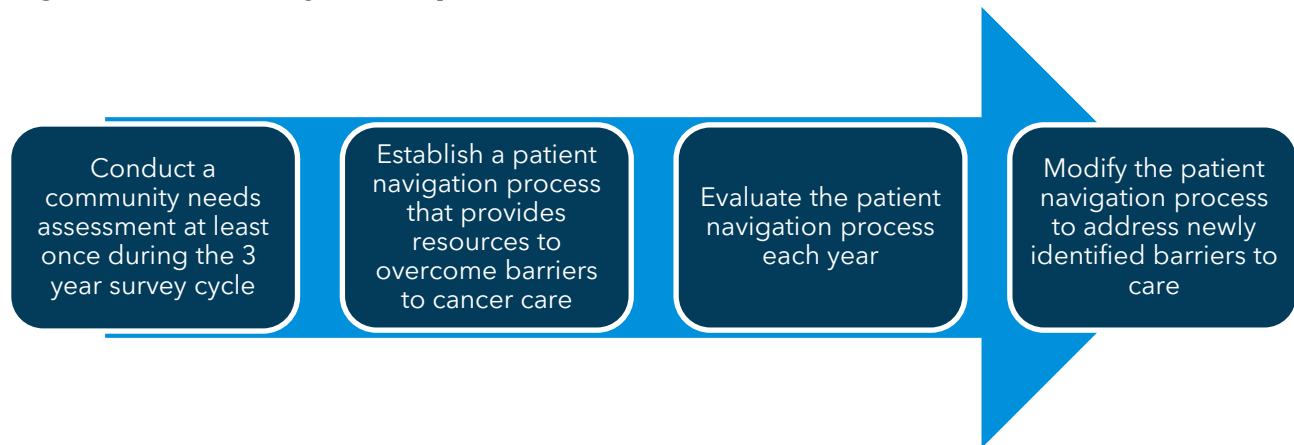
Questions you can answer with formative evaluation include:

- 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^{241,242}

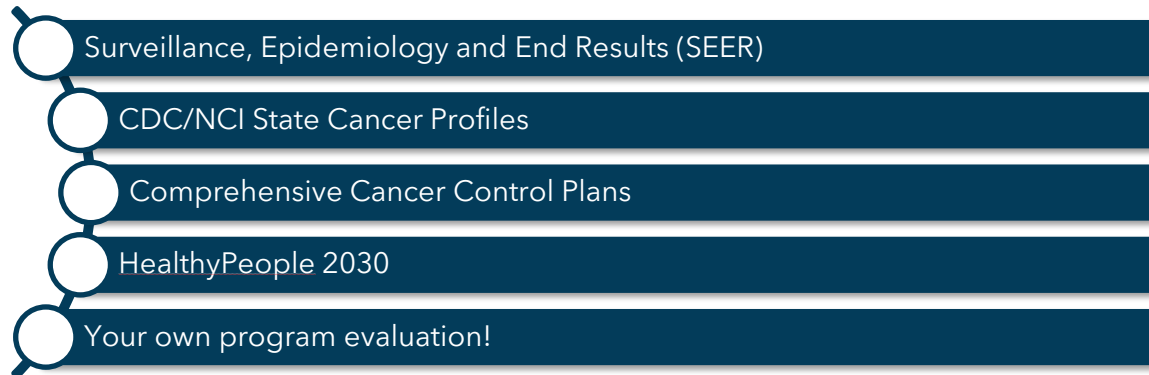
The Commission on Cancer, or CoC, accredits about 1,500 cancer programs across the country. Starting in 2016, the CoC added a new standard related to patient navigation that CoC-accredited programs must address. In 2020, the CoC changed this standard to Addressing Barriers to Care. For a step-by-step 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



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

MEASURE EXAMPLE	DATA SOURCE
Who provides the services	Descriptive data
Types of services provided	Tracking log
# of patients navigated	Tracking log
# patient barriers	Tracking log
# barriers resolved	Tracking log
# patients receiving co-pay assistance due to navigation	Tracking log
Communication between navigator and patients	Patient surveys
Patient satisfaction	Patient surveys

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

MEASURE EXAMPLE	DATA SOURCE
Time from screening to diagnostic resolution	Medical record abstraction Tracking log
Time from diagnosis to treatment	Medical record abstraction Tracking log
Patient adherence to scheduled appointments	Medical record abstraction Medical Outcomes Study Adherence Survey
Patient satisfaction with navigation	National Cancer Institute Patient Experience Survey
Patient-reported outcomes: fatigue, distress, pain, quality of life, functionality	FACT-C PROMIS
Time from screening to diagnostic resolution	Medical record abstraction Tracking log

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

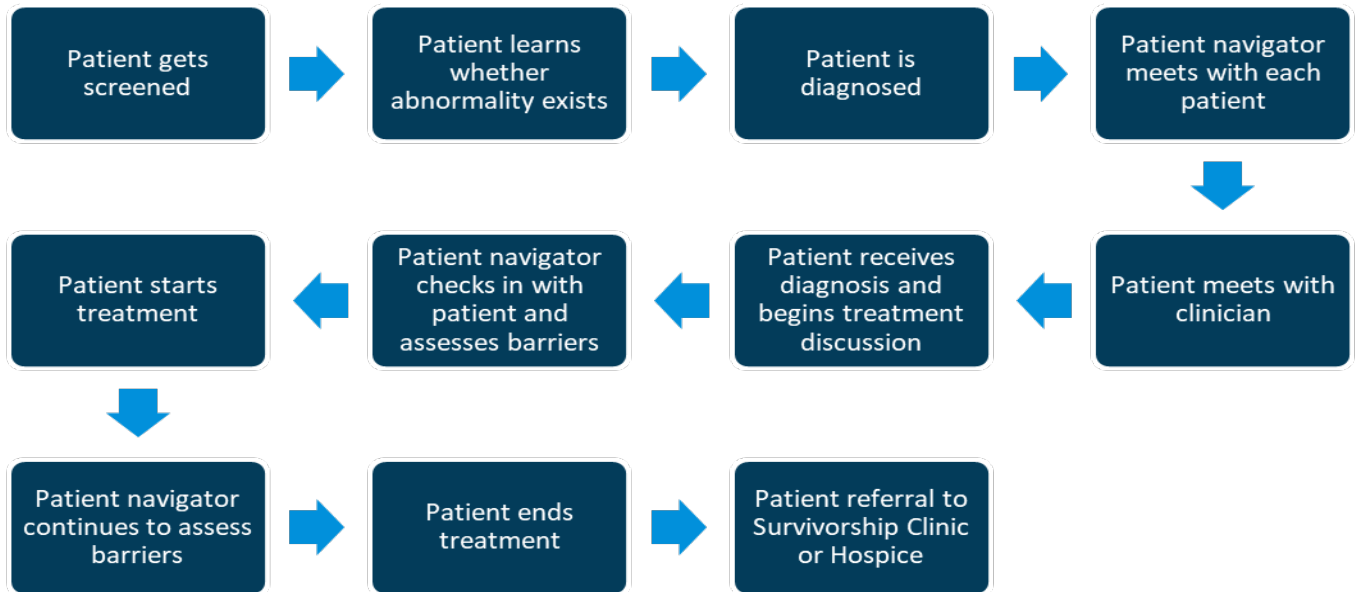
Quality Improvement

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?

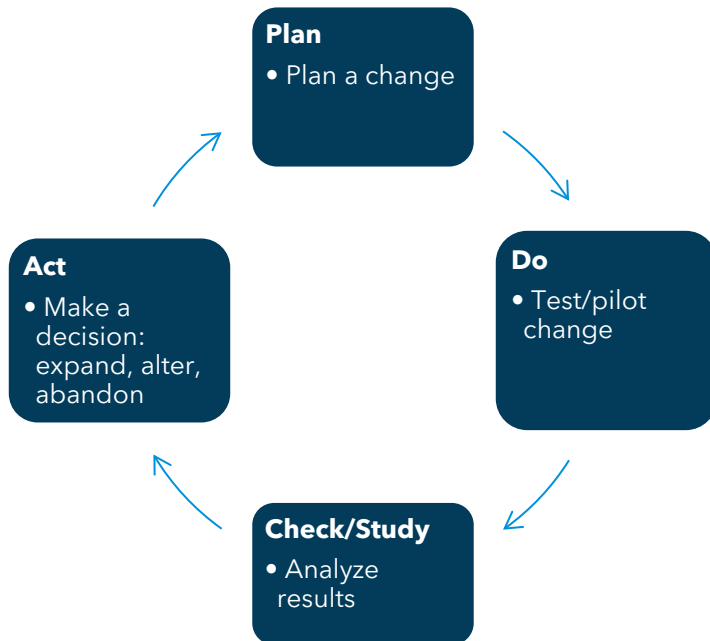
Figure 82. Example of patient flow/process map



Making Improvements: The PDCA Cycle²⁴⁵

The PDCA Cycle can be used to make improvements:

Figure 83. PDCA cycle



Demonstrating Value to Stakeholders²⁴³

Table 46. Difference between internal and external stakeholders

INTERNAL STAKEHOLDERS	EXTERNAL STAKEHOLDERS
Administration	Funders
Clinicians	Colleagues
Navigators	Patients

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 Speech²⁴⁴

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

Providers	Patients	Organizations	Funders
<ul style="list-style-type: none"> • Reduce no-shows/missed appointments • Support adherence to treatment • Assist with non-clinical issues (administrative, financial and practical) • Free up their time to address clinical issues 	<ul style="list-style-type: none"> • Provide information • Connect them to support resources • Help them troubleshoot barriers that impact access to screening, treatment and supportive care • Help them navigate the health care system • Provide emotional support 	<ul style="list-style-type: none"> • Reinforce organizational mission, vision and values • Increase patient satisfaction • Retain patients within the system • Support community outreach goals • Leverage community resources 	<ul style="list-style-type: none"> • # of patients served • # of barriers eliminated • # of uninsured/underserved patients • Outputs and outcomes of your services • "Reach" • Public health impact

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 Tracts, 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.
- Kapp H, Pratt-Chapman M. [Patient Experience Mapping: A Quality Improvement Tool for Patient Navigators](#). *Journal of Oncology Navigation and Survivorship*. 2015.
- 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^{78,191,251-253}

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

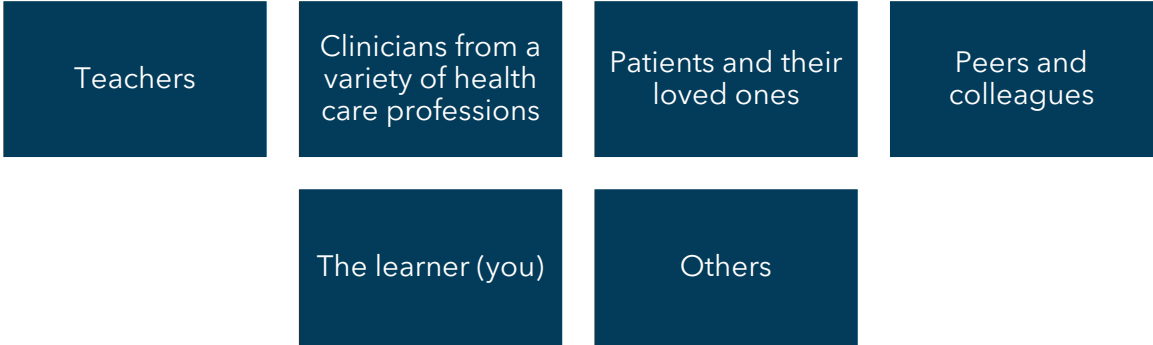
- The purpose of feedback is to encourage the recipient to assess their performance and use the information provided to make changes toward improvement
- Once you receive feedback, you can incorporate it into a plan for improving your daily work
- A professional development plan can serve as a guide 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

- It's important for you to understand what stress is, the signs that stress is becoming negative and unhealthy and how you can care for yourself to balance your stress levels

Feedback Overview

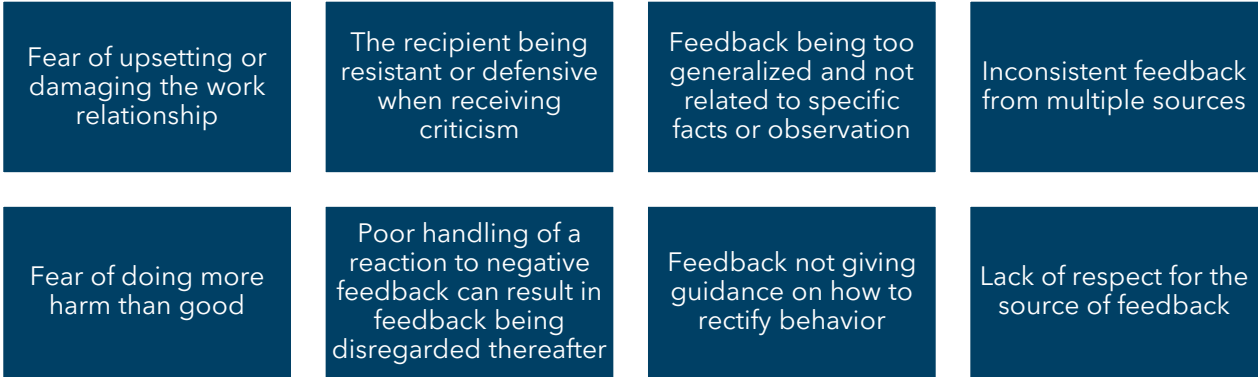
The purpose of feedback is to encourage the recipient to assess their performance and use the information provided to make changes toward improvement. Feedback is used in many settings, including clinical, educational, and home settings. It can improve performance and modify or reinforce behavior. Providing 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



Barriers of Giving Effective Feedback²⁵¹

Figure 85. Summary of potential barriers to giving effective feedback



Principles of Giving Feedback

Figure 86. Tips for giving feedback

- View feedback as a normal part of your role
- Be clear about your understanding of your role and what is expected of you
- Be specific
- Provide feedback in a non judgmental way and as someone that has directly observed the behavior or interaction
- Give feedback in a timely manner
- Focus on one to two concepts
- Have the recipient of the feedback assess their performance and encourage them to routinely do so
- Effective feedback results in a change in behavior that is noticeable in practice

Principles of Receiving Feedback^{251,252}

Figure 87. Tips for receiving feedback

- Listen with intent rather than preparing your defense or response
- Ask for clarification if needed
- Assume positive intent
- Allow yourself time to collect your thoughts and communicate a response
- Be willing to constructively provide your perspective
- Ask for suggestions to modify your behavior
- Take time to respectfully thank the person providing the feedback
- Clarify that you have received and understand the feedback and will look to improve

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



Sources of New Knowledge²⁵³

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



Figure 90. Steps for creating a professional development plan

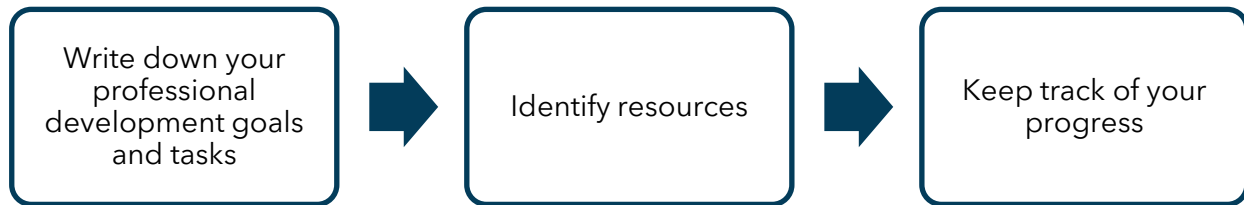


Table 49. Sample professional development plan

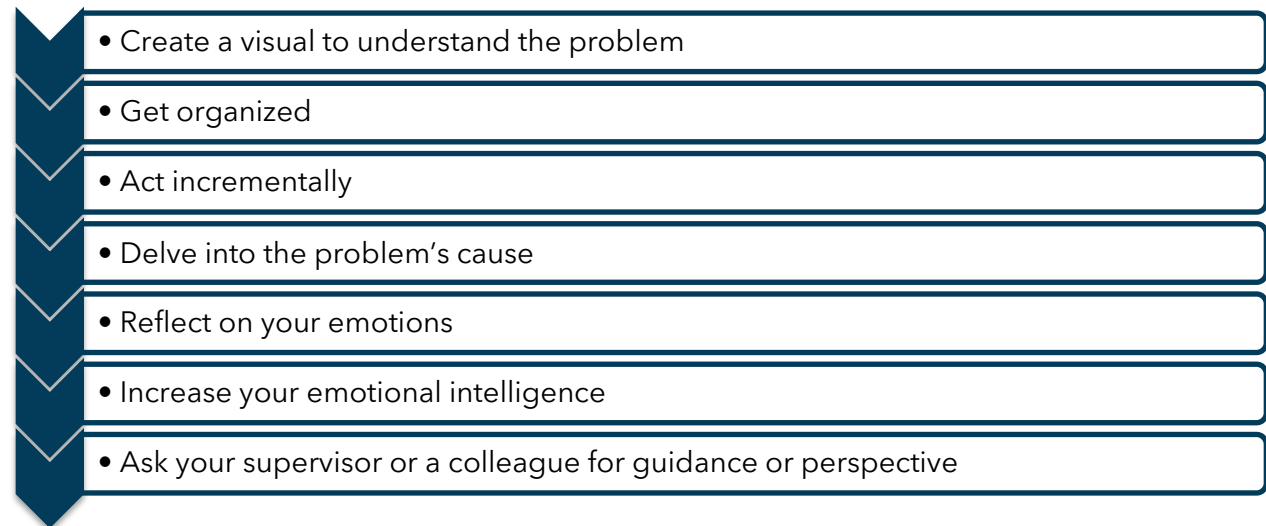
GOAL	RESOURCES	PLAN	PROGRESS
1. Improve Excel skills to help with documentation	Co-workers Free course offered through the library or LinkedIn Learning (subscription required)	Sit down with co-workers by the end of the month to do a brief tutorial Enroll in free course	Meeting scheduled Registered for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

	Oncology Navigation & Survivorship		

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 Stress¹⁹¹

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



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

Compassion Fatigue Symptoms
<ul style="list-style-type: none">• More frequent or misplaced anger• Irritability• Substance abuse: food, alcohol, or drugs• Blaming “them”• Being late frequently• Depression or feelings of hopelessness• Obsessive worry that you aren’t doing enough; irrationally high self-expectation• Less joy toward people or activities that usually bring you happiness• Lower sense of personal accomplishment• Low self-esteem• Workaholism• Less balance between empathy and objectivity• Hypertension• Physical or emotional exhaustion• Frequent headaches• Gastrointestinal problems• Insomnia or problems sleeping• Frequent vague illnesses

Self-Care: Taking Action to Minimize Stress⁷⁸

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^{78,191}

- 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.

- 1.1** 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.
- 1.2** 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.
- 1.3** 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.
- 1.4** 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.
- 1.5** Invite patients to participate in their wellness by providing self-management and health promotion resources and referrals.
- 1.6** 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

- 2.1** Demonstrate basic knowledge of medical and cancer terminology.
- 2.2** Demonstrate familiarity with and know how to access and reference evidence-based information regarding cancer screening, diagnosis, treatment, and survivorship.
- 2.3** 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).

5.8 Perform administrative duties accurately and efficiently.

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 Care²⁵⁴⁻²⁸⁰

Medical Specialty	Relevance to Cancer Patients
Allergy and Immunology	Specialize in evaluation, diagnosis and management of diseases related to immune system
Anesthesiology	Provide pain relief during or following the surgery, diagnostic or other procedures
Colon and Rectal Surgery	Treat intestinal tract, colon, rectum, anal canal, and perianal cancer types
Dermatology	Identify skin toxicity due to cancer treatment and other skin reactions
Emergency Medicine	Immediate care for injuries, acute illness, or other life-threatening conditions
Family Medicine	Manage general conditions of patients, perform screening and evaluation, and care coordination
Family Practice	General care of patients to optimize total health care
Internal Medicine	Manage long-term comprehensive care for common and complex illnesses in hospital and office settings
Internal Medicine-Pediatrics	Manages complex care for pediatric patients
Medical Genetics	Identify genetic disorders and birth defects
Neurological Surgery	Specialize in care management for disorders related to different nervous systems
Neurology	Treat illness or impaired function of the brain, spinal cord, peripheral and autonomic nervous systems
Nuclear Medicine	Specialize in cancer detection
Obstetrics and Gynecology	Manage women care before, during, and after the pregnancy; in addition, diagnosis and treatment of disorders related to female reproductive system
Ophthalmology	Manage treatment of eye tumors
Orthopedic Surgery	Restore form and functions of various parts of the body, such as extremities, spine, and other conditions
Otolaryngology	Treat cancers related to head, neck, ear, nose, or throat
Pathology-Anatomic and Clinical	Identify causes and nature of the disease
Pediatrics	Specialize in child cancer care
Physical Medicine and	Improve cancer related symptoms to enhance quality of

Rehabilitation	life
Plastic Surgery	Perform reconstructive surgery as cancer treatment and prevention
Psychiatry	Provide treatment to improve quality of life of cancer patients by reducing distress, anxiety, and other cancer related psychosocial and cognitive effects
Radiation Oncology	Manage radiation therapy for cancer treatment by reducing the symptoms or preserving organ functions
Radiology-Diagnostic	Diagnose a wide range of cancer types
Sleep Medicine	Specialize in treatment of sleep related issues
Surgery-General	Provide surgical treatment for a broad spectrum of diseases
Thoracic Surgery	Specialize in treatment of cancers that have originated in the chest area, such as esophagus and lung cancers
Urology	Manage treatment of cancers related to male genitourinary system, female urinary tract, and the adrenal gland

*The table was adapted from a list created by the [Association of American Medical Colleges](#)

Appendix C. Navigator Types and Roles⁶

FUNCTIONAL AREA	COMMUNITY (Community Health Worker)	COMMUNITY /HEALTH CARE INSTITUTION (Patient Navigator)	HEALTH CARE INSTITUTION (Nurse Navigator/ Social Work Navigator)
Professional Roles and Responsibilities	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> - Address barriers to accessing the health care system - Focus on reduction of general health 	<ul style="list-style-type: none"> - Address structural, cultural, social, emotional, and administrative barriers to care 	<ul style="list-style-type: none"> - Address clinical and service delivery barriers to care - Provision of services to at-risk populations,

	disparities	- 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
Patient Empowerment	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 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

		their care and into survivorship or end-of-life care. Work in collaboration with licensed team members	
Communication	<ul style="list-style-type: none"> - Promote healthy behaviors - Facilitate communication with the community about access and utilization of the health care system 	<ul style="list-style-type: none"> - Assist patient and provider with communicating expectations, needs, and perspectives 	<ul style="list-style-type: none"> - 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	<ul style="list-style-type: none"> - Provide referral to evidence-based health promotion programs - Aid with accessing health insurance 	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 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

			to access psychosocial support throughout treatment (Social Work Navigators)
Education, Prevention, and Health Promotion	<p>- Provide general health promotion at the individual and community level, including:</p> <ul style="list-style-type: none"> • physical activity • healthy eating habits • stress reduction • sunscreen use • tobacco cessation • reduction of other risky behaviors 	<p>- Educate patients on practical concerns and next steps in treatment with regard to what to expect</p> <p>- Identify the educational needs of patients to advocate on their behalf with the care team</p> <p>- Inform patients of the importance and benefit of clinical trials and connect them with additional resources</p>	<p>- Assess the educational needs of patients</p> <p>- Identify the educational needs of patients to advocate on their behalf with the care team</p> <p>- Inform patients of the importance and benefit of clinical trials and connect them with additional resources</p> <p>- Provide clinical education (Nurse Navigators)</p>
Ethics and Professional Conduct	- 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
Cultural Competency	- 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

	culturally appropriate educational materials	<p>Appropriate Services (CLAS) Standards in Health and Health Care)</p> <ul style="list-style-type: none"> - Educate providers to increase their understanding of the community's history, culture, and needs 	
Outreach	<ul style="list-style-type: none"> - Work with the community to identify education needs and opportunities 	<ul style="list-style-type: none"> - Educate on cancer-related topics to reduce fears and barriers related to cancer screening - Effectively link patients referred from the community to resources that can improve care coordination and timeliness to treatment 	<ul style="list-style-type: none"> - Consult and counsel patients on their unique risks
Care Coordination	<ul style="list-style-type: none"> - Provide case management, service coordination, and system navigation - Assist with access to care or transition from community organization to health system 	<ul style="list-style-type: none"> - Identify the pathway in the continuum and document the next steps to ensure the patient's optimal outcomes - Identify unmet needs and facilitate cancer care resources to eliminate barriers along the cancer continuum 	<ul style="list-style-type: none"> - Assess and facilitate coordination of psychosocial and medical/clinical care along the care continuum

<p>Psychosocial Support Services/ Assessment</p>	<ul style="list-style-type: none"> - Identify resources in the community for emotional and social support 	<ul style="list-style-type: none"> - Administer distress screening and aid with administrative, practical, or social issues identified 	<ul style="list-style-type: none"> - 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) - Educate patients and caregivers on their biopsychosocial concerns regarding their diagnosis and treatment (Social Work Navigators)
<p>Advocacy</p>	<ul style="list-style-type: none"> - Speak up for individual and community needs 	<ul style="list-style-type: none"> - Educate providers on individual preferences of care and needs 	<ul style="list-style-type: none"> - Assure patients' needs and preferences are integrated into treatment and care delivery

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.



I WANT YOU TO KNOW...

My legal name is: Please call me:

My pronouns are: (ex. she/her, they/them, he/him)

I identify as a person who is: race/ethnicity, sexual orientation & gender identity

I am most comfortable using this language or languages:


I believe in: religion/faith

These are the people I want involved in my care (check all that apply):

<input type="checkbox"/> Spouse/Partner	<input type="checkbox"/> Child	<input type="checkbox"/> Friend	Anyone else?
<input type="checkbox"/> Parent	<input type="checkbox"/> Sibling	<input type="checkbox"/> Relative	<input type="checkbox"/> No one <input type="text"/>

I would like them to be able to (check all that apply):

<input type="checkbox"/> Come to appointments	<input type="checkbox"/> Ask for information, materials, and resources
<input type="checkbox"/> Come into the exam room	<input type="checkbox"/> Discuss treatments
<input type="checkbox"/> Stay in the waiting room	<input type="checkbox"/> Help make financial decisions
<input type="checkbox"/> Help make decisions	Anything else?
<input type="checkbox"/> Ask questions	<input type="text"/>



I WANT YOU TO KNOW...

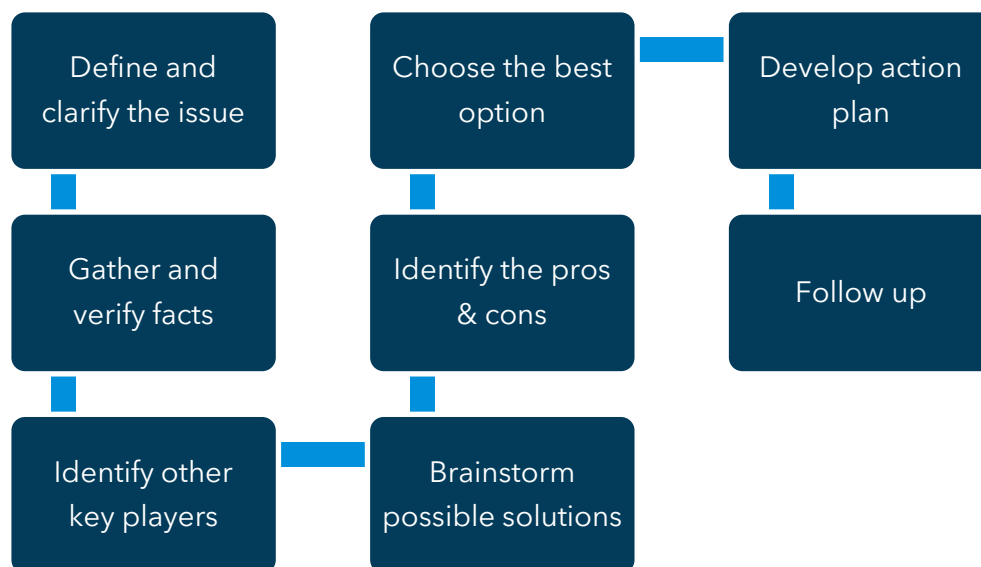
Over the past three (3) months, I have been worried about:

<input type="checkbox"/> Transportation	<input type="checkbox"/> School
<input type="checkbox"/> Childcare	<input type="checkbox"/> Personal safety
<input type="checkbox"/> Housing	<input type="checkbox"/> Insurance
<input type="checkbox"/> Money	<input type="checkbox"/> Spiritual concerns
<input type="checkbox"/> Food	Anything else?
<input type="checkbox"/> Job or work	<input type="text"/>

Anything else you should know about me:

Appendix F. The Problem-Solving Cycle⁷⁸

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 Networks⁷⁸

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 Tips¹⁶³

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.

Organization Profile		
Date		
Contact Information		
Organization Name	Contact Name	Contact Title
Address City, State, Zip Code		
Email	Phone 1	Phone 2
Resource Information		
Type of Organization <input type="checkbox"/> Agency <input type="checkbox"/> Business <input type="checkbox"/> Community-based organization <input type="checkbox"/> School <input type="checkbox"/> Informal neighborhood organization <input type="checkbox"/> Religious/spiritual organization <input type="checkbox"/> Other:		
Services provided for patients typically served by navigator with specific conditions? <input type="checkbox"/> Yes <input type="checkbox"/> No	Type of patients served:	Eligibility requirements:
Application process <input type="checkbox"/> Applied/Pending <input type="checkbox"/> Need to apply <input type="checkbox"/> Applied/Approved <input type="checkbox"/> Program Name:	Time for application to be reviewed and approved:	Limitation on services:
Fees <input type="checkbox"/> Fee for service: \$ _____ <input type="checkbox"/> No Fee for service	Bilingual <input type="checkbox"/> Bilingual staff available and someone who answers the phone in _____ language	Comments

*This source is no longer posted online.

Appendix J. Framework for Ethical Decision-Making²¹⁶

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).

BARRIER TYPE	DATE ASSESSED	DATE RESOLVED	ACTION TAKEN	TIME TO RESOLVE BARRIER
Logistical Barriers				
Transportation				
Housing				
Utilities				
Dependent Care				
Food and Nutrition				
Clothing				
Immigration Status				
Insurance Barriers				
Uninsured				
Underinsured				
High Deductible/ Copays				
Financial Barriers				
Financial Planning				
Low Financial Literacy				
Other Non-medical Financial Needs				
Employment Barriers				
Unemployed				
Job Accommodations				
Ability to Work through Treatment				

Family Member's Employment				
Communication Barriers				
Language				
Literacy				
Health Literacy				
Patient Empowerment				
Other				
Care Coordination Barriers				
Coordinating Appointments				
Coordinating Referrals				
Other				
Distress Barriers				
Difficulty Coping with Diagnosis				
Difficulty Coping with Treatment				
Difficulty Coping with Survivorship				
Difficulty Coping with End of Life				
Family Member(s) Distress				
Cultural and Religious Barriers				
Beliefs Conflict with Treatment				
Fear or Negative Perceptions				
Stigma or Discrimination				
TOTAL				

References

1. Social Determinants of Health. Office of Disease Prevention and Health Promotion. <https://www.healthypeople.gov/node/3499/closer-look>. Accessed January 3, 2022.
2. Freeman HP, Rodriguez RL. History and principles of patient navigation. *Cancer*. 2011;117(15 Suppl):3539-3542.
3. Pratt-Chapman M, Willis A. Community cancer center administration and support for navigation services. *Semin Oncol Nurs*. 2013;29(2):141-148.
4. Core Competencies for Non-Clinically Licensed Patient Navigators. The George Washington University (GW) Cancer Institute. <https://smhs.gwu.edu/gwci/sites/gwci/files/PN%20Competencies%20Report.pdf>. Published 2014. Accessed January 4, 2022.
5. Pratt-Chapman M, Willis A, Reed E, Hatcher E. Best practices in patient navigation and cancer survivorship: moving toward quality patient-centered care. *J Oncol Navig Surviv*. 2015;5(2).
6. Willis A, Reed E, Pratt-Chapman M, et al. Development of a framework for patient navigation: delineating roles across navigator types. *J Oncol Navig Surviv*. 2013;4(6).
7. National Patient Navigation Leadership Summit (NP-NLS): measuring the impact and potential of patient navigation. *Cancer*. 2011;117(15 Suppl):i-ii.
8. Cancer Health Disparities: Challenges and Opportunities. American Association for Cancer Research. <https://www.youtube.com/watch?v=0C5KEoydluc>. Published 2011. Accessed January 3, 2022.
9. Blaseg KD, Daugherty P, Gamblin KA. *Oncology Nurse Navigation: Delivering Patient-Centered Care Across the Continuum*. Pittsburg (PA): Oncology Nursing Society 2014.
10. Social Determinants of Health. Center for Health Progress. <https://www.youtube.com/watch?v=I7iSYi3ziTI&index=3&list=PLAO0U2GXUBQFyPdyzgZ1h4cljJp7caG8h>. Published 2013. Accessed January 3, 2022.
11. Social Determinants of Health. Colorado Coalition for the Medically Underserved. <https://www.youtube.com/watch?v=I7iSYi3ziTI&index=3&list=PLAO0U2GXUBQFyPdyzgZ1h4cljJp7caG8h>. Published 2003. Accessed January 3, 2022.
12. *The Burden of Cancer Among Ethnic Minorities and Medically Underserved Populations*. Washington (DC): National Academies Press (US): Institute of Medicine (US) Committee on Cancer Research Among Minorities and the Medically Underserved. In Haynes MA, Smedley BD (Eds.). *The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*.
13. Cancer Health Disparities Definitions. National Cancer Institute. <https://www.cancer.gov/about-nci/organization/crchd/about-health-disparities/definitions#:~:text=Cancer%20Health%20Disparities%20Definitions%20and%20Examples%201%20General,...%203%20Examples%20of%20Cancer%2>

- [0Health%20Disparities.%20](#). Published 2015. Accessed January 4, 2022.
14. Cancer Health Disparities. National Cancer Institute. <http://www.cancer.gov/cancertopics/disparities>. Published 2015. Accessed January 5, 2022.
 15. Patient Navigation Research Program (PNRP). National Cancer Institute. <https://www.cancer.gov/pnrp-brochure.pdf>. Published 2015. Accessed January 5, 2022.
 16. Equity and Health. World Health Organization. <https://www.who.int/teams/social-determinants-of-health/equity-and-health>. Accessed January 5, 2022.
 17. The Boston Medical Center Patient Navigation Toolkit, 1st Edition. Avon Foundation for Women. <https://sites.bu.edu/coeinwomenshealth/resources/avontoolkits/>. Accessed January 5, 2022.
 18. Achieving Equity in Health. Health Affairs. http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=53. Published 2011. Accessed January 5, 2022.
 19. Paskett ED, Harrop JP, Wells KJ. Patient navigation: an update on the state of the science. *CA Cancer J Clin*. 2011;61(4):237-249.
 20. Pratt-Chapman M, Kapp H, Willis A, Bires J. Catalyzing patient-centered care: start where you are and share what you know. *Oncology Issues*. 2014;29(1):30-39.
 21. Pratt-Chapman M, Willis A, Masselink L. Core competencies for oncology patient navigators. *J Oncol Navig Surviv*. 2015;6(2).
 22. Vargas RB, Ryan GW, Jackson CA, Rodriguez R, Freeman HP. Characteristics of the original patient navigation programs to reduce disparities in the diagnosis and treatment of breast cancer. *Cancer*. 2008;113(2):426-433.
 23. Wells KJ, Battaglia TA, Dudley DJ, et al. Patient navigation: state of the art or is it science? *Cancer*. 2008;113(8):1999-2010.
 24. Health Impact Assessment: The Determinants of Health. World Health Organization. <https://www.who.int/news-room/q-a-detail/determinants-of-health>. Accessed January 5, 2022.
 25. Online Etymology Dictionary. <https://www.etymonline.com/>. Accessed January 5, 2022.
 26. Medical Terminology. Penguin Prof Pages. <https://www.youtube.com/watch?v=3fiEszFPRE8&feature=youtu.be>. Published 2011. Accessed January 5, 2022.
 27. Penguin Prof Pages. <https://www.penguinprof.com/>. Accessed January 5, 2022.
 28. Collins English Dictionary. <https://www.collinsdictionary.com/dictionary/english>. Accessed January 5, 2022.
 29. Dictionary.com Unabridged. <http://dictionary.reference.com/>. Accessed January 5, 2022.
 30. NCI Dictionary of Cancer Terms. National Cancer Institute. <http://www.cancer.gov/dictionary>. Accessed January 5, 2022.
 31. The American Heritage Science Dictionary of the English Language.

- <https://www.ahdictionary.com/>. Accessed January 5, 2022.
32. The American Heritage Stedman's Medical Dictionary. <https://stedmansonline.com/>. Accessed January 5, 2022.
 33. Banay GL. An introduction to medical terminology I. Greek and Latin derivations. *Bull Med Libr Assoc*. 1948;36(1):1-27.
 34. Wulff HR. The language of medicine. *J R Soc Med*. 2004;97(4):187-188.
 35. What Is Cancer? National Cancer Institute. <https://www.cancer.gov/about-cancer/understanding/what-is-cancer>. Accessed January 5, 2022.
 36. Understanding Cancer. National Cancer Institute. <https://www.cancer.gov/about-cancer/understanding>. Accessed January 5, 2022.
 37. Cancer Prevention Overview (PDQ®)-Patient Version. National Cancer Institute. <https://www.cancer.gov/about-cancer/causes-prevention/patient-prevention-overview-pdq#section/all>. Accessed January 5, 2022.
 38. Alcohol. National Cancer Institute <https://www.cancer.gov/about-cancer/causes-prevention/risk/alcohol>. Published 2015. Accessed January 5, 2022.
 39. Obesity. National Cancer Institute. <https://www.cancer.gov/about-cancer/causes-prevention/risk/obesity>. Published 2015. Accessed January 5, 2022.
 40. Diet. National Cancer Institute. <https://www.cancer.gov/about-cancer/causes-prevention/risk/diet>. Published 2015. Accessed January 5, 2022.
 41. Radiation. National Cancer Institute. <https://www.cancer.gov/about-cancer/causes-prevention/risk/radiation>. Published 2019. Accessed January 5, 2022.
 42. Tobacco. National Cancer Institute. <https://www.cancer.gov/about-cancer/causes-prevention/risk/tobacco>. Published 2017. Accessed January 5, 2022.
 43. Infectious Agents. National Cancer Institute. <https://www.cancer.gov/about-cancer/causes-prevention/risk/infectious-agents>. Published 2019. Accessed January 5, 2022.
 44. Immunosuppression. National Cancer Institute. <https://www.cancer.gov/about-cancer/causes-prevention/risk/immunosuppression>. Published 2015. Accessed January 5, 2022.
 45. Physical Activity and Cancer. National Cancer Institute. <https://www.cancer.gov/about-cancer/causes-prevention/risk/obesity/physical-activity-fact-sheet>. Published 2020. Accessed January 5, 2022.
 46. Cancer-Causing Substances in the Environment. National Cancer Institute. <https://www.cancer.gov/about-cancer/causes-prevention/risk/substances>. Published 2018. Accessed January 5, 2022.
 47. Hayes RB, Pottner LM, Strickler H, et al. Sexual behaviour, STDs and risks for prostate cancer. *Br J Cancer*. 2000;82(3):718-725.
 48. Giovannucci E, Harlan DM, Archer MC, et al. Diabetes and cancer: a consensus report. *Diabetes Care*. 2010;33(7):1674-1685.
 49. Hormones. National Cancer Institute. <https://www.cancer.gov/about-cancer/causes-prevention/risk/hormones>. Published 2015. Accessed January 5, 2022.

50. Caughey AB, Krist AH, Wolff TA, et al. USPSTF approach to addressing sex and gender when making recommendations for clinical preventive services. *JAMA*. 2021;326(19):1953-1961.
51. Cancer Staging. National Cancer Institute. <http://www.cancer.gov/cancertopics/factsheet/detection/staging>. Published 2015. Accessed January 5, 2022.
52. 6 Things To Know When Selecting a Complementary Health Practitioner. NIH National Center for Complementary and Integrative Health. <https://www.nccih.nih.gov/health/tips/things-to-know-when-selecting-a-complementary-health-practitioner>. Accessed January 5, 2022.
53. Cancer Screening Guidelines. American Cancer Society. <https://www.cancer.org/healthy/find-cancer-early/cancer-screening-guidelines.html>. Accessed January 5, 2022.
54. Cancer Basics. American Cancer Society. <https://www.cancer.org/cancer/cancer-basics.html>. Accessed January 5, 2022.
55. Exercise, Lifestyle Habits Can Prevent 1 of 3 Breast Cancer Cases. American Institute for Cancer Research. <https://www.aicr.org/news/exercise-lifestyle-habits-can-prevent-1-of-3-breast-cancer-cases/>. Published 2017. Accessed January 5, 2022.
56. Guidelines, Tools, & Resources. American Society of Clinical Oncology. <https://www.asco.org/research-guidelines/quality-guidelines/guidelines>. Accessed January 5, 2022.
57. 3D Medical Animation-What Is Cancer? BioDigital. [https://www.bing.com/videos/search?q=BioDigital.+\(2008\).+3D+Medical+animation%e2%80%90what+is+cancer%3f&qvpt=BioDigital.+\(2008\).+3D+Medical+animation%e2%80%90what+is+cancer%3f&view=detail&mid=5616CFC0AAAB1A80A5385616CFC0AAAB1A80A538&&FORM=VRDGAR&ru=%2Fvideos%2Fsearch%3Fq%3DBioDigital.%2B\(2008\).%2B3D%2BMedical%2Banimation%25e2%2580%2590what%2Bis%2Bcancer%253f%26qvpt%3DBioDigital.%2B\(2008\).%2B3D%2BMedical%2Banimation%25e2%2580%2590what%2Bis%2Bcancer%253f%26FORM%3DVDRE](https://www.bing.com/videos/search?q=BioDigital.+(2008).+3D+Medical+animation%e2%80%90what+is+cancer%3f&qvpt=BioDigital.+(2008).+3D+Medical+animation%e2%80%90what+is+cancer%3f&view=detail&mid=5616CFC0AAAB1A80A5385616CFC0AAAB1A80A538&&FORM=VRDGAR&ru=%2Fvideos%2Fsearch%3Fq%3DBioDigital.%2B(2008).%2B3D%2BMedical%2Banimation%25e2%2580%2590what%2Bis%2Bcancer%253f%26qvpt%3DBioDigital.%2B(2008).%2B3D%2BMedical%2Banimation%25e2%2580%2590what%2Bis%2Bcancer%253f%26FORM%3DVDRE). Published 2008. Accessed January 6, 2022.
58. Lynch Syndrome. American Society of Clinical Oncology. <https://www.cancer.net/cancer-types/lynch-syndrome>. Published 2020. Accessed January 6, 2022.
59. What Is Personalized Cancer Medicine? American Society of Clinical Oncology. <https://www.cancer.net/navigating-cancer-care/how-cancer-treated/personalized-and-targeted-therapies/what-personalized-cancer-medicine>. Published 2020. Accessed January 6, 2022.
60. Cunha JP. Cancer Risk Factors and Causes. MedicineNet.com. http://www.medicinenet.com/cancer_causes/page7.htm. Published 2021. Accessed January 6, 2022.
61. David's Palliative Care Story. Get Palliative Care. <https://getpalliativecare.org/davids-palliative-care-story/>. Published 2014.

- Accessed January 6, 2022.
62. Rehabilitation after Cancer. LIVESTRONG Foundation. <https://www.livestrong.org/we-can-help/healthy-living-after-treatment/rehabilitation-after-cancer>. Accessed January 6, 2022.
 63. The Numbers Are in: As Many As 2 in 3 Smokers Will Die from Their Habit. Medical News Today. <http://www.medicalnewstoday.com/releases/289925.php?tw>. Published 2015. Accessed January 6, 2022.
 64. BRCA Gene Mutations: Cancer Risk & Genetic Testing. National Cancer Institute. <https://www.cancer.gov/about-cancer/causes-prevention/genetics/brca-fact-sheet>. Accessed January 6, 2022.
 65. Cancer and Prevention. National Cancer Institute. <http://www.cancer.gov/cancertopics/causes>. Accessed January 6, 2022.
 66. Genetic Testing for Inherited Cancer Susceptibility Syndromes. National Cancer Institute. <https://www.cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet>. Published 2019. Accessed January 6, 2022.
 67. Hormone Therapy for Breast Cancer. National Cancer Institute. <https://www.cancer.gov/types/breast/breast-hormone-therapy-fact-sheet>. Published 2021. Accessed January 6, 2022.
 68. Hormone Therapy for Prostate Cancer. National Cancer Institute. <https://www.cancer.gov/types/prostate/prostate-hormone-therapy-fact-sheet>. Published 2021. Accessed January 6, 2022.
 69. Mammograms. National Cancer Institute. <http://www.cancer.gov/cancertopics/factsheet/Detection/mammograms>. Published 2021. Accessed January 6, 2022.
 70. Targeted Cancer Therapies. National Cancer Institute. <https://www.cancer.gov/about-cancer/treatment/types/targeted-therapies/targeted-therapies-fact-sheet>. Published 2021. Accessed January 6, 2022.
 71. Screening Tests to Detect Colorectal Cancer and Polyps. National Cancer Institute. <https://www.cancer.gov/types/colorectal/screening-fact-sheet>. Published 2021. Accessed January 6, 2022.
 72. Are You Considering a Complementary Health Approach? National Center for Complementary and Integrative Health. <https://nccih.nih.gov/health/decisions/consideringcam.htm>. Published 2016. Accessed January 6, 2022.
 73. NCCN Guidelines: Treatment by Cancer Site. National Comprehensive Cancer Network. https://www.nccn.org/professionals/physician_gls/default.aspx#site. Accessed January 6, 2022.
 74. Silver JK, Baima J, Mayer RS. Impairment-driven cancer rehabilitation: an essential component of quality care and survivorship. *CA Cancer J Clin*. 2013;63(5):295-317.

75. Final Recommendation Statement. Lung Cancer: Screening. U.S. Preventive Services Task Force.
<https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/lung-cancer-screening>. Published 2021. Accessed January 6, 2022.
76. Recommendation Tools - A and B Recommendations. U.S. Preventive Services Task Force.
[https://www.uspreventiveservicestaskforce.org/uspstf/recommendation-topics/uspstf-and-b-recommendations#:~:text=The%20USPSTF%20recommends%20offering%20or,healthy%20diet%20and%20physical%20activity.&text=The%20USPSTF%20recommends%20screening%20for%20hepatitis%20B%20virus%20\(HBV\)%20infection,at%20increased%20risk%20for%20infection](https://www.uspreventiveservicestaskforce.org/uspstf/recommendation-topics/uspstf-and-b-recommendations#:~:text=The%20USPSTF%20recommends%20offering%20or,healthy%20diet%20and%20physical%20activity.&text=The%20USPSTF%20recommends%20screening%20for%20hepatitis%20B%20virus%20(HBV)%20infection,at%20increased%20risk%20for%20infection). Accessed January 6, 2022.
77. Next Steps after an Abnormal Cervical Cancer Screening Test: Understanding HPV and Pap Test Results. National Cancer Institute.
<https://www.cancer.gov/types/cervical/understanding-abnormal-hpv-and-pap-test-results>. Published 2021. Accessed January 14, 2022.
78. Patient Navigator Training Collaborative. <https://patientnavigatortraining.org/>. Accessed January 14, 2022.
79. Prostate Cancer Screening (PDQ®)-Health Professional Version. National Cancer Institute. <https://www.cancer.gov/types/prostate/hp/prostate-screening-pdq>. Published 2021. Accessed January 14, 2022.
80. Hyperplasia. National Cancer Institute.
<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/hyperplasia>. Accessed January 6, 2022.
81. Understanding Cancer Risk. American Society of Clinical Oncology.
<https://www.cancer.net/navigating-cancer-care/prevention-and-healthy-living/understanding-cancer-risk>. Published 2018. Accessed March 9, 2022.
82. The Genetics of Cancer. American Society of Clinical Oncology.
<https://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/genetics-cancer>. Published 2018. Accessed March 9, 2022.
83. Genetic Testing for Cancer Risk. American Society of Clinical Oncology.
<https://www.cancer.net/navigating-cancer-care/cancer-basics/genetics/genetic-testing-cancer-risk>. Published 2018. Accessed March 9, 2022.
84. Medicare Coverage Issues Manual. Centers for Medicare & Medicaid Services.
<http://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/downloads/R126CIM.pdf>. Published 2000. Accessed January 14, 2022.
85. Module 1: What Is a Clinical Trial? Patient Navigator Training Collaborative.
http://www.patientnavigatortraining.org/clinical_trials/module_1/index.htm. Accessed January 14, 2022.
86. Clinical Trials Information for Patients and Caregivers. National Cancer Institute.
<https://www.cancer.gov/about-cancer/treatment/clinical-trials>. Accessed January 22, 2022.

87. Clinical Research Trials: The Basics. OncoLink. <https://www.oncolink.org/cancer-treatment/clinical-trials/clinical-research-trials-the-basics>. Published 2020. Accessed January 14, 2022.
88. Adolescents and Young Adults with Cancer. National Cancer Institute. <https://www.cancer.gov/types/aya>. Published 2020. Accessed January 14, 2022.
89. Cancer Clinical Trials: What Is a Clinical Trial? National Institutes for Health. <https://www.youtube.com/watch?v=ZxwKggJ2ACs>. Published 2008. Accessed January 14, 2022.
90. Getting Treatment in a Clinical Trial. American Society of Clinical Oncology. <https://www.cancer.net/navigating-cancer-care/how-cancer-treated/getting-treatment-clinical-trial>. Published 2019. Accessed January 14, 2022.
91. Managing Physical Side Effects. American Society of Clinical Oncology. <http://www.cancer.net/navigating-cancer-care/side-effects>. Accessed January 14, 2022.
92. Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults With Cancer. Report of the Adolescent and Young Adult Oncology Progress Review Group. U.S. Department of Health and Human Services. https://www.livestrong.org/sites/default/files/what-we-do/reports/ayao_prg_report_2006_final.pdf. Published 2006. Accessed January 14, 2022.
93. Understanding Advanced and Metastatic Cancer. American Cancer Society. <https://www.cancer.org/treatment/understanding-your-diagnosis/advanced-cancer/what-is.html>. Published 2020. Accessed January 14, 2022.
94. Changing the Landscape for People Living With Metastatic Breast Cancer. Metastatic Breast Cancer Alliance. https://www.mbcalliance.org/wp-content/uploads/Executive-Summary_Dec2014_published.pdf. Published 2014. Accessed January 14, 2022.
95. Breast Cancer: A Story Half Told Press Kit. Pfizer Oncology. <https://www.pfizer.com/news/press-kits/breast-cancer>. Published 2014. Accessed January 14, 2022.
96. Survivorship: During and After Treatment. American Cancer Society. <https://www.cancer.org/treatment/survivorship-during-and-after-treatment.html>. Accessed January 14, 2022.
97. Hewitt ME, Ganz PA, Institute of Medicine (U.S.), American Society of Clinical Oncology (U.S.). *From cancer patient to cancer survivor : lost in transition : an American Society of Clinical Oncology and Institute of Medicine Symposium*. Washington, D.C.: National Academies Press; 2006.
98. Cancer Survivors: Late Effects of Cancer Treatment. Mayo Clinic. <http://www.mayoclinic.org/diseases-conditions/cancer/in-depth/cancer-survivor/art-20045524>. Published 2014. Accessed January 14, 2022.
99. Cancer Survivorship E-Learning Series for Primary Care Providers. GW School of Medicine and Health Science, GW Online Academy <https://cme.smhs.gwu.edu/gw-cancer-center-/content/cancer-survivorship-e->

- [learning-series-primary-care-providers#group-tabs-node-course-default3](#). Accessed January 14, 2022.
100. Nearing the End of Life. American Cancer Society. <https://www.cancer.org/treatment/end-of-life-care/nearing-the-end-of-life.html>. Accessed January 14, 2022.
 101. Cancer Treatment & Survivorship Facts & Figures. American Cancer Society. http://www.cancer.org/acs/groups/content/@research/documents/document/acs_pc-042801.pdf. Accessed January 14, 2022.
 102. Astrow AB, Wexler A, Texeira K, He MK, Sulmasy DP. Is failure to meet spiritual needs associated with cancer patients' perceptions of quality of care and their satisfaction with care? *J Clin Oncol*. 2007;25(36):5753-5757.
 103. ASCO Cancer Treatment and Survivorship Care Plans. American Society of Clinical Oncology. <http://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-summaries-and-survivorship-care-plans>. Accessed January 14, 2022.
 104. Chochinov HM, Breitbart W. *Handbook of Psychiatry in Palliative Medicine*. Oxford ; New York: Oxford University Press; 2000.
 105. Holland JC, Andersen B, Breitbart WS, et al. Distress management. *J Natl Compr Canc Netw*. 2010;8(4):448-485.
 106. Identifying and Addressing the Needs of Adolescents and Young Adults With Cancer—Workshop Summary. Institute of Medicine. <https://www.nap.edu/catalog/18547/identifying-and-addressing-the-needs-of-adolescents-and-young-adults-with-cancer>. Published 2013. Accessed January 14, 2022.
 107. The Only Metastatic Cancer Survivor Retreat of Its Kind. Johns Hopkins Medicine. <https://www.youtube.com/watch?v=Bg02G2a7uHo#t=419>. Published 2013. Accessed January 14, 2022.
 108. Dating and Sex: A Video Series for Young Adults With Cancer. LIVESTRONG Foundation. <https://www.youtube.com/watch?v=lkUIXLQRcoM&index=25&list=PL88EAB22E9D8ACD85>. Published 2013. Accessed January 14, 2022.
 109. Statistics, Graphs and Definitions. National Cancer Institute Division of Cancer Control & Population Science. <http://cancercontrol.cancer.gov/ocs/statistics/graphs.html>. Published 2021. Accessed January 14, 2022.
 110. End-of-Life Care for People Who Have Cancer. National Cancer Institute. <http://www.cancer.gov/cancertopics/advanced-cancer/care-choices/care-fact-sheet>. Published 2015. Accessed January 14, 2022.
 111. Puchalski CM, Ferrell B, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the consensus conference. *J Palliat Med*. 2009;12(10):885-904.
 112. Smith AW, Reeve BB, Bellizzi KM, et al. Cancer, comorbidities, and health-related quality of life of older adults. *Health Care Financ Rev*. 2008;29(4):41-56.

113. Glorfeld L. An improvement on Horn's parallel analysis methodology for selecting the correct number of factors to retain. *Educ Psychol Meas.* 1995;55(3):377-393.
114. Simone JV. Understanding cancer centers. *J Clin Oncol.* 2002;20(23):4503-4507.
115. Emergency Medical Treatment & Labor Act (EMTALA). Centers for Medicare & Medicaid Services. <https://www.cms.gov/Regulations-and-Guidance/Legislation/EMTALA>. Published 2021. Accessed January 18, 2022.
116. Weaver AJ. Clergy as health care providers. *South Med J.* 2005;98(12):1237.
117. Understanding Radiation Therapy. American Society of Clinical Oncology. <https://www.cancer.net/navigating-cancer-care/how-cancer-treated/radiation-therapy/understanding-radiation-therapy>. Accessed January 18, 2022.
118. Horwitz JR. Making profits and providing care: comparing nonprofit, for-profit, and government hospitals. *Health Aff (Millwood).* 2005;24(3):790-801.
119. Obedin-Maliver J, Goldsmith ES, Stewart L, et al. Lesbian, gay, bisexual, and transgender-related content in undergraduate medical education. *JAMA.* 2011;306(9):971-977.
120. Sloan FA, Picone GA, Taylor DH, Chou SY. Hospital ownership and cost and quality of care: is there a dime's worth of difference? *J Health Econ.* 2001;20(1):1-21.
121. Urgent Care Vs. Primary Care Physicians: What's the Difference? Patch. <https://patch.com/michigan/birmingham/bp--urgent-care-vs-primary-care-physicians-whats-the-difference>. Published 2012. Accessed January 18, 2022.
122. Health Insurance and Obamacare Terms. HealthInsurance.org. <https://www.healthinsurance.org/glossary/>. Accessed January 18, 2022.
123. Glossary. Wisconsin Office of the Commissioner of Insurance. <https://oci.wi.gov/Pages/Consumers/Glossary.aspx>. Accessed January 18, 2022.
124. Costs in the Coverage Gap Centers for Medicare & Medicaid Services. <https://www.medicare.gov/drug-coverage-part-d/costs-for-medicare-drug-coverage/costs-in-the-coverage-gap>. Accessed January 18, 2022.
125. What You Should Know About Provider Networks. Centers for Medicare & Medicaid Services. <https://marketplace.cms.gov/outreach-and-education/what-you-should-know-provider-networks.pdf>. Published 2021. Accessed January 18, 2022.
126. Braun KL, Kagawa-Singer M, Holden AE, et al. Cancer patient navigator tasks across the cancer care continuum. *J Health Care Poor Underserved.* 2012;23(1):398-413.
127. Fiore MC, Bailey WC, Cohen SJ. *Treating Tobacco Use and Dependence. Clinical Practice Guideline.* Rockville, MD: U.S.: Department of Health and Human Services. Public Health Service;2000.
128. Five Major Steps to Intervention (The "5 A's"). Agency for Healthcare Research and Quality. <https://www.ahrq.gov/prevention/guidelines/tobacco/5steps.html>. Published 2012. Accessed January 19, 2022.
129. CR's Guide To Health Insurance. Consumer Reports. <http://www.consumerreports.org/cro/2012/09/understanding-health->

- [insurance/index.htm](#). Published 2021. Accessed January 18, 2022.
130. Pratt-Chapman M. The cancer survivorship movement exemplar of cancer activism. *Cancer and health policy. Oncol Nurs Forum*. 2015.
 131. Healthcare/ FEHB Plan Information for 2022. The U.S. Office of Personnel Management. <https://www.opm.gov/healthcare-insurance/healthcare/plan-information/plans>. Published 2022. Accessed January 19, 2022.
 132. Eligibility. Medicaid. <https://www.medicaid.gov/medicaid/eligibility/index.html>. Accessed January 19, 2022.
 133. Hopkins J, Mumber MP. Patient navigation through the cancer care continuum: an overview. *J Oncol Pract*. 2009;5(4):150-152.
 134. Chapter 23: Modifying Access, Barriers, and Opportunities. Section 6: Using Outreach to Increase Access. Community Toolbox. <https://ctb.ku.edu/en/table-of-contents/implement/access-barriers-opportunities/outreach-to-increase-access/main>. Published 2014. Accessed January 18, 2022.
 135. Pre-Existing Condition Exclusion Period (Job-Based Coverage). HealthCare.gov. <https://www.healthcare.gov/glossary/pre-existing-condition-exclusion-period-job-based-coverage/#:~:text=The%20time%20period%20during%20which,months%20for%20a%20late%2Denrollee>. Accessed March 9, 2022.
 136. Health Benefits Advisor for Employers. U.S. Department of Labor. [https://webapps.dol.gov/elaws/ebsa/health/employer/glossary.htm?wd=Preexisting Condition Exclusion](https://webapps.dol.gov/elaws/ebsa/health/employer/glossary.htm?wd=Preexisting%20Condition%20Exclusion). Accessed March 9, 2022.
 137. Parker VA, Clark JA, Leyson J, et al. Patient navigation: development of a protocol for describing what navigators do. *Health Serv Res*. 2010;45(2):514-531.
 138. Care Coordination Measures Atlas Update. Chapter 2. What is Care Coordination? Agency for Healthcare Research and Quality. <https://www.ahrq.gov/ncepcr/care/coordination/atlas/chapter2.html>. Published 2014. Accessed January 19, 2022.
 139. Bone LR, Edington K, Rosenberg J, et al. Building a navigation system to reduce cancer disparities among urban Black older adults. *Prog Community Health Partnersh: Res Educ Action*. 2013;7(2):209-218.
 140. Cancer Disparities. National Cancer Institute. <https://www.cancer.gov/about-cancer/understanding/disparities>. Published 2020. Accessed January 19, 2022.
 141. Cultural and Linguistic Competency. The U.S. Department of Health and Human Services Office of Minority Health. <http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=1&lvlid=6>. Published 2021. Accessed January 19, 2022.
 142. Back AL, Arnold RM. Discussing prognosis: "How much do you want to know?" Talking to patients who are prepared for explicit information. *J Clin Oncol*. 2006;24(25):4209-4213.
 143. Jacobsen J, Jackson VA. A communication approach for oncologists: understanding patient coping and communicating about bad news, palliative care, and hospice. *J Natl Compr Canc Netw*. 2009;7(4):475-480.

144. Generalized Anxiety Disorder. National Institute of Mental Health. <https://www.nimh.nih.gov/health/publications/generalized-anxiety-disorder-gad>. Published 2016. Accessed January 19, 2022.
145. Depression. National Institute of Mental Health. <https://www.nimh.nih.gov/health/topics/depression>. Published 2018. Accessed January 19, 2022.
146. The Office of Minority Health. (2021). Cultural and Linguistic Competency. The U.S. Department of Health and Human Services Office of Minority Health. <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=1&lvlid=6>. Published 2021. Accessed January 19, 2022.
147. Coping With Uncertainty. American Society of Clinical Oncology. <https://www.cancer.net/coping-with-cancer/managing-emotions/coping-with-uncertainty>. Published 2019. Accessed January 19, 2022.
148. Rollnick S, Miller WR, Butler C. *Motivational interviewing in health care : helping patients change behavior*. New York: Guilford Press; 2008.
149. Rollnick S, Heather N, Bell A. Negotiating behaviour change in medical settings: the development of brief motivational interviewing. *J Ment Health*. 1992;1(1):25-37.
150. Steinberg MP, Miller WR. *Motivational interviewing in diabetes care*. New York: The Guilford Press; 2015.
151. Ogden J. *Stress and Illness. Health Psychology: A Textbook. 4th Edition*. New York: McGraw-Hill; 2007.
152. Butterworth SW, Linden A, McClay W. Health coaching as an intervention in health management programs. *Dis Manag Health Out*. 2007;15(5):299-307.
153. Miller WR, Rollnick S. *Motivational Interviewing: Preparing People For Change*. 2nd ed. New York: Guilford Press; 2002.
154. Lazarus RS, Folkman S. *Stress, Appraisal, and Coping*. New York: Springer Pub. Co.; 1984.
155. Rappaport J, Seidman E. *Handbook of Community Psychology*. New York: Kluwer Academic/Plenum; 2000.
156. Beagley L. Educating patients: understanding barriers, learning styles, and teaching techniques. *J Perianesth Nurs*. 2011;26(5):331-337.
157. Epstein RM, Street RLJ. *Patient-Centered Communication In Cancer Care: Promoting Healing and Reducing Suffering*. Bethesda, MD: National Cancer Institute;2007. NIH Publication No. 07-6225.
158. Fraenkel L, McGraw S. What are the essential elements to enable patient participation in medical decision making? *J Gen Intern Med*. 2007;22(5):614-619.
159. Kutner M, Greenberg E, Jin Y, C. P. *The Health Literacy Of America's Adults: Results From the 2003 National Assessment Of Adult Literacy*. Washington, DC: U.S. Department of Education;2006. NCEs 2006-483.
160. Nielsen-Bohlman L, Institute of Medicine (U.S.). Committee on Health Literacy. *Health Literacy: A Prescription To End Confusion*. Washington, D.C.: National Academies Press; 2004.

161. Miller WR, Rollnick S. *Motivational interviewing : helping people change*. 3rd ed. New York, NY: Guilford Press; 2013.
162. Health Literacy Online. U.S. Department of Health and Human Services. <https://health.gov/our-work/national-health-initiatives/health-literacy/health-literacy-online>. Published 2009. Accessed January 19, 2022.
163. Cornette S. Assessing and addressing health literacy. *Online J Issues Nurs*. 2009;14(3).
164. What's in a Word? A Guide to Understanding Interpreting and Translation in Health Care. National Council on Interpreting in Health Care https://www.ncihc.org/assets/documents/publications/Whats_in_a_Word_Guide.pdf. Published 2010. Accessed January 19, 2022.
165. Fleming ND, M. C. Not another inventory, rather a catalyst for reflection. *J Educ Dev*. 1992;11(1):137-155.
166. Inott T, Kennedy BB. Assessing learning styles: practical tips for patient education. *Nurs Clin North Am*. 2011;46(3):313-320, vi.
167. McCorkle R, Ercolano E, Lazenby M, et al. Self-management: enabling and empowering patients living with cancer as a chronic illness. *CA Cancer J Clin*. 2011;61(1):50-62.
168. Balogh EP, Ganz PA, Murphy SB, Nass SJ, Ferrell BR, Stovall E. Patient-centered cancer treatment planning: improving the quality of oncology care. Summary of an Institute of Medicine workshop. *Oncologist*. 2011;16(12):1800-1805.
169. Butterworth SW. Influencing patient adherence to treatment guidelines. *J Manag Care Pharm*. 2008;14(6 Suppl B):21-24.
170. Lowes R. Patient-centered care for better patient adherence. *Fam Pract Manag*. 1998;5(3):46-47, 51-44, 57.
171. Adams KG, Greiner AC, Corrigan JM. *Committee on the Crossing the Quality Chasm: Next Steps Toward a New Health Care System. The 1st Annual Crossing the Quality Chasm Summit: A Focus on Communities*. Washington, DC: National Academies Press;2004.
172. Pearson ML, Mattke S, Shaw R, Ridgely MS, Wiseman SH. *Patient Self-Management Support Programs: An Evaluation. Final Contract Report (Prepared by RAND Health Under Contract No. 282-00-0005)* Rockville, MD: Agency for Healthcare Research and Quality;2007.
173. World Health Organization. Regional Office for Europe, Health Evidence Network, European Observatory on Health Systems and Policies, Coulter A, Parsons S, Askham J. *Where Are the Patients in Decision-Making about Their Own Care?* Copenhagen: World Health Organization. Regional Office for Europe; 2008.
174. Robinson TE, White GL, Jr., Houchins JC. Improving communication with older patients: tips from the literature. *Fam Pract Manag*. 2006;13(8):73-78.
175. Sheridan SL, Harris RP, Woolf SH. Shared decision making about screening and chemoprevention. A suggested approach from the U.S. Preventive Services Task Force. *Am J Prev Med*. 2004;26(1):56-66.
176. *Supporting Patients' Decision-Making Abilities and Preferences*. Washington (DC):

- National Academies Press (US): In Institute of Medicine (US) Committee on Crossing the Quality Chasm: Adaptation to Mental Health and Addictive Disorders. Improving the Quality of Health Care for Mental and Substance-Use Conditions: Quality Chasm Series;2006.
177. Executive Training on Navigation and Survivorship. GW School of Medicine and Health Science, GW Online Academy <https://cme.smhs.gwu.edu/gw-cancer-center-/content/executive-training-navigation-and-survivorship#group-tabs-node-course-default3>. Accessed January 20, 2022.
 178. Accessed January 20, 2022.
 179. Communicating with Patients: Advice for medical practitioners. Australian Government, National Health and Medical Research Council. <http://doctor-communication.vn.ua/wp-content/uploads/2018/08/Communicatig-with-Patients.-Advice-for-Practitioners.pdf>. Published 2004. Accessed January 20, 2022.
 180. Effective Communication: Barriers and Strategies. University of Waterloo. <https://uwaterloo.ca/centre-for-teaching-excellence/teaching-resources/teaching-tips/communicating-students/telling/effective-communication-barriers-and-strategies>. Published 2000. Accessed January 20, 2022.
 181. Communication in Cancer Care (PDQ®)-Patient Version. National Cancer Institute. <https://www.cancer.gov/about-cancer/coping/adjusting-to-cancer/communication-pdq>. Published 2021. Accessed January 20, 2022.
 182. Baile WF, Buckman R, Lenzi R, Gliber G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist*. 2000;5(4):302-311.
 183. How to Find and Use Your Voice in Healthcare. Ausmed Education. <https://www.ausmed.com/cpd/articles/the-patient-advocate-handbook>. Published 2019. Accessed January 20, 2022.
 184. Hagan TL, Donovan HS. Self-advocacy and cancer: a concept analysis. *J Adv Nurs*. 2013;69(10):2348-2359.
 185. Cox C, Fritz Z. What is in the toolkit (and what are the tools)? How to approach the study of doctor-patient communication. *Postgrad Med J*. 2022.
 186. Kaur JS. How should we “empower” cancer patients? *Cancer*. 2014;120(20):3108-3110.
 187. Betancourt JR, Green AR, Carrillo JE, Ananeh-Firempong O, 2nd. Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Rep*. 2003;118(4):293-302.
 188. Blair IV, Steiner JF, Havranek EP. Unconscious (implicit) bias and health disparities: where do we go from here? *Perm J*. 2011;15(2):71-78.
 189. Leavitt RL. Developing Cultural Competence in a Multicultural World. <https://learningcenter.apta.org/student/MyCourse.aspx?id=018ed5c8-7220-4abc-865b-7e42a12c97da&programid=dcca7f06-4cd9-4530-b9d3-4ef7d2717b5d>. Published 2011. Accessed January 20, 2022.
 190. Campinha-Bacote J. Many faces: addressing diversity in health care. *Online J*

- Issues Nurs.* 2003;8(1):3.
191. Birkenmaier J, Berg-Weger M. *The Practicum Companion for Social Work: Integrating Class and Field Work*. 2nd ed. Boston, MA: Pearson A and B; 2007.
 192. Brewer MB, Weber JG, Carini B. Person memory in intergroup contexts - categorization versus individuation. *J Pers Soc Psychol.* 1995;69(1):29-40.
 193. Devine PG, Forscher PS, Austin AJ, Cox WTL. Long-term reduction in implicit race bias: a prejudice habit-breaking intervention. *J Exp Soc Psychol.* 2012;48(6):1267-1278.
 194. Fiske ST, Neuberg SL. A continuum of impression formation, from category-based to individuating processes: influences of information and motivation on attention and interpretation. In: Zanna MP, ed. *Adv Exp Soc Psychol*. Vol 23. Academic Press; 1990:1-74.
 195. Galinsky AD, Moskowitz GB. Perspective-taking: decreasing stereotype expression, stereotype accessibility, and in-group favoritism. *J Pers Soc Psychol.* 2000;78(4):708-724.
 196. Monteith MJ. Self-regulation of prejudiced responses: implications for progress in prejudice-reduction efforts. *J Pers Soc Psychol.* 1993;65(3):469.
 197. Mercer SW, Reynolds WJ. Empathy and quality of care. *Br J Gen Pract.* 2002;52 Suppl:S9-12.
 198. Riess H, Kelley JM, Bailey RW, Dunn EJ, Phillips M. Empathy training for resident physicians: a randomized controlled trial of a neuroscience-informed curriculum. *J Gen Intern Med.* 2012;27(10):1280-1286.
 199. Berlin EA, Fowkes WC, Jr. A teaching framework for cross-cultural health care. Application in family practice. *West J Med.* 1983;139(6):934-938.
 200. Welch M. *Enhancing Awareness and Improving Cultural Competence in Health Care. A Partnership Guide for Teaching Diversity and Cross-Cultural Concepts in Health Professional Training* San Francisco: University of California at San Francisco; 1998.
 201. Empathy: The Human Connection to Patient Care. Cleveland Clinic. https://www.youtube.com/watch?v=cDDWvj_q-o8. Published 2013. Accessed January 21, 2022.
 202. Blair IV, Ma JE, Lenton AP. Imagining stereotypes away: the moderation of implicit stereotypes through mental imagery. *J Pers Soc Psychol.* 2001;81(5):828-841.
 203. Ten Tips for Good Cross-Cultural Communication. Intercultural Talk. <https://interculturaltalk.com/2014/06/03/10-tips-for-good-cross-cultural-communications/>. Published 2014. Accessed January 21, 2022.
 204. Occupational Outlook Handbook, Teacher's Guide. Bureau of Labor Statistics. <https://www.bls.gov/ooh/about/teachers-guide.htm>. Published 2021. Accessed January 21, 2022.
 205. Watson J. Caring Science Theory and Research. Watson Caring Science Institute. <https://www.watsoncaringscience.org/jean-bio/caring-science-theory>. Published 2021. Accessed January 21, 2022.
 206. Strom-Gottfried K. Chapter 5. *Conflicts of Interest. In Straight Talk about*

- Professional Ethics (2nd ed.)* Lyceum Books; 2014.
207. Hepworth DH. *Direct Social Work Practice: Theory and Skills*. 8th ed. Australia ; Belmont, CA: Brooks/Cole Cengage Learning; 2010.
 208. Watson J. *Human Caring Science - A Theory of Nursing* Ontario, Canada: Joens & Bartlett Learning; 2012.
 209. Ethical Decision Making. Markkula Center for Applied Ethics at Santa Clara University. <https://www.scu.edu/ethics/ethics-resources/ethical-decision-making/>. Accessed January 24, 2022.
 210. Appendix A: Consumer Bill of Rights and Responsibilities. U.S. Department of Health and Human Services. https://archive.ahrq.gov/hcqual/final/append_a.html. Published 1998. Accessed January 24, 2022.
 211. Health Information Privacy. U.S. Department of Health and Human Services. <https://www.hhs.gov/hipaa/index.html>. Accessed January 24, 2022.
 212. Garvey KA, Penn JV, Campbell AL, Esposito-Smythers C, Spirito A. Contracting for safety with patients: clinical practice and forensic implications. *J Am Acad Psychiatry Law*. 2009;37(3):363-370.
 213. Reporting Abuse or Neglect. New York State Office of Children and Family Services. https://ocfs.ny.gov/main/assets/CPS_Reporting_NYC_OCFS.pdf. Accessed January 24, 2022.
 214. Mental Health Professionals' Duty to Warn. National Conference of State Legislatures. <https://www.ncsl.org/research/health/mental-health-professionals-duty-to-warn.aspx>. Published 2018. Accessed January 24, 2022.
 215. Privacy. UC Davis Health Compliance and Privacy Services. <https://health.ucdavis.edu/compliance/privacy/>. Accessed January 24, 2022.
 216. Lee D, Lim JYS, Phoon KF. *Foundations for Fintech*. Hackensack, NJ: World Scientific; 2021.
 217. Module 4: Ethics and the Law. Who needs to follow HIPAA rules? Patient Navigator Training Collaborative. http://www.patientnavigatortraining.org/healthcare_system/module4/4_who_needs_to_follow_HIPAA.htm. Published 2011. Accessed January 26, 2022.
 218. Daum K. 8 Things Really Efficient People Do. Inc. <https://www.inc.com/kevin-daum/8-things-really-efficient-people-do.html>. Accessed January 24, 2022.
 219. McGurgan H. What Is Customer Responsiveness? <https://smallbusiness.chron.com/customer-responsiveness-31487.html>. Accessed January 24, 2022.
 220. Hou SI, Roberson K. A systematic review on US-based community health navigator (CHN) interventions for cancer screening promotion--comparing community-versus clinic-based navigator models. *J Cancer Educ*. 2015;30(1):173-186.
 221. Scheffer BK, Rubenfeld MG. Critical Thinking: What Is It and How Do We Teach It? In: *Dochterman, J. M., Grace, H. K. (Eds.). Current Issues in Nursing*. Mosby Inc. 2001.
 222. Scheffer BK, Rubenfeld MG. A consensus statement on critical thinking in nursing. *J Nurs Educ*. 2000;39(8):352-359.

223. Swinscoe A. Five Ways To Become More Agile And Responsive To Your Customers' Needs. Forbes. <https://www.forbes.com/sites/adrianswinscoe/2014/03/18/five-ways-to-become-more-agile-and-responsive-to-your-customers-needs/?sh=dbe637313b5d>. Published 2014. Accessed January 24, 2022.
224. Coulter A. Patients' views of the good doctor. *BMJ*. 2002;325(7366):668-669.
225. Stickley T, Freshwater D. The art of listening in the therapeutic relationship. *J Ment Health Practice*. 2006;9(5).
226. Code of Ethics for Nurses With Interpretive Statements. American Nurses Association. <https://www.nursingworld.org/practice-policy/nursing-excellence/ethics/code-of-ethics-for-nurses/coe-view-only/>. Published 2015. Accessed January 24, 2022.
227. Cheshire J, William P. Multitasking and the neuroethics of distraction. *J Bioeth Inq*. 2015;31(1).
228. Rodak S. 10 Best Practices for Securing Protected Health Information. Becker's Health IT. <http://www.beckershospitalreview.com/healthcare-information-technology/10-best-practices-for-securing-protected-health-information.html>. Published 2011. Accessed January 24, 2022.
229. Mitchell R, Parker V, Giles M, White N. Review: toward realizing the potential of diversity in composition of interprofessional health care teams: an examination of the cognitive and psychosocial dynamics of interprofessional collaboration. *Med Care Res Rev*. 2010;67(1):3-26.
230. O'Daniel M, Rosenstein A. Chapter 33. Professional Communication and Team Collaboration. In: *Hughes RG (Ed.) Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Agency for Healthcare Research and Quality (US). 2008.
231. Lee JI, Cutugno C, Pickering SP, et al. The patient care circle: a descriptive framework for understanding care transitions. *J Hosp Med*. 2013;8(11):619-626.
232. Dreachslin JL, Hunt PL, Sprainer E. Workforce diversity: implications for the effectiveness of health care delivery teams. *Soc Sci Med*. 2000;50(10):1403-1414.
233. Roth LM, Markova T. Essentials for great teams: trust, diversity, communication ... and joy. *J Am Board Fam Med*. 2012;25(2):146-148.
234. Shaw-Taylor Y, Benesch B. Workforce diversity and cultural competence in healthcare. *J Cult Divers*. 1998;5(4):138-146; quiz 147-138.
235. Marcus LJ, Dorn BC, McNulty EJ. The walk in the woods: a step-by-step method for facilitating interest-based negotiation and conflict resolution. *Negot*. 2012;28(3):337-349.
236. Clements D, Dault M, Priest A. Effective teamwork in healthcare: research and reality. *Healthc Pap*. 2007;7 Spec No:26-34.
237. Galanti G-A. The challenge of serving and working with diverse populations in American hospitals. *Diversity Factor*. 2001;9(3):21-26.
238. Jeffreys M. Dynamics of diversity: becoming better nurses through diversity awareness. *Imprint*. 2008;55(5):36-41.
239. Marcus LJ. A culture of conflict: lessons from renegotiating health care. *J Health*

- Care L & Pol'y. 2002;5:447.
240. Newcomer KE, Hatry HP, Wholey JS. Planning and designing useful evaluations. In: *Wholey, J. S., Hatry, H. P., Newcomer, K. E. (Eds.). Handbook of Practical Program Evaluation (3rd ed)*. Jossey-Bass.2010.
 241. Wright J, Williams R, Wilkinson JR. Development and importance of health needs assessment. *BMJ*. 1998;316(7140):1310-1313.
 242. 2020 Standards and Resources. Commission on Cancer. <https://www.facs.org/quality-programs/cancer/coc/standards/2020>. Published 2021. Accessed January 24, 2022.
 243. Wilcox B, Bruce SD. Patient navigation: a "win-win" for all involved. Paper presented at: Oncology nursing forum2010.
 244. Carroll JK, Humiston SG, Meldrum SC, et al. Patients' experiences with navigation for cancer care. *Patient Educ Couns*. 2010;80(2):241-247.
 245. What Is the Plan-Do-Check-Act (PDCA) Cycle? American Society for Quality. <https://asq.org/quality-resources/pdca-cycle>. Accessed January 24, 2022.
 246. Functional Assessment of Cancer Therapy - Colorectal (FACT-C). FACIT. <https://www.facit.org/measures/FACT-C>. Accessed January 24, 2022.
 247. PROMIS. Health Measures. <https://www.healthmeasures.net/explore-measurement-systems/promis>. Accessed January 24, 2022.
 248. Measures of Patient Adherence Survey. RAND. https://www.rand.org/health-care/surveys_tools/mos/patient-adherence.html. Accessed January 24, 2022.
 249. Pratt-Chapman ML KH. Patient experience mapping: a quality improvement tool for patient navigators. *J Cancer Surviv*. 2015;6:20-24.
 250. Gandolf S. What to Say to Warren Buffett: Sharing Value and Piquing Interest in 50 Words or Less. Healthcare Success. <https://healthcaresuccess.com/blog/physician-marketing/elevator-speech.html>. Accessed January 25, 2022.
 251. Hesketh EA, Laidlaw JM. Developing the teaching instinct, 1: feedback. *Med Teach*. 2002;24(3):245-248.
 252. Cantillon P, Sargeant J. Giving feedback in clinical settings. *BMJ*. 2008;337:a1961.
 253. Successful Goal Setting. UC Berkeley People & Culture. <https://hr.berkeley.edu/successful-goal-setting>. Accessed January 25, 2022.
 254. The Important Role Plastic Surgery Plays in Cancer Treatment & Recovery. Banner Health. <https://www.bannerhealth.com/healthcareblog/teach-me/the-important-role-of-plastic-surgery-in-cancer-treatment-and-recovery#:~:text=Reconstructive%20surgeons%20are%20well%2Dsuited,damage%20from%20radiation%20and%20chemotherapy>. Published 2021. Accessed January 26, 2022.
 255. Valentini V, Boldrini L, Mariani S, Massaccesi M. Role of radiation oncology in modern multidisciplinary cancer treatment. *Mol Oncol*. 2020;14(7):1431-1441.
 256. Chaturvedi SK. Psychiatric oncology: cancer in mind. *Indian J Psychiatry*. 2012;54(2):111-118.
 257. Who Treats Children with Cancer? American Cancer Society. <https://www.cancer.org/treatment/children-and-cancer/when-your-child-has->

- [cancer/finding-treatment/cancer-care-team.html](#). Published 2017. Accessed January 26, 2022.
258. Colon and Rectal Surgery. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/colon-and-rectal-surgery>. Accessed January 26, 2022.
 259. Thoracic Surgery. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/thoracic-surgery>. Accessed January 26, 2022.
 260. Sleep Medicine. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/sleep-medicine>. Accessed January 26, 2022.
 261. Eye cancer. UC Davis Health Comprehensive Cancer Center. <https://agewell.ucdavis.edu/cancer/cancer-types/eye.html#:~:text=Eye%20cancer%20treatment%20frequently%20requires%20the%20collaboration%20among,provide%20the%20appropriate%20evaluation%20and%20treatment%2C%20as%20needed>. Accessed January 26, 2022.
 262. Urology. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/urology>. Accessed January 26, 2022.
 263. General Surgery. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/general-surgery>. Accessed January 26, 2022.
 264. Diagnostic Radiology. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/diagnostic-radiology>. Accessed January 26, 2022.
 265. Crevenna R. Cancer rehabilitation and palliative care-two important parts of comprehensive cancer care. *Support Care Cancer*. 2015;23(12):3407-3408.
 266. Allergy and Immunology. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/allergy-and-immunology>. Accessed January 26, 2022.
 267. Anesthesiology. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/anesthesiology>. Accessed January 26, 2022.
 268. Kwong BY. Outcomes of embedding dermatologic care within oncology practices for patients with cancer. *Jama Dermatol*. 2020;156(10):1051-1052.
 269. Emergency Medicine. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/emergency-medicine>. Accessed January 26, 2022.
 270. Klabunde CN, Ambs A, Keating NL, et al. The role of primary care physicians in cancer care. *J Gen Intern Med*. 2009;24(9):1029-1036.
 271. Internal Medicine. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/internal-medicine>. Accessed January 26, 2022.
 272. Internal Medicine-Pediatrics. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/internal-medicine-pediatrics>. Accessed January 26, 2022.
 273. Medical Genetics and Genomics. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/medical-genetics-and-genomics>. Accessed January 26, 2022.
 274. Neurological Surgery. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/neurological-surgery>. Accessed January 26, 2022.
 275. Neurology. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/neurology>. Accessed January 26, 2022.

276. Nuclear Medicine. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/nuclear-medicine>. Accessed January 26, 2022.
277. Orthopaedic Surgery. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/orthopaedic-surgery>. Accessed January 26, 2022.
278. Obstetrics and Gynecology. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/obstetrics-and-gynecology>. Accessed January 26, 2022.
279. What Is an Otolaryngologist? Cancer Treatment Centers of America. <https://www.cancercenter.com/cancer-types/head-and-neck-cancer/treatments/what-is-an-otolaryngologist#:~:text=An%20otolaryngologist%20has%20a%20role,using%20chemotherapy%20and%20other%20therapies>. Published 2021. Accessed January 26, 2022.
280. Anatomic and Clinical Pathology. AAMC. <https://www.aamc.org/cim/explore-options/specialty-profiles/anatomic-and-clinical-pathology>. Accessed January 26, 2022.