



THE GW CANCER INSTITUTE'S
CENTER FOR THE ADVANCEMENT OF CANCER SURVIVORSHIP,
NAVIGATION AND POLICY (CASNP)

Guide for Patient Navigators

A SUPPLEMENT TO THE ONCOLOGY PATIENT NAVIGATOR TRAINING: THE FUNDAMENTALS



Cancer Institute



THE GEORGE
WASHINGTON
UNIVERSITY
WASHINGTON, DC

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WELCOME

The George Washington University (GW) Cancer Institute 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 across the country. In 2013 we started an 18-month process to create the first-ever competencies for non-clinically licensed Oncology Patient Navigators. In 2015 we launched this free, competency-based training through a cooperative agreement with the Centers for Disease Control and Prevention. We have included the foundational knowledge that patient navigators need as well as our comprehensive *Guide for Patient Navigators*, which includes free resources and tools you can put into practice immediately.

Our vision for this training is to help support Oncology Patient Navigators in their important work and build a qualified workforce to increase cancer patients' access to care. Patient navigation is a relatively new field, and training can help standardize the 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.

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

Sincerely,



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About GW Cancer Institute

The GW Cancer Institute is dedicated to understanding cancer disparities and the unequal burden of cancer in vulnerable populations and to achieving health equity.

The vision of the GW Cancer Institute is a cancer-free world and health care that is patient-centered, accessible and equitable. The mission of the GW Cancer Institute is to foster healthy communities, prepared patients, responsive health care professionals and supportive health care systems through applied cancer research, education, advocacy and translation of evidence to practice. For more information, visit www.cancerinstitute.gwu.edu.

Disclaimer

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AN OVERVIEW OF THE TRAINING

This training course is comprised of seven modules and their components.

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. Reviewing this material upon completion of each module ensures you have all the information you need to complete the course while acquiring the necessary knowledge and skills.

* 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 in-depth information and activities is optional but strongly suggested.

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 the materials in the Activities section. The content in the Activities section is required to complete the module. 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 have been completed for each lesson, you will be able to move to the next module.

Patient Navigation Training Modules and Lessons

Module 1 - Welcome and Introduction

Module 2 - Overview of Patient Navigation and the Oncology Patient Navigator Training

- Lesson 1: An Overview of Patient Navigation

Module 3 - The Basics of Health Care

- Lesson 1: Medical Terminology
- Lesson 2: Cancer Basics
- Lesson 3: Clinical Trials
- Lesson 4: Impact of Cancer
- Lesson 5: U.S. Healthcare System and Patient Access

- Lesson 6: Healthcare Financing - The Basics

Module 4 - The Basics of Patient Navigation

- Lesson 1: The Role of the Oncology Patient Navigator
- Lesson 2: Patient Assessment
- Lesson 3: Shared Decision- Making
- Lesson 4: Identifying Resources

Module 5 - Enhancing Communication

- Lesson 1: Communicating with Patients
- Lesson 2: Patient Advocacy
- Lesson 3: Cultural Competency

Module 6 - Professionalism

- Lesson 1: Scope of Practice
- Lesson 2: Ethics and Patient Rights

Module 7 - Enhancing Practice

- Lesson 1: Practicing Efficiently and Effectively
- Lesson 2: Healthcare Team Collaboration
- Lesson 3: Program Evaluation and Quality Improvement
- Lesson 4: Personal and Professional Development

MODULE 2: OVERVIEW OF PATIENT NAVIGATION AND THE ONCOLOGY PATIENT NAVIGATOR TRAINING

Resources

Lesson 1: An Overview of Patient Navigation and Competencies

Learning Objectives

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

Key Takeaways

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

MODULE 2: OVERVIEW OF PATIENT NAVIGATION AND THE ONCOLOGY PATIENT NAVIGATOR TRAINING

Resources

LESSON 1: AN OVERVIEW OF PATIENT NAVIGATION AND COMPETENCIES

Principles of Patient Navigation
Oncology Patient Navigator Core
Competencies
Relevant Articles on Patient Navigation
Resources for Patient Navigators

Principles of Patient Navigation

In an article on the history and principles of patient navigation, Harold P. Freeman and Rian L. Rodriguez identified the following 9 principles:

1. Patient navigation is a patient-centric healthcare service delivery model.
2. Patient navigation serves to virtually integrate a fragmented healthcare system for the individual patient.
3. The core function of patient navigation is the elimination of barriers to timely care across all segments of the healthcare continuum.
4. Patient navigation should be defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of all other providers.
5. Delivery of patient navigation services should be cost-effective and commensurate with the training and skills necessary to navigate an individual through a particular phase of the care continuum.
6. The determination of who should navigate should be determined by the level of skills required at a given phase of navigation.
7. In a given system of care there is the need to define the point at which navigation begins and the point at which navigation ends.
8. There is a need to navigate patients across disconnected systems of care, such as primary care sites and tertiary care sites.
9. Patient Navigation systems require coordination.

Source: Freeman et al. 2011.

MODULE 2: OVERVIEW OF PATIENT NAVIGATION AND THE ONCOLOGY PATIENT NAVIGATOR TRAINING

Resources

Oncology Patient Navigator Core Competencies

The Core Competencies for Non-Clinically Licensed Patient Navigators were developed by the GW Cancer Institute through a collaborative, multi-phase process. The competencies can also be found on the [GW Cancer Institute website](#). The full competencies are also listed here.

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** Empower 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** Empower 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 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.

MODULE 2: OVERVIEW OF PATIENT NAVIGATION AND THE ONCOLOGY PATIENT NAVIGATOR TRAINING

Resources

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 navigation process and participate in quality improvement.

3.3 Incorporate feedback on performance to improve daily work.

3.4 Use information technology to maximize 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.

MODULE 2: OVERVIEW OF PATIENT NAVIGATION AND THE ONCOLOGY PATIENT NAVIGATOR TRAINING

Resources

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 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 Support a smooth transition of patients across screening, diagnosis, active treatment, survivorship and/or end-of-life care, working with the patient's clinical care team.

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.

MODULE 2: OVERVIEW OF PATIENT NAVIGATION AND THE ONCOLOGY PATIENT NAVIGATOR TRAINING

Resources

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.

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

MODULE 2: OVERVIEW OF PATIENT NAVIGATION AND THE ONCOLOGY PATIENT NAVIGATOR TRAINING

Resources

Relevant Articles on Patient Navigation

- Pratt-Chapman M, Willis A. [Community Cancer Center Administration and Support for Navigation Services](#). *Seminars in Oncology Nursing* May 2013.
- Pratt-Chapman M, Willis A, Masselink L. [Core Competencies for Non-Clinically Licensed Patient Navigators](#). *Journal of Oncology Navigation and Survivorship*. 2015.
- Willis A, Pratt-Chapman M, Reed E, Hatcher, E. [Best Practices in Patient Navigation and Cancer Survivorship: Moving Toward Quality Patient-Centered Care](#). *Journal of Oncology Navigation and Survivorship*. 2014.
- Willis A, Reed, Pratt-Chapman M, Kapp H, Hatcher E, Vaitones V, Collins S, Bires J, Washington E-C. [Development of a Framework for Patient Navigation: Delineating Roles Across Navigator Types](#). *Journal of Oncology Navigation and Survivorship*. 2013.
- [National Patient Navigation Leadership Summit \(NPNLS\): Measuring the Impact and Potential of Patient Navigation](#). Supplement to *Cancer*. 2011.

Resources for Patient Navigators

- [Colorado Coalition for the Medically Underserved](#) (CCMU)
CCMU offers information for health care professionals who work with the underserved. You can go through their [study guide on the medically underserved](#) after watching the video in the lesson.
- [Intercultural Cancer Council](#) (ICC)
The ICC offers a series of [Cancer Fact Sheets](#) on a variety of medically underserved populations.
- National Cancer Institute's [Center to Reduce Health Disparities](#) (CRCHD)
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 2: OVERVIEW OF PATIENT NAVIGATION AND THE ONCOLOGY PATIENT NAVIGATOR TRAINING

Resources

Module 2, Lesson 1: An Overview of Patient Navigation and Competencies

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MODULE 2: OVERVIEW OF PATIENT NAVIGATION AND THE ONCOLOGY PATIENT NAVIGATOR TRAINING

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Lesson 1: Medical Terminology

Learning Objectives

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

Key Takeaways

- Most science and medical 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.

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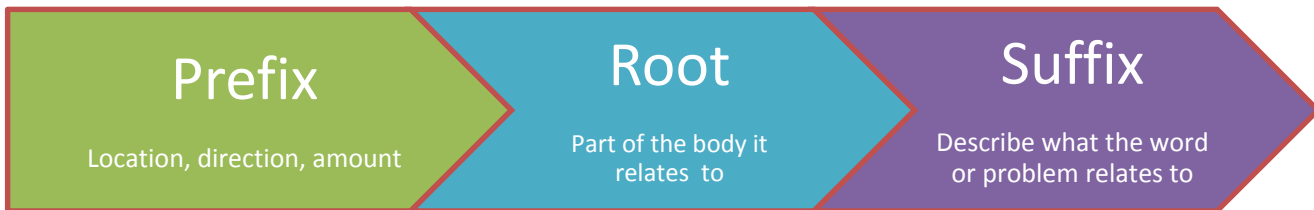
THE BASICS OF HEALTH CARE

LESSON 1: MEDICAL TERMINOLOGY

Prefixes, Roots and Suffixes
Common Words Used in Cancer
Medical Terminology Cheat Sheet
Resources for Patient Navigators

Prefixes, Roots and Suffixes

Most medical and science terms will have three parts and may seem very complex. But they can be broken down into their parts to give you a basic idea of what they mean. Each word has a prefix, root, or suffix that can help you determine the meaning of the term being used.



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

This part can also help describe size, shape or color but more importantly can tell you what the problem actually is.

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THE BASICS OF HEALTH CARE

Here is a list of common prefixes. Remember that a prefix will usually help you determine size, color, shape as well as location, direction and amount. Take a moment and go through each one. It is good to review so that words can become easier for you to recognize and define. Pre means “before.” Prefixes are typically found at the beginning of the word.

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	hyperglycaemia = 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
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

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Example #1 (Prefixes)

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*.

Example #2 (Prefixes)

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*.

Example #3 (Prefixes)

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*.

This table summarizes 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)
	Intra (within)
	Inter (between, together, during)
	Peri (about, around, surround)
	Trans (across, beyond, through)

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THE BASICS OF HEALTH CARE

Here is a list of common root words, their meanings, and examples. Root words help you know which part of the body a word relates to.

ROOT	WHAT IT DESCRIBES	EXAMPLE
BLAST-	germ, immature cell	blastoma = a 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
HISTIO-	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

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THE BASICS OF HEALTH CARE

Example #1 (Root Words)

WORD: Dermatitis

No prefix

The root “DERMA” means skin.

The suffix “-itis” describes inflammation.

The combination of this root and suffix yields, (Derma-)(-itis), a word that means *inflammation of the skin*.

Example #2 (Root Words)

WORD: Nephrotoxic

The prefix/root “nephro-” 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*.

Example #3 (Root Words)

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.

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

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Example #1 (Suffix)

WORD: Nephrectomy

The root “Nephro-” means kidney.

The suffix “-ectomy” means excision or removal.

The combination of this root and suffix yields, (nephr-)(-ectomy), a word that means excision or removal of a kidney.

Example #2 (Suffix)

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.

There are some other root words and suffixes that may be helpful to review. This table summarizes common roots and suffixes that are used to describe common tests and procedures.

ROOT	WHAT IT DESCRIBES	EXAMPLE
ECHO-	Using ultrasonic waves	Echocardiogram = use of sound waves to create a picture of the heart
ELECTRO-	Using electricity	Electrocardiogram = records the electrical activity of the heart
SUFFIX		
-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

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-OTOMY	Making a cut in	Lobotomy = making a cut in connections in the prefrontal lobe of the brain
-SCOPY	Using an instrument for viewing	Endoscopy = procedure to examine the digestive tract using an endoscope
-STOMY	Create an opening	Colostomy = an opening made in the colon

Sources: [Online Etymology Dictionary](#). 2014; [Penguin Prof Pages](#). 2015.

Common Words Used in Cancer

The table below summarizes cancer-related words that you may hear or see.

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 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.

<u>ROOT</u>	<u>MEANING</u>
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 BLOT
HEPATO	LIVER
MAMMO	BREAST
COLO	COLON OR LARGE INTESTINE
GASTRO	STOMACH
ILEO	SMALL INTESTINE
THORACO	THORAX
PNEUMO/ PLEURO	LUNGS OR RESPIRATORY FUNCTIONS

Source: [Online Etymology Dictionary](#). 2014.

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THE BASICS OF HEALTH CARE

Medical Terminology Cheat Sheet

PREFIX	WHAT IT DESCRIBES	EXAMPLE
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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	hyperglycaemia = excessive blood sugar levels
HYPO-	Beneath / Below	hypodermic = injection below the skin
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PARA-	Beside, About, Near	parathyroid = beside the thyroid gland
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
ROOT	WHAT IT DESCRIBES	EXAMPLE
BLAST-	germ, immature cell	blastoma = a cancer made of immature cells

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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
HISTIO-	tissue	histology = study of tissue
HEPATI-	liver	hepatoblastoma = liver cancer
MALIGN-	bad / harmful	malignant = growing, spreading
NEPHRO-	kidney	nephrotoxic = harmful to the kidneys
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OSTEO-	bone/bony tissue	osteosarcoma = bone cancer
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TOXO-	poison	toxicology = study of poisons
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-ITIS	inflammation	hepatitis = inflammation of the liver
-OLOGY	study / science of	cytology = the study of cells
-OMA	tumor	retinoblastoma = tumor of the eye
-PATHY	disease	neuropathy = disease of the nervous system
-OSIS	disease /condition	necrosis = dying cells

Sources: [Online Etymology Dictionary](#). 2014; [Penguin Prof Pages](#). 2015.

Oncology Patient Navigator Training: The Fundamentals

George Washington University (GW) Cancer Institute © 2015

Resources for Patient Navigators

- American Cancer Society's [Guide to Treatment Types](#)
You may want to use this resource to become familiar with the names of some of the more common drugs 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.

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THE BASICS OF HEALTH CARE

Module 3, Lesson 1: Medical Terminology

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Lesson 2: Cancer Basics

Learning Objectives

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

Key Takeaways

- Cancer is the uncontrolled growth of abnormal cells that divide and invade others within a person's body.
- Different kinds of cancers include carcinomas, sarcomas, lymphomas and leukemias.
- Cancers are named based on where they start in the body.
- There are many risk factors for cancer, and there are ways to reduce the risk for cancer.
- Avoiding 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's or surgery. Sometimes several methods are used.
- 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. Cancers range 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. While there are benefits to some of these treatments, there are also potentially serious risks. If you know a patient is using these therapies, you should let the doctor know to make sure there are no risks to the patient.

LESSON 2: CANCER BASICS

Defining Cancer
Cancer Risk Factors and Prevention
Screening and Testing to Detect Cancers
Cancer Staging
Cancer Treatment
Tips for Selecting a Complementary Health Practitioner
Resources for Patient Navigators
Resources for Patients

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 don't 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

Normal cells can undergo hyperplasia or dysplasia and become cancerous. In hyperplasia, there is an increase in the number of cells in an organ or tissue. These cells still appear normal under a microscope. In dysplasia, the cells look abnormal under a microscope but are not considered cancer. Hyperplasia and dysplasia may or may not become cancer.

Normal cells	Tumors
<ul style="list-style-type: none">• <i>Can undergo hyperplasia or dysplasia and become cancerous</i>	<ul style="list-style-type: none">• <i>Can be benign or malignant</i>

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.”

Benign

- *Non-cancerous*
- *Do not grow into other tissue*

Malignant

- *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.

Carcinomas

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

Sarcomas

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

Lymphomas

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

Leukemias

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

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

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

Cancers are capable of spreading throughout the body by two mechanisms: invasion and metastasis. Invasion refers to the direct migration and penetration by cancer cells into neighboring tissues. Metastasis refers to the ability of cancer cells to penetrate into lymphatic and blood vessels, circulate through the bloodstream or lymphatic system, and then invade normal tissues elsewhere in the body.

Sources: National Cancer Institute. [What is Cancer?](#) 2015; National Cancer Institute. Understanding Cancer Series. 2009.

Cancer Risk Factors and Prevention

Scientists study risk factors and protective factors to find ways to prevent new cancers from starting. Anything that increases your chance of developing cancer is called a cancer risk factor; anything that decreases your chance of developing cancer is called a cancer protective factor.

Some risk factors for cancer can be avoided, but many cannot. For example, both smoking and inheriting certain genes are risk factors for some types of cancer, but only smoking can be avoided. Risk factors that a person can control are called modifiable risk factors.

Many other factors in our environment, diet, and lifestyle may cause or prevent cancer. This summary reviews only the major cancer risk factors and protective factors that can be controlled or changed to reduce the risk of cancer. Risk factors that are not described in the summary include certain sexual behaviors, the use of estrogen, and being exposed to certain substances at work or to certain chemicals.

Factors that are known to increase the risk of cancer include:

- Cigarette Smoking and Tobacco Use
- Infections
- Radiation
- Immunosuppressive Medicines

Factors that may affect the risk of cancer include:

- Diet
- Alcohol
- Physical Activity
- Obesity
- Environmental Risk Factors

Source: National Cancer Institute. [Cancer Prevention Overview](#). 2014.

Genetic Risk Factors

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

BRCA1 and BRCA2

Mutations on the BRCA1 and BRCA2 genes can increase a woman's risk of developing breast and/or ovarian cancer. 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](#).

Genetic testing may be needed. The National Cancer Institute has a fact sheet on [Genetic Testing for Hereditary Cancer Syndromes](#).

Screening and Testing to Detect Cancers

The following organizations provide comprehensive guidelines and recommendations for screening; the recommendations are not always the same across organizations.

- 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](#).
- [US Preventive Services Task Force](#) (USPSTF)
The USPSTF is an independent panel of experts in primary care and prevention who systematically review evidence and develop recommendations for clinical preventive services. [Recommendations are available](#) for bladder, breast, cervical, colorectal, lung, oral, ovarian, pancreatic, prostate, skin, testicular and thyroid cancers.

Here is a summary of common cancer screenings and resources for more information.

CANCER TYPE	SCREENING TEST	DESCRIPTION
BREAST CANCER SCREENING	Mammogram	<p>Breast cancer can sometimes be detected in its early stages using a mammogram, which is an X-ray of the breast. Mammography is beneficial for most women as they age and undergo menopause. Mammography is a screening tool that can detect the possible presence of an abnormal tissue mass. By itself, it is not accurate enough to prove if there is or isn't breast cancer. If a mammogram indicates the presence of an abnormality, further tests must be done to determine whether breast cancer actually is present.</p> <p>FACT SHEET (USPSTF) FACT SHEET (ACS)</p>
CERVICAL CANCER SCREENING	Pap test (or Pap smear)	<p>A screening technique called the Pap test (or Pap smear) allows early detection of cancer of the cervix, the narrow portion of the uterus that extends down into the upper part of the vagina. In this procedure, a doctor uses a small brush or scraper to remove a sample of cells from the cervix and upper vagina. The cells are placed on a slide or in liquid and sent to a laboratory, where the sample is checked for abnormalities in the cervical cells.</p> <p>If abnormalities are found, additional tests or procedures may be necessary. There are tests available to detect high-risk types of Human Papilloma Virus (HPV). These tests sometimes can detect the virus</p>

		<p>before it causes any visible changes to the cervical cells.</p> <p>FACT SHEET (USPSTF) FACT SHEET (ACS)</p>
<p>COLORECTAL (COLON/RECTUM) CANCER SCREENING</p>	<p>Fecal Occult Blood Test (FOBT)</p>	<p>Detects small amounts of blood in stool</p>
	<p>Sigmoidoscopy</p>	<p>Uses lighted instrument in rectum and lower colon</p>
	<p>Colonoscopy</p>	<p>Uses lighted instrument in colon, including upper colon</p>
	<p>Double contrast barium enema</p>	<p>An X-ray test of the colon and rectum</p>
	<p>CT colonography (virtual colonoscopy)</p>	<p>A type of CT scan of the colon and rectum</p> <p>FACT SHEET (USPSTF) FACT SHEET (ACS)</p>
<p>LUNG CANCER SCREENING</p>	<p>LDCT or low-dose CT scan</p>	<p>Screening with low-dose computed tomography can help to detect lung cancer. Screening is recommended for adults between certain ages with an extensive smoking history who still smoke or quit smoking within the past 15 years. During this test an x-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>
<p>PROSTATE CANCER SCREENING</p>	<p>Prostate Specific Antigen test (PSA)</p> <p>Digital Rectal Exam (DRE)</p>	<p>Prostate-specific antigen, or PSA, is a protein produced by cells of the prostate gland. PSA and DRE may be used to screen for prostate cancer. The PSA test measures the level of PSA in a man’s blood. In a Digital Rectal Exam, 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> <p>FACT SHEET (USPSTF) FACT SHEET (ACS)</p>

Cancer Staging

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

Stage 0	<ul style="list-style-type: none"> •Carcinoma in situ
Stage I, Stage II, Stage III	<ul style="list-style-type: none"> •Higher numbers mean the disease is more extensive, such as larger tumor size and/or spread
Stage IV	<ul style="list-style-type: none"> •Spread to distant tissues/organs

Source: National Cancer Institute. [Cancer Staging](#). 2015.

Cancer Treatment

Cancer treatment depends on the cancer's type and stage. Cancer can be treated with surgery, radiation, chemotherapy, targeted therapy, hormone therapy or other types of treatment. Treatments may also be combined. For example, some tumors are removed with surgery which is followed by radiation and/or chemotherapy. Sometimes radiation or chemotherapy is done before surgery as a way to shrink a tumor. Some treatment is done, not to cure or remove a cancer, but to ease a patient's symptoms or suffering. This is called palliative treatment. This table summarizes common cancer treatment options.

Treatment	Description
Surgery	Operation to remove a tumor.
Radiation	Therapy uses high-energy radiation to shrink tumors and kill cancer cells. Radiation can damage normal cells so possible side effects include: swelling, skin changes and fatigue. Radiation can be given in several ways. It can be beamed at a cancer from a machine outside the body. It can also be swallowed, injected, or placed as a radioactive "seed" near the tumor.
Chemotherapy	Chemotherapy is a type of treatment that includes drugs that can either kill cancer cells or slow or stop them from growing. Chemotherapy can also harm healthy cells. Side effects of chemotherapy are different for different people. Possible side effects depend on the amount and types of drug received and may include fatigue or tiredness, nausea, vomiting, hair loss, mouth sores or pain. Chemotherapy can be given orally, or by mouth, as a pill or liquid; injected as a shot; rubbed on skin as a cream; or given through a needle in a vein or artery.
Neo-adjuvant (Given before)	Neo-adjuvant treatment is treatment given BEFORE a patient’s main treatment and as the first step to shrink a tumor. The main treatment is usually surgery. These neo-adjuvant treatments could include chemotherapy, radiation therapy and hormone therapy.
Adjuvant (Given after)	Adjuvant treatment is defined as additional cancer treatment to lower the risk that the 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	“Molecularly targeted drugs” or “precision medicines”

	Hormone therapy, angiogenesis inhibitors, immunotherapies, monoclonal antibodies.
Hormone Therapy	Drugs given to block the body’s natural hormones to slow or stop the growth of cancer.
Palliative Medicine	Focuses on providing patients with relief from their symptoms. It is a myth that palliative care can only be used at end of life. Palliative care is actually helpful throughout the cancer experience. A patient can receive palliative care at the same time as treatment. Pain management benefits patients.
Complementary and Integrative Health Approaches	<p>Complementary health approaches can be helpful to many patients. 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: Used together with conventional medicine <i>Example:</i> Using acupuncture for pain management, while also using medications and physical therapy.</p> <p>Alternative: Used in place of conventional medicine <i>Example:</i> 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>

Source: National Cancer Institute. Understanding Cancer Series. 2009.

Treatment Guidelines

As a patient navigator you are not responsible for talking with patients about clinical care, but you 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 outline appropriate methods of treatment and care.
- National Comprehensive Cancer Network [Clinical Practice Guidelines in Oncology](#) (NCCN Guidelines®)
NCCN publishes guidelines for 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:

Psychosocial support services

Rehabilitation (lymphedema therapy, physical therapy, occupational therapy, speech therapy)

Spiritual support/chaplaincy services

Hospice

Tips for Selecting a Complementary Health Practitioner

The NIH National Center for Complementary and Integrative Health offers the following tips to patients looking for a complementary health practitioner:

1. If you need names of practitioners in your area, first check with your doctor or other health care provider.
2. Find out as much as you can about any potential practitioner, including education, training, licensing, and certifications.
3. Find out whether the practitioner is willing to work together with your conventional health care providers.
4. Explain all of your health conditions to the practitioner, and find out about the practitioner's training and experience in working with people who have your conditions.
5. Don't assume that your health insurance will cover the practitioner's services.
6. Tell all your health care providers about all complementary approaches you use and about all practitioners who are treating you.

Source: NIH National Center for Complementary and Integrative Health. [Time to Talk Tips](#). 2015.

Resources for Patient Navigators

- Medicine.net's [Cancer 101: A Visual Guide to Understanding Cancer](#)
This slideshow provides a visual overview of cancer.
- National Cancer Institute's [What is Cancer?](#)
This webpage provides information about what cancer is, how it spreads and types of cancer.
- National Cancer Institute's [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 healthcare, 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.

Resources for Patients

- American Cancer Society offers a [Prevention Checklist for Women](#) and a [Prevention Checklist for Men](#).
- American Cancer Society's [Questions to Ask My Doctor About My Cancer](#)
This resource provides a list of questions when you're told you have cancer, when deciding on a treatment plan, before treatment, during treatment and after treatment.
- Center for Advancing Health's [Talking About Medical Tests with Your Health Care Team](#)
This webpage includes questions patients can ask about medical tests as well as information on how to prepare for medical tests and which screening tests are needed.
- Center for Advancing Health's [Seeking A Second...or Third...Opinion](#)
This webpage includes information on seeking a second opinion.
- 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, Lesson 2: Cancer Basics

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Lesson 3: Clinical Trials

Learning Objectives

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

Key Takeaways

- The goal of a clinical trial is to find better and safer ways to prevent, screen for, diagnose or treat disease. A clinical trial may also look for ways to improve patients' quality of life.
- There are 4 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. 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.
- Common patient concerns about clinical trials are related to quality of care, new treatment not working as well as standard treatment, mistrust of medical research and being used as a "guinea pig" and getting a placebo instead of "real treatment."

LESSON 3: CLINICAL TRIALS

FAQs about Clinical Trials
Patient Protections
The Navigator Role in Clinical Trials
Helping Patients Understand Clinical Trials
Possible Questions to Ask Patients
How to Find Clinical Trials
Resources for Patient Navigators
Resources for Patients

Frequently Asked Questions (FAQs) About Clinical Trials

WHY ARE CLINICAL TRIALS IMPORTANT?

Clinical trials are important because they help us find ways to improve people's health. Advances in medicine are the result of discoveries made through research. The treatments we use today were found to be safe and effective through clinical trials.

WHO ARE THE PEOPLE INVOLVED IN A CLINICAL TRIAL?

Although researchers collect data and study results, they are not the only people involved in a clinical trial. Clinical trials require a team of doctors, nurses, patient navigators, pharmacists, researchers, other healthcare team members and patients.

WHAT DO CLINICAL TRIALS STUDY?

Clinical trials study a variety of ways to find, prevent, diagnose or treat disease:

- ✚ Prevention trials explore ways to keep people from getting a disease. They also look for ways to keep a disease from returning. These studies may look at diet, exercise, preventive medicine, vitamins, vaccines or lifestyle changes.
- ✚ Screening trials study the best ways to detect diseases or health conditions.
- ✚ Diagnosis trials look for better tests or procedures to diagnose a disease or health condition.
- ✚ Treatment trials test new drugs, treatments, surgery options or combinations of treatments.
- ✚ Quality of Life trials look for ways to assess and improve comfort or quality of life for individuals with a chronic disease or medical condition.

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 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 can be unethical. However, some clinical trials pay small amounts of money for costs related to the clinical trial such as travel or day care expenses.

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 the 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?

Yes, sometimes; but this is very rare in a cancer clinical trial. If a placebo is used in a cancer clinical trial, this will be part of the information a patient receives before they consent to participate in the trial. A placebo, "sugar pill," or "fake pill" is a medicine that has no effect. Placebos are not used when patients need real treatment. However, if there is no known effective treatment for a condition, a placebo may be used. In this case, one group of patients is given the placebo and the other group is given the new treatment. Most cancer treatment clinical trials provide the current standard of care as a comparison, meaning that one group of patients will get the usual treatment and another group will get the experimental 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.

These are some clinical trial participation facts:

- ✚ 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

WHICH PATIENTS CAN JOIN A CLINICAL TRIAL?

It depends on the study. Clinical trials are scientific experiments and have strict requirements for who can join. Requirements may be based on many factors such as age, gender, disease or treatment history. If a patient is eligible for a clinical trial, it means that they meet the requirements for who can participate in that study. Although clinical trials have eligibility requirements, it is also important that they include a wide variety of patients.

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

Clinical trials need a wide variety of people to participate so that researchers know that a treatment works on people with different characteristics. If a new treatment works but is only tested on one group of people, we know it works for that group, but it may not work for others. For example, if a clinical trial tests a new medication only on young Asian females, we can learn how well it works for young Asian females, but we don't know how well it works for other age groups, races or males.

WHY IS IT IMPORTANT TO INCLUDE UNDERSERVED PATIENTS IN CLINICAL TRIALS?

Underserved patients may be people in a racial or ethnic minority group or people who have low income or low education. Older adults, people who live in rural areas or patients who have a co-morbidity, which means more than one disease, can also be underserved. They must be included in trials so we know whether treatment options work for that population, and historically these populations have often been left out of therapeutic trials.

WHY ARE NAVIGATORS IMPORTANT TO UNDERSERVED PATIENTS?

Clinical trials usually require that patients have health insurance, an address and a phone number. Underserved patients do not always meet these requirements. This is why a patient navigator is so important: you may need to address barriers to help underserved patients join and stay 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

Patient safety and protection is very important in clinical trials. Before a clinical trial is approved, it goes through an ethical review process. Researchers must comply with laws that protect and inform people who take part in research studies. This is important to note because in the past, there were no guidelines or laws to protect people from harmful research studies. Some people were forced to be in research studies. Others agreed to take part in research but were not given treatment or information about their illness.

Patient Protections

There are several procedures and laws that protect patients from unethical, or abusive, treatment in a clinical trial. Protections include:

MEDICAL ETHICS: Because of unfair and abusive past research, the government and medical groups created 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.

SCIENTIFIC REVIEW: Before a clinical trial begins, the study must be reviewed by a group of researchers, doctors and other professionals to determine if the study is safe, ethical and well designed. The scientific review is done by a group called an Institutional Review Board, or IRB. An IRB is a committee of people where the study is taking place. The goal of an IRB is to protect patient safety. They do this by reviewing, approving and checking on clinical trials. Federal law requires IRBs for research done on humans and there are strict rules about who can serve on an IRB and how IRBs are run. Some institutions have additional review committees that must also approve a study.

STRICT RESEARCH PROTOCOLS: Clinical trials follow very strict rules about how they are carried out. These rules are spelled out in a document called a research protocol, a detailed plan about what researchers and doctors will do in a study.

INFORMED CONSENT: Federal laws require that patients give their informed consent to participate in a clinical trial. This means that they are informed of the study’s procedures, risks and benefits, and they agree, or give consent, to participate. Sometimes patients give verbal informed consent to participate in a study if the primary risk to the patient is disclosure of his/her 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
- ✚ Patients’ rights and who to contact if the patient has questions or feels they have been mistreated
- ✚ Rules that guide informed consent are very strict. It is important that patients understand the clinical trial. For patients who do not speak English, the informed consent form must be written in their language.

Sources: National Cancer Institute. [Clinical Trials](#). 2013; [Centers for Medicare & Medicaid Services](#). 2000; [PNTC](#).

The Navigator 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

Helping Patients Understand Clinical Trials

Verbal information

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

Written information

- Consult with clinical coordinator for answers
- Review written materials with patients
- Write down medical term definitions

Possible Questions to Ask Patients

- 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?

Source: [PNTC](#).

How to Find Clinical Trials

The National Cancer Institute offers a 10-step guide on [How to Find a Cancer Treatment Trial](#). It goes into detail on the following steps:

- [Step 1: Understand Clinical Trials](#)
- [Step 2: Talk With Your Doctor](#)
- [Step 3: Complete the Checklist](#)
- [Step 4: Search NCI's List of Trials](#)
- [Step 5: Other Lists of Trials](#)
- [Step 6: Identify Potential Trials](#)
- [Step 7: Contact the Trial Team](#)
- [Step 8: Ask Questions](#)
- [Step 9: Talk to Your Doctor](#)
- [Step 10: 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.
- Accessing the American Cancer Society's Clinical Trials Matching Service that is available by phone at 800-303-5691.
- 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.

Resources for Patients

- OncoLink's [Clinical Research Trials: The Basics](#)
This webpage provides basic information about clinical trials.
- National Cancer Institute [Clinical Trials](#)
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.
- Cancer.net's [PRE-ACT](#)
PRE-ACT (Preparatory Education About Clinical Trials) is an educational program designed to provide general information about clinical trials.
- Cancer.net's [Deciding to Participate 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.

Module 3, Lesson 3: Clinical Trials

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Lesson 4: Impact of Cancer

Learning Objectives

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

Key Takeaways

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

LESSON 4: IMPACT OF CANCER

Physical, Psychosocial, Practical and Spiritual Impacts
Issues Unique to Adolescents and Young Adults (aged 15-40)

Issues Unique to Those Living with Advanced Cancer
Post-Treatment Survivorship
Resources for Patient Navigators and Patients

Physical, Psychosocial, Practical and Spiritual Impacts

Cancer can impact patients in many ways. Each patient is different and will experience treatment differently, even if they have the same treatment regimen.

Physical Impacts

- Pain
- Fatigue
- Anemia
- Weight gain/loss
- Nausea/vomiting
- Self-care and mobility issues
- Other treatment side effects
- Life-threatening medical emergencies

Psychosocial Impacts

- Body image issues
- Anxiety and depression
- Changes in relationships and roles in family
- Caregiver burden and support needs
- Stigma, fear, social isolation
- Mental health

Practical Impacts

- Financial
- Ability to work
- Food, housing, utilities
- Legal

Spiritual Impacts

- Finding meaning in illness
- Changes in belief
- End-of-life

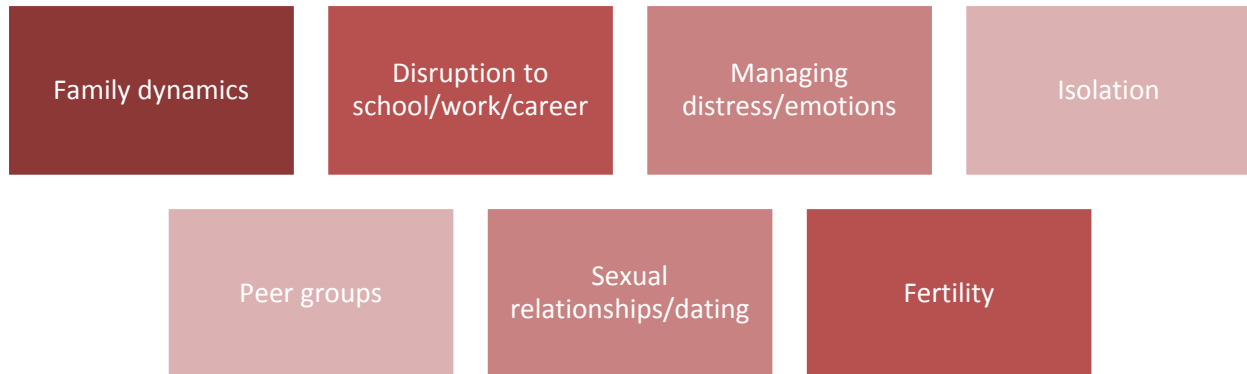
Source: Cancer.Net. [Side Effects](#). 2014.

MODULE 3:

Resources

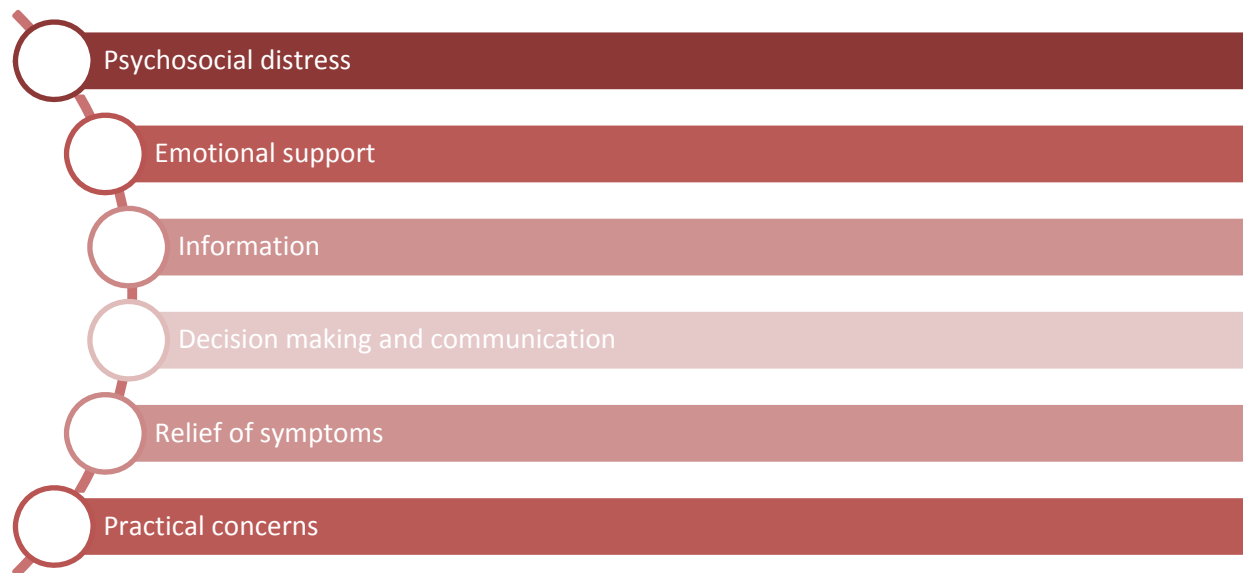
THE BASICS OF HEALTH CARE

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



Source: U.S. Department of Health and Human Services. [Closing the Gap](#). 2006.

Issues Unique to Those Living with Advanced Cancer



Sources: Metastatic Breast Cancer Alliance. [Changing the Landscape](#). 2014; Pfizer Oncology. [Breast Cancer: A Story Half Told](#). 2014.

Post-Treatment Survivorship

Long-term and Late Effects

Cancer survivors are at risk for long-term and late effects. A long-term effect is something that started 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.

Treatment	Long-term side effects	Late side 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

Sources: Hewitt et al. [From Cancer Patient to Cancer Survivor: Lost in Transition](#). 2005; Mayo Clinic. [Cancer Survivors: Late Effects of Cancer Treatment](#). 2014.

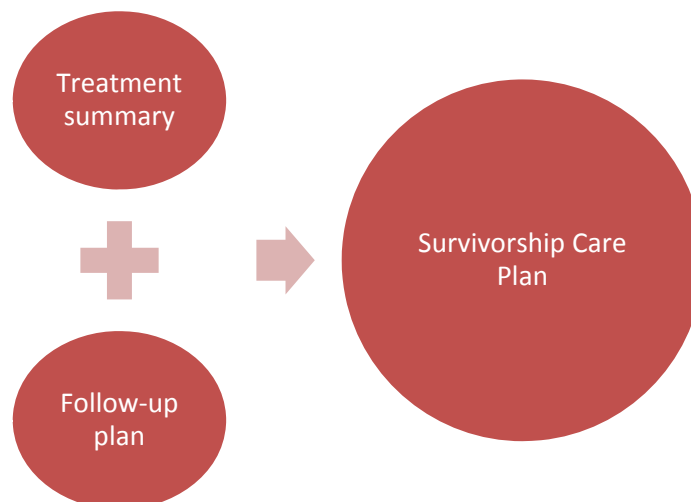
Components of Survivorship Care

According to the [Lost in Transition Report](#), survivorship care should include these 4 components:

- **Prevention and detection** of new cancers and recurrent cancer
- **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 after they are done with treatment.



The following are free Survivorship Care Plan templates:

- [ASCO Cancer Treatment Summaries and Survivorship Care Plans](#)
- [Journey Forward](#)
- [LIVESTRONG Care Plan](#)

Resources for Patient Navigators and Patients

- American Cancer Society's [Treatment and Side Effects Section](#)
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](#)
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 Section](#)
This webpage has links to a variety of information about life after cancer treatment.
- Center for Advancing Health's [Making Plans For Your End-Of-Life Care](#)
This webpage includes information on advance directives.

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Lesson 5: U.S. Health Care System

Learning Objectives

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

Key Takeaways

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

LESSON 5: U.S. HEALTH CARE SYSTEM

Cancer Care Delivery
 Overview of Health Care Specialists
 Overview of Oncology Specialists
 Mental Health Professionals
 Resources for Patient Navigators

Cancer Care Delivery

Cancer care can be delivered through the following ways:

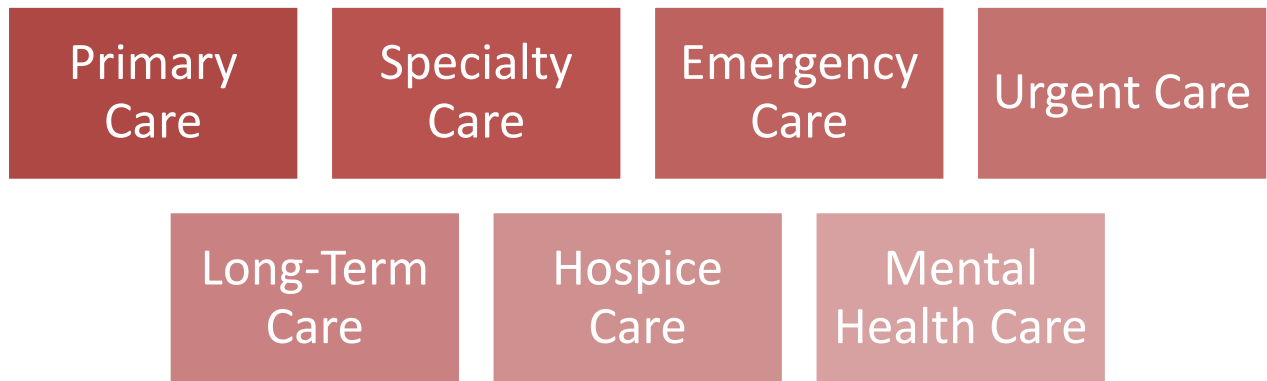
- **Hospital-based programs**
 Some care, like surgery, can be hospital-based. Children often receive chemotherapy in a hospital, while adults more often receive chemo in an ambulatory care setting, which may be called a cancer center.

Hospitals may be:

Public	Non-profit	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, however, 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.

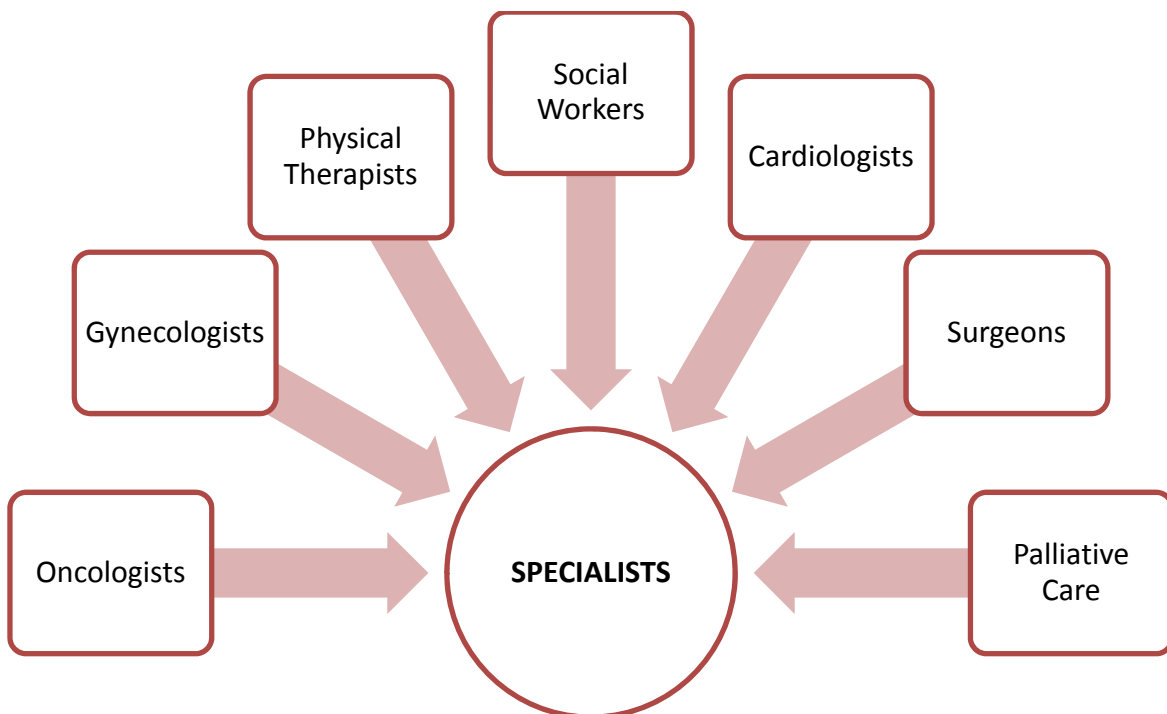
Patients may also experience different types of care settings, such as:



Sources: [PNTC](#); Simon. 2002.

Overview of Health Care Specialists

Cancer care is a team effort. Each health care provider is a member of the team with a special 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.



According to the [Association of American Medical Colleges](#), the following is a list of medical specialties that may also be involved in a patient's care:

- **Allergy and Immunology**
 - Clinical & Laboratory Immunology
- **Anesthesiology**
 - Critical Care Medicine
 - Obstetric Anesthesiology
 - Pain Medicine
 - Pediatric Anesthesiology
- **Colon and Rectal Surgery**
- **Dermatology**
 - Dermatopathology
 - Procedural Dermatology
- **Emergency Medicine**
 - Medical Toxicology
 - Pediatric Emergency Medicine
 - Sports Medicine
- **Family Medicine**
 - Geriatric Medicine
 - Sports Medicine
- **Family Practice**
 - Geriatric Medicine
- **Internal Medicine**
 - Advanced Heart Failure & Transplant Cardiology
 - Cardiovascular Disease
 - Clinical Cardiac Electrophysiology
 - Critical Care Medicine
 - Endocrinology, Diabetes & Metabolism
 - Gastroenterology
 - Geriatric Medicine
 - Hematology
 - Hematology & Oncology
 - Infectious Disease
 - Interventional Cardiology
 - Nephrology
 - Oncology
 - Pulmonary Disease
 - Pulmonary Disease & Critical Care Medicine
 - Rheumatology
 - Sports Medicine
 - Transplant Hepatology
- **Internal Medicine-Pediatrics**
- **Medical Genetics**
 - Biochemical Genetics
 - Molecular Genetic Pathology
- **Neurological Surgery**
 - Endovascular Surgical Neuroradiology
- **Neurology**
 - Child Neurology
 - Clinical Neurophysiology
 - Endovascular Surgical Neuroradiology
 - Neuromuscular Medicine
 - Pain Medicine
- **Nuclear Medicine**
- **Obstetrics and Gynecology**
 - Female Pelvic Medicine & Reconstructive Surgery
- **Ophthalmology**
 - Ophthalmic Plastic & Reconstructive Surgery
- **Orthopaedic Surgery**
 - Adult Reconstructive Orthopaedics
 - Foot & Ankle Orthopaedics
 - Hand Surgery
 - Musculoskeletal Oncology
 - Orthopaedic Sports Medicine
 - Orthopaedic Surgery of the Spine
 - Orthopaedic Trauma

- Pediatric Orthopaedics
- **Otolaryngology**
 - Otology - Neurotology
 - Pediatric Otolaryngology
- **Pathology-Anatomic and Clinical**
 - Blood Banking - Transfusion Medicine
 - Chemical Pathology
 - Cytopathology
 - Forensic Pathology
 - Hematology
 - Medical Microbiology
 - Neuropathology
 - Pediatric Pathology
- **Pediatrics**
 - Adolescent Medicine
 - Neonatal - Perinatal Medicine
 - Pediatric Cardiology
 - Pediatric Critical Care Medicine
 - Pediatric Emergency Medicine
 - Pediatric Endocrinology
 - Pediatric Gastroenterology
 - Pediatric Hematology - Oncology
 - Pediatric Infectious Diseases
 - Pediatric Nephrology
 - Pediatric Pulmonology
 - Pediatric Rheumatology
 - Pediatric Sports Medicine
 - Pediatric Transplant Hepatology
- **Physical Medicine and Rehabilitation**
 - Neuromuscular Medicine
- Pain Medicine
- Spinal Cord Injury Medicine
- Sports Medicine
- **Plastic Surgery**
 - Craniofacial Surgery
 - Hand Surgery
 - Preventive Medicine
 - Medical Toxicology
- **Psychiatry**
 - Addiction Psychiatry
 - Child & Adolescent Psychiatry
 - Forensic Psychiatry
 - Geriatric Psychiatry
- **Radiation Oncology**
- **Radiology-Diagnostic**
 - Abdominal Radiology
 - Cardiothoracic Radiology
 - Endovascular Surgical Neuroradiology
 - Musculoskeletal Radiology
 - Neuroradiology
 - Nuclear Radiology
 - Pediatric Radiology
 - Vascular & Interventional Radiology
- **Sleep Medicine**
- **Surgery-General**
 - Hand Surgery
 - Pediatric Surgery
 - Surgical Critical Care
 - Vascular Surgery
- **Thoracic Surgery**
 - Congenital Cardiac Surgery
 - Thoracic Surgery - Integrated
- **Urology**
 - Pediatric Urology

Overview of Oncology Specialists

Within oncology there are several types of specialties. Although some of these may sound similar, specialists in these fields provide very different services.

Radiology is the medical field of imaging. Doctors trained in this field are called radiologists. Radiologists provide diagnostic services for patients by taking images of the body. This field is not limited to cancer. Radiologists are focused on the detection of cancer.

Pathology is the field focused on diagnosis. Doctors trained in this field are called pathologists. They look at body fluids like blood and urine as well as tissues to diagnose cancer.

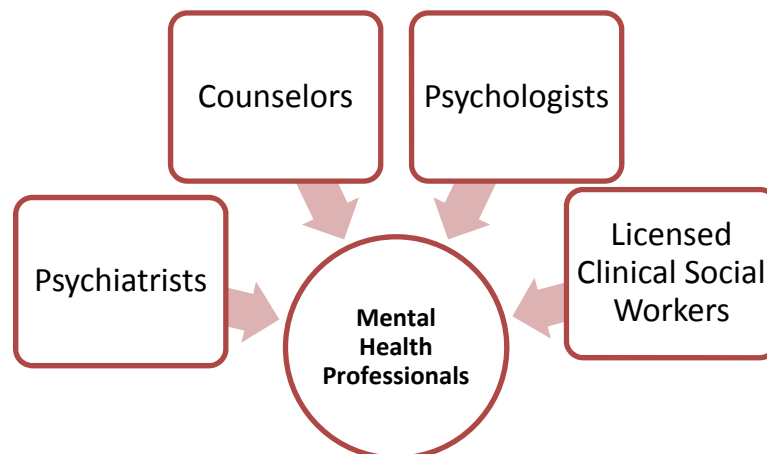
Radiation oncology is a field focused on providing cancer treatment to patients using radiation. Doctors trained in this field are called radiation oncologists.

Hematology/oncology is the specialty that provides chemotherapy treatment to cancer patients. Doctors who practice in this field are called medical oncologists or simply oncologists.

Surgery is another specialty that treats cancer patients. Doctors who practice surgery are called surgeons.

Mental Health Professionals

Special health care professionals are required for treating any mental health conditions a patient may experience.



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.

Module 3, Lesson 5: U.S. Health Care System**References: Presentations**

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MODULE 3:

Resources

THE BASICS OF HEALTH CARE

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Lesson 6: Health Care Payment and Financing

Learning Objectives

- Understand how health insurance works
- Define key insurance terms
- Describe public and private health insurance options, including patient 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, S-CHIP and the VA) or private (through employers or through exchanges).
- Health plans can be health maintenance organizations, preferred provider organizations, point of sale, fee for service or high deductible.
- Medicare covers individuals aged 65 and over and some disabled individuals.
- Medicaid covers very poor pregnant women, children, elderly, disabled and sometimes parents/caretaker relatives and is based on federal poverty levels (FPL) or a percentage of FPL.
- The Patient Protection and Affordability Act, also called the ACA or Obamacare, created health insurance marketplaces, formerly called exchanges. The ACA identified ten essential health benefits, provides more coverage and makes coverage more affordable, more easily accessible and easier to understand.

LESSON 6: HEALTH CARE PAYMENT AND FINANCING

A Dictionary of Common Insurance Terms
Types of Health Insurance and Eligibility
Federal Poverty Guidelines
Health Plan Types Comparison
Affordable Care Act
Resources for Patient Navigators
Resources for Patients

A Dictionary of Common Insurance Terms (Alphabetical)

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 usually are 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—the amount of money you must pay each year to cover eligible medical expenses before your insurance policy starts paying.

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 an 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 of 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 age 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—the 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. Also, the period of time beginning with a policy's effective date during which a health plan may not pay benefits for certain pre-existing conditions.

Sources: Healthinsurance.gov. [Health insurance terms](#). 2015; HealthCare.gov [Glossary](#).

n.d.; Wisconsin Office of the Commissioner of Insurance. [Glossary of Insurance Terms](#). 2010.

Types of Health Insurance and Eligibility

The following table shows different types of insurance, eligibility criteria and resources for each.

Insurance Type	Eligibility	Resources
Medicaid	Covers very poor pregnant women, children, elderly, disabled and sometimes parents/caregiver relatives	Medicaid.gov
Medicare	Covers individuals aged 65 and over and some individuals with disabilities	Medicare.gov
S-CHIP	Covers children whose families make too much money to qualify for Medicaid but make too little to purchase private health insurance	InsureKidsNow.gov
The VA	Offers extremely affordable (if not free) 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	California , Colorado , Connecticut , District of Columbia , Hawaii , Idaho , Kentucky , Maryland , Massachusetts , Minnesota , New Mexico , New York , Oregon , Rhode Island , Vermont , Washington
National Health Insurance Marketplace or Exchange	National marketplace for residents of states that do not have a state-based 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 may want to become familiar with these poverty levels or have them readily accessible so you can better develop solutions for a patient based on their income.

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. For example, pregnant women are eligible for Medicaid at 250% FPL in Connecticut, but they are eligible only at 100% in Wyoming. Parents of minors in North Carolina are only eligible for Medicaid if they make less than 45% of the FPL.

The table below shows the 2015 FPL at 100% for families of 1-8. These levels change each year, so it is important to stay up to date on the FPL and your state's eligibility criteria.

Family Size	100% FPL
1	\$11,770
2	\$15,930
3	\$20,090
4	\$24,250
5	\$28,410
6	\$32,570
7	\$36,730
8	\$40,890

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

Health Plan Type Comparison

Health Maintenance Organization (HMO)

- Comprehensive services available
- Patients can only see HMO doctors and hospitals
- No deductible
- Small copay
- Must have a primary care provider
- Must get referral for specialty care
- Cannot use out-of-network providers

Preferred Provider Organization (PPO)

- A “network” of providers agree 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)

- Patient can see providers outside of network but will pay more
- Copays and deductibles are low
- Referral required to see a specialist

Fee for Service (FFS)

- 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

- Low premiums but high deductibles
- Patients can see any doctor or hospital
- Insurance pays for coverage after high deductible is met

Source: US Office of Personnel Management. [Healthcare Plan Information](#). n.d.

The Affordable Care Act

The law provides more coverage, makes coverage more affordable, makes coverage more accessible and makes insurance 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
- ✚ Closing the Medicare Part D “donut hole”
- ✚ Providing clinical trials coverage
- ✚ 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 available

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

Source: American Cancer Society. [The Health Care Law: How It Can Help People with Cancer and Their Families](#). 2010.

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 [Marketplace Insurance Categories](#)
This webpage highlights the differences between bronze, silver, gold, platinum and catastrophic health insurance plans.
- American Cancer Society's [The Health Care Law: How It Can Help People With Cancer and Their Families](#)
This easy-to-read guide explains how the Affordable Care Act helps cancer patients and their families.
- [The Affordable Care Act, Section by Section](#)
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 perspective from a variety of individuals are included on the site.

Resources for Patients

- About.com's [HMO, PPO, EPO, POS—What's the Difference & Which Is Best?](#) compares 6 ways that health plans differ.
- American Cancer Society's [The Health Care Law: How It Can Help People With Cancer and Their Families](#) explains how the Affordable Care Act helps cancer patients and their families.
- Center for Advancing Health's [How To Find and Use Health Insurance](#) has information for patients on how to find and use health insurance.
- 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](#) webpage 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 3, Lesson 6: Health Care Payment and Financing

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Lesson 1: The Role of the Patient Navigator

Learning Objectives

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

Key Takeaways

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

LESSON 1: THE ROLE OF THE PATIENT NAVIGATOR

The Patient Navigator's Role
 Sample Patient Navigator Job Description
 Possible Barriers
 Patient Navigator Duties
 Day in the Life of a Patient Navigator
 Resources for Patient Navigators

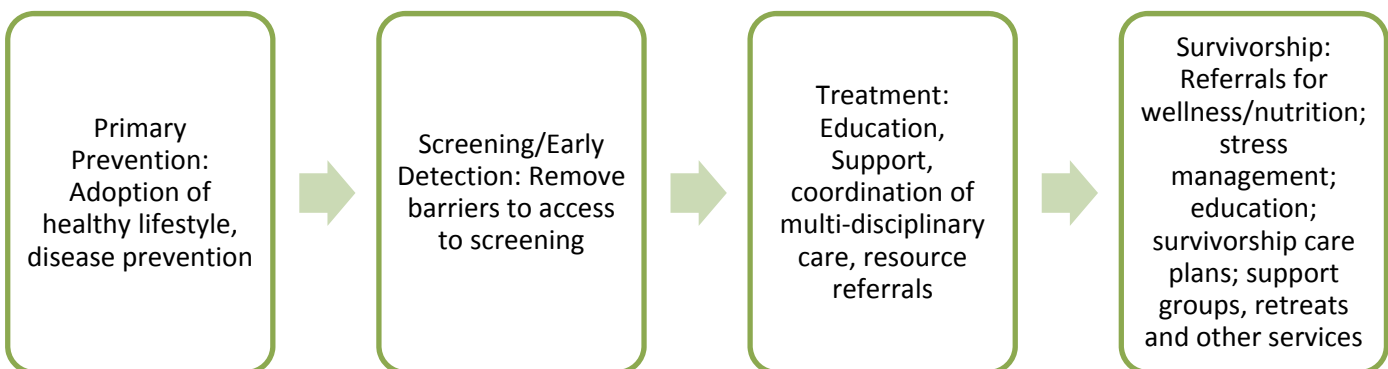
The Patient Navigator's Role

Patient navigator duties vary, but **the main role that all have in common is addressing barriers to care**. The patient navigator helps patients identify and overcome challenges to getting medical care. Sometimes the navigator directly removes barriers for patients, but often the navigator helps the patients remove barriers themselves. There are some general functional categories that describe patient navigator functions:

- 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

Source: Willis et al. 2013.

All patient navigators address barriers to care, no matter where they work in the cancer continuum:



On the next page you will find a sample patient navigator job description, which is also available in the learning management system.

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. S/he works with other health care professionals to establish and maintain a climate of mutual respect, dignity, diversity, ethical integrity and trust and participates in multi-disciplinary teams to provide patient care that is safe, timely, efficient, effective and equitable. S/he uses 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. S/he is 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.
- ✚ Empower patients to communicate their preferences and priorities for treatment to their health care team; facilitate shared decision making in the patient's health care.
- ✚ Empower 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 normal business office environment and/or in a community-based setting exterior to the normal 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.

Possible Barriers

There are generally five types of barriers to care that you may need to assist with:

Practical

- Treatment costs
- Transportation
- Language barriers
- Work
- Food insecurity
- Insurance problems
- Stable housing
- Immigration status

Psychosocial

- Anxiety and depression
- Changes in relationships and roles in family
- Family and social support
- Stigma, fear, social isolation
- Mental health

Provider

- Biases in medical recommendations
- Poor communication with patients with low literacy
- Poor communication with limited English-proficient patients
- Cultural dissonance

Systems

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

Personal

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

Source: [PNTC](#).

Patient Navigator Duties

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

Navigator Tasks

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 Duties



Source: Parker et al. 2010.

A Day in the Life of a Patient Navigator

The table below summarizes a day in the life of a patient navigator who works with breast cancer patients.

Barrier/Event	Action/Next Step
Call from patient who has surgery in 2 days. Patient would like to speak with anesthesiologist about nerve block. Patient also needs information about bras/garments she should wear after the surgery.	Mail patient information on camisole, including a prescription and a list of places she can get it; ask 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: BSGI (refer to nurse to explain procedure).
Patient has concerns about 6 month follow-up screening plan given to her by doctor. She is supposed to have a mammogram, but one of her cancers was not visible on mammography.	Ask physician to clarify screening plan with patient; supply patient with correct order if needed and tell her how to schedule procedure(s).
Patient calls with questions about radiation (has not been in for her consult yet).	Assist patient with scheduling 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.
Patient beginning chemo needs her doctor to speak with surgeon ASAP regarding recommendations. Other doctor is going on vacation tomorrow.	Get doctor’s direct phone number, track down surgeon, ask her to call doctor.

MODULE 4:

Resources

THE BASICS OF PATIENT NAVIGATION

Patient applying for disability and Medicaid, needs referral to infectious disease, psychiatry. Needs PET/CT.	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.
Patient 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.
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 medical oncologist for patient to see dietitian.	Call patient and set up time to meet with dietitian; add patient to dietitian's schedule.
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 measure tool.
- C-Change's [Cancer Patient Navigation Overview](#)
This website includes information to promote patient navigation and the development of community-based patient navigation programs.
- 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.
- Willis A, Pratt-Chapman M, Reed E, Hatcher E. [Best Practices in Patient Navigation and Cancer Survivorship: Moving Toward Quality Patient-Centered Care](#). *Journal of Oncology Navigation and Survivorship*. 2014.
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Module 4, Lesson 1: The Role of the Oncology Patient Navigator

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MODULE 4:

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THE BASICS OF PATIENT NAVIGATION

Willis A, Reed E, Pratt-Chapman M, et al. Development of a framework for patient navigation: Delineating roles across navigator types. *Journal of Oncology Navigation & Survivorship*. 2013; 4(6):20-26.

Lesson 2: Patient Assessment

Learning Objectives

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

Key Takeaways

- The 5A's can be used to help patients: Ask, Assess, Advise, Assist, Arrange.
- Building rapport with patients is critical.
- A strengths-based approach can help you as you work with patients to address barriers.
- Patient navigators must remain neutral and non-judgmental.
- A helpful strategy to guide your communication is Elicit-Provide-Elicit.
- The patient, not the patient navigator, should determine the priority of needs. As the navigator, you can help the patient think about which barriers have the most impact.
- The Problem-Solving Cycle can be used when working with patients.
- You will need to help the patient create an action plan. To help the patient put their plan into action, document with the patient what tasks will be done, who will do them and what the deadline will be.
- 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.
- Each patient will have a different way of expressing emotions, coping, and communicating. It's hard to know exactly when to refer a patient to a mental health specialist, but as a rule of thumb, it is better to over-refer than under-refer.

LESSON 2: PATIENT ASSESSMENT

The 5 A's

Sample Patient Intake Form

Barriers Assessment Tool

Tips for Building Rapport

Tips for Asking and Assessing

A Strengths-Based Approach

Conversation Tips

The Problem-Solving Cycle

Barriers and Actions

Assessing Emotional Needs

Signs and Symptoms of Mental illness

When to Refer to a Mental Health

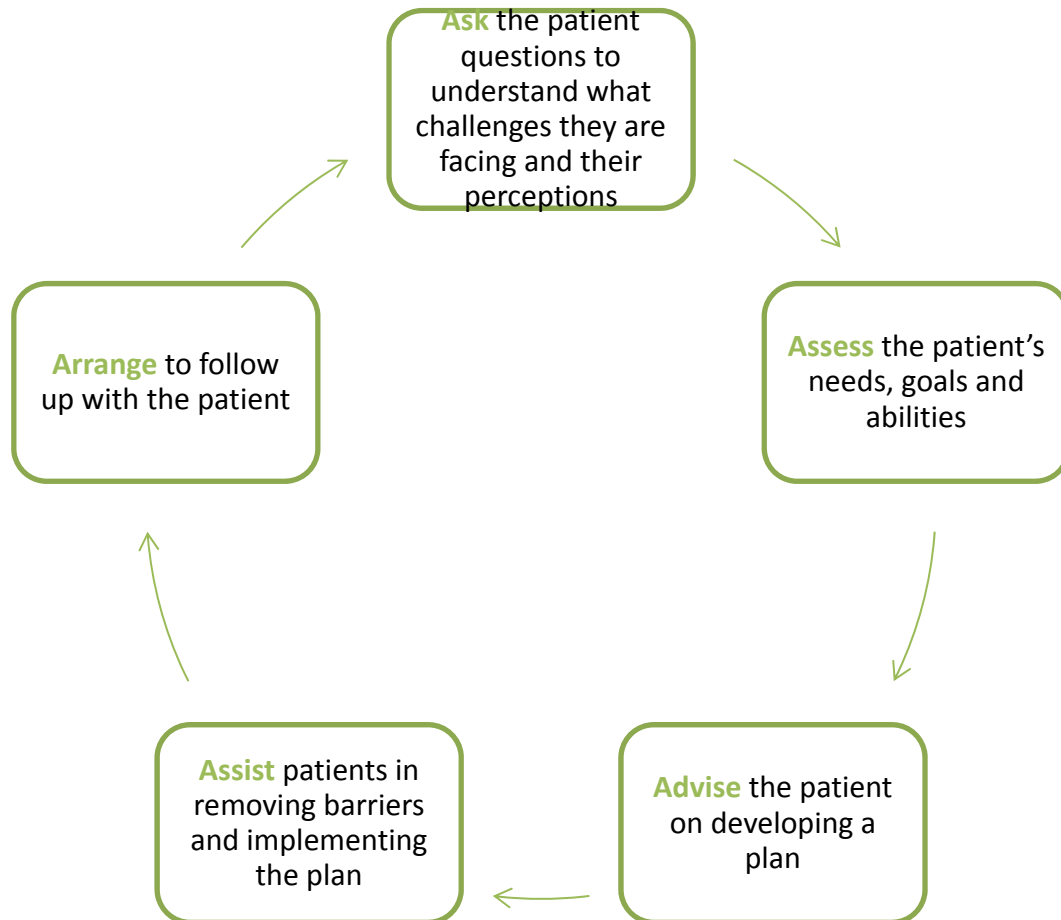
Specialist

Resources for Patient Navigators

Resources for Patients

The 5 A's

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



Source: Agency for Healthcare Research and Quality. [Five Major Steps to Intervention \(The "5 A's"\)](#). 2012.

MODULE 4:

Resources

THE BASICS OF PATIENT NAVIGATION

Sample Patient Intake Form

Name _____ Birth Date ____/____/____

Street Address _____

City/State _____ Zip _____

Email _____

Phone Numbers: Home (____) _____ Work (____) _____ Cell (____) _____

Gender: Female Male Prefer not to answer

Race: African American /Black Asian Caucasian/White Hispanic/Latino

American Indian/Alaskan Native Pacific Islander Other _____

Declined

Primary Language: English Spanish Other _____ Declined

Type of Cancer: _____ Date of Diagnosis: ____/____/____

Please check all that apply:

Insurance: Private Medicare Medicaid Uninsured Military Declined

Information/Service(s) Requested (please check all needed):

Cancer-related information

Transportation assistance

Clinical trials information

Cancer support groups (general cancer support groups for patients and family members)

Financial assistance (assistance with medications, insurance, etc.)

Information regarding: Palliative Care Hospice Support Services

Additional Comments:

Barriers Assessment Tool: Barriers Checklist

You can use this tool to help you assess your patient’s barriers. A modifiable version is available in the resources section.

Patient Name _____ Date _____

Financial and Insurance

- Difficulty meeting copays
- Financial planning
- Low financial literacy
- Non-medical financial needs
- Uninsured
- Underinsured
- Other _____

Logistical

- Clothing
- Dependent Care
- Food
- Housing
- Transportation
- Utilities
- Other _____

Care coordination

- Appointment making
- Home health care
- Incorrect referrals or orders
- Needs referral
- Next stage of care
- Physical comorbidity
- Rx or medical supplies
- Other _____

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
- Other _____

Employment

- Ability to work through treatment
- Family member’s employment
- Needs job accommodations
- Stigma/discrimination
- Unemployed
- Other _____

Communication

- Cultural barriers to communication
- Health literacy
- Language barrier
- Literacy
- Other _____

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 and 'safe topics' for initial small talk
- Listen to what the other person is saying and use open-ended questions
- Be aware of your body language and other non-verbal signals you are sending
- Be empathetic

Tips for Asking and Assessing

Asking and assessing are starting points for helping patients. The navigator shouldn't 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	Look	Clarify	Ask
<ul style="list-style-type: none"> •Patient expresses worries, fear, concern, anger 	<ul style="list-style-type: none"> •Expression of doubt or anger, disinterest 	<ul style="list-style-type: none"> •You sound worried that you will not be able to... 	<ul style="list-style-type: none"> •What may make it difficult to attend your appointment?

Source: [PNTC](#).

A Strengths-Based Approach

A strengths-based approach can help you as you work with them to resolve barriers. Strengths can be:

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

Example strengths include:



Here are some 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 life worth living for you?
- Who is important in your life?
- What is going well in your life now?
- What do you do to enjoy yourself?

Source: [PNTC](#).

Conversation Tips

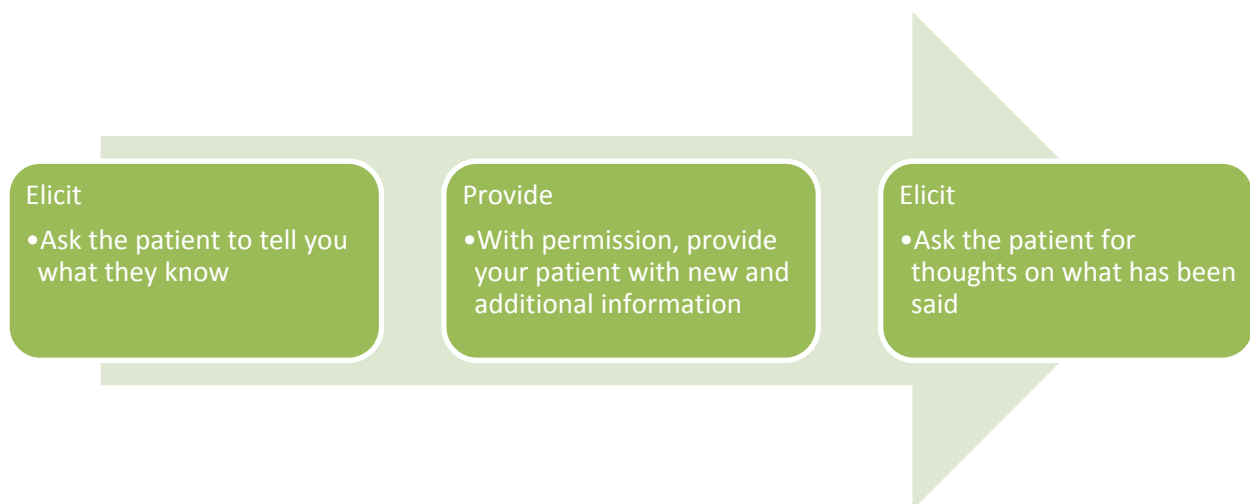
Ambivalence means having mixed feelings about something. Some patients may be ambivalent about their illness and may not know how much information they want or can handle. The navigator's goal is to further explore and help resolve ambivalence before moving on. You can address ambivalence by:

- 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

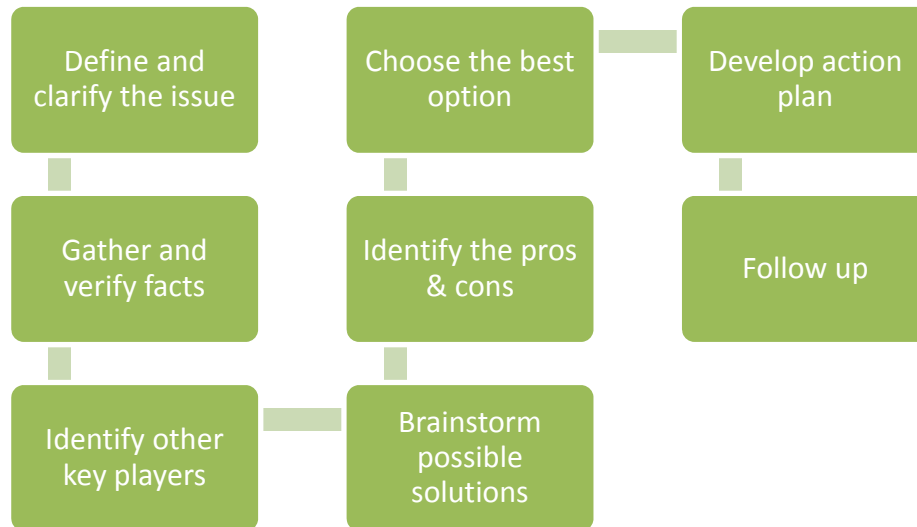
You may also find the Elicit-Provide-Elicit strategy helpful:



Sources: Jacobsen et al. 2009; Back et al. 2006; [PNTC](#).

The Problem-Solving Cycle

You can use these steps to help your patients solve their own issues. 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. 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 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 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 to a colleague to help them. With the patient's permission, bring in a counselor or a social worker to work with the patient.

Source: [PNTC](#).

Barriers and Actions

Below is a list of barriers and possible actions a patient navigator can take.

Barrier	Possible Actions
Treatment costs	<ul style="list-style-type: none"> Identify financial assistance programs and work with patient to complete paperwork Refer to financial navigator, financial counselor or billing specialist
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
Language barrier	<ul style="list-style-type: none"> Schedule a medical interpreter to attend next appointment Provide educational materials in patient's preferred language
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
Anxiety	<ul style="list-style-type: none"> Refer to social worker
Need support	<ul style="list-style-type: none"> Refer to support group Refer to counseling
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

The following tips can help you address patient support needs:

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

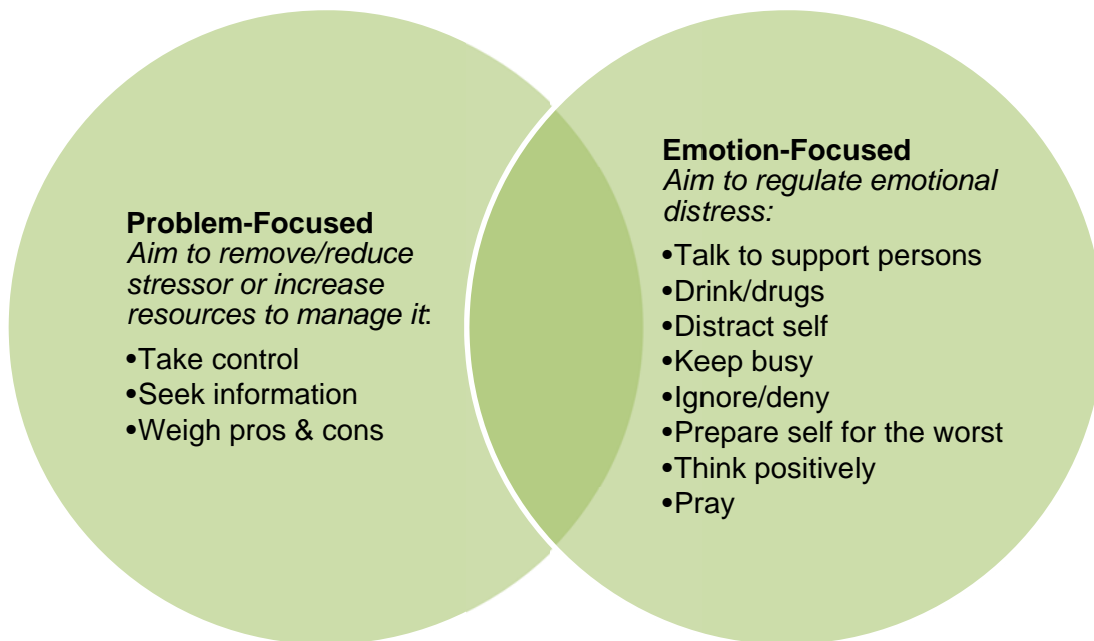
- Remind patients to speak with their supervisor and HR department if they need work accommodations. They may well qualify for accommodations through the American Disabilities Act.
- For patients with small children, swapping child care can allow for 'days off' following difficult treatment.
- Churches or other community organizations like PTA or senior centers can be a good source of support for things such as rides to a doctor appointment, bringing in meals, or helping with chores.

Source: [PNTC](#).

Assessing Emotional Needs

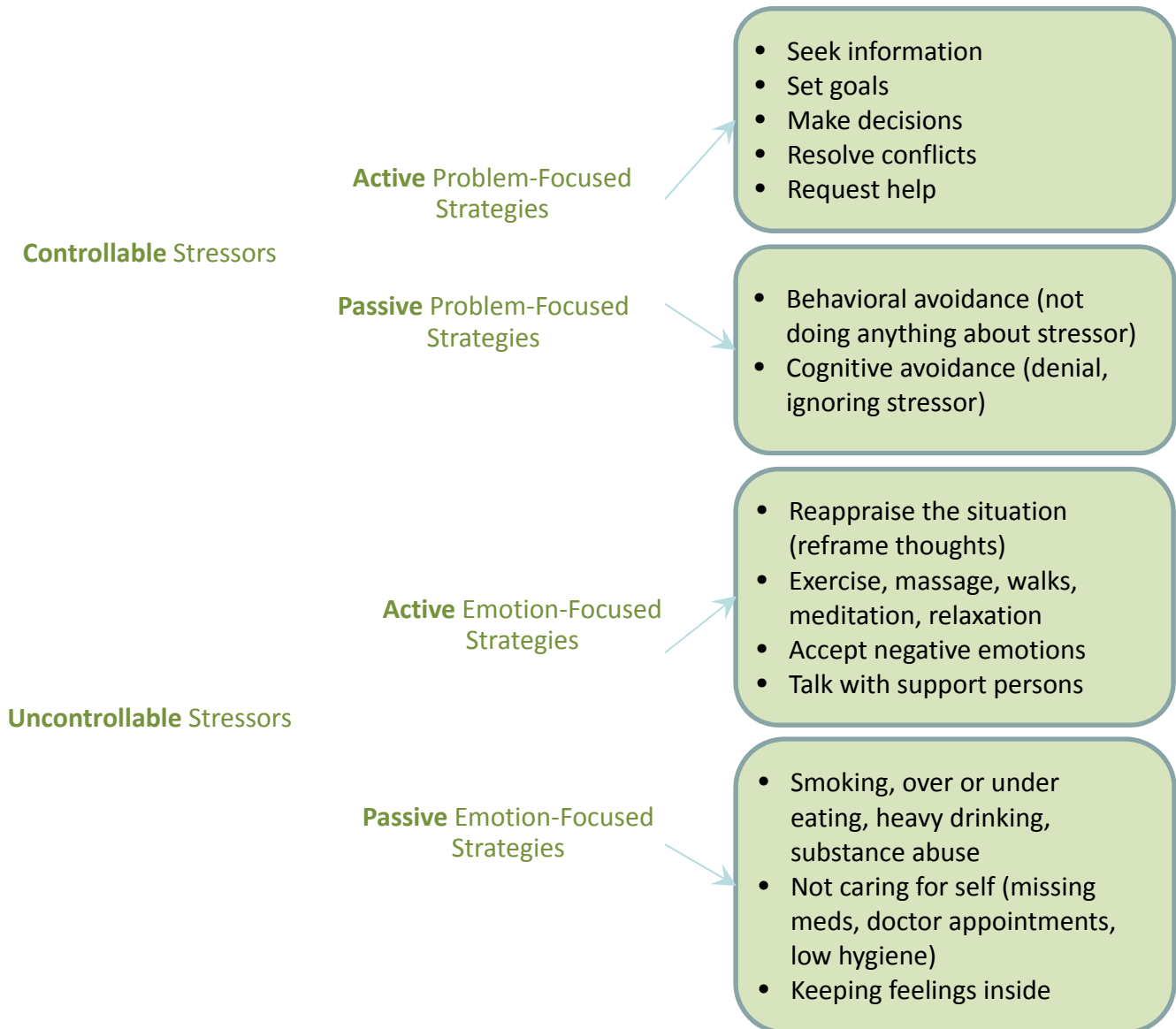
The emotional challenges of cancer can be significant, and the patient should work with clinicians who have been trained to address these impacts.

Patient Navigator's Role	NOT A Patient Navigator's Role
<ul style="list-style-type: none"> • Help assess how much information a patient wishes to know about his or her illness • Be aware of the signs and symptoms of mental illness • Know when to refer to a mental health specialist • Build patient's awareness of coping strategies and matching stressors with strategies • Assess patient's support system and help enhance it 	<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 sole source of patient's social support



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 he has no control over a situation, he can begin the process of accepting the situation and finding emotional support.



Sources: Ogden 2007; [PNTC](#).

Signs and Symptoms of Mental Illness

You need to be able to recognize the signs and symptoms of mental illness. 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.

Generalized Anxiety Disorder –
Excessive or out of control worry that hinders daily function (6+ months)

- Cannot relax
- Startle easily
- Poor concentration
- Irritability
- Muscle fatigue, tension, aches
- Headaches
- Sleep disturbances
- Sweaty palms
- Dry mouth, difficulty swallowing
- Trembling, twitching
- Nausea, lightheadedness
- Shortness of breath
- Frequent trips to bathroom
- Hot flashes

Depression – Severe symptoms that interfere with the ability to work, sleep, study, eat, and enjoy life

- Persistent sad, anxious, or "empty" feelings
- Feelings of hopelessness or pessimism
- Feelings of guilt, worthlessness, or helplessness
- Irritability, restlessness
- Loss of interest in activities or hobbies once pleasurable, including sex
- Fatigue and decreased energy
- Difficulty concentrating, remembering details, and making decisions
- Insomnia, early-morning wakefulness, or excessive sleeping
- Overeating, or appetite loss
- Thoughts of suicide, suicide attempts
- Aches or pains, headaches, cramps, or digestive problems that do not ease even with treatment

Sources: National Institute of Mental Health. Depression and Generalized Anxiety Disorder. n.d.; Reist. Psychiatric Treatment. n.d.

When to Refer to a Mental Health Specialist

Each patient will have a different way of expressing emotions, coping, and communicating. It's hard 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.

Exhibits or reports symptoms consistent with anxiety, depression or other mental illness

Exhibits or reports significant distress, difficulty or inability to make medical decisions or take action regarding the illness or in other areas of life, difficulty in significant relationships (family, couple, etc.)

Displays sudden changes in behavior or acts out aggressively

Becomes impulsive in actions or decision making

Engages in risky or self-destructive behavior, drug or alcohol abuse, risky or compulsive sexual behavior, illegal activities or abuse of others

Expresses a desire to hurt him or herself or others

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 measure 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.

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 40 affiliates across the country that provide in-person services.

Module 4, Lesson 2: Patient Assessment

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Lesson 3: Shared Decision-Making

Learning Objectives

- Encourage active participation by the patient in decision-making and explain choices or rights to the patient in a patient-centered manner
- Assess patient desire and capacity to be involved and responsible in the decision-making process
- Determine patient preferences and priorities for treatment
- Identify strategies to assist patients in discussing preferences and priorities with clinician
- Support the patient in the decision-making process in alignment with 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 and outcomes. Even among patients who do not wish to actively participate in decision-making, having an interactive discussion with their provider improves 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.
- Patients may face challenges adhering to their treatment plan. Clinicians should always be made aware of adherence challenges.
- Patients can help self-manage their disease, and patient navigators can provide support to patients. However, patient navigators should never provide clinical information to patients.

LESSON 3: SHARED DECISION-MAKING

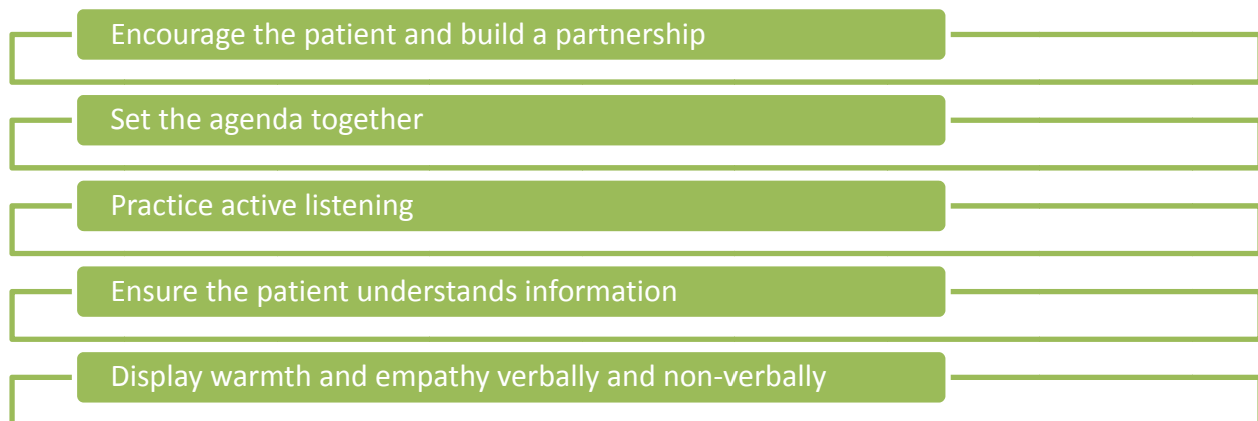
- Shared Decision-Making
- Engagement Behavior Framework
- Understanding Health Literacy
- Health Literacy Checklist
- Summary of Learning Styles
- Treatment Plan and Adherence
- Self-Management
- Self-Management Resources for Patients
- Cancer Organizations
- Resources for Patient Navigators
- Resources for Patients

Shared Decision-Making

Certain elements must be in place to encourage patients' active participation in care. These include:

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

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



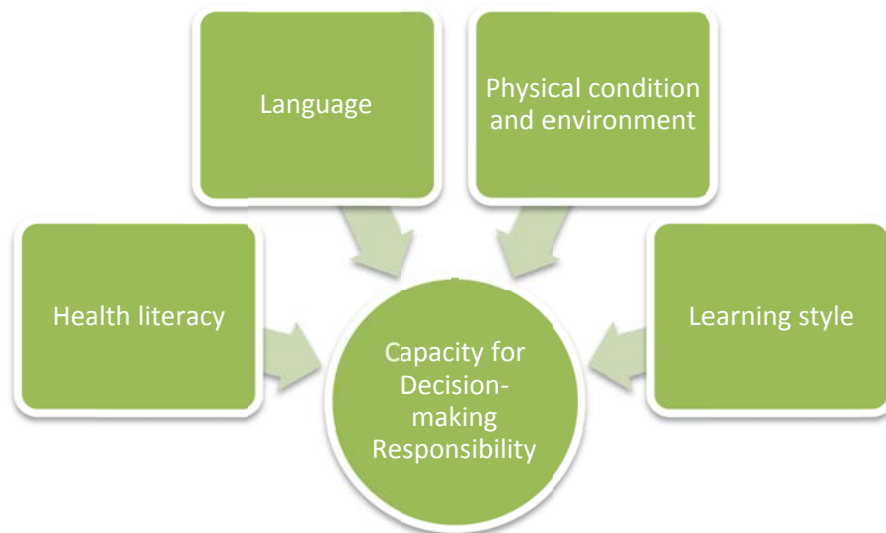
Patient navigators can use different approaches to help patients in discussing treatment preferences and priorities. The goal is to make sure patients understand and have their questions answered. The patient navigator facilitates this process rather than answering questions or making recommendations.

- 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)

Here are some questions a navigator might ask to start a conversation with a patient about 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?

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



Sources: Fraenkel et al. 2007; Epstein et al. 2007; U.S. Department of Health and Human Services. Improve the Usability of Health Information. n.d.; Nielsen-Bohlman et al. 2004; Beagley. 2011; Kutner et al. 2006; Beagley. 2011.

Engagement Behavior Framework

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



Learn more about the [Engagement Behavior Framework](#).

Understanding Health Literacy

Literacy, health literacy and limited English proficiency are related, but different, concepts. They are distinguished below:

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 interpretor services

Source: EuroMedInfo. [Designing Low Literacy Materials](#). n.d.

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

Source: Cornette, 2009.

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, asking 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

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 more 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.

Sources: Cornett. 2009; U.S. Department of Health and Human Services. Health Literacy Basics. n.d.

Summary of Learning Styles

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



Strategies that patient navigators can use to support patients:

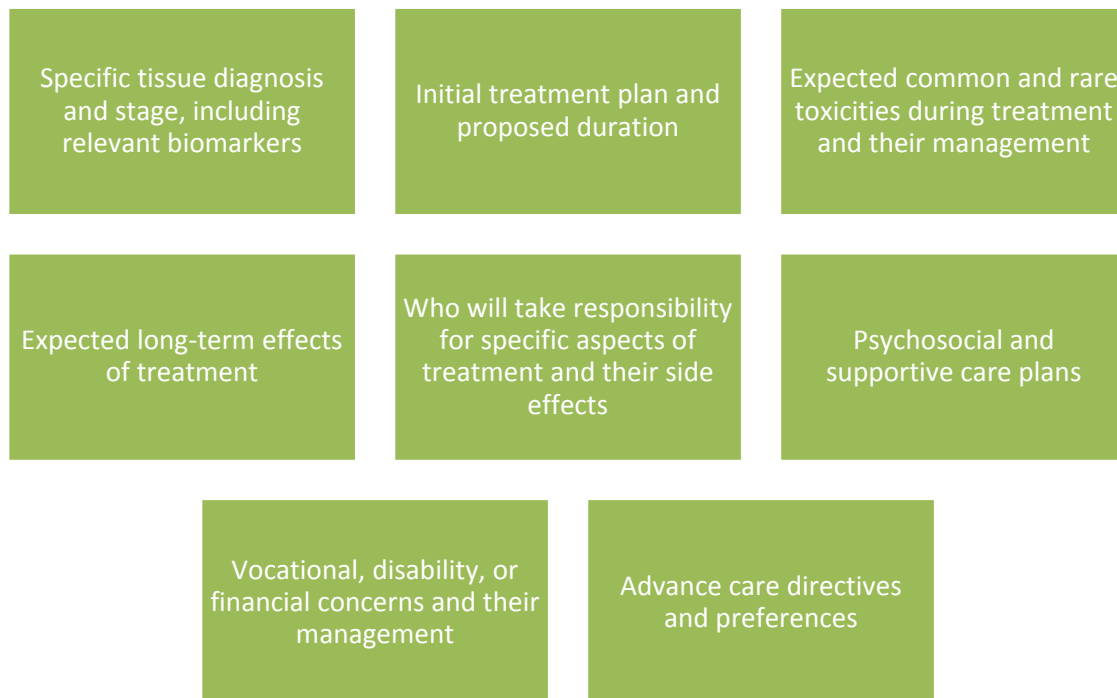
- Provide information in a user-friendly way
- Provide verbal support of patient’s ability to make decisions
- Understand patients’ decisions and preferences may change
- Facilitate open dialogue between the patient and the physician that identifies goals that are important to patients
- Provide ongoing support and encouragement
- Refer to community-based organizations and encourage patients to use them

Sources: Beagley. 2011; Inott et al. 2011; Fleming et al. n.d.; Institute of Medicine Committee on Health Literacy. Health Literacy: A Prescription to End Confusion. 2004; McCorkle et al. 2011.

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:



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

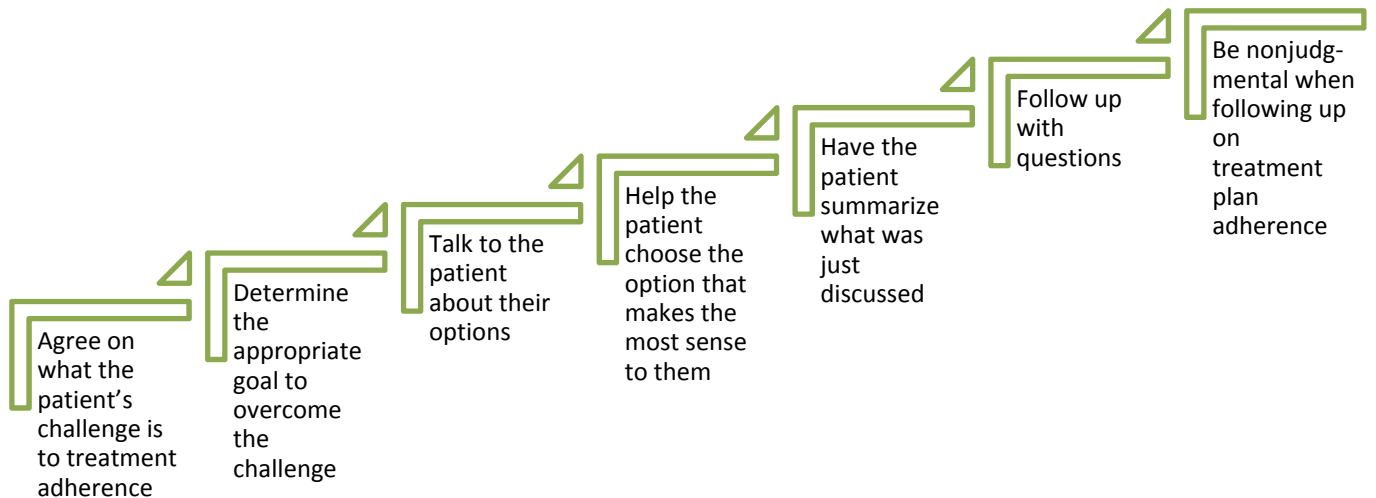
- Fail to fill prescriptions because they
 - Feel that the medication isn't necessary
 - Are unable to afford the medication
 - Do not want to take the medication
 - Do not believe the medication will be effective
- Not want to change their behavior
- Want to avoid the side effects of treatment
- Have 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

MODULE 4:

Resources

THE BASICS OF PATIENT NAVIGATION

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.



Sources: Balogh et al. 2011; Lowes. 1998; Butterworth. 2008.

Self-Management

A part of adhering to the treatment plan means encouraging 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. Self-management includes:



Sources: Adams et al. 2004; Pearson et al. 2007.

MODULE 4:

Resources

THE BASICS OF PATIENT NAVIGATION

Self-Management Resources for Patients

Self-Management Resources	Examples (Resources, Tools, Organizations, Services, Programs , Mobile Apps)
Exercise	<p>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</p> <p>General fitness trackers/apps: SuperTracker, My Fitness Pal, Runkeeper, Moves, Fitocracy</p>
Coping	<p>Cancer Support Community, CancerCare, Cancer Hope Network</p>
Stress Management	<p>Mindfulness-Based Stress Reduction Information, Relaxation Techniques for Health: What You Need to Know</p>
Quitting Tobacco Consumption	<p>Smokefree.gov, American Lung Association: Getting Help to Quit Smoking, American Cancer Society: Guide to Quitting Smoking (also available in Spanish)</p>
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 (meal services, transportation through local church or volunteer organizations, child care or elder care support and respite services) or local funds providing financial assistance</p>

Cancer Organizations

National General Cancer Resources	Website
ASCO Cancer Foundation	Cancer.net
American Cancer Society	Cancer.org
Cancer Support Community	CancerSupportCommunity.org
LIVESTRONG	LIVESTRONG.org
National Cancer Institute	Cancer.gov
National Coalition for Cancer Survivorship	Canceradvocacy.org
Support Group Organizations by Cancer Type	
Bladder	
Bladder Cancer Advocacy Network	BCAN.org
Brain	
American Brain Tumor Association	ABTA.org
National Brain Tumor Society	Braintumor.org
The Brain Tumor Foundation	BrainTumorFoundation.org
Breast	
Susan G. Komen Foundation	Komen.org
Breastcancer.org	Breastcancer.org
Avon Foundation for Women	AvonFoundation.org
Carcinoid	
Caring for Carcinoid Foundation	CaringForCarcinoid.org
The Carcinoid Cancer Foundation	Carcinoid.org
Cervical	
National Cervical Cancer Coalition	NCCC-Online.org
Colorectal	
Colorectal Cancer Coalition	FightColorectalCancer.org
Gastric	
Gastric Cancer Fund	GasticCancer.org
GIST (gastrointestinal stromal tumors)	
GIST Support International	GistSupport.org
Head and Neck, Esophageal	
Head and Neck Cancer Alliance	HeadAndNeck.org
Lung	
Lung Cancer Alliance	LungCancerAlliance.org
American Lung Association	LungUSA.org
Leukemia and Lymphoma	
Leukemia and Lymphoma Society	LLS.org
Liver	

MODULE 4:

Resources

THE BASICS OF PATIENT NAVIGATION

American Liver Foundation	LiveFoundation.org
Melanoma	
American Melanoma Foundation	MelanomaResearchFoundation.org
Melanoma Research Foundation	Melanoma.org
Oral	
Cancer	
Support for People with Oral and Head and Neck	SPOHNC.org
Ovarian	
Ovarian Cancer National Alliance	OvarianCancer.org
Rhonda's Club	RhondasClub.org
Pancreatic	
Pancreatic Cancer Action Network	PanCan.org
Prostate	
Prostate Cancer Research Institute	Prostate-Cancer.org
Us Too International	UsToo.org
Renal	
Kidney Cancer Association	KidneyCancer.org
Sarcoma	
Sarcoma Foundation of America	CureSarcoma.org
Sarcoma Alliance	SarcomaAlliance.org
Testicular	
Stanford Medical Center	TesticularCancerSociety.org
Thyroid	
Thyroid Cancer Society	Thyca.org
Uterine, Vulvular	
Foundation for Women's Cancer	FoundationForWomensCancer.org

Resources for Patient Navigators

- [Introduction to VARK](#) (learning styles)
This website provides information about different learning styles.
- [Engagement Behavior Framework](#)
The Engagement Behavior Framework outlines activities patients can do to be more engaged.
- National Comprehensive Cancer Network's (NCCN) [Distress Thermometer](#)
The NCCN Distress Thermometer is an easy tool to use to assess patient distress.
- Agency for Healthcare 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 style.
- [Engagement Behavior Framework](#)
The Engagement Behavior Framework outlines activities patients can do to be more engaged.
- [Ottawa Personal Decision Guides](#)
These guides can help with any health-related or social decisions.
- LIVESTRONG Foundation's [Developing Your Treatment Plan](#)
This website provides guidance on working with a health care provider to create a treatment plan.
- Agency for Healthcare Research and Quality's [Question Builder](#)
This tool lets patients build questions to ask their health care team.
- American Cancer Society's [Questions to Ask My Doctor About My Cancer](#)
This resource provides a list of questions when you're 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.

Module 4, Lesson 3: Shared Decision-Making

References: Presentation

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Beagley L. Educating patients: understanding barriers, learning styles, and teaching techniques. *J Perianesth Nurs.* 2011; 26(5):331-337. doi: 10.1016/j.jopan.2011.06.002.

Butterworth SW. Influencing patient adherence to treatment guidelines. *J Manag Care Pharm.* 2008; 14(6 Suppl B):21-24.

Coulter A, Parsons S, Askham J. Where are the patients in decision-making about their own care. 2008. Retrieved from: <http://www.who.int/management/general/decisionmaking/WhereArePatientsinDecisionMaking.pdf>.

Epstein RM, Street RL Jr. Patient-centered communication in cancer care: Promoting healing and reducing suffering. National Cancer Institute, NIH Publication No. 07-6225. Bethesda, MD, 2007.

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. doi: 10.1007/s11606-007-0149-9.

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Robinson TE 2nd, White GL Jr, Houchins JC. Improving communication with older patients: tips from the literature. *Fam Pract Manag*. 2006; 13(8):73-78.

Sheridan SL, Harris RP, Woolf SH, Shared Decision-Making Workgroup of the U.S. Preventive Services Task Force. Shared decision making about screening and chemoprevention: A suggested approach from the U.S. preventative task force. *Am J Prev Med*. 2004; 26(1):56-66. doi: 10.1016/j.amepre.2003.09.011.

Lesson 4: Identifying Resources

Learning Objectives

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

Key Takeaways

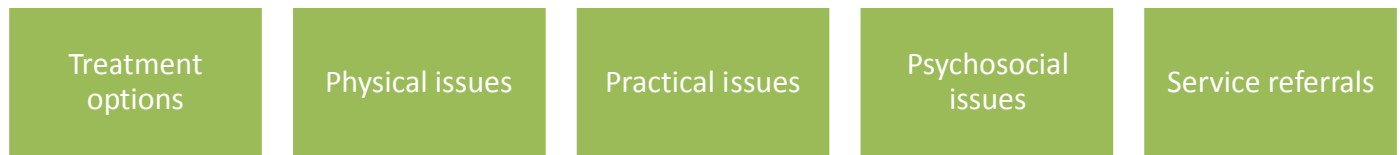
- Asset mapping helps you identify resources that can be helpful to your patients. These might include individuals, such as friends, families or other individuals in a patient's support network.
- A resource directory can help you organize information about resources and systematically capture the same 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. Websites with an HON logo assure the patient navigator that the website is credible, current, contains pertinent information and states privacy and financial disclosures.
- Try to prepare before contacting organizations, and make sure you maintain professional relationships with them.
- Because 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.
- Always refer to a clinician for emergencies, medical advice or consultation and counseling.

LESSON 4: IDENTIFYING RESOURCES

- Asset Mapping
- Sample Resource Directory
- Tips for Making Your Resource Directory
- Evaluating Resources
- Calling organizations
- Tips for Stewarding Resources
- Resources for Patient Navigators
- Resources for Patients

Asset Mapping

Many of the resources patients need will fall in these general content areas:



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

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

Assets can be:

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

Source: [PNTC](#).

MODULE 4:

Resources

THE BASICS OF PATIENT NAVIGATION

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		
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"/> Informal neighborhood organization <input type="checkbox"/> Religious/spiritual organization <input type="checkbox"/> School <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

Source: Adapted from [Drisko](#). n.d.

MODULE 4:

Resources

THE BASICS OF PATIENT NAVIGATION

Tips for Making Your Resource Directory

Below are some tips for making your own resource directory:

Identify personal, network and community assets

Interview individuals from formal and informal organizations

Look for resources at Local, State and National levels

Include resources to meet basic needs in addition to disease-specific resources

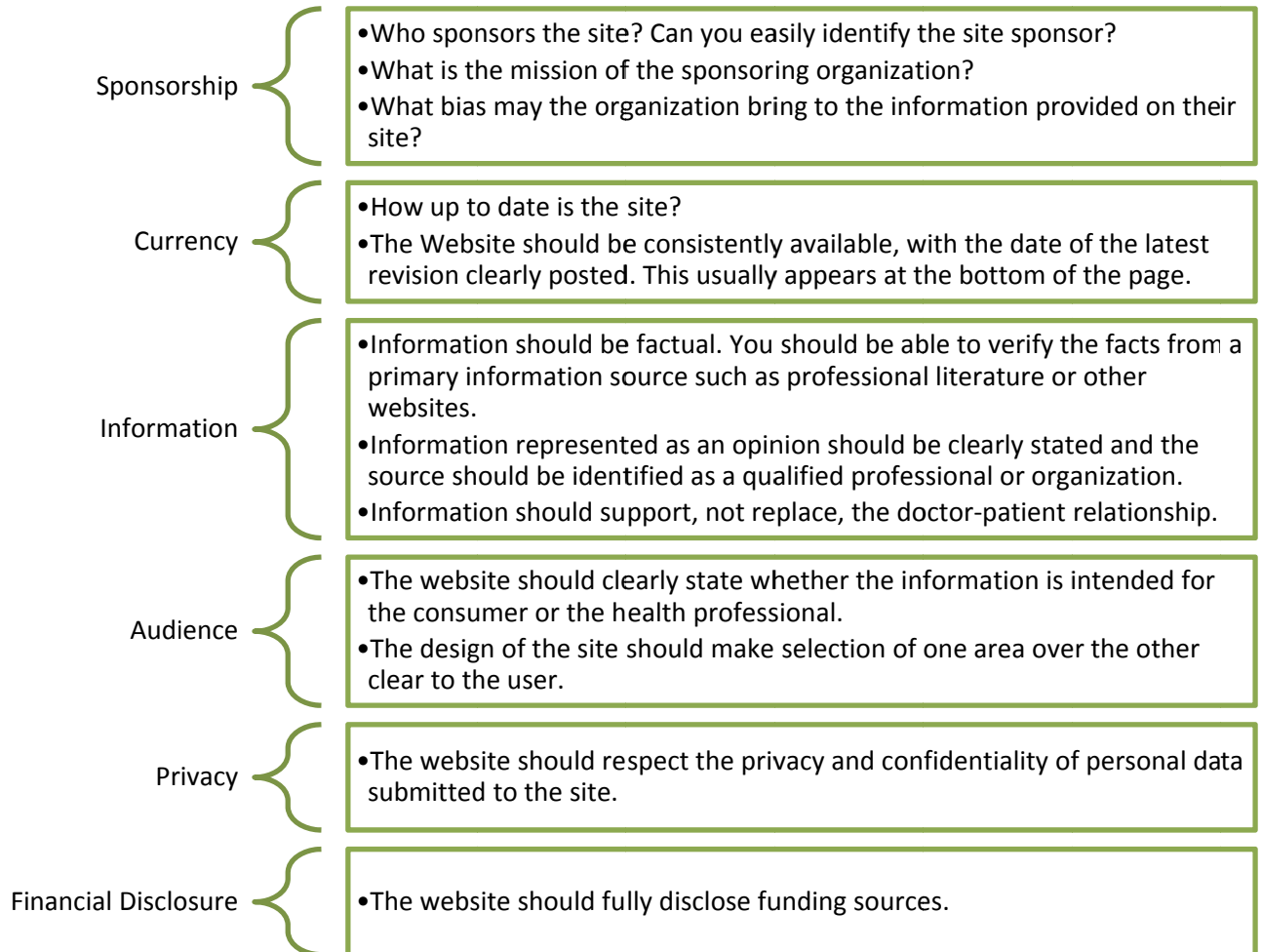
Complete the resource directory form(s)

Compile in a notebook or enter in database and use existing resource directories

Source: [PNTC](#).

Evaluating Resources

There are several criteria you can use to assess resources:



Resources that have the HON Code logo have been deemed reliable by the Health on the Net Foundation, or HON.



HONcode

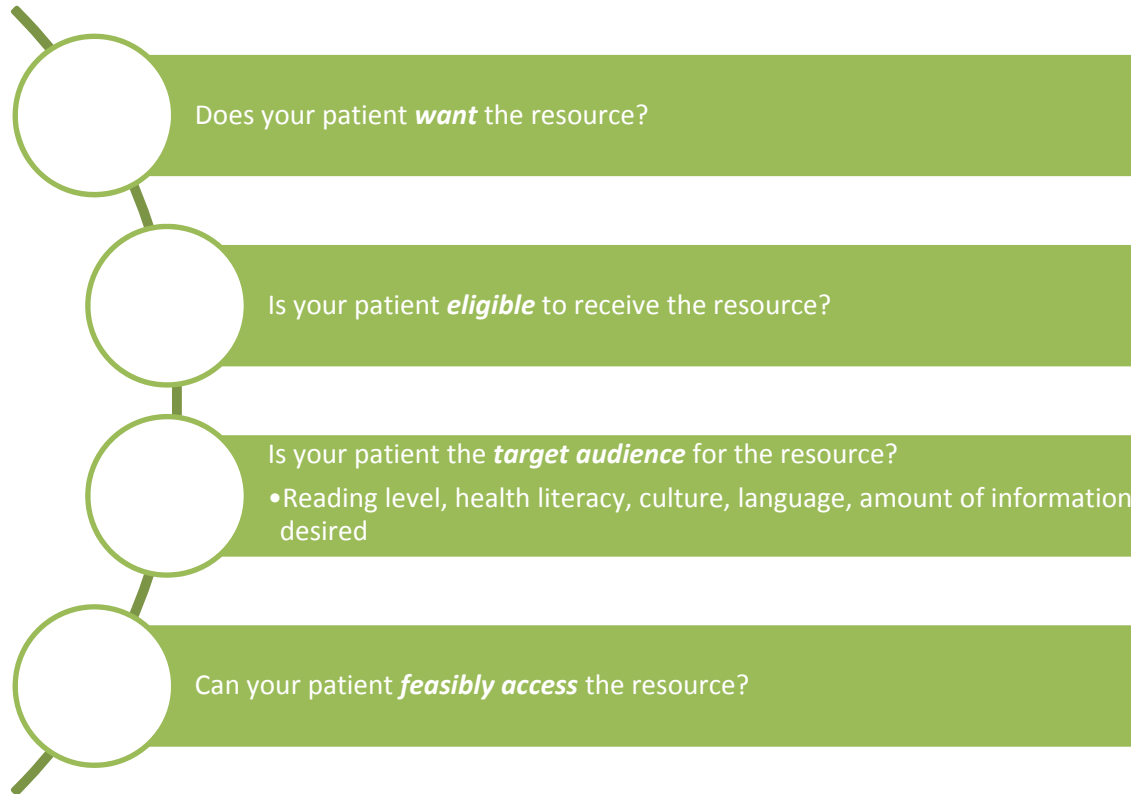
HONcode certification:
Improving the quality of
online health information

MODULE 4:

Resources

THE BASICS OF PATIENT NAVIGATION

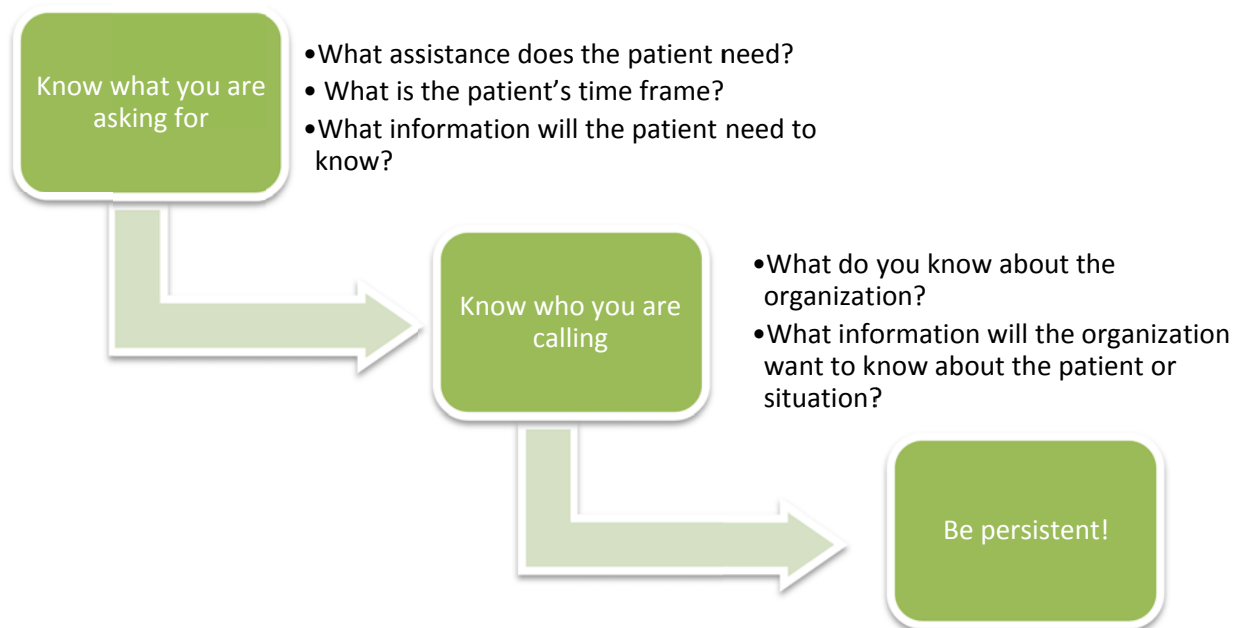
Once you know a resource is credible, you need to assess whether it is a good fit for your patient. You can ask yourself the following questions:



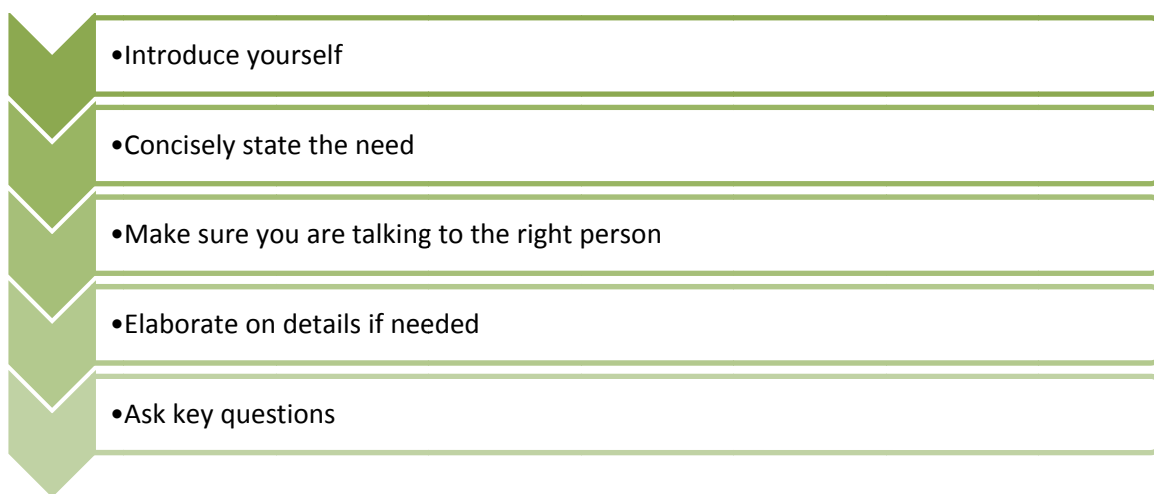
Sources: [PNTC](#); HON. 2015.

Calling Organizations

Once you have identified some potential appropriate sources of assistance, it is time to start taking steps to access those resources for your patient. Before contacting an organization to access a resource for your patient, it is important that you are prepared so that you appear professional and have all the information needed to avoid unnecessary additional calls or follow up.



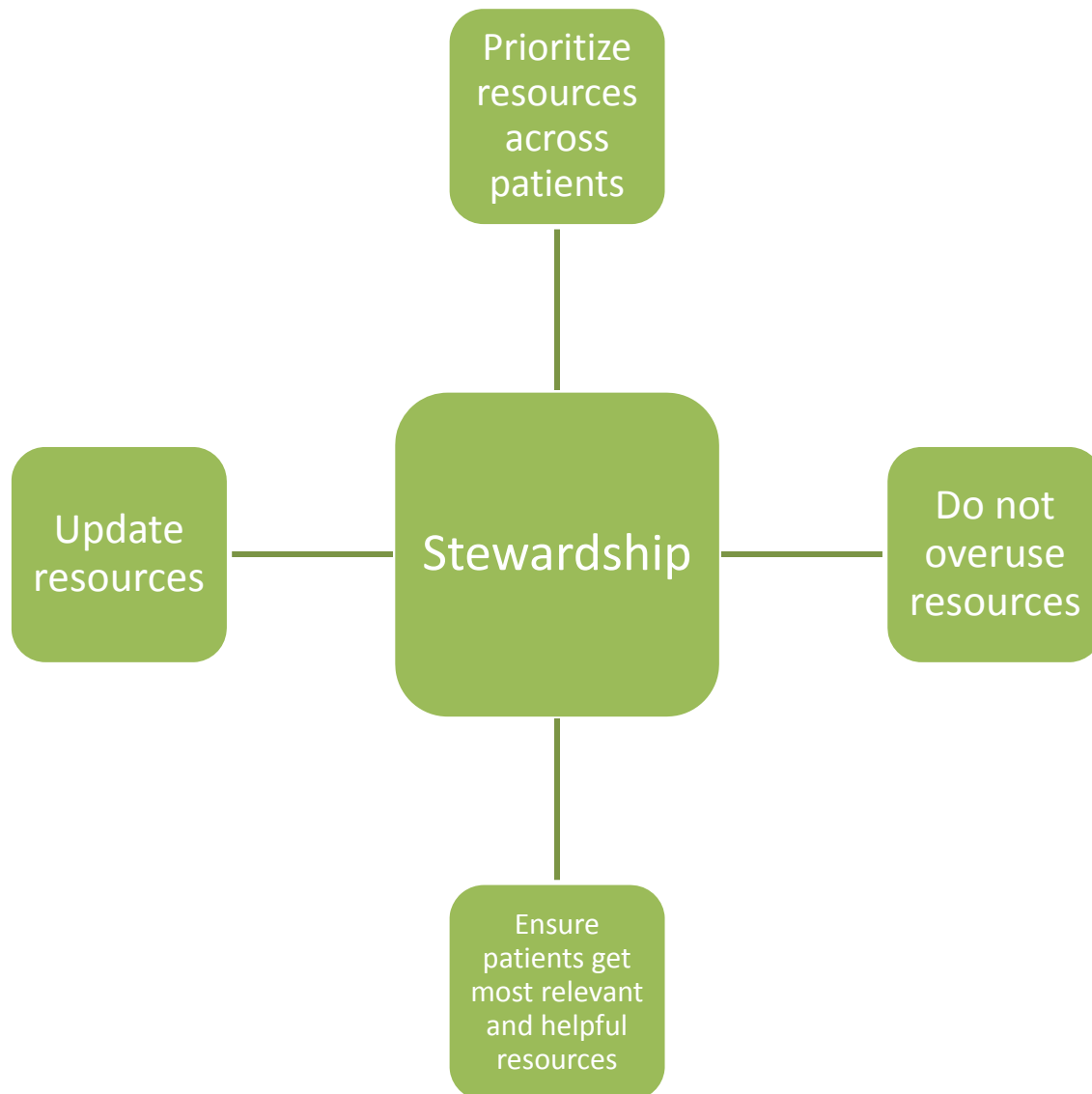
Once you have prepared to contact the organization you can use the following steps:



Source: [PNTC](#).

Tips for Stewarding Resources

Because 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.



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 Healthcare Research and Quality's [Choose More Understandable and Actionable Materials](#)
AHRQ's Patient Education Materials Assessment Tool (PEMAT) and User's Guide provides a systematic method to evaluate and compare the understandability and actionability of patient education materials. By selecting health materials that score better on the PEMAT, you can be more confident that people of varying levels of health literacy will be able to process and explain key messages, and identify what they can do based on the information presented.

Resources for Patients

- National Coalition for Cancer Survivorship's [Cancer Survival Toolbox](#)[®]
The Cancer Survival Toolbox is a free, self-learning audio program that people develop skills to better meet and understand the challenges of their illness. It includes sections on communicating, finding Information, making decisions, solving problems, negotiating and standing up for your rights.
- The Joint Commission's [Patient 101: How to Find Reliable Health Information](#)
This guide helps people find reliable, trusted sources of healthcare information on the internet.
- MedicineNet.com's [Tips: Searching for Credible Health Information on the Internet](#)
This webpage provides tips for patients on finding credible health information online.

Module 4, Lesson 4: Identifying Resources**References: Presentation**

Cancer Survival Toolbox. n.d. Weighing the Pros and Cons [Audio file]. Retrieved from: <http://www.canceradvocacy.org/resources/cancer-survival-toolbox/basic-skills/making-decisions/>.

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MODULE 5: ENHANCING COMMUNICATION

Resources

Lesson 1: Communicating with Patients

Learning Objectives

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

Key Takeaways

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

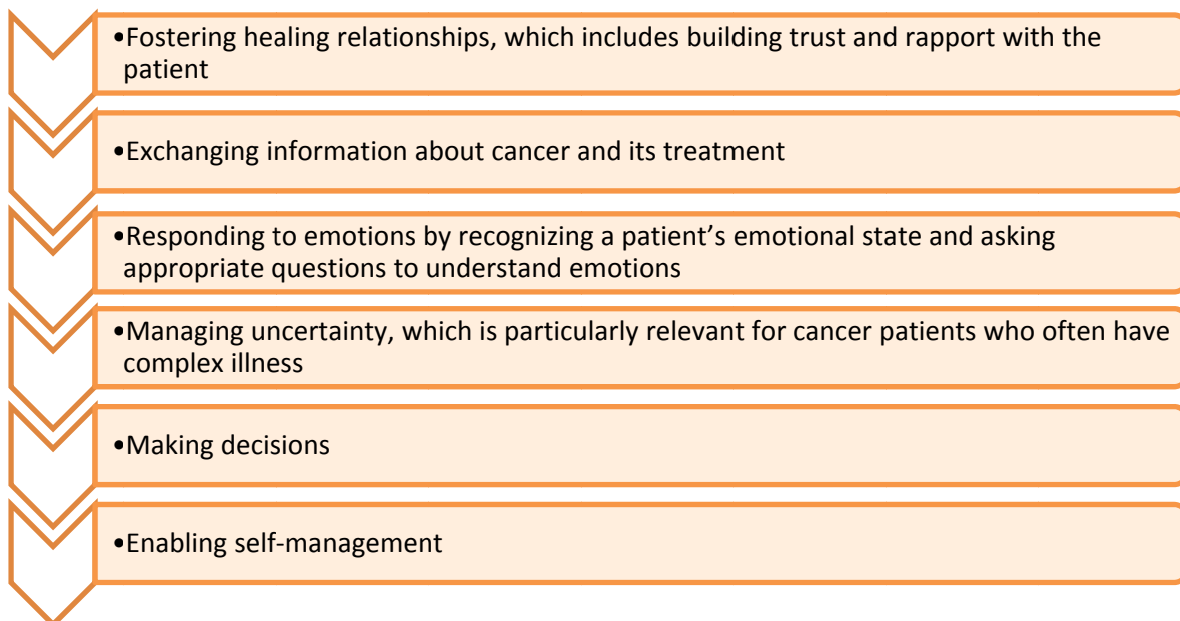
LESSON 1: COMMUNICATING WITH PATIENTS

Patient-Centered Communication Framework
Common Communication Barriers and Solutions
Strategies for Improving Communication
Communication Tips for Patients
Conflict Resolution Strategies
Breaking Bad News
Resources for Patient Navigators
Resources for Patients

Patient-Centered Communication Framework

The National Cancer Institute's Patient Centered Communication Framework consists of 6 core functions that overlap and interact, leading to communication that can improve outcomes.

Note: many of the skills necessary to implement the NCI patient-centered communication framework are covered in Module 4.



Source: Epstein et al. [Patient-Centered Communication in Cancer Care](#). 2007.

Common Communication Barriers and Solutions

Good communication is not always easy. Barriers may make communication hard between you and the patient. Below you will find some common communication barriers as well as possible solutions to those barriers.

Common Barriers	Solutions
<ul style="list-style-type: none"> • Physical environment • Not listening to the patient <ul style="list-style-type: none"> Being distracted Judging the patient Information overload Focusing on a personal agenda • Misperception of patient’s meaning <ul style="list-style-type: none"> Stereotyping and generalizing Rushing Distorted focus Making assumptions Getting mixed signals • Poor verbal communication by navigator <ul style="list-style-type: none"> Lacking clarity Using stereotypes and generalizations Jumping to conclusions Dysfunctional responses Lacking confidence 	<ul style="list-style-type: none"> • Quiet, private, non-distracting location • Effective listening <ul style="list-style-type: none"> Stop, look, listen Be empathetic Ask questions • Accurate perception <ul style="list-style-type: none"> Analyze your own perceptions Work to improve them Focus on others • 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

Source: University of Waterloo. [Effective Communication: Barriers and Strategies](#). 2000.

MODULE 5: ENHANCING COMMUNICATION

Resources

Strategies for Improving Communication

The following are strategies you can use to improve your communication.

Active/Reflective Listening

- Appropriate eye contact early in the interaction
- Attending to verbal and non-verbal cues
- Clarifying the information provided by the patient
- Clarifying the patient's understanding of the information provided by the doctor
- Making statements that capture and return to patients something about what they have just said and/or makes a guess about an unspoken meaning

Open-ended Questions

- Cannot be answered with "yes" or "no"
- Allow for a fuller, richer discussion
- Are non-judgmental
- Let the patients you work with think out loud
- Allow them to do most of the talking, using their own words
- Let them know the conversation is about them

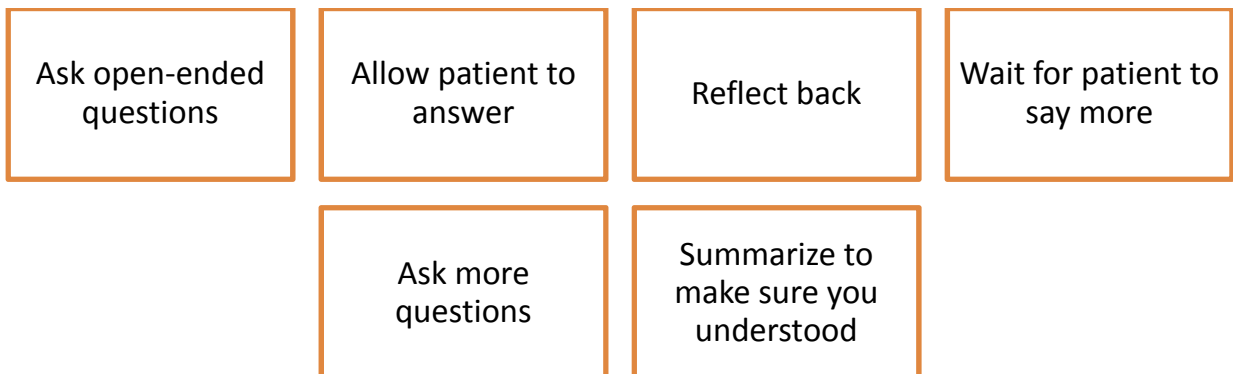
Affirmations

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

Summarizing

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

Other tips include:



Sources: [PNTC](#); Commonwealth of Australia National Health and Medical Research Council. [Communicating with Patients: Advice for Medical Practitioners](#). 2004; Miller et al. 2002.

Communication Tips for Patients

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

Be assertive

Use "I" messages

Active listening

Match what you say in words with what you "say" without words

Express your feelings

Source: National Coalition for Cancer Survivorship. [Cancer Survival Toolbox®](#). n.d.

MODULE 5: Resources ENHANCING COMMUNICATION

Conflict Resolution Strategies

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

Work at talking about the issues

- It may be difficult to talk about conflict, but avoidance usually ends up leading to others making assumptions and an increase in anger. 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 and 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.

- Around any given topic there are different goals- for example, “we both want you to get quality medical care.” 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.

Source: [PNTC](#).

Breaking Bad News

Often in the health care setting, the term “difficult conversation” refers to telling a patient that treatment isn’t working. As a patient navigator, you should not be telling patients that their treatment isn’t working. However, you might encounter difficult conversations related to highly emotional patients, difficult patients, family member confrontations or the need to tell a patient something they might find disappointing, such as denial for financial aid. The SPIKES protocol is used for breaking bad news.

SETTING up the interview

- Privacy
- Family/Friends
- Sit
- Connect with the patient

PERCEPTION

What is the patient’s understanding of the situation?

INVITATION

Assess patient preference for information

Give **KNOWLEDGE** and information to the patient

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

Assess **EMOTIONS** with **EMPATHIC** Responses

- Observe patient’s reaction
- Allow for silence
- Use empathic statements (“I know this isn’t what you wanted to hear. I wish the news were better.”)

STRATEGY and **SUMMARY**

- Check for understanding
- Make an action plan

Source: Baile et al. 2000.

MODULE 5: ENHANCING COMMUNICATION

Resources

Resources for Patient Navigators

- National Cancer Institute's [Patient-Centered Communication in Cancer Care](#)
This book provides information for healthcare 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.
- [Oncotalk® Teach](#)
This free training program contains many resources to help cancer care professionals better communicate with patients. The site has written lessons and videos.

Resources for Patients

- National Coalition for Cancer Survivorship's [Cancer Survival Toolbox®](#)
The Cancer Survival Toolbox is a free, self-learning audio program that people develop skills to better meet and understand the challenges of their illness. It includes sections on communicating, finding information, making decisions, solving problems, negotiating and standing up for your rights.
- 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.
- CancerCare's [Communicating With Your Healthcare Team](#)
This module walks patients through how to communicate with the health care team.

Module 5, Lesson 1: Communicating With Patients**References: Presentation**

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Lesson 2: Patient Advocacy**Learning Objectives**

- Describe the terms advocacy and self-advocacy
- Implement strategies for advocating for your patient
- Describe components of self-advocacy
- Assess patient capacity to advocate for her or himself
- Empower patients 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

- Over the years, patient-provider communication has moved from paternalism, where the providers dominate the communication relative to the patient, to patient-centered communication, where patients are able 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 to: 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. The organization also has other self-advocacy resources.
- Patient navigators are in a unique role to see system issues for patients. Patient navigators know if there are certain barriers many patients face, and it is the navigator's role to advocate on behalf of patients in general in addition to advocating on behalf of individual patients.

LESSON 2: PATIENT ASSESSMENT

Advocacy Overview
Self-Advocacy Overview
Supporting Patient Empowerment
Engagement Behavior Framework
Resources for Patient Navigators
Resources for Patients

Advocacy Overview

Advocacy can be defined as:

“The act of pleading for supporting or recommending”

- Dictionary.com

“The act or process of supporting a cause or proposal”

- Merriam-Webster

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

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

A key role for the patient navigator is advocating for the patient. Advocating is about speaking up when a problem goes unnoticed. You may have to advocate for your patient to the doctor, the family or the spouse. Here are some tips for advocating for your patients:

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

Sources: [Dictionary.com Unabridged](#). 2015; [Merriam-Webster Online Dictionary](#). 2015.; National Cancer Institute. [Dictionary of Cancer Terms](#). n.d.; Ausmed Education. 2014.

Self-Advocacy Overview

Self-advocacy has been defined as:

“An assertiveness and willingness to represent one’s own interests when managing a life-threatening disease.”

Remember that self-advocacy is more than just self-efficacy, or the confidence in abilities, and self-management, or completing the tasks necessary to manage one’s care. Self-advocates stand up for their needs, and patient navigators equip patients with the skills and confidence to do so. There are three basic elements that patients need to be able to advocate for themselves:

Thoughts/Cognitions

- Accepting that cancer is a part of their life
- Prioritization of needs and wants throughout the cancer continuum
- Sense of empowerment

Actions

- Take command of care through assertion
- See themselves as members of their health care team
- Make informed decisions about whether to adhere to or modify treatment

Use Of Resources

- Seek individual and group support for cancer care
- Identify with the larger cancer community
- Contribute to cancer awareness, policy and advocacy, research

Self-advocacy is also influenced by:

Personal characteristics, which impact the patient’s ability to

- Manage symptoms
- Make role adjustments
- Plan for end of life

Learned skills, which impact a patient’s ability to

- Communicate
- Navigate the health care system
- Make informed decisions
- Problem-solve
- Exercise information-seeking skills

Attainability of support, which impact a patient’s ability to

- Informal support (family and friends)
- Formal support (support groups/organizations)

MODULE 5: ENHANCING COMMUNICATION

Resources

You will need to observe some these behaviors to know if the patient is capable of self-advocating. The following questions can guide your assessment of a patient's ability to self-advocate:

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

Source: Hagan et al. 2012.

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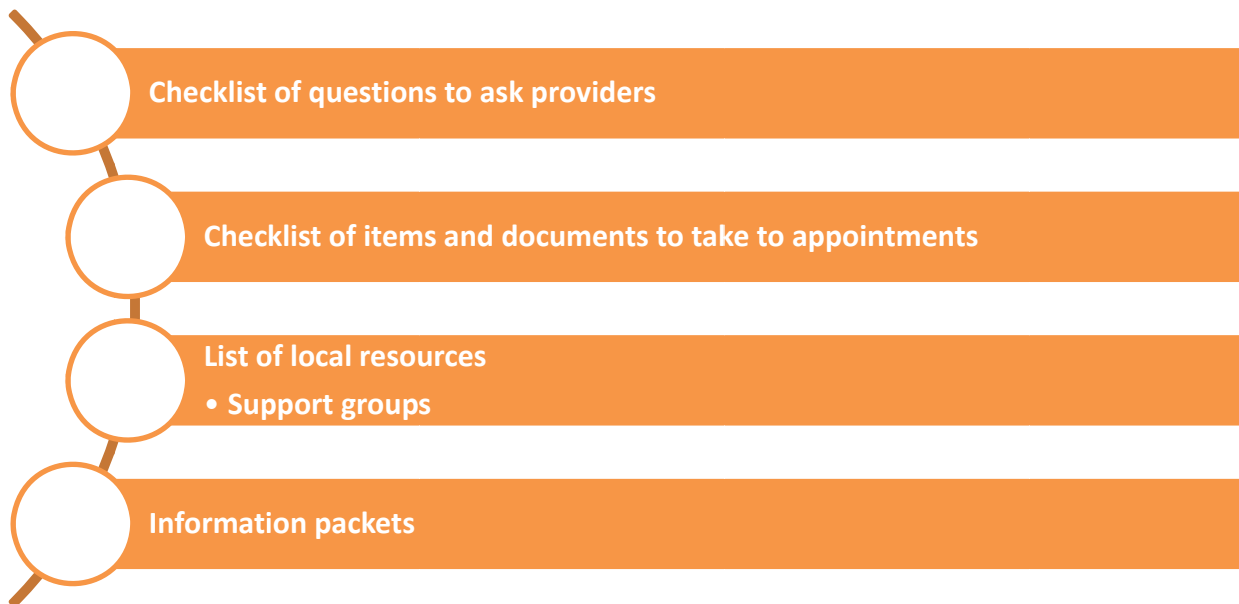
Resources

Supporting Patient Empowerment

As a patient navigator, you can support patient empowerment through helping them by:

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

Examples of self-advocacy tools you can use to help you support patients include:



Source: [PNTC](#).

Engagement Behavior Framework

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

Find good health care

Communicate with health care professionals

Organize health care

Pay for health care

Make good treatment decisions

Participate in treatment

Promote health

Get preventive health care

Plan for end of life

Seek health knowledge

Learn more about the [Engagement Behavior Framework](#).

MODULE 5: ENHANCING COMMUNICATION

Resources

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 Healthcare Research and Quality's [Question Builder](#)
This tool lets patients build questions to ask their health care team.
- 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](#)
This resource provides a list of questions when you're told you have cancer, when deciding on a treatment plan, before treatment, during treatment and after treatment.
- 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](#)
This booklet 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.
- 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.

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Lesson 3: Culturally Competent Communication

Learning Objectives

- Define cultural competency
- 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 be sensitive to this, not only to support the delivery of quality care, but also to help make sure they get care that best suits their preferences and needs. This sensitivity is sometimes called cultural competency.
- Many factors, such as person's personal, cultural, ethnic and spiritual beliefs significantly impact a person's life and their future. As a culturally sensitive navigator, you must acknowledge this influence and use your understanding of a person's beliefs, attitudes and behaviors to guide your interactions.
- You need to be aware of your own biases. 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. 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.

LESSON 3: CULTURALLY COMPETENT COMMUNICATION

Cultural Competency and Bias
Stakeholder Perspectives
Steps for Gaining Cultural Knowledge
Assessing Your Bias
Strategies for Improved Communication
Strategies for Cross-Cultural Communication
CLAS Standards
Resources for Patient Navigators

Cultural Competency and Bias

As a patient navigator, you will see patients from a variety of backgrounds and cultures, so it is important to be sensitive to this, not only to support the delivery of quality care, but also to help make sure they get 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.” -- Betancourt et al. 2003

Keep in mind that cultural competence is not something that you acquire and permanently have. Cultural competence happens along a continuum, starting with cultural sensitivity and knowledge of your own perceptions and biases and growing with experience and an openness to learning and actively listening to your patients.

Each person has their own experience and styles, 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.

Sources: Betancourt et al. 2003; Leavitt. 2012; Blair et al. 2011.

MODULE 5: ENHANCING COMMUNICATION

Resources

Stakeholder Perspectives

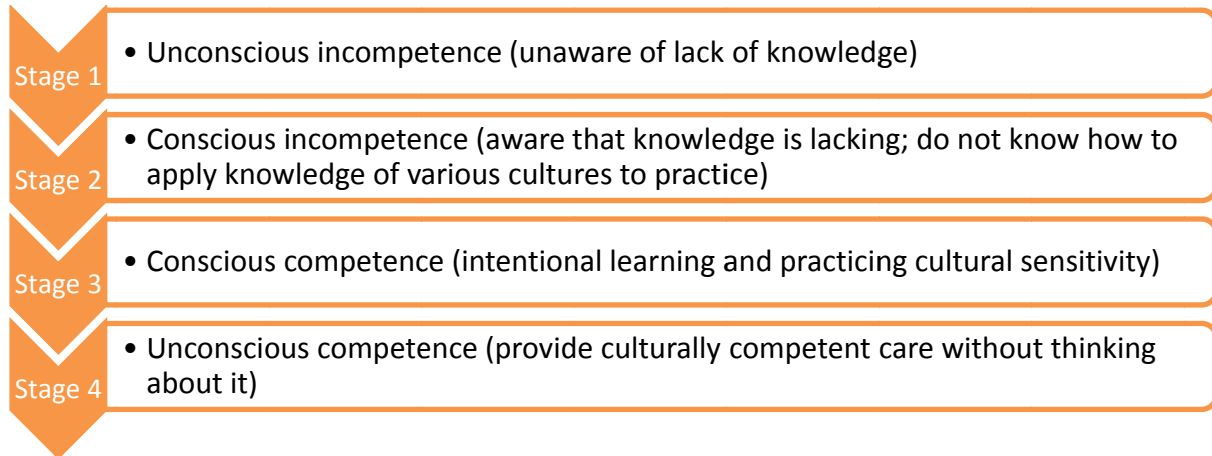
Different stakeholders have similar and different perspectives. For example, the figure below shows what several stakeholders want related to cancer care.

Patient/Family	Patient Navigator	Clinicians	Health Systems
<ul style="list-style-type: none">• Someone to help patient meet health care needs• Feel heard & respected• Receive medical services and available resources• Able to determine decision making role (active or passive)• Be clear about expectations - financial costs, time, level of engagement• Confidentiality and privacy respected• Access to medical services (no barriers)• Good communication with and among service providers regarding care	<ul style="list-style-type: none">• Help patient access care through system• Share responsibilities for patient care with patient and family and other care team• Patient engagement• Coordination among health care team so roles and responsibilities are respected and patient receives needed care• Good communication with patient and support system• Good communication with other members of care team• Ability to access resources to meet patient needs	<ul style="list-style-type: none">• Patient and family-centered, team-based activity to assess and meet needs of patients• Clinical coordination determines where to send patient, what info is important to share, how accountability and responsibility for patient is managed• Patient adherence to treatment recommendation• Patient ability to conduct self-care management practices• Ability to provide high quality care without barriers (i.e. insurance, financial issues)	<ul style="list-style-type: none">• Integrate personnel, info and other needed resources to carry out all patient care activities between and among participants• Facilitation of appropriate and efficient delivery of health care services within and across systems• Access payor sources for medical services rendered• High level of patient satisfaction• High quality services• Positive reputation• Clear roles among service delivery (no duplication of services)

Source: [PNTC](#).

Steps for Gaining Cultural Knowledge

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. There are 4 stages of gaining cultural knowledge.



Source: Campinha-Bacote. 2003.

MODULE 5: ENHANCING COMMUNICATION

Resources

Assessing Your Bias

You can assess your self-awareness of bias using the questions below:

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

MODULE 5: Resources

ENHANCING COMMUNICATION

When you have identified your biases, you can use the strategies below to help deal with them.

Stereotype replacement

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

Counter-stereotypic imaging

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

Individuation

- Prevent stereotypes by learning about individual group members

Perspective taking

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

Increasing opportunities for contact

- Seek opportunity for engagement in positive interactions between different groups of people

Sources: [PNTC](#); Birkenmaier et al. 2007; Devine et al. 2012; Monteith. 1993; Blair et al. 2001; Brewer. 1995; Fiske et al. 1990; Galinsky et al. 2000.

Strategies for Improved Communication

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

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

Non-verbal communication can help you with empathy. You can use the acronym E.M.P.A.T.H.Y, which stands for:

Eye contact

Muscles of facial expression

Posture

Affect

Tone of voice

Hearing the whole patient

Your response

Sources: Mercer et al. 2002; Riess et al. 2014.

MODULE 5: ENHANCING COMMUNICATION

Resources

Strategies for Cross-Cultural Communication

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

Strategies include:

Slow down and speak clearly

Encourage patients

Do not use slang, idioms and sayings

Avoid humor

Avoid asking two questions at once; both questions may not have been comprehended

Avoid asking negative questions

Consider writing down something if you are unsure that it has been made clear

Take turns in your conversation, being sure to listen fully to responses

Summarize and repeat what has been said

Two models may also help you with cross-cultural communication: RESPECT and LEARN.

MODULE 5: ENHANCING COMMUNICATION

Resources

The RESPECT Model includes:

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

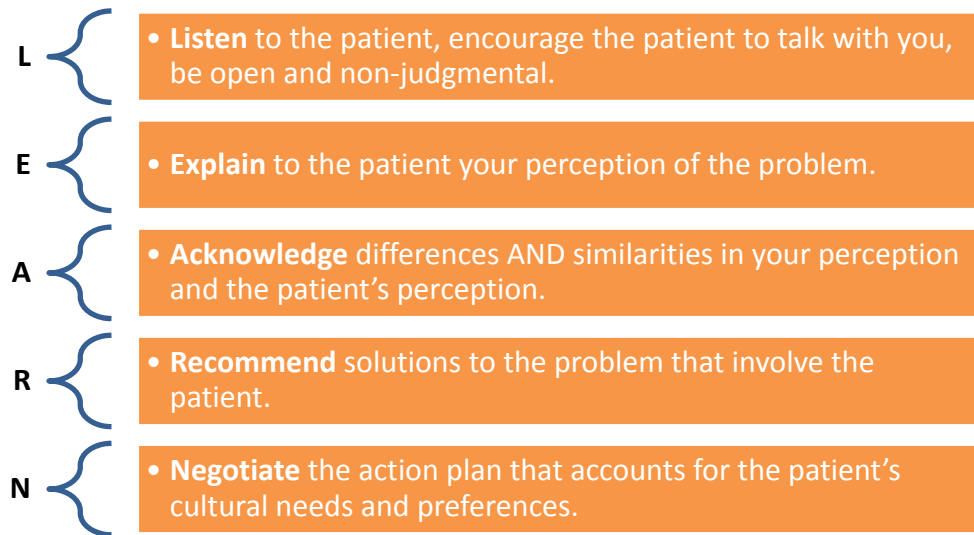
Cultural Competence (Humility)

- 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

The Learn Model includes:



Sources: Kwintessential. 2014; Welch. 1998; Berlin. 1983.

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CLAS Standards

Developed by the HHS Office of Minority Health, the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (the National CLAS Standards) are:

Principal Standard

- Provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs

Governance, Leadership and Workforce

- Advance and sustain organizational governance and leadership that promotes CLAS and health equity through policy, practices, and allocated resources
- Recruit, promote, and support a culturally and linguistically diverse governance, leadership, and workforce that are responsive to the population in the service area
- Educate and train governance, leadership, and workforce in culturally and linguistically appropriate policies and practices on an ongoing basis

Communication and Language Assistance

- Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to all health care and services
- Inform all individuals of the availability of language assistance services clearly and in their preferred language, verbally and in writing
- Ensure the competence of individuals providing language assistance, recognizing that the use of untrained individuals and/or minors as interpreters should be avoided
- Provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area

Engagement, Continuous Improvement and Accountability

- Establish culturally and linguistically appropriate goals, policies, and management accountability, and infuse them throughout the organization's planning and operations
- Conduct ongoing assessments of the organization's CLAS-related activities and integrate CLAS-related measures into measurement and continuous quality improvement activities
- Collect and maintain accurate and reliable demographic data to monitor and evaluate the impact of CLAS on health equity and outcomes and to inform service delivery
- Conduct regular assessments of community health assets and needs and use the results to plan and implement services that respond to the cultural and linguistic diversity of populations in the service area
- Partner with the community to design, implement, and evaluate policies, practices, and services to ensure cultural and linguistic appropriateness
- Create conflict and grievance resolution processes that are culturally and linguistically appropriate to identify, prevent, and resolve conflicts or complaints
- Communicate the organization's progress in implementing and sustaining CLAS to all stakeholders, constituents, and the general public

MODULE 5: ENHANCING COMMUNICATION

Resources

As a navigator, you can support the CLAS Standards by:

Making others aware of CLAS Standards

Providing effective, equitable, respectful care and services

Being responsive to diverse cultural beliefs and practices

Supporting provision of services in the patient's preferred language

Assessing and supporting health literacy

Communicating effectively and compassionately

Source: U.S. Department of Health & Human Services. Office of Minority Health. [Think Cultural Health](#). n.d.

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.
- Patient Navigator Training Collaborative's [2013 CLAS Standards Tips for Patient Navigators](#)
This 23-minute presentation covers what Patient Navigators need to know from the CLAS Standards.
- Stanford School of Medicine's [Working with Professional Interpreters](#)
This 18-minute video provides an overview of working with professional interpreters.

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Lesson 1: Scope of Practice

Learning Objectives

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

Key Takeaways

- It is essential that patient navigators know what they can and cannot do. For example, patient navigators do NOT provide health care services, such as “hands-on” patient care; physical assessments, diagnoses or treatment; counseling; or interpretation, unless you are a certified medical interpreter. Also, patient navigators do NOT offer opinions or judgments about the quality of physicians or medical care, diagnosis or treatment options, any aspect of healthcare. For any of these issues it is critical that you refer to the appropriate licensed professional. Check with your supervisor or employer for other policies on what to avoid.
- 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. These consequences depend on the issue, your institution and state laws and can include job loss, a lawsuit, loss of license for your supervisor, a fine or jail time.
- Boundaries are important to make sure that you stay within your scope of practice. If you do things that are outside of that scope, you may harm patients and you put yourself at risk for legal and other consequences.
- Boundaries distinguish a professional relationship from a social or personal relationship.
- Dual relationships are relationships formed in settings where you are seen as a professional but want to participate as a peer. Dual relationships should be avoided. Seek help from a supervisor if you are ever uncertain about whether or not a dual relationship exists to make sure you are following all organizational policies and laws.
- Being a navigator is different from being a patient’s friend.
- 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. Patient navigators can use various strategies to avoid and manage conflicts of interest.

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LESSON 1: SCOPE OF PRACTICE

Roles of Different Health Care Professionals
Tips for Staying In Bounds
Conflicts of Interest
Resources for Patient Navigators

Roles of Different Health Care Professionals

Below you will find the 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 issues	<ul style="list-style-type: none">• Technologists, technicians, therapists or rehabilitation specialists

Below you will find the 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 prevention and screening	<ul style="list-style-type: none">• Support resolving medical bills, job discrimination, and healthcare issues	<ul style="list-style-type: none">• Help patients achieve “optimal wellness, self-management and functional capability”

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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
such as:**

- “Hands-on” patient care
- Physical assessments, diagnoses or treatment
- Counseling
- Interpretation, unless you are a certified medical interpreter

Do NOT offer opinions or judgments about:

- The quality of physicians or medical care
- Diagnosis or treatment options
- Any aspect of health care

Sources: Bureau of Labor Statistics. [Occupational Outlook Handbook](#). 2015; Wells et al. 2008; [PNTC](#).

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Tips for Staying In Bounds

BEHAVIOR THAT BLURS BOUNDARIES	TIPS FOR STAYING IN BOUNDS
SHARING PERSONAL INFORMATION/ SELF-DISCLOSURE/ TOO MUCH INFORMATION (TMI)	<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 • 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 appropriate trained team member

Source: [PNTC](#).

Conflicts of Interest

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 use the following strategies to resolve it:

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

Source: Strom-Gottfried. 2014.

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.
- [Professional Ethics: Boundaries in Helping Relationships](#)
This self-guided presentation provides an overview of boundaries for helping workers. It is focused on social workers but most of it is applicable to patient navigators.
- University of Iowa Hospitals & Clinics [Conflict of Interest: The Policy](#)
This webpage is an example of a conflict of interest policy.

Module 6, Lesson 1: Scope of Practice

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Lesson 2: Ethics and Patient Rights

Learning Objectives

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

Key Takeaways

- Ethics is a process of navigating and negotiating values in order to act with integrity as an individual, organization or society. When we are thinking about what is “ethical,” we are not simply choosing what is the right thing to do. Ethics is about working through values conflicts.
- 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. As you work with patients to address barriers and find them services, you may learn about patients’ personal lives and develop trusting relationships with them. 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, including duty to warn if a patient is likely to hurt himself or someone else, abuse reporting and safety contracting. Legal requirements often vary by state, and patient navigators need to be aware of any legal obligations that may apply to them.

LESSON 2: ETHICS AND PATIENT RIGHTS

- Overview of Ethics
- Sources of Ethical Standards
- Framework for Ethical Decision-Making
- Standards for Ethical Health Care Systems
- Patient Bill of Rights
- Informed Consent
- HIPAA
- Protected Health Information
- Legal Obligations
- Resources for Patient Navigators

Overview of Ethics

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

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

Ethics does not equal emotions. Our emotions may discourage us from doing what is right if it is hard to do.

Ethics does not equal religion. Many people are not religious, but ethics is not based on religion. Ethics applies to everyone.

Ethics does not equal law. The law may not uphold what is considered ethical.

Ethics does not equal culture. Although an act may be considered a societal norm, it may not take into consideration ethical standards.

Ethics does not equal science. Science and ethics are not the same. Science describes human behavior, but ethics provides a reason behind how people should behave.

Sources: Santa Clara University. [Ethical Decision Making](#). 2009; [PNTC](#).

Sources of Ethical Standards

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

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.

Source: Santa Clara University. [Ethical Decision Making](#). 2009.

Framework for Ethical Decision-Making

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

Step 1: Recognize an Ethical Issue

- ✦ Could this decision or situation be damaging to someone or to some group?
- ✦ Does this decision involve a choice between a good and bad alternative, or perhaps between two “goods” or between two “bads”?
- ✦ Is this issue about more than what is legal or what is most efficient? If so, how?

Step 2: Get the Facts

- ✦ What are the relevant facts of the case? What facts are not known? Can I learn more about the situation? Do I know enough to make a decision?
- ✦ Make sure that you collect all of the relevant information you need to take action.
- ✦ What individuals and groups have an important stake in the outcome? Are some concerns more important? Why?
- ✦ As a patient navigator, your primary concern is your patient. Find out what concerns your patient, and how they are being impacted by this situation.
- ✦ What are the options for acting? Have all the relevant persons and groups been consulted? Have I identified creative options?

Step 3: Evaluate Alternative Actions

- ✦ Which option will produce the most good and do the least harm? (Utilitarian Approach)
- ✦ Which option best respects the rights of all who have a stake? (Rights Approach)
- ✦ Which option treats people equally or proportionately? (Justice Approach)
- ✦ Which option best serves the community as a whole, not just some members? (Common Good Approach)
- ✦ Which option leads me to act as the sort of person I want to be? (Virtue Approach)

Make a Decision and Test It

- ✦ Considering all these approaches, which option best addresses the situation?
- ✦ If I told someone I respect - or told a television audience - which option I have chosen, what would they say?

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?

Source: Santa Clara University. [Ethical Decision Making](#). 2009.

Standards for Ethical Health Care Systems

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



Source: Wells et al. 2008.

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Patient Bill of Rights

In 1997, President Clinton established the Advisory Commission on Consumer Protection and Quality in the Health Care Industry to report on changes in the healthcare 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 a 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.

The Patient Bill of Rights includes:

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

Sources: U.S. Department of Health and Human Services. Appendix A: [Consumer Bill of Rights and Responsibilities](#). 1998; [PNTC](#).

Informed Consent

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

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

Source: [PNTC](#).

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Health Insurance Portability and Accountability Act (HIPAA)

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

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

Breaking HIPAA rules can result in fines or prison terms. For accidental violations, an organization can be fined \$100 each time a person's health information is not protected. When someone knows they are violating HIPAA rules, fines can be \$250,000 with prison terms up to 10 years. HIPAA violations may also harm an organization's image and their ability to get funding. The organization you work for may also have rules about how they punish violations.

There are two major categories of organizations 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)

Not every organization is subject to HIPAA rules. Many other organizations follow different or rules for protecting health information. Check to see if your organization is subject to HIPAA.

Source: U.S. Department of Health and Human Services. [Health Information Privacy](#). 2015.

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Protected Health Information (PHI)

Information protected under HIPAA is called Protected Health Information, or PHI. PHI can be written, spoken or in an electronic format. The specific types of protected health information (PHI) that are protected under HIPAA are:

Contact information
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
Web URL (web address) Internet Protocol (IP) address numbers
Dates related to a patient or their care
Birth or death date Admission or discharge date
Identifying numbers
Social Security Number Medical record number Health plan beneficiary number Account number Certificate/license number
Device or vehicle numbers
Device identifiers or serial numbers Any vehicle or other device serial number
Pictures, finger prints or voice recordings
Any other characteristic that could uniquely identify the 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.

Guidelines exist to help you protect PHI.

Guideline 1: Use only the minimum information needed to do your job.

When you use patient information, use only what you need to do your job. When others request PHI, give them only the information they need. Examples of using and giving the minimum information needed:

- ✚ **Service Providers.** Give service providers only the information they need to provide their service. For example, a transportation service will only need appointment dates, times and locations.
- ✚ **Family members.** If a family member, friend or other caregiver asks questions about the patient you may give information related to that person's part in the patient's care if you believe it will help the patient. Do not give information if the patient has asked you not to. Also, do not give information if you believe that giving the information would be inappropriate. For example, if the wife of a patient with memory problems calls to ask about her husband's medication, you can give her that information.

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

If you do not know if you should give PHI to a person or organization, ask the patient to sign an authorization form. An authorization form gives you permission to release, or give out, information. Check to see if authorization forms may already be in a patient's file.

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:

- ✚ If PHI is in a place where patients or others can see it, cover or move it
- ✚ If you work with PHI on your desk or on a computer, make sure no one can walk up behind you without knowing it
- ✚ When PHI is not in use, store it in a locked office or a locked file cabinet
- ✚ Remove documents from faxes and copiers as soon as you can
- ✚ Do not talk about patients where others can hear you or in public areas
- ✚ Close your office door when talking to patients
- ✚ Do not take files or documents with PHI out of the office or clinic
- ✚ Shred PHI when documents or files are no longer needed
- ✚ When PHI is stored on a computer or storage device, use passwords, anti-virus software, data backups, and encryption

Sources: U.S. Department of Health & Human Services. [Health Information Privacy](#). 2015; [PNTC](#).

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Legal Obligations

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

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.
 - And 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.

Sources: National Conference of State Legislatures. [Mental Health Professionals’ Duty to Warn](#). 2013; New York State Office of Children and Family Services. [Reporting Abuse or Neglect](#). n.d.; Garvey et al. 2009.

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 a 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 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 6, Lesson 2: Ethics and Patient Rights

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Lesson 1: Practicing Efficiently and Effectively

Learning Objectives

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

Key Takeaways

- You will need to be able to build trust with your patients and your colleagues. Trust leads to better communication, which leads to 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.

LESSON 1: PRACTICING EFFICIENTLY AND EFFECTIVELY

Components for Building Trust
Skills for Being Responsive
Example Patient Tracking Tool
Example Navigation Software Options
Resources for Patient Navigators

Components for Building Trust

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



Source: [PNTC](#).

Skills for Being Responsive

Organization

- Avoid multi-tasking, prioritize, delegate, communicate appropriately, be organized, plan your projects

Time Management

- Structure your schedule, time activities, commit to downtime, be organized

Problem Solving

- Use Problem Solving Cycle: 1) define and clarify the issue, 2) gather and verify facts, 3) identify other key players, 4) brainstorm possible solutions, 5) identify the pros & cons, 6) choose the best option, 7) develop action plan, 8) follow-up

Critical Thinking

- Analyzing (what's the issue?), applying standards (where have I seen this before?), discriminating (what's the priority?), information seeking (what don't I know?), logical reasoning (why is this the way it is?), predicting (what's going to happen?), transforming knowledge (what's worked before that I could try again?)

Workload Management

- Recognize that being actively engaged in a task doesn't necessarily mean you are being productive, track progress, plan your workload, use technology to work, one activity at a time, schedule tasks that are more difficult to complete during the times you work best, explore your own work style and patterns to build on them, take breaks when necessary; leave time for unplanned activities or tasks

Sources: Hou et al. 2014; Swinscoe. 2014; Daum. 2013; [PNTC](#); Scheffer et al. 2000; Scheffer et al. 2001; Birkenmaier et al. 2007.

MODULE 7: ENHANCING PRACTICE

Resources

Example Patient Tracking Tool

You can use Excel to create patient tracking tool. Below is an example of a tool, and you can download this and others in the resources section.

BARRIER TYPE	DATE ASSESSED	DATE RESOLVED	ACTION TAKEN TO RESOLVE BARRIER	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				

MODULE 7: ENHANCING PRACTICE

Resources

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				

MODULE 7: ENHANCING PRACTICE

Resources

Example Navigation Software Options

Software	Website
Nursenav	nursenav.com
MagView	magview.com
Cordata	cordatahealth.com
OncoNav	onco-nav.com
Social Solutions (ETO)	socialsolutions.com

Resources for Patient Navigators

- Lynda.com
Lynda.com is a subscription-based learning company that helps anyone learn business, software, technology and creative skills to achieve personal and professional goals.
- Mindtools.com
This website includes professional development articles and tools.
- 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.

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Lesson 2: Health Care Team Collaboration**Learning Objectives**

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

Key Takeaways

- Teamwork is essential in cancer care.
- Effective teams are based on mutual trust, respect and collaboration. Collaboration in health care means that health care professionals assume complementary roles and cooperate, sharing responsibility for problem-solving and making decisions to make and carry out plans for patient care.
- Collaborative work environments consist of diverse teams that share knowledge, provide high quality health care that is patient-focused, offers effective clinical care and seeks improved patient outcomes. Employees who work in collaborative environments report increased job satisfaction, and there is a decrease in staff turnover and an overall reduction of health care costs in collaborative environments.
- 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.

LESSON 2: HEALTH CARE TEAM COLLABORATION

Components of Successful Teamwork
Supporting a Smooth Care Transition
Common Communication Barriers
Conflict Resolution Strategies
Resources for Patient Navigators

Components of Successful Teamwork

There are many barriers to team collaboration, including:

It takes time

Perceived loss of autonomy

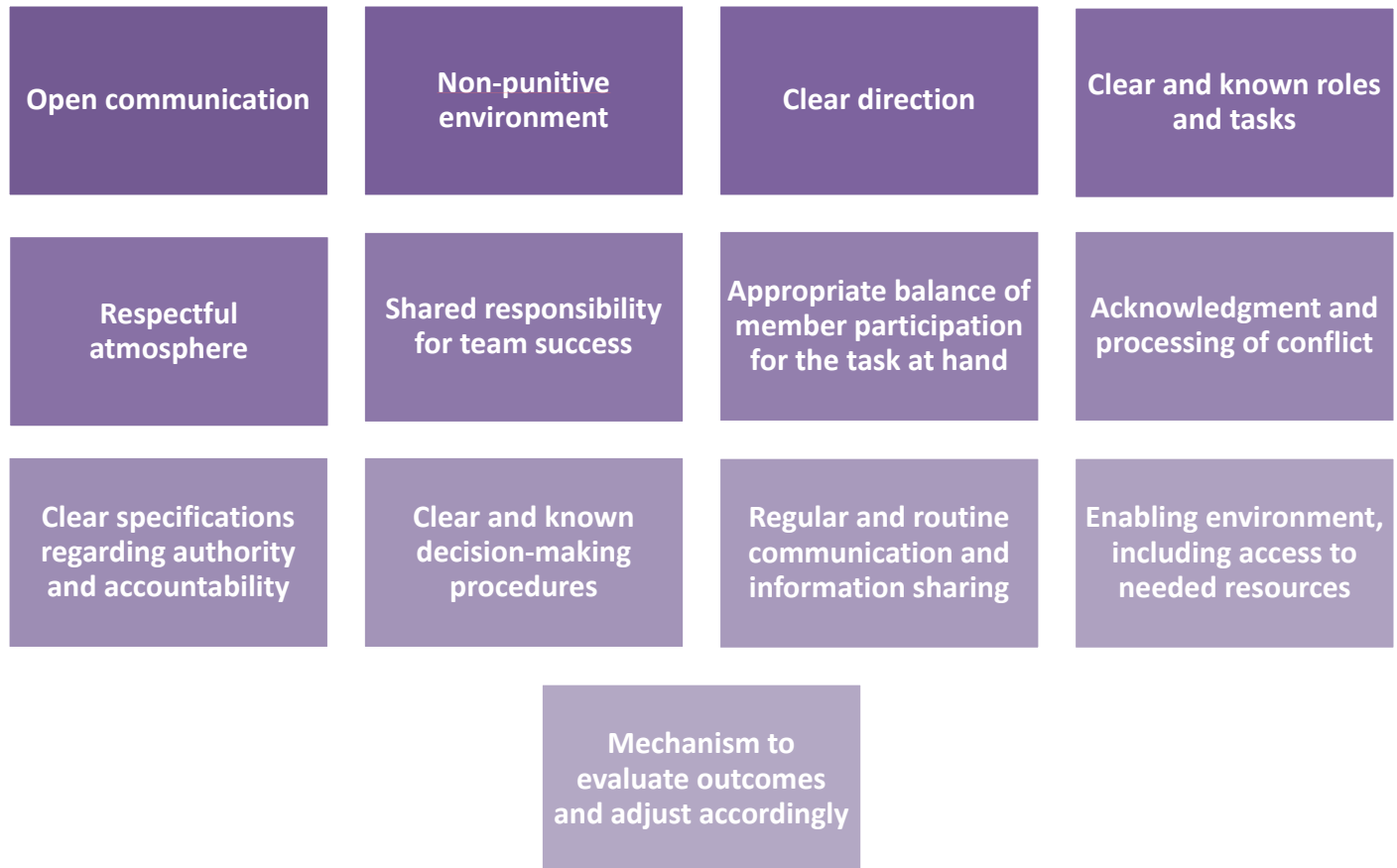
Lack of trust or confidence in others' decisions

Clashing perceptions/approaches

Territorialism

Lack of awareness about the education, knowledge and skills of team members from different professional disciplines

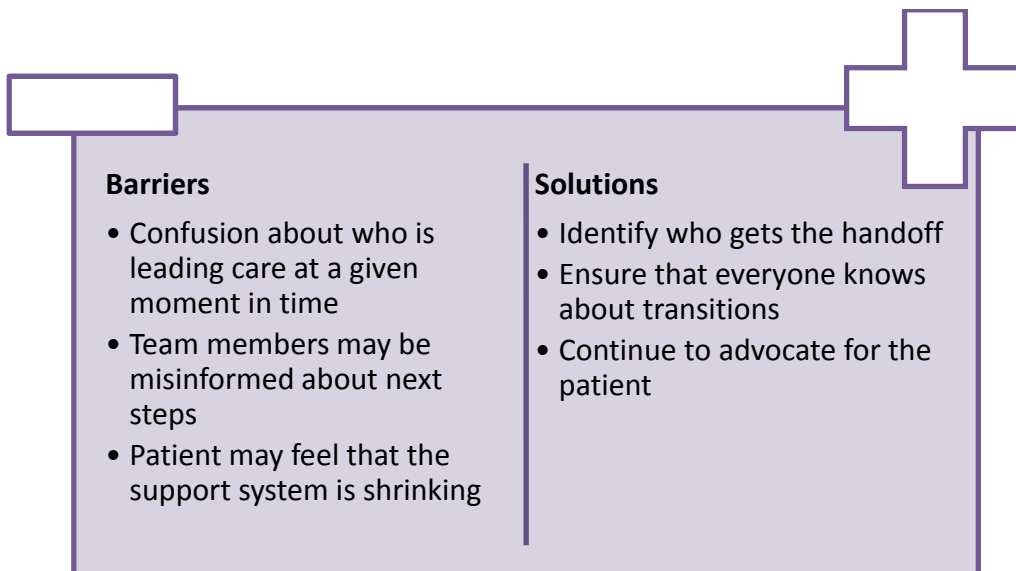
There are numerous components of successful teamwork. Although as a patient navigator you may not have control of all these factors, think about which of these you can contribute to.



Source: O'Daniel et al. 2008.


















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. Barriers and solutions include:



Common Communication Barriers

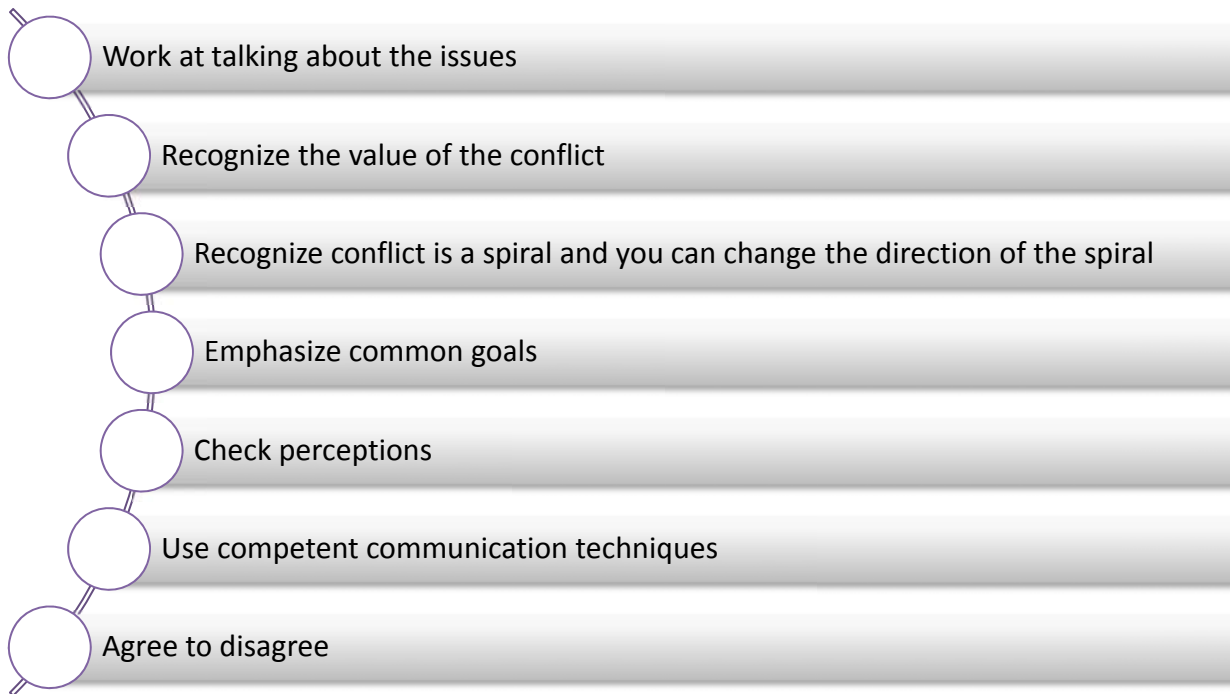
These are contextual factors that may create conflict between professionals:

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

To mitigate barriers that impact communication, patient navigators should foster a culture of common purpose, intent, trust, respect and collaboration. You can accomplish this by starting with something in common - like a goal. For example, you and 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.

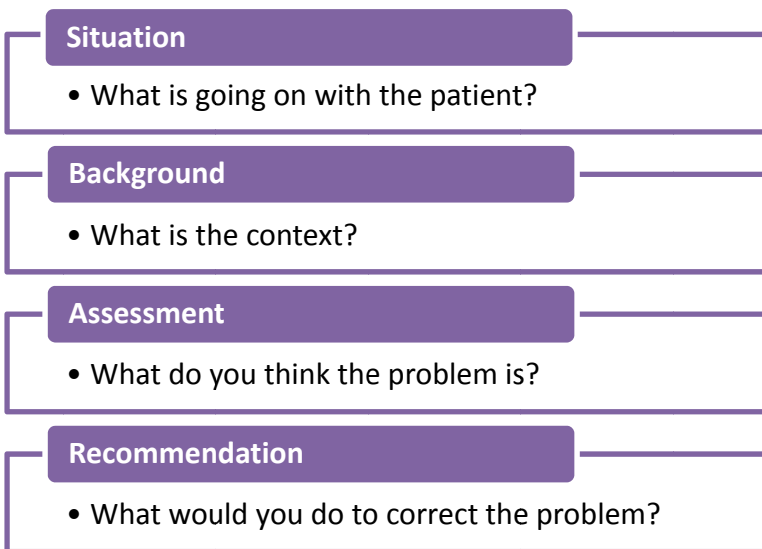
Source: O'Daniel et al. 2008.

Conflict Resolution Strategies



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

SBAR: Situation, Background, Assessment and Recommendation



Walk in the Woods: Self-Interests, Enlarged Interests, Enlightened Interests and Aligned Interests

STEP 1: Self Interests

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

STEP 2: Enlarged Interests

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

STEP 3: Enlightened Interests

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

STEP 4: Aligned Interests

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

Sources: [PNTC](#); O’Daniel et al. 2008; Marcus et al. 2012.

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 Healthcare Improvement's Course on Demand: [Effective Teamwork as a Care Strategy — SBAR and Other Tools for Improving Communication Between Caregivers](#)
Through this free 49-minute streaming video presentation, you will understand and be able to implement the SBAR approach and other tools and behaviors for effective teamwork and communication to help ensure clear, accurate information between caregivers.
- Safer Healthcare's [Why is SBAR Communication So Critical?](#)
This webpage provides information and resources about SBAR.
- Safer Healthcare's [Effective Communication](#)
This webpage provides information about and tips for effective communication.
- Harvard School of Public Health's [The Walk in the Woods: A Guide for Meta-Leaders](#)
This booklet provides tools to help you use the Walk in the Woods strategy.
- 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.

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Lesson 3: Program Evaluation and Quality Improvement

Learning Objectives

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

Key Takeaways

- Program evaluation is important in patient navigation because it helps 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.
- Patient navigators are valuable members of the health care team, although sometimes other members of the team are unaware of what patient navigators do. Patients and others in the community may also be unaware. So it is important that patient navigators be able to talk about what they do and why other people should find their work valuable. When you have data to help justify the impact of the patient navigation program, this information can be used to help promote the program to internal and external stakeholders, including patients, providers and the larger community.
- 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.

LESSON 3: PROGRAM EVALUATION AND QUALITY IMPROVEMENT

- Program Evaluation Overview
- Formative Evaluation
- Process Evaluation
- Outcomes Evaluation
- Tips for Tracking Data
- Quality Improvement
- Promoting Patient Navigation
- Targeting Your Message
- Resources for Patient Navigators

Program Evaluation Overview

Some important definitions for program evaluation include:

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 who have the power to influence your program, a political interest in your program, or would be impacted by your program's evaluation or outcomes

MODULE 7: ENHANCING PRACTICE

Resources

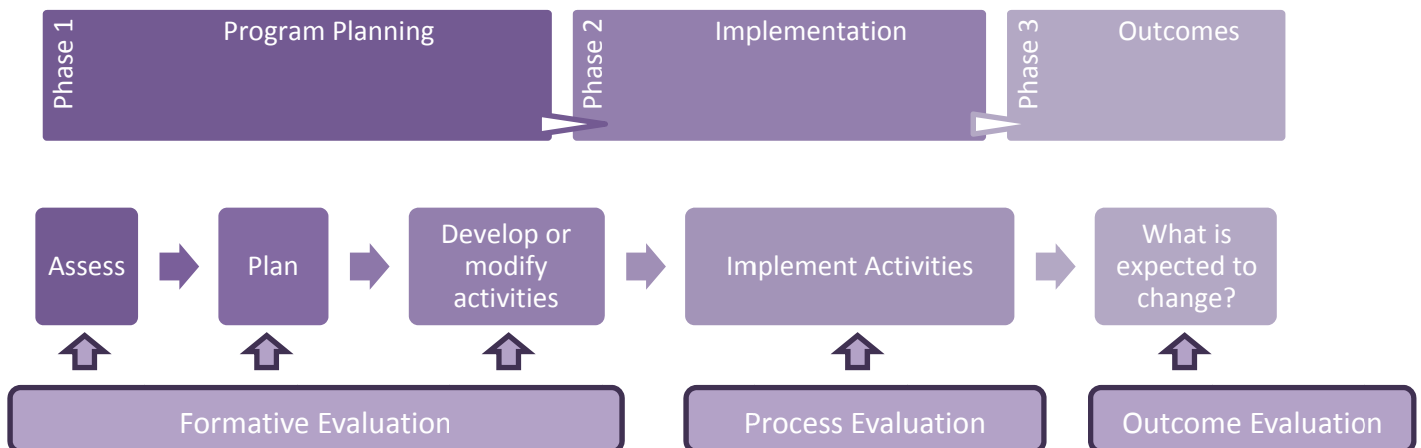
Program evaluation is important because it can help to:

- 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?

There are 3 types of evaluation that occur at different points:



Patient navigators can be involved with evaluation in several ways:

Data Collection	Data Analysis	Data Reporting
<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:

<u>Where</u> can we find the information?	<u>How</u> do we obtain the information?
<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

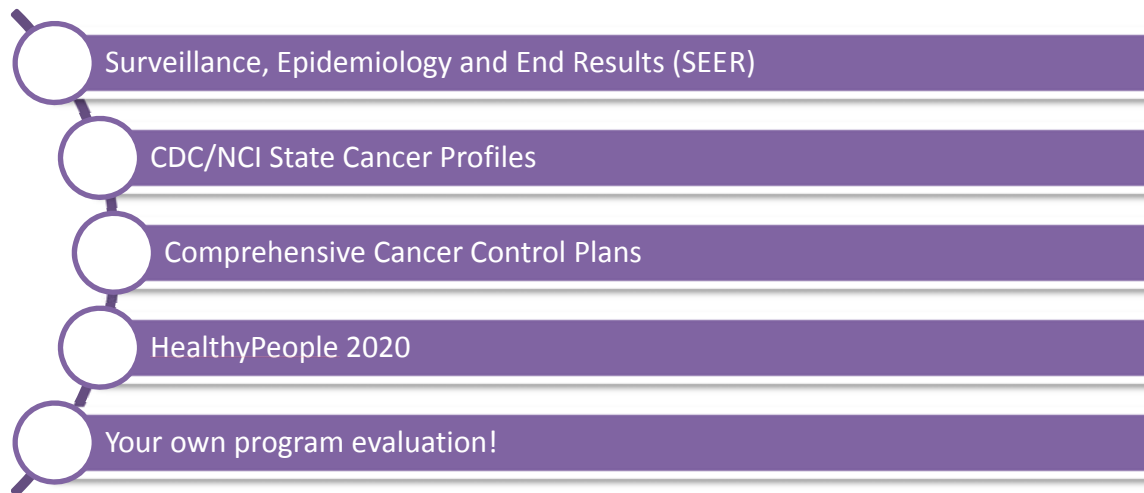
Sources: Newcomer et al. 2010; [PNTC](#).

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?

Data sources for a Community Needs Assessment include:



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?

Navigation process measures include:

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:

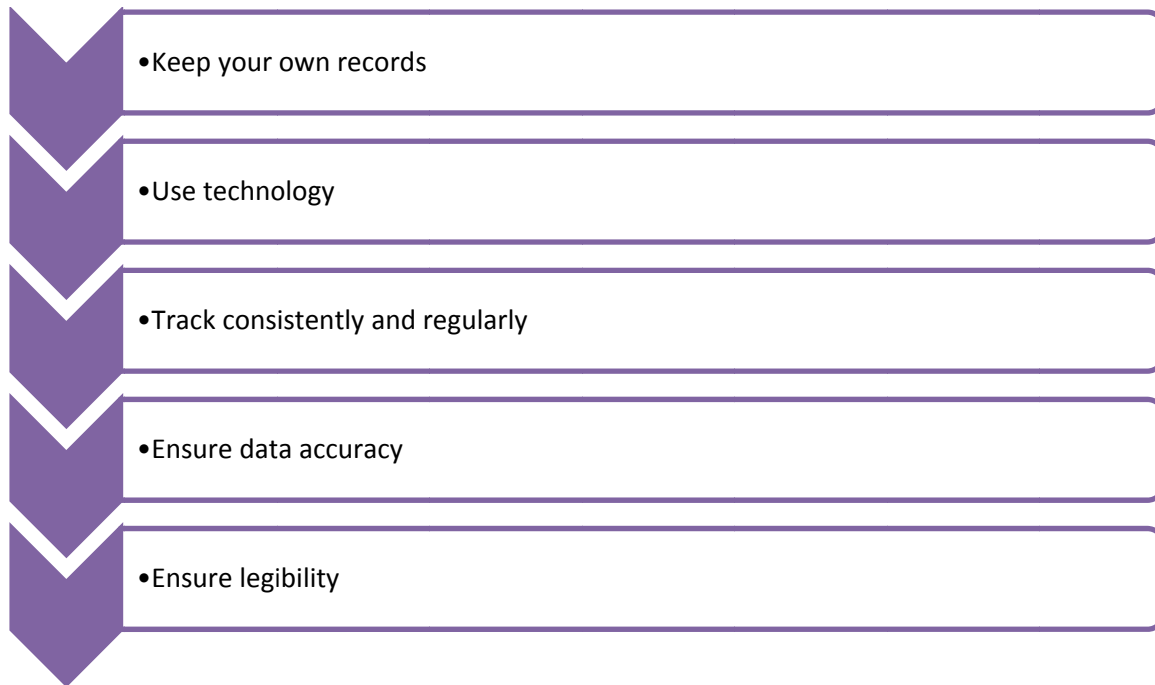
-  Did we reach our program goals?
-  How did the program impact the patient?
-  What evidence demonstrates that our administrators, funders, etc. should continue to support and fund the program?

Sample outcomes evaluation measures include:

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

Tips for Tracking Data

Below are some tips for tracking data:

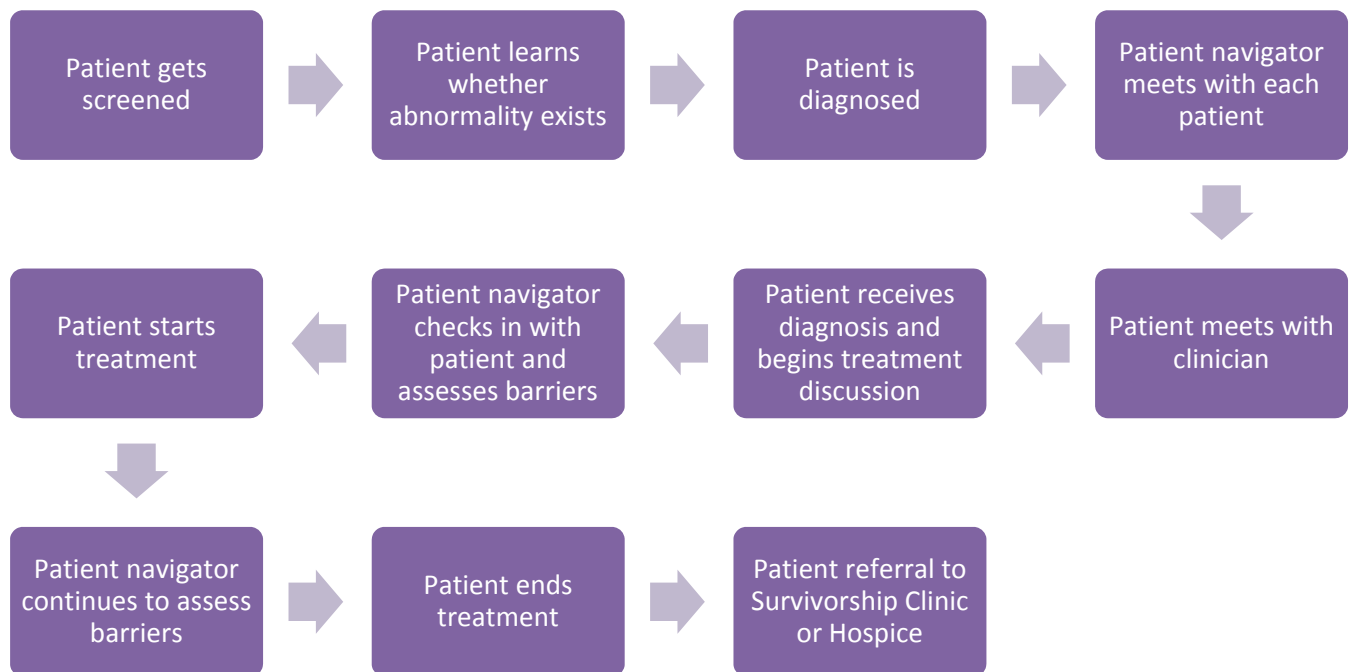
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- Keep your own records
 - Use technology
 - Track consistently and regularly
 - Ensure data accuracy
 - Ensure legibility

Quality Improvement

Understanding the Problem: Patient Flow/Process Map

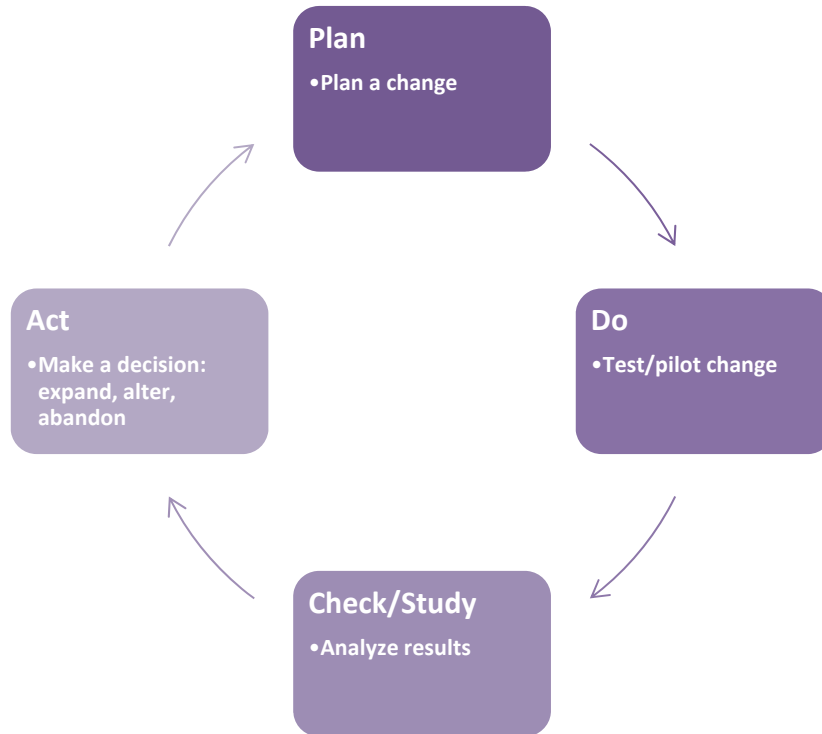
- 🚧 How many times is the patient passed from one person to another (hand-off)?
- 🚧 Where are delays, queues and waiting built into the process?
- 🚧 Where are the bottlenecks?
- 🚧 What are the longest delays?
- 🚧 What is the approximate time taken for each step (task time)?
- 🚧 What is the approximate 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?

An example patient flow or process map could look like:



Making Improvements: The PDCA Cycle

The PDCA Cycle can be used to make improvements:



Sources: The Scottish Government. [Understanding the Patient Journey - Process Mapping](#). n.d.; American Society for Quality. [Plan-Do-Check-Act \(PDCA\) Cycle](#). n.d.

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

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!

When making your elevator speech, think about your value to particular audiences:

Providers	Patients	Organizations	Funders
<ul style="list-style-type: none"> •Reduce no-shows/missed appointments •Support adherence to treatment •Assist with nonclinical issues (administrative, financial and practical) •Free up their time to address clinical issues 	<ul style="list-style-type: none"> •Provide information •Connect them to community/culture •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

Source: Carroll et al. 2010.

Targeting Your Message

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

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 [Program Standards 2012](#)
Learn more about the patient navigation 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.

Module 7, Lesson 3: Program Evaluation and Quality Improvement**References: Presentation**

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Lesson 4: Personal and Professional Development**Learning Objectives**

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

Key Takeaways

- The purpose of feedback is to encourage the recipient to assess their performance and use the information provided to make changes toward improvement.
- Once you receive feedback you can incorporate it into a plan for improving your daily work.
- A professional development plan can serve as a guide for your career, providing a tool to measure your progress and steer your development activities.
- Ambiguity, or uncertainty, is common in most work environments and settings. 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.
- The nature of the work of patient navigation can at times be stressful. 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.

LESSON 4: PERSONAL AND PROFESSIONAL DEVELOPMENT

Feedback Overview
Professional Development Plans
Dealing with Ambiguity
Stress and Self-Care Strategies
Resources for Patient Navigators

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 bidirectional 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.

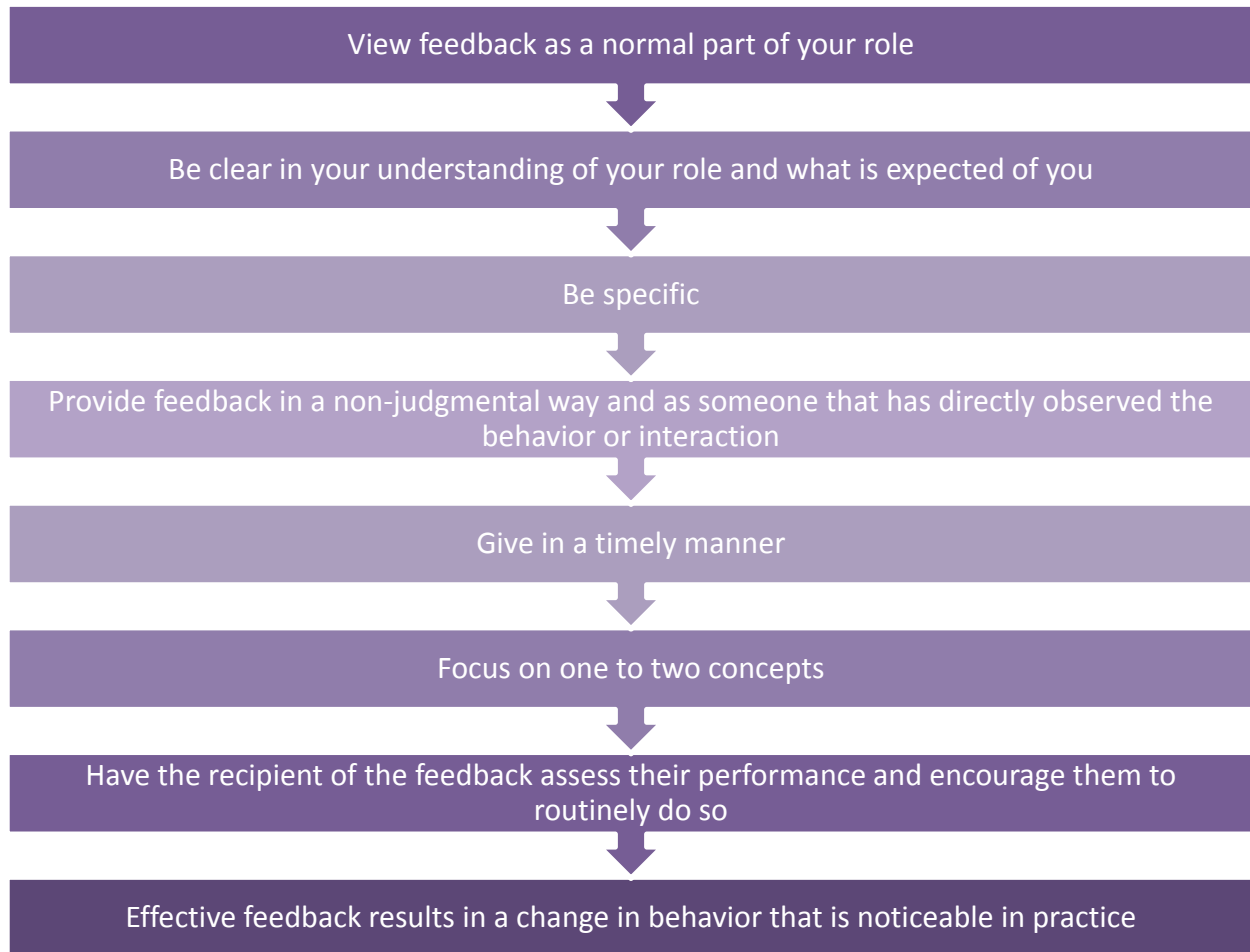
There are many sources of feedback, including:



MODULE 7: ENHANCING PRACTICE

Resources

Some tips for giving feedback include:



MODULE 7: Resources

ENHANCING PRACTICE

Some tips for receiving feedback include:



You can incorporate feedback into your daily work by:

- ✚ Taking time to write down the suggested areas of improvement. These can be 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

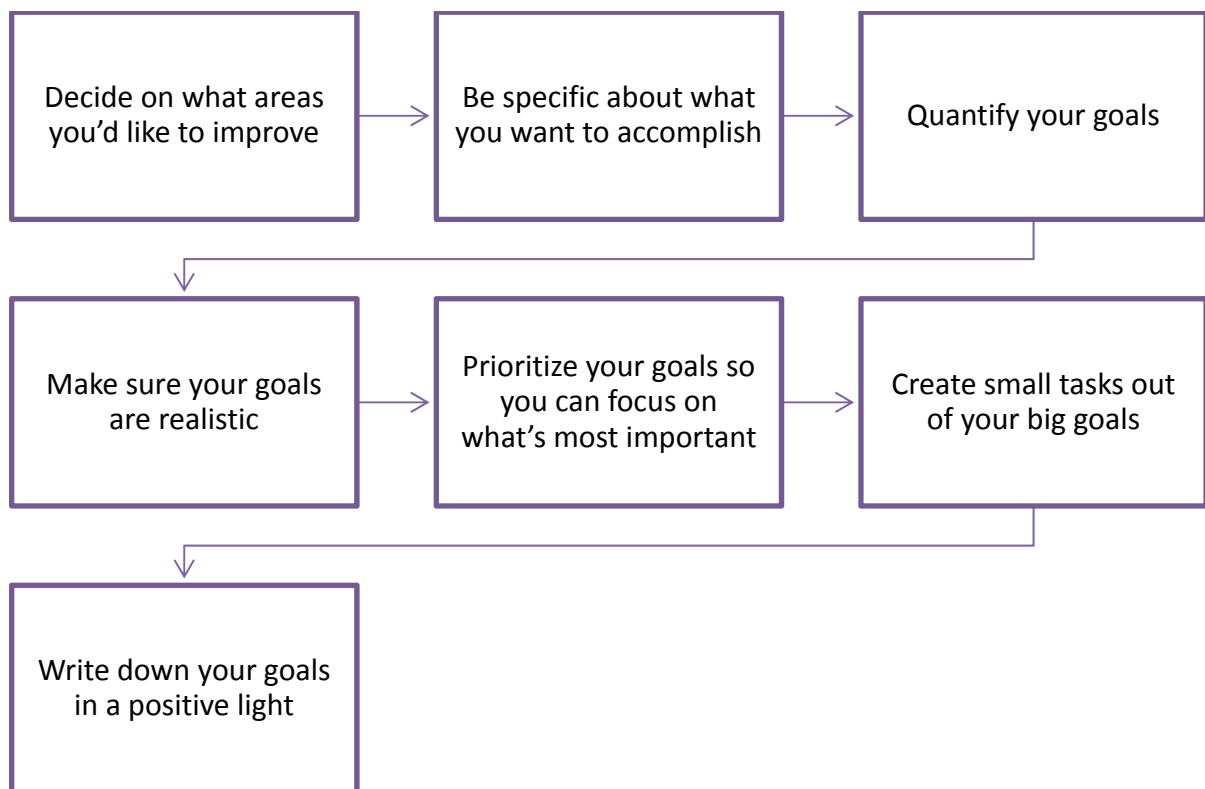
Sources: Cantillion et al. 2008; London Deanery. n.d.; Hesketh et al. 2002.

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 grown professionally. Having concrete goals helps:

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

Here are some steps to setting professional development goals.

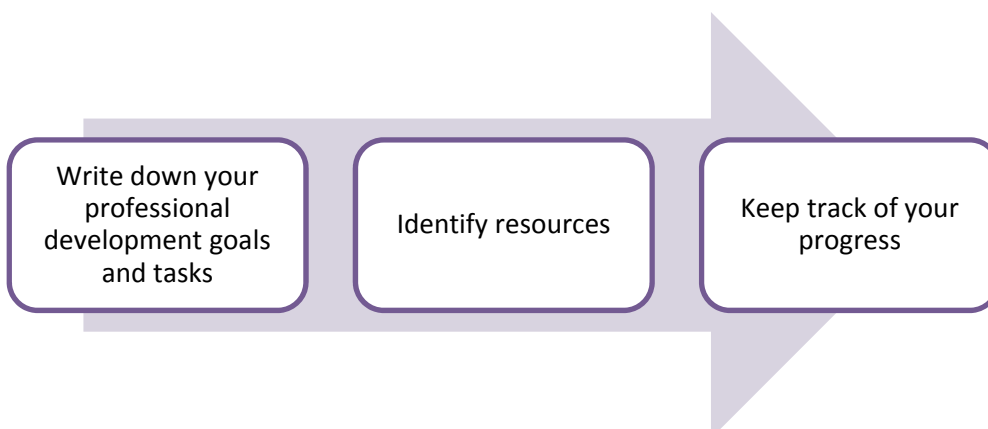


MODULE 7: Resources ENHANCING PRACTICE

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



To create your professional development plan:



MODULE 7: ENHANCING PRACTICE

Resources

Here is a sample professional development plan. You can find a template in the resources section.

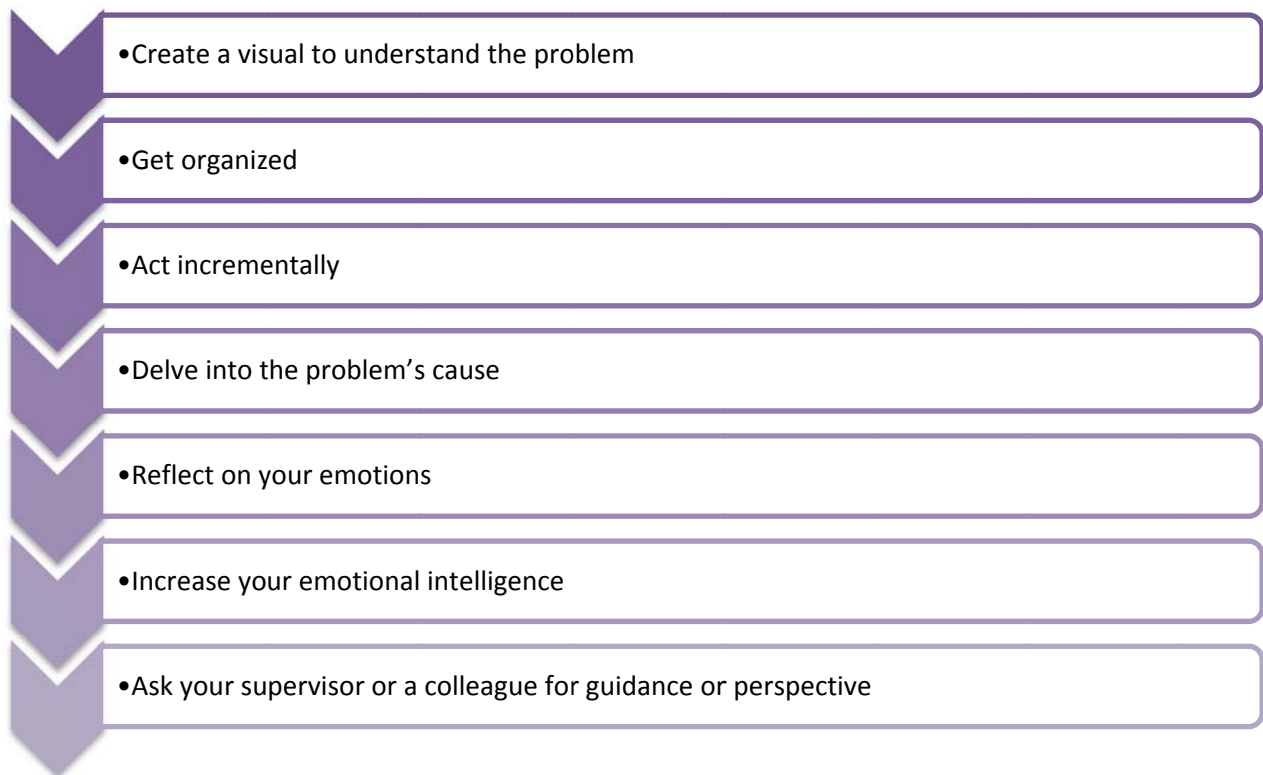
GOAL	RESOURCES	PLAN	PROGRESS
1. Improve Excel skills to help with documentation	Co-workers Free course offered through the library Lynda.com (subscription required)	Sit down with co-workers by the end of the month to do a brief tutorial Enroll in free course	Meeting scheduled Registered for course
2. Stay up to date on patient navigation issues and research	GW Cancer Institute listserv AONN+ journal	Register for listserv and AONN+ membership by the end of the month	Assessed cost of AONN+ membership
3. Enhance time management skills	MindTools.com	Review content online by the end of the quarter	Identified lessons to read

Sources: UC Berkeley. [Goal-Setting: Developing a Vision & Goals for Your Career Plan](#). n.d.; AARP Foundation. [Create Your Professional Development Plan](#). n.d.

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.

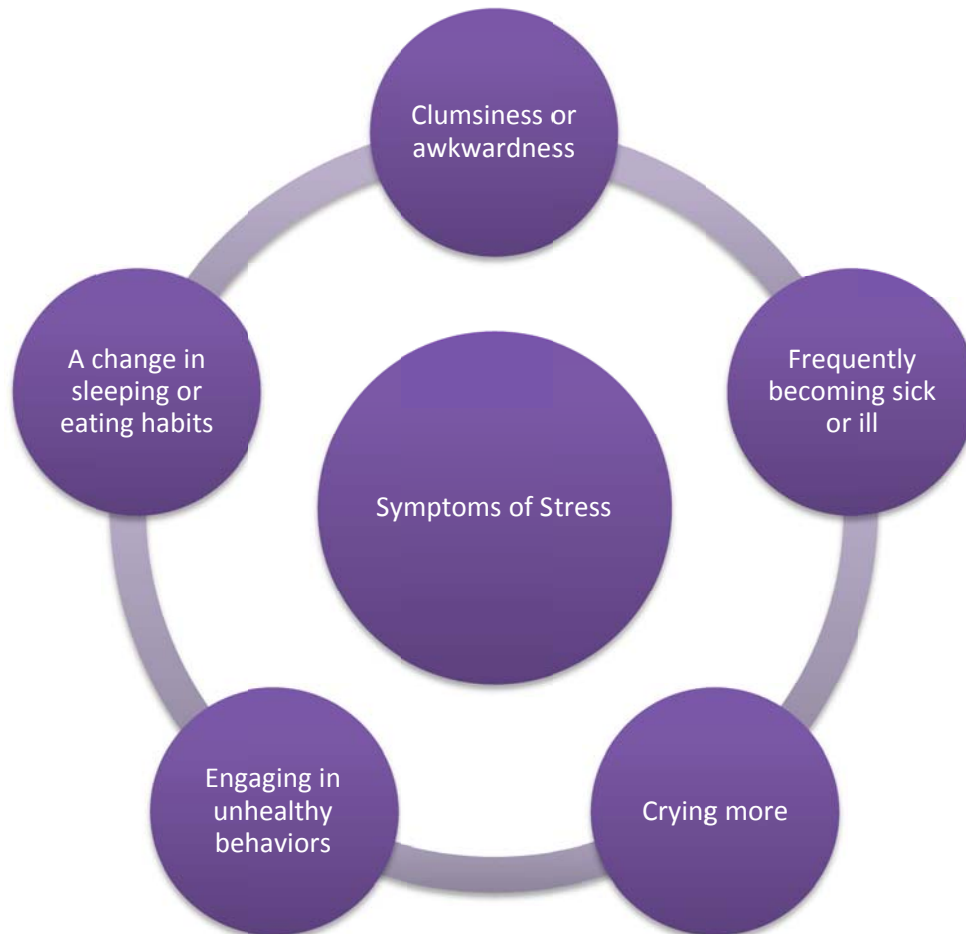
The best way to deal with this uncertainty is to learn how best to respond and to develop the skills necessary to be adaptable to change. You can also:

- 
- 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

Source: The George Washington University Human Resources. [Dealing with Ambiguity](#). n.d.

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:



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. Symptoms of compassion fatigue include:

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

Tips for self-care include:

-  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

MODULE 7: Resources

ENHANCING PRACTICE

- ✚ Stay focused on meeting the goals outlined in your professional development plan
- ✚ Do not overexert or overextend yourself; know your limits and when you need a break
- ✚ Stay positive and maintain a sense of humor
- ✚ Take responsibility for yourself; don't assume others should take responsibility for your well-being
- ✚ 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, instead of resorting to unhealthy limits of caffeine, drugs or other artificial and potentially harmful substances

Sources: Birkenmaier et al. 2007; [PNTC](#).

Resources for Patient Navigators

- Free Management Library's [Giving and Receiving Feedback](#)
This webpage includes tips for giving and receiving feedback as well as links to other resources on the topic.
- [Lynda.com](#)
Lynda.com is a subscription-based learning company that helps anyone learn business, software, technology and creative skills to achieve personal and professional goals.
- [Mindtools.com](#)
This website includes professional development articles and tools.
- 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.

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- The George Washington University Human Resources. Dealing with Ambiguity. n.d. Retrieved from: <https://ode.hr.gwu.edu/dealing-ambiguity>.