

Patient Navigator Training 2025



Cancer
Center **TAP**
Technical Assistance Program



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The George Washington University (GW) Cancer Center's Technical Assistance Program advances patient navigation and cancer survivorship efforts locally and nationally through training, research, policy analysis, community engagement, and education. Our goal is to provide a foundation of knowledge for all patient navigators who work with people affected by cancer.

We are excited to offer our 2025 Oncology Patient Navigator Training: The Fundamentals at no cost. The original training was released in 2015 after a two-year process of developing the first-ever competencies for oncology patient navigators. A revised and updated training is now available that continues to meet the training requirements for the Centers for Medicare and Medicaid (CMS) Medicare Fee Schedule Payment Rule for Principle Illness Navigation (PIN) reimbursement.

In the 2025 training, you will find that we have consolidated content, eliminated content that has not proven to be evidence-based, added standards that have developed since the release of our original 2015 training, and optimized the learner experience. We have also collaborated with numerous partners at standard setting organizations to ensure greater inclusivity and address blind spots in our 2015 training.

Our vision is to support a qualified workforce to increase cancer patient access to and quality of care. Competency-driven training can standardize core duties of the navigation profession, so that patients and health care professionals understand the scope of practice and boundaries of what a navigator does and does not do. Training also sustains the profession by helping patient navigators demonstrate their value to administrators and other interest holders. Additional training that addresses requirements at the local jurisdiction level as well as ongoing training to learn from the communities that you serve is also critical.

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

With much gratitude to the Centers for Disease Control and Prevention for funding this work,

Mandi Pratt-Chapman, MA, Ph.D., Hon-OPN-CG

A handwritten signature in black ink, appearing to read "Mandi Pratt-Chapman".

Associate Professor, Department of Medicine, School of Medicine and Health Sciences
Associate Professor, Prevention and Community Health, Milken Institute School of Public Health
Associate Center Director, Community Outreach and Engagement, GW Cancer Center

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Revision Committee

We thank the revision committee:

Alex Hurst, MHA	National Council for Mental Wellbeing
Erika Bergeron, MPH	Gallaudet University
Flint Huffman, MEd	National LGBT Cancer Network
Janette Merrill, HDA, CHES	American Society of Clinical Oncology
Jess Quiring, CN-BA, OPN-CG	Patient Navigation Advisors
Julie McMahon, MPH	Susan G. Komen
Katie Garfield, JD	Harvard Law School
Laurie Kierstein, MD, FACS	American College of Surgeons, Commission on Cancer
Marcela Gaitán, MPH, MA	Nuestra Voces, National Alliance for Hispanic Health (The Alliance)
Monica Dean, HON-OPN-CG	Academy of Oncology Nurse and Patient Navigators
Nancy Peña, OPN-CG, CMI	Navegación de Pacientes Internacional, Inc. (NPI)
Reesa Sherin, MBA, MSN, RN	Association of Cancer Care Centers
Samarah Tamid, MPH	National Council for Mental Wellbeing
Shonta Chambers, MSW	Patient Advocate Foundation
Va'a Tofaeono, MBA	American Samoa Community Cancer Coalitions
Zarek Mena, OPN-CG	Patient Navigation Advisors

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Accreditation Requirements

All lessons, evaluations and quizzes (**with score of 70% or higher**) are required for completion and receipt of credits. Fast forwarding of lesson videos will result in incomplete status

Credit Type	Accrediting Body	Credit Hours
Nursing Contact Hours	Maryland Nurses Association (MNA)	14
AMA PRA Category 1 Credit™	George Washington University School of Medicine and Health Sciences	14
Certified Health Education Specialist (CHES®/MCHES®)	National Commission for Health Education Credentialing (NCHEC)	14
Certificate of Completion	George Washington University School of Medicine and Health Sciences	14

About GW Cancer Center

The George Washington University (GW) Cancer Center incorporates all existing cancer-related activities at GW, with a vision to create a cancer-free world through groundbreaking research, innovative education and equitable care for all. Learn more about the GW Cancer Center at gwcancercenter.org.

The George Washington University (GW) Cancer Center Technical Assistance Program (TAP) is funded through cooperative agreements from the Centers for Disease Control and Prevention (CDC) to design and implement training and technical assistance to comprehensive cancer control (CCC) programs and partners. CCC is an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, and survivorship. The project supports CCC programs in all 50 states and the District of Columbia, U.S. Associated Pacific Islands/territories, tribes, and tribal organizations. As part of the project, the Cancer Control TAP website provides a centralized library of resources, training, and technical assistance on a variety of cancer-related topics. Access the site at cancercontroltap.org.

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An Overview of the Training

This training course consists of an introduction and 14 lessons, divided into three sections. For each section there is a pre-lesson and post-lesson evaluation to measure learner confidence in learning objectives. After each section there is a multiple choice question quiz. Lessons one through five focus on cancer and navigation basics in the context of the U.S. healthcare system. Lessons six through ten provide instruction to build competence and skills in navigating patients. Lessons eleven through fourteen include important considerations for patient navigators, including attention to ethics, quality improvement, clinical trials and demonstrating navigation value.

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

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

	Lesson Title	Estimated Completion Time
✓	Pre-evaluation (2 min)	
1	Cancer Basics: Continuum of Cancer Care	1 hr 30 min
2	Medical Terminology	15 min
3	What is Patient Navigation & What does a Navigator do?	1 hr
4	Team-Based Navigation and Role Delineation	55 min
5	US Healthcare System, Payment and Financing	1 hr
✓	Lessons 1-5 Quiz (20 min) Post-evaluation (2 min)	

	Lesson Title	Estimated Completion Time
✓	Pre-evaluation (5 min)	
6	Professional Development and Practice-Based Learning	1 hr 30 min
7	Communication with Patients and Caregivers	1 hr 30 min
8	Shared Decision-Making with Patients and Caregivers	1 hr
9	Patient Advocacy	40 min
10	Addressing Barriers to Care with Strengths-based Community and Individual Assessments	2 hrs
✓	Lessons 6-10 Quiz (30 min) Post-evaluation (5 min)	

	Lesson Title	Estimated Completion Time
✓	Pre-evaluation (2 min)	
11	Ethics and Patient Rights	1 hr
12	Program Evaluation and Quality Improvement	30 min
13	Clinical Trials	55 min
14	Value of Patient Navigation	10 min
✓	Lessons 11-14 Quiz (15 min) Post-evaluation (2 min)	
✓	Overall Course Evaluation (2 min)	

Lesson 1:

Continuum of Care

Learning Objectives

1. Describe what cancer is
2. Describe current cancer screening guidelines and tests to detect cancer
3. Summarize basic cancer treatment options
4. Identify supportive care services
5. Identify professional resources
6. Describe potential physical, psychological, social and spiritual effects of cancer and cancer treatments

Key Takeaways

- Cancer is the uncontrolled multiplication of cells that do not die.
- Avoiding certain behaviors, like smoking, can decrease a person's cancer risk.
- Routine screening is critical for early detection and decreasing mortality rates.
- Early detection can allow for less intensive treatment plans.
- Cancer treatments are dependent on the type and stage of cancer.
- Cancer survivors may require or request support services ranging from psychosocial care to physical activity and nutritional guidance.
- Cancer diagnosis and treatment can have psychosocial, physical, practical, and spiritual side effects.
- A person is considered a cancer survivor from the moment of diagnosis and after the completion of treatment.



What is Cancer?

Cancer is a group of over 100 diseases characterized by abnormal, uncontrolled cell growth. In a healthy body, cells grow, die, and are replaced in a controlled way. Damage or change in the genetic material of cells by environmental or internal factors sometimes results in cells that do not die and continue to multiply until a mass of cancer cells, or a tumor, develops. Cancers are named based on the location where the cancer began.¹

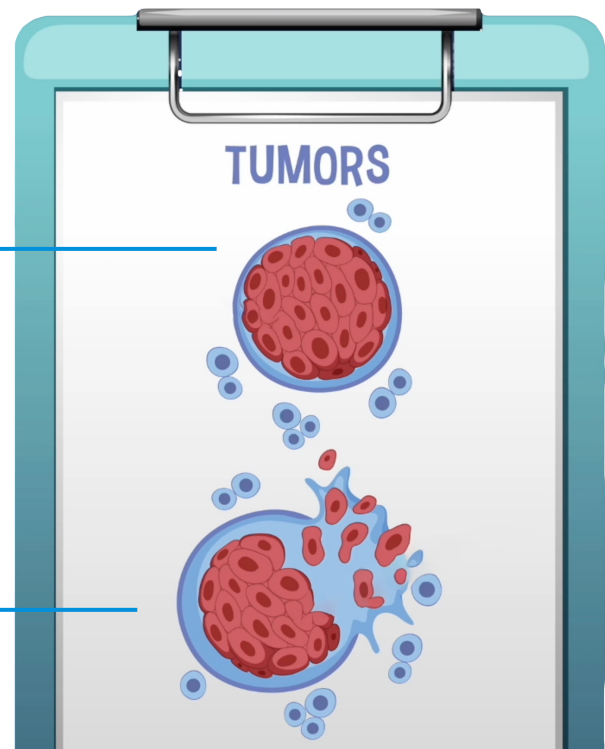
Benign vs Malignant Tumors

Benign:

- Non-cancerous
- Do not grow into other tissue

Malignant:

- Cancerous
- Invade tissue or spread



Most cancer deaths are caused by metastatic cancer. Metastasis occurs when cancer cells break off from the original tumor, travel through the body, and begin to grow in other tissue and organs.

Types of Cancer

Carcinomas	Start in the cells that cover external and internal organs or glands
Sarcomas	Start in cells of 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	Start in the immature blood cells that grow in the bone marrow ²

Naming of Cancers³

Adreno	=	gland	Lympho	=	lymphocyte
Chondro	=	cartilage	Melano	=	pigment cell
Erythro	=	red blood cell	Myelo	=	bone marrow
Hemangio	=	blood vessels	Myo	=	muscle
Hepato	=	liver	Nephro	=	kidney
Lipo	=	fat	Osteo	=	bone





Behaviors to Avoid



Smoking and e-cigarettes (This is the single most effective lifestyle decision to prevent cancer)⁴



Alcohol



Exposure to carcinogens



Excessive sun/UV exposure

Additional Cancer Risk Factors^{5,6}



Infections like HPV and Hepatitis



Immunosuppressive medicine



Radiation (sun, UV, radon)



Environmental exposures



Inherited genes

Cancer Signs & Symptoms⁷

- Breast Changes (lumps, nipple changes or discharge)
- Bladder changes (trouble urinating, blood in the urine)
- Bleeding or bruising with no known cause
- Persistent cough or hoarseness
- Eating problems (trouble swallowing, nausea and vomiting)
- Fatigue (severe and lasting)
- Fever or night sweats with no known cause
- Mouth changes (white or red patches on the tongue, bleeding)
- Neurological problems (headaches, seizures, vision changes, etc.)
- Skin changes (lumps that bleed or turn scaly, sores that do not heal, jaundice)
- Swelling or lumps
- Unintentional weight gain with no known cause

Early cancer may not have any symptoms.

Cancer Detection & Diagnosis⁸

- Cancer can be diagnosed with biopsies, blood tests, urine tests, colonoscopies or sigmoidoscopies, X-rays, ultrasounds, bone scans, CT scans, MRIs and/or surgery
- When cancer is found, a doctor will determine what type it is and how fast it is growing
- Finding cancer early may decrease a person's risk of dying from the cancer. For this reason, improving methods for early detection is a high priority



Screening

Routine cancer screening can detect cancer early and increase the likelihood that treatment will be successful. Screening is important for the early detection of the following cancers along with their common screening methods:

Cervical cancer

- Pap Smear or Pap test, HPV test⁹

Breast cancer

- Mammogram, Ultrasound, MRI, Biopsy¹⁰

Prostate cancer

- PSE test, Digital rectal exam¹¹

Colorectal cancer

- Stool test, Sigmoidoscopy, Liquid biopsy, Colonoscopy¹²

Lung cancer

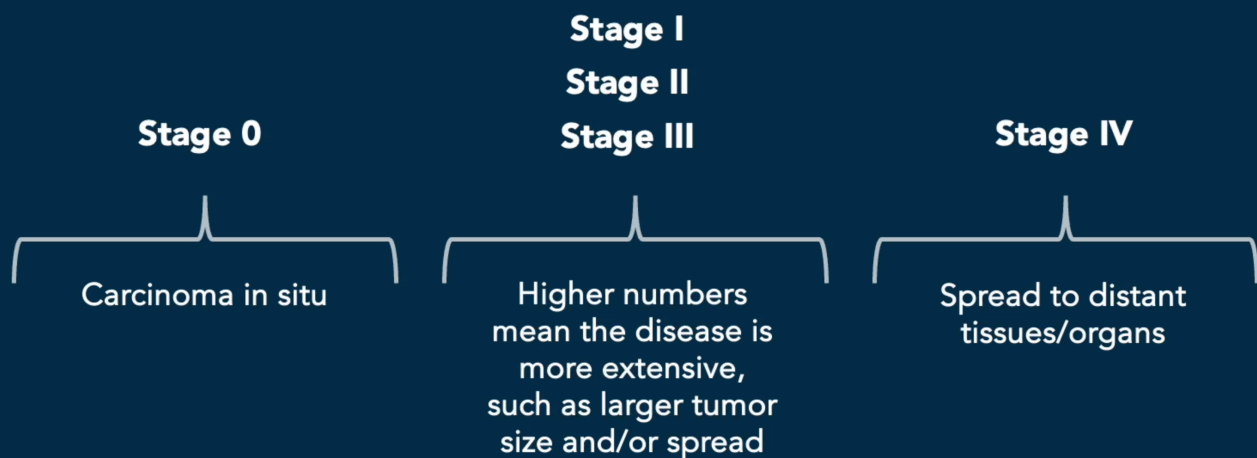
- Low-dose computed tomography (low-dose CT scan)¹³

Staging

Cancer staging is helpful to a doctor when planning the appropriate treatment.¹⁴
It can:

- Help estimate a person's chance of recovery
- Aid in identifying appropriate clinical trials that are suitable
- Help providers exchange information about a person and any results of clinical trials

T = Primary Tumor	N = Lymph Nodes	M = Metastasis (spread)
TX = Unknown	NX = Unknown	M0 = No evidence of spread
T0 = Noninvasive tumor without spread	N0 = No lymph node involvement	M1 = Distant spread
Tis = Carcinoma in situ, invasive tumor without spread	N1-3 = Regional node involvement with # of nodes or group	
T1-4= Invasive tumor, size and/or local extension		



Cancer Treatment

Cancer treatments depend on cancer type and stage.¹⁵ Treatments can be neoadjuvant (before main treatment) or adjuvant (after primary treatment) and include:

Surgery

Remove or debulk a tumor; ease cancer symptoms¹⁶

Radiation

A treatment that uses high doses of radiation to kill cancer cells and shrink tumors¹⁷

Chemotherapy

Stops or slows down the growth of cancer cells¹⁸

Targeted therapy

Molecularly targeted drugs or precision medicines¹⁹

Palliative treatment

Improves quality of life and addresses symptoms of people with cancer²⁰

Immunotherapy

Helps immune system fight cancer and stimulates immune system to work harder and smarter to attack cancer. Effective for certain types of cancer and can be used alone or in combination with other cancer treatments²¹

Photodynamic therapy

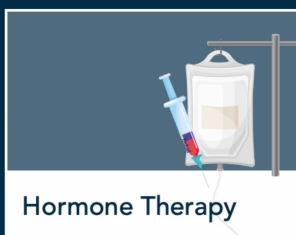
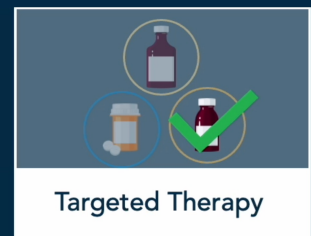
Uses a drug that is activated by light, called a photosensitizer or photosensitizing agent, to kill cancer cells²²

Hyperthermia

A procedure in which tissue is heated to as high as 113 °F to kill cancer cells with little or no harm to normal tissue²³

Hormone therapy

Drugs are given to block the body's natural hormones to slow or stop the growth of cancer²⁴



Supportive Care Services²⁵

- Psychosocial support
- Rehabilitation (Lymphedema therapy, physical therapy, speech therapy, etc.)
- Spiritual support
- Palliative care
- Hospice (end-of-life)

Adolescents and Young Adults²⁷

People between the ages of 15 to 40 years old.

- Limited personal experience with cancer
- Entering or in reproductive years
- Disruption to significant life events
- Increased decision-making challenges
- Social disconnectivity



Rehabilitation Services



Spiritual Support



Integrative Therapies

Commonly Requested Support Services²⁶

- Nutrition information
- Yoga
- Cooking classes
- Aerobics
- Meditation
- Swedish massage
- Information on herbal and dietary supplements

Effects of Cancer Diagnosis & Treatment²⁸

Physical

- Pain
- Fatigue
- Anemia
- Weight gain/loss
- Nausea/vomiting

Psychosocial

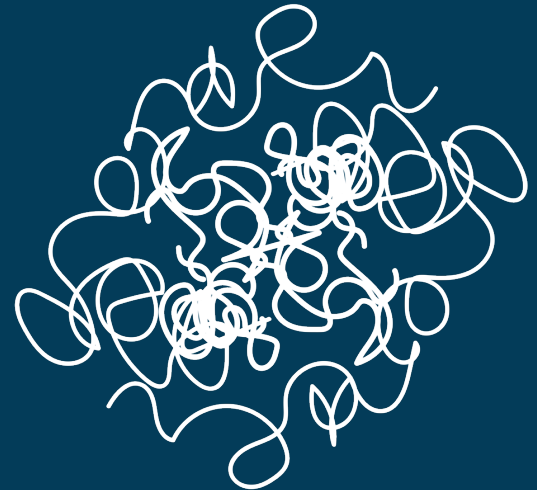
- Anxiety and depression
- Mental distress
- Social isolation
- Changes in relationships

Practical

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

Spiritual

- Finding meaning and purpose
- Changes in belief
- End-of-life



Cancer Survivors

A person is considered a cancer survivor from the moment of diagnosis and throughout and after treatment. Holistic survivorship care encompasses:

- 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

Palliative Care



Pain and
Symptom
Management



Psychosocial and
Spiritual Support



Advance
Directives

End of Life Care²⁹



Hospice
Care



Counseling and
Bereavement Support



Learning Objectives

1. Define basic medical terms using prefixes, root words and suffixes
2. Describe common words used in oncology
3. Identify resources on basic medical terms

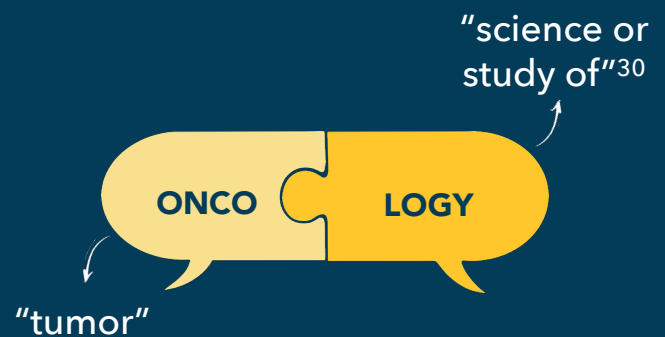
Key Takeaways

Understanding the Latin prefixes, roots, and suffixes of common oncology terms can help you to describe cancer-related topics and identify relevant resources.



How to Approach Medical Terminology

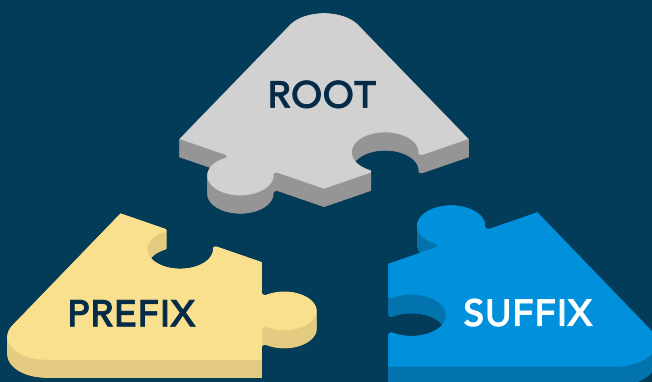
- Find a resource that will help you understand Greek/Latin word roots
- Learn to break down words to smaller components
- Keep your own list of common words



Word Breakdown: Prefix, Suffix, Root^{31,32,33,34}

Prefix: Describes the size, location, direction, amount

- **Location:** near, towards, upon, within, around,
- **Direction:** away from, beneath, above, between, before, after
- **Amount:** lack of, without, excessive, difficult



Prefixes (Size)

Macro

Describes something large

Micro

Describes something small

Megalo or Megaly

Describes something abnormally large

Prefixes (Direction & Location)

- Hyper (fast, elevated, overproducing, energetic)
- Hypo (slow, low, under-producing, low energy)
- Tachy (rapid)
- Brady (slow)
- Extra (outside, excess, beyond)
- Endo (within)
- Intra (within)
- Inter (between, together, during)
- Peri (about, around, surround)
- Trans (across, beyond, through)

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/increased	hyperglycaemia = excessive blood sugar levels
HYPO-	beneath / below/decreased	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



PREFIX	WHAT IT DESCRIBES	EXAMPLE
PRE-	before	prenatal = before birth
POST-	after	post surgical stage = stage after surgery
SUB-	under/below	sub mucosa = tissue below mucus membrane
SUPRA-	above	supra clavicular, above the clavicle
SYN-	together with	synd rome = group of symptoms occurring together

Root

Determines which part of the body it relates to

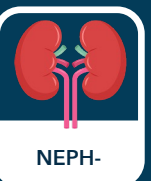
ROOT	WHAT IT DESCRIBES	EXAMPLE
BLAST-	germ, immature cell	blast oma = a cancer made of immature cells
CARCINO-	cancer	carcin ogenic = cancer causing
CARDIO-	heart	cardi otoxicity = toxicity to the heart
CYTO-	cell	cyto toxic = toxic to the cell
DERMA-	skin	derma titis = inflammation of the skin
HISTIO-	tissue	histo logy = study of tissue

ROOT	WHAT IT DESCRIBES	EXAMPLE
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-	tumor	oncology = the study of tumors
OSTEO-	bone/body tissue	osteosarcoma = bone cancer
PED-	child	pediatric oncology = study of childhood cancer
TOXO-	poison	toxicology = study of poisons

Frequent Root Words

- Oste(o) – Bone
- Myo – Muscle
- Neuro – Nerves
- Derm – Skin
- Angi(o) – Skin
- Ven(o) or Phleb(o) – Veins
- Cardio – Heart
- Rhino – Nose
- Neph - Kidney
- Cranio – Skull

- Ophthalmo or oculo – Eye
- Oto – Ear
- Thromb(o) – Blood clot
- Hepato – Liver
- Mamm(o) – Breast
- Colo – Large Intestine
- Gastro – Stomach
- Ileo – Small intestine
- Thorac(o) – Chest
- Pneumo or pleuro – Lung



Suffix

Describes what the word or problem relates to

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

Other Common Roots & Suffixes

Tests and Procedures

ECHO-	using ultrasonic waves
ELECTRO-	using electricity
-GRAM	picture
-GRAPH(Y)	process of making an image

-OTOMY	making a cut in
-SCOPY	using an instrument for viewing
-STOMY	create an opening

Lesson 3:

What is Patient Navigation and What Does a Navigator Do?

Learning Objectives

1. Describe political and social determinants of health and why these are relevant to patient navigation
2. Describe why certain populations continue to experience cancer health disparities
3. Define what patient navigation is and what a patient navigator does

Key Takeaways

- A significant portion of the US population lacks the health literacy to navigate the healthcare system effectively. This, coupled with social determinants of health, leads to health disparities, particularly among marginalized groups.
- Patient navigation is a strategy to address health disparities by providing personalized assistance to people with cancer. Navigators help patients overcome barriers to care such as lack of insurance, transportation, or understanding of medical information.
- There are various roles within the healthcare system that perform navigation functions, including community health workers, patient navigators, and social workers.
- Navigators tailor their support to each patient's specific needs and preferences.
- Navigators engage in a variety of tasks, including coaching, facilitating communication, researching resources, and maintaining systems.
- By understanding and addressing the social and political determinants of health, navigators can improve patient outcomes and reduce health disparities.



Health Literacy

88%

of adults in the US have health literacy inadequate to navigate the healthcare system and promote their well-being.³⁵



- **Personal health literacy** is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.
- **Organizational health literacy** is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

Low health literacy is linked to:³⁶



Lower use of
preventative
care



Less
adherence to
treatment



More hospital
stays



Higher
mortality rates

Navigation Support across the Cancer Continuum³⁷

Prevention

- Promote healthy behaviors within specific communities in a culturally-affirming way

Detection

- Educate regarding cancer screening guidelines and resources: age, intervals, risk
- Help patients access insurance & screening programs

Diagnosis

- Educate regarding health care system protocols
- Ensure coverage of diagnostic procedures
- Check patient understanding of next steps

Treatment

- Assess language & literacy; check for understanding
- Help prioritize patient questions
- Educate on team roles
- Support adherence to treatment plan
- Support self-advocacy & shared decision-making
- Help with financial assistance

Survivorship

- Educate regarding importance of longitudinal follow up care
- Provide reading-level, culturally appropriate evidence-based information on cancer survivorship
- Serve as liaison for patient & survivorship clinicians

End-of-Life Care

- Educate regarding difference between palliative care and hospice
- Support advance care directive completion

Social Determinants of Health³⁸

Social determinants of health refer to the ways that genetics, individual behaviors, environmental circumstances and physical influences, and social factors (such as age, race, gender, etc.) can affect a person's health, functioning, and quality of life.

Proximity of services and transportation to services also affects accessibility. This is because being close enough to a service or social benefit or reliable transportation to that social benefit—such as the ability to reach school, a job, a doctor, or emergency care—are fundamental to being able to benefit from that service.³⁹

By understanding a person's social and political circumstances, navigators can better address barriers to care that directly affect the health and wellbeing of that person.

Five main social determinants of health are:



Medically underserved populations⁴⁰ include people who are or experience:



Factors that Contribute to Cancer Health Disparities⁴¹

- Lack of adequate medical coverage
- Barriers to early detection and screening
- Unequal access to improvements in treatment
- Socioeconomic status
- Bias and stigma

The opposite of health disparities is the achievement of **health equity**—the absence of unfair, avoidable or remediable differences among groups of people.⁴²



Patient Navigation

According to CMS, patient navigation refers to “providing individualized help to the patient (and caregiver, if applicable) to identify appropriate practitioners and providers for care needs and support, and access necessary care, especially when the landscape is complex and delaying care can be deadly.”⁴³

Patient navigation is an evidence-based strategy to address health disparities by providing personalized assistance to people with cancer, survivors, and their families and began as a way to address barriers to care among those with the most trouble attaining basic standards of care. Barriers can include lack of reliable transportation, lower health literacy, difficulty communicating with healthcare providers, and financial constraints. Patient navigators play an important role in addressing these challenges.



Key Aspects of Patient Navigation:

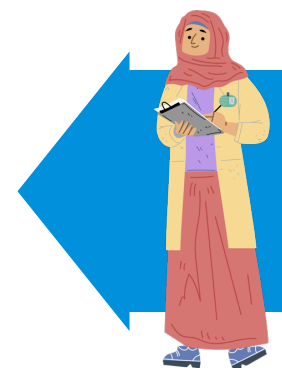
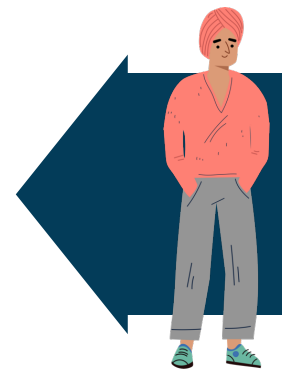
- **Addressing Barriers:** Patient navigators help people overcome obstacles that make accessing care difficult. For instance, they can arrange transportation to treatment appointments, explain medical information in understandable terms, facilitate communication between people and healthcare teams, and find financial assistance programs.
- **Individualized Assistance:** A core function of patient navigators is to assess each person's unique needs and preferences. They develop personalized plans to help people overcome barriers, ensuring that the support provided is tailored to each individual's circumstances.

Note that there are limits to what a navigator can do, so while navigators can address barriers to care, not all barriers can be removed for every person.

Role Definitions

There are different roles within and outside the healthcare system that perform navigating functions. Though they may fall under the umbrella term of “navigator,” confusion exists about their unique roles and responsibilities. Community health workers (CHWs), navigators, and social workers, all may have overlapping yet distinct roles and responsibilities.

- **A Community Health Worker** According to the Community Health Worker Core Consensus Project, a community health worker “is a frontline public health worker who is a trusted member of and/or has a close understanding of the community served. This trusting relationship enables the worker to serve as a liaison, link, or intermediary between health, social services and the community, to facilitate access to services and improve the quality and cultural appropriateness of service delivery. A community health worker also builds individual and community capacity by increasing health knowledge and self-sufficiency through outreach, community education, informal counseling, social support and advocacy.”⁴⁴
- **A Professional Navigator** According to the Professional Oncology Navigation Taskforce a professional navigator “is a trained individual who is employed and paid by a healthcare-, advocacy-, and/or community-based organization to fill the role of navigator. Positions that fall under the professional navigator category include oncology patient navigators and clinical navigators. Clinical navigators include oncology nurse navigators and oncology social work navigators.”⁴⁵
- **A Social Worker** According to the National Association of Social Workers, a social worker “is a person with various professional activities or methods concretely concerned with providing social services and assisting people by helping them cope with issues in their everyday lives, deal with their relationships, and solve personal and family problems. Some social workers help clients who face a disability or a life-threatening disease or a social problem, such as inadequate housing, unemployment, or substance abuse. Social workers also assist families that have serious domestic conflicts, sometimes involving child or spousal abuse. Some social workers conduct research, advocate for improved services, engage in systems design, or are involved in planning or policy development. Many social workers specialize in serving a particular population or working in a specific setting, like oncology.”⁴⁶



Types of Professional Navigators⁴⁷

A **Professional Navigator** is a trained individual who is employed and paid by a healthcare-, advocacy-, and/or community-based organization to fill the role of oncology navigator. Positions that fall under the professional navigator category include oncology patient navigators and clinical navigators.

Oncology Navigation is defined as individualized assistance offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from pre-diagnosis through all phases of the cancer experience.



An Oncology Patient Navigator is a professional who provides individualized assistance to people with cancer and families affected by cancer to improve access to healthcare services. A patient navigator may work within the healthcare system at the point of screening, diagnosis, treatment, or survivorship or across the cancer care spectrum or outside the healthcare system at a community-based organization or as a freelance patient navigator. A patient navigator may be employed by a clinic or a community-based organization and work throughout the community, crossing the clinic threshold to continue to provide a consistent person of contact and support within the healthcare system. A patient navigator does not have or use clinical training.



A Clinical Navigator/Oncology Nurse Navigator is a professional registered nurse with oncology-specific clinical knowledge who offers individual assistance to people with cancer, families, and caregivers to help overcome healthcare system barriers. Using the nursing process, an oncology nurse navigator provides education and resources to facilitate informed decision-making and timely access to quality health and psychosocial care throughout all phases of the cancer continuum.



A Clinical Navigator/Oncology Social Work Navigator is a professional social worker with a master's degree in social work and a clinical license (or equivalent as defined by state laws) with oncology-specific and clinical psychosocial knowledge who offers individual assistance to people with cancer, families, and caregivers to help overcome healthcare system barriers. Using the social work process, an oncology social worker provides education and resources to facilitate informed decision-making and timely access to quality health and psychosocial care throughout all phases of the cancer continuum.

Professional Training and Knowledge (Adapted From PONT Standards)⁴⁸

	Oncology Patient Navigator (PN)	Clinical Navigator/Oncology Nurse Navigator (NN)	Clinical Navigator/Oncology Social Work Navigator (SW)
Training & Education	Complete competency-based navigation training sessions or courses. Does not currently have licensure requirements; however, states may have requirements for training and/or credentialing. Visit the National Academy for State Health Policy to see how each state is defining, training, certifying, and paying.	Have at least a bachelor's degree in nursing from an accredited university. Comply with registered nurse licensing and certification requirements and the scope of practice as defined by the state(s) or jurisdiction(s) in which they practice.	Have at least a master's degree in social work. A general social work license is required for basic navigation interventions. A clinical social work license is required for clinical interventions such as diagnosis of mental and behavioral health conditions or the provision of psychotherapy.
Knowledge	Knowledge of evidence-based information to ensure the quality of navigation practice. Integrate evidence and research findings into their practice. Collaborate with other healthcare and services providers to refer patients when the patient's needs are beyond the knowledge base or scope of practice of the navigator.	Knowledge and competence that reflect current nursing practice, oncology care, and navigation practice. Use the nursing process when providing oncology navigation services.	Knowledge and competence that reflect current social work practice, oncology care, and navigation practice. Use the social work process when providing oncology navigation services.
Screening	Assist with the implementation of programs to improve access to cancer screening. Conduct culturally appropriate education about the potential benefits and limitations of contemporary genetic counseling and related genetic risk assessments.	Assist in the identification of candidates for molecular testing and/or genetic testing and counseling and facilitate appropriate referrals.	Use appropriate screening and assessment tools and methods to provide holistic care plan.
Treatment	Refer to nurse, nurse navigator, social worker, and physician colleagues to answer questions about clinical information, treatment choices. Assist to resolve logistical barriers to accessing and completing treatment.	Monitor and facilitate interventions to address symptoms and side effects. Use knowledge of clinical trial processes, requirements, and the specific treatment regimen to guide, direct, and support the patient in their informed decision making and consent.	Use knowledge of clinical trial processes, requirements, and the specific treatment regimen to guide, direct, and support the patient in their decision-making and informed consent. Implement evidence-based psychosocial support programs, services, and interventions.

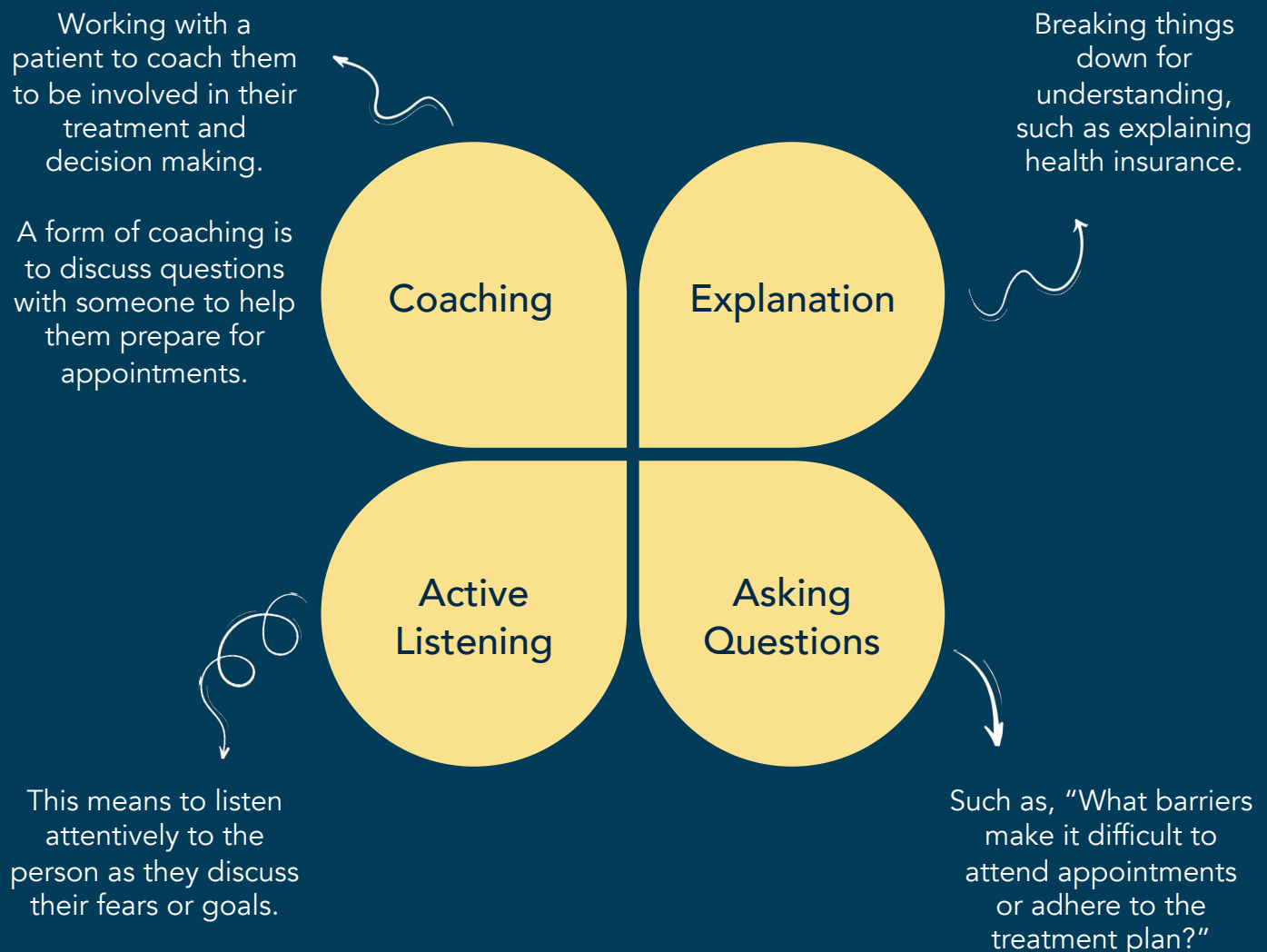
Professional Training and Knowledge

	Oncology Patient Navigator (PN)	Clinical Navigator/Oncology Nurse Navigator (NN)	Clinical Navigator/Oncology Social Work Navigator (SW)
Assessment	<p>Assess social risk factors. Assist patients in coping with the diagnosis of cancer.</p> <p>Administer evidence-based patient-reported distress screening.</p> <p>Remain current on standardized instruments helpful in identifying and responding to patient needs and concerns.</p> <p>Refer to clinical navigators regarding psychosocial information and to clinical social workers, clinical social work navigators or other licensed mental health professionals for more specific psychosocial information and treatment.</p>	<p>Provide psychosocial assessment and support and facilitate appropriate referrals for patients, families, and caregivers, especially during periods of high emotional stress and anxiety.</p>	<p>Conduct ongoing biopsychosocial assessments with patients to determine the needs, assets, and priorities of the patient.</p> <p>Provide clinical psychosocial diagnostic, assessment, and treatment services to support patients' identified social and emotional needs.</p> <p>Sit on institutional boards and committees that implement and monitor psychosocial assessment and intervention.</p>
Survivorship	<p>Support and facilitate a smooth transition of patients from active treatment into survivorship or chronic cancer management.</p> <p>Provide psychosocial support to patients transitioning into post treatment care and survivorship phase. Facilitate community-clinical linkages to support quality of life.</p>	<p>Provide and reinforce education to patients, families, and caregivers about post treatment care and survivorship.</p>	<p>Provide clinical psychosocial services to patients transitioning into post treatment care and survivorship.</p>
End of Life Care	<p>Support a smooth transition of patients from treatment into end-of-life care.</p> <p>Collaborate with the patient, interdisciplinary team, and others when developing expected outcomes to improve quality of life.</p>	<p>Provide psychosocial support to patients as they transition into end-of-life decision-making and supportive care. Prepare patients for the signs and symptoms of the end of life.</p> <p>Provide symptom management at the end of life.</p>	<p>Provide clinical psychosocial services to patients as they transition into end-of-life decision-making and supportive care.</p>



Categories of Navigator Tasks⁴⁹

- Navigating
- Facilitating
- Researching Resources
- Maintaining Systems
- Documenting and Receiving Information



Facilitating Tasks

- **Finding patients:** Identifying patients who need navigation to follow up and ensure they are adhering to treatment.
- **Coordinating team communication:** Updating members of the healthcare team on patient concerns.
- **Integrating information:** Documenting and sharing information with the team.
- **Collaborating:** Referring people to appropriate members of the healthcare team and community resources to address their needs and concerns.

Maintaining Systems

- Identifying potential patients
- Building networks and referral routines
- Reviewing cases

Other Tasks

- Charting to track navigation activities
- Supporting research through administrative duties
- Collaborating with healthcare team



Lesson 4:

Team-Based Navigation & Role Delineation

Learning Objectives

1. Compare standards and role delineation across navigating professions
2. Describe different healthcare professionals and how they may interact with patient navigators
3. Identify and implement strategies for acting within professional boundaries
4. Describe potential conflicts and strategies for a constructive negotiation in a healthcare team
5. Describe how culture, background, religious beliefs and attitudes impact patient care and the working environment
6. 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
7. Identify potential conflicts of interest between personal and professional responsibilities
8. Identify and apply strategies for managing conflicts of interest

Key Takeaways

- Recognizing the unique roles of various healthcare professionals, such as social workers, oncology nurses, case managers, and patient navigators, is important for effective patient care coordination.
- Familiarity with industry standards and core competencies supports quality patient care and professional accountability.
- Practicing effective teamwork and collaboration among healthcare professionals can optimize patient outcomes and improve the overall patient experience.
- Learning effective conflict resolution strategies helps to maintain positive working relationships and avoid negative impacts on patient care.
- Recognizing the impact of culture, background, and beliefs on patient care and workplace dynamics is essential for providing culturally sensitive and effective care.
- Maintaining appropriate professional boundaries with other healthcare professionals and patients is crucial for ethical and legal compliance.
- Identifying and addressing potential barriers to a smooth patient transition can minimize patient confusion and ensure continuity of care.
- Practicing effective communication and coordination among healthcare providers is crucial for seamless patient care transitions.

Patient Navigation

Various healthcare professionals contribute to the navigation of patients through the complexities of their care. Patient navigators have many colleagues who also perform navigating functions, each with their own rich professional history. Professions like social work, oncology nursing, and case management have provided lifesaving support for patients with cancer for a long time. While these roles share many navigating functions and shared goals with patient navigators, each profession brings specialized skills to the table.

Patient Navigation Activities

- Conduct person-centered assessment, including assessment of social risk factors
- Identify or refer patient (and caregiver or family) to appropriate services
- Coordinate practitioner, home, and community-based care
- Provide health education
- Build patient self-advocacy skills
- Support health care access/health system navigation
- Facilitate behavioral changes as necessary for meeting diagnosis and treatment goals
- Facilitate and provide social and emotional support
- Leverage knowledge of the condition and/or lived experience when applicable to provide support, mentorship, or inspiration to meet treatment goals



Core Competencies & Standards

Here is a summary of the GW Core Competency Domains⁵⁰, 2024 Centers for Medicare and Medicaid Services (CMS) requirements⁵¹ and 2022 Patient Oncology Navigation Taskforce (PONT) standards⁵². This summary is provided to show how this training is aligned with CMS requirements.

GW Core Competencies 8 Domains 45 statements	<ul style="list-style-type: none"> • Patient care • Knowledge of practice • Practice-based learning and improvement • Interpersonal and communication skills • Professionalism • Systems-based practice • Interprofessional collaboration • Personal and professional development
CMS Requirements 9 Competencies	<ul style="list-style-type: none"> • Patient and family communication • Interpersonal and relationship-building • Patient and family capacity building • Service coordination and systems navigation • Patient advocacy • Facilitation • Individual and community assessment • Professionalism and ethical conduct • Knowledge base, including certification or training on the serious, high-risk condition being addressed
PONT Standards 19 Standards	<ul style="list-style-type: none"> • Ethics • Qualifications • Knowledge • Cultural and linguistic humility • Interdisciplinary and interorganizational collaboration • Communication • Professional development • Supervision • Mentorship and leadership • Self-care • Prevention, screening and assessment • Treatment, care Planning and intervention • Psychosocial assessment and intervention • Survivorship • End-of-life • Advocacy • Operational management • Practice evaluation and quality improvement • Evidence-based care

Patient Navigator Levels of Experience

Entry – One to two years or equivalent experience. Starting a new position without experience in navigation and builds on resources for addressing barriers (logistical, economic, cultural & linguistics, communication, and provider centered) and basic Oncology Patient Navigator-Certified Generalist (OPN-CG)⁵³⁻⁵⁴ principles to guide practice.

Intermediate – Three to four years or equivalent experience. Possesses a basic understanding of how patient care flows within job boundaries, matching resources to the unique needs of the patient, identifying resources lacking in the community of care, beginning to analyze needs and gaps, and exploring/collaborating with multidisciplinary team members to advocate for resources for unmet needs for community or clinical settings.

Advanced – Five or more years. Skilled in the ability to perceive patient situations holistically based on past experiences, focusing on the unique aspects of the patient assessment, and uses critical thinking and decision-making skills pertaining to navigation processes. Builds on and includes all knowledge, skills, roles, and responsibilities from Entry and Intermediate navigators⁵⁵.



Teamwork

Teams are two or more people working together (collaborating) to accomplish a common goal.⁵⁶

Teamwork and collaboration are not the same thing. Professionals can work together to meet the needs of their patients without identifying as a part of a team. Teams, however, can't be effective unless all members collaborate on their work. Team members coordinate with each other to accomplish a common goal and take responsibility to manage conflicts.

Coordinating Care

Because numerous roles are involved with patient care, one problem being addressed by patient navigation is coordinating care across fragmented health care systems. Fragmentation may result due to a patient receiving different therapies in different settings, such as different hospitals, clinics, and community agencies. Communication across many different healthcare team members and organizations can be challenging. Having a patient navigator connect and coordinate communication across these settings can have a huge impact on patient understanding, adherence, and quality of care.⁵⁷

Key Team Members

-  Advanced Practitioners
-  Doctors
-  Nurses
-  Patient Navigators
-  Pharmacists
-  Social Workers
-  Technologists & Technicians
-  Therapists & Rehabilitation Specialist

Diversity on Health Care Teams Provides⁵⁸:

- Better working environments
- Improved problem solving
- Connection between clinical and cultural knowledge
- A better informed patient environment
- Increased information about differences can mitigate conflicts from cultural differences

Why Diversity in the Workplace is Important to Patient Care⁵⁹

- Improves attitudes and awareness of people with different lived experiences
- Increases patient comfort and trust
- Expands healthcare access
- Increases cultural awareness
- Improves research
- Influences policymakers

Allied Health Professionals⁶⁰

Allied health may be defined as health professions that are distinct from medicine and nursing. Allied health professionals are involved with the delivery of health or related services pertaining to the identification, evaluation and prevention of diseases and disorders; dietary and nutrition services; and rehabilitation and health systems management, among others.



Nuances of Oncology Patient Navigator Role⁶¹

Patient Navigators DO:

- **Provide emotional support to a patient.** Patient navigators should always offer empathy and support to patients. Oncology social work navigators can provide emotional support and counseling while they are interacting with patients. However, providing general emotional support is a key part of a navigator's role, regardless of background. Non-clinical patient navigators who encounter patients with significant emotional concerns, acute distress, depression or anxiety should refer patients to a mental health professional for assessment and care.
- **Tailor information and referrals based on the patient's needs and abilities.**
- **Assist patients with filling out forms and applications as needed.** However, the primary goal should be to empower patients to take an active role in their own care, guiding them toward self-activation and supporting patient empowerment wherever possible.



Patient Navigators DO NOT provide:

- Clinical counseling
- Legal advice
- Mental health counseling
- Interpretation, unless you are a certified medical interpreter

Patient Navigators DO NOT offer opinions or judgments about:

- The quality of physicians or medical care
- Diagnosis or treatment options
- Aspects of care delivery system patient is experiencing.

Check with your supervisor or employer for other policies on what to avoid.

Maintaining Boundaries with Other Professionals⁶²

If you do things that are outside of your scope of practice, you may harm patients and you put yourself at risk for legal and other negative consequences.

Maintaining boundaries with other health care professionals and with patients can be challenging.

It is important that you maintain appropriate boundaries.

Strategies:

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

What is the Difference Between Multidisciplinary and Interprofessional?

A **multidisciplinary team (MDT)** is the cooperation between different specialized professionals involved in cancer care with the overarching goal of improving treatment efficiency and patient care. The core function of a multidisciplinary team (MDT) is to bring together a group of healthcare professionals from different fields in order to determine patients' treatment plan. Cancer MDTs typically include surgeons, medical and radiation oncologists, pathologists, radiologists, nutrition experts, geriatricians, nurses, social workers, patient navigators, and other professionals who are involved in the care of patients with cancer.⁶³

An **interprofessional team** is a team of individuals who identify with different specialties or disciplines who work together and communicate to make well-informed decisions. Interprofessional teams collaborate across disciplinary boundaries to integrate knowledge to achieve shared goals, such as optimizing patient care and wellbeing.

What Prevents Collaboration & Interprofessional Teamwork in Health Care?⁶⁴

- Communication silos
- Sense of superiority
- Absence of trust
- Avoidance
- Lack of commitment
- Inattention to results
- Fear of conflict

Understanding Conflict⁶⁵

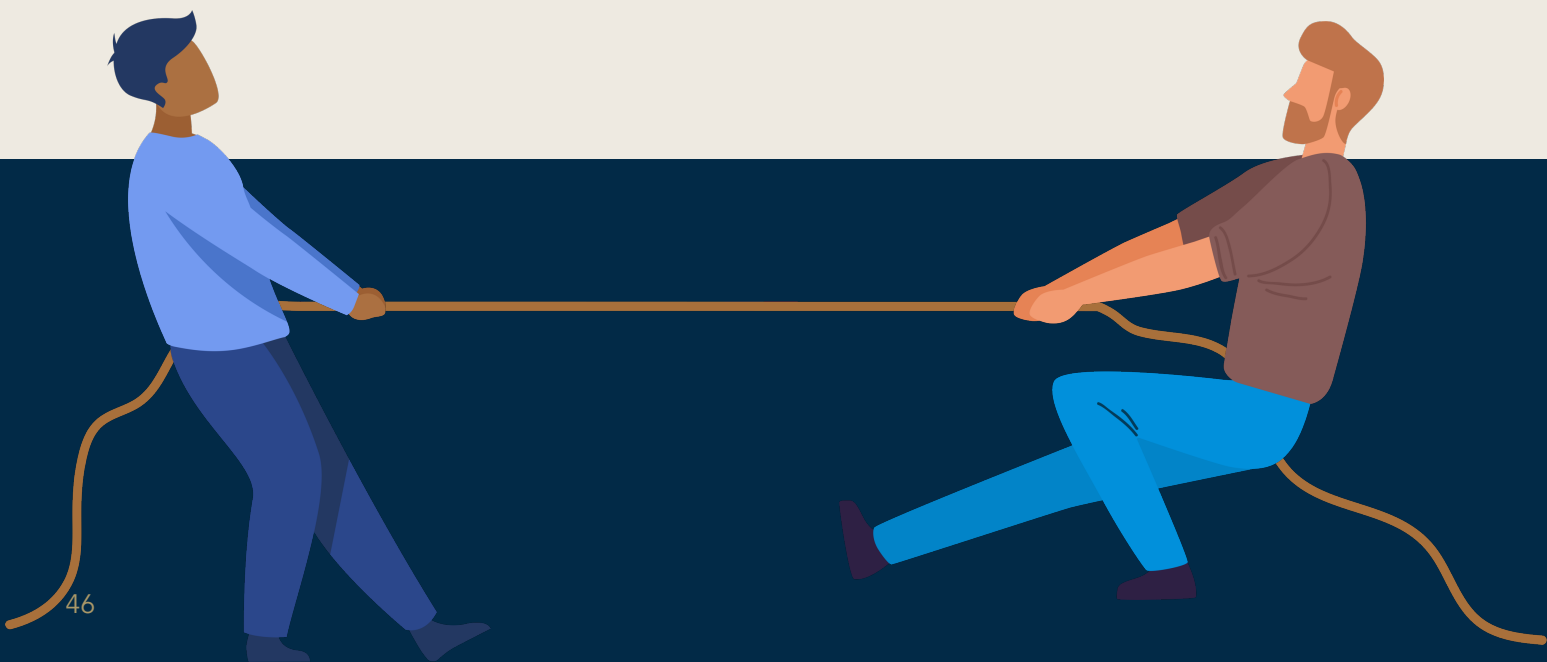
To understand conflict, you must have:

- At least two parties
- Parties must be interdependent (need each other)
 - Perceived differences in values
 - Perceived differences in goals
 - Communication issues



Common Sources of Workplace Conflict⁶⁶

- Insufficient resources
- Conflicting personalities and work styles
- Delegating power and authority
- Conflicting values
- Lack of acknowledgment of contributions
- Disagreements over roles and responsibilities
- Intercultural misunderstandings
- Poor communication
- Poor leadership and unpredictable policies
- Conflicting pressures
- Perceived threat to one's identity



Method for Solving Conflict: SBAR⁶⁷

Situation

"What is going on with the patient?"

Background

"What is the context?"

Assessment

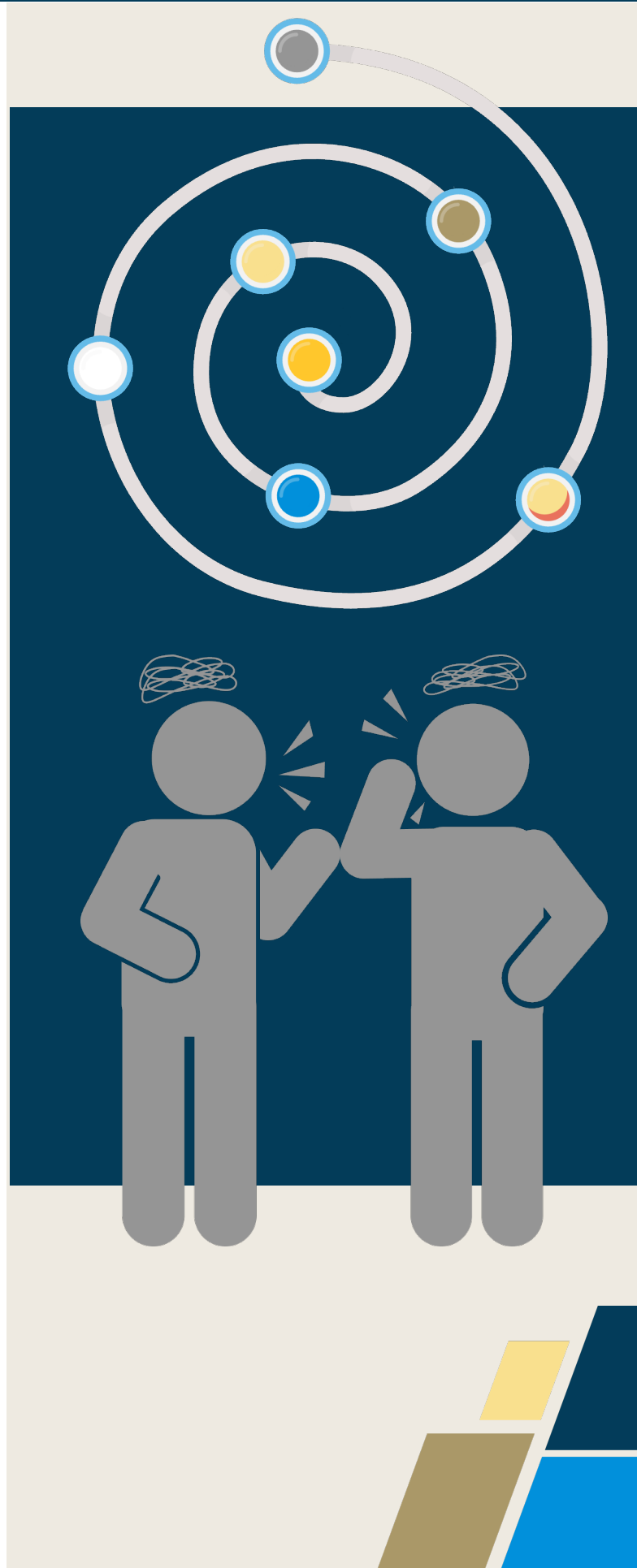
"What do you think the problem is?"

Recommendation

"What would you do to correct the problem?"

Resolving Conflict

- Work at talking about the issues
- Recognize the value of the conflict
- Recognize conflict is a spiral, and you can change the direction of the spiral
- Emphasize common goals
- Check perceptions
- Use strong communication techniques
- Agree to disagree
- Attack the problem, not the person



Impact of Dysfunctional Teams⁶⁸

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

Characteristics of Effective Teams⁶⁹

- Value contributions
- Mutual respect
- Honor diversity
- Shared responsibility
- Shared goals
- Structured protocols

Successful Teamwork^{70,71}

The 7 Cs	Practical Applications
Cooperation	<ul style="list-style-type: none">• Build collective efficacy through promoting early wins• Build trust through the discussion of past experiences relevant to the team goal
Coordination	<ul style="list-style-type: none">• Self-correct via huddles and debriefs• Team member roles are clear but not overly rigid
Communication	<ul style="list-style-type: none">• Share unique information among team members• Utilize closed-loop communication pattern
Cognition	<ul style="list-style-type: none">• Foster understanding of roles and how these roles fit together through cross-training• Establish a clear shared understanding of team functioning through self-correction
Conflict	<ul style="list-style-type: none">• Be proactive—set expectations for how to handle conflict• Be reactive—confront conflict when it occurs instead of ignoring it
Coaching	<ul style="list-style-type: none">• Use coaches to diagnose and address teamwork problems• Distribute leadership responsibilities among multiple members of the team
Conditions	<ul style="list-style-type: none">• Easy to understand workflow protocols• Team-lead creation of set of rules, norms, and expectations



Solutions for Effective Communication⁷²

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

Barriers to Team Collaboration

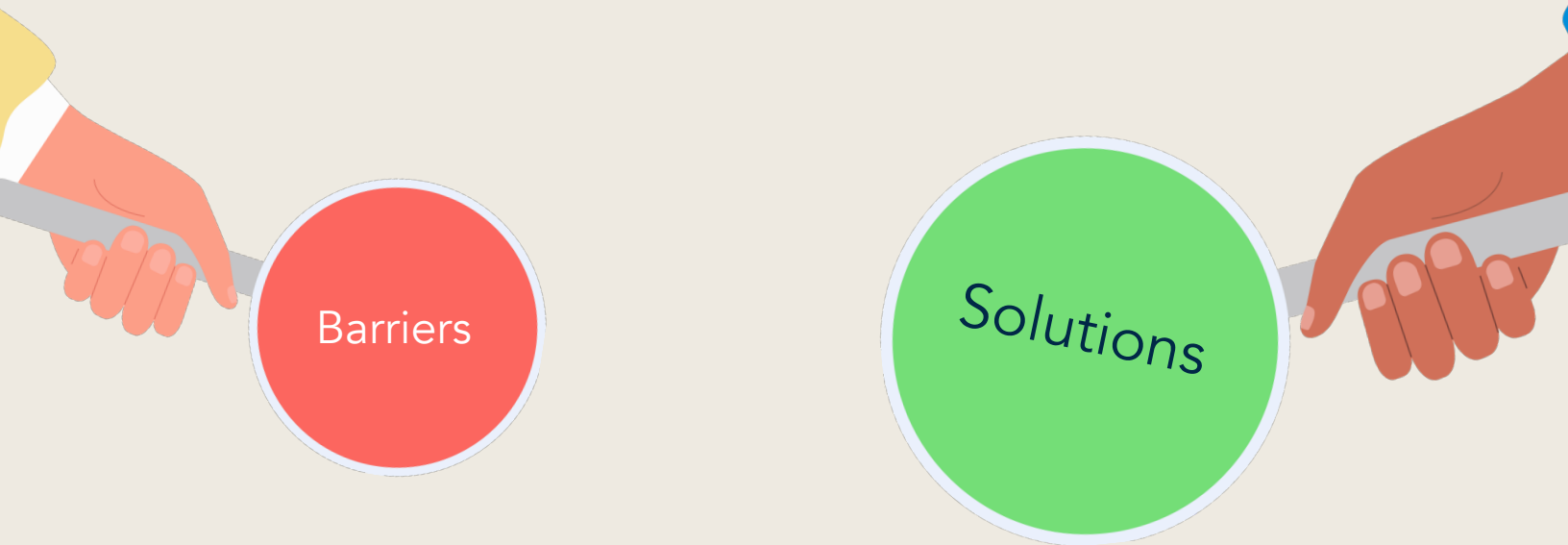
- It takes time
- Perceived loss of autonomy
- Lack of trust
- Clashing perceptions/approaches
- Territorialism
- Lack of awareness

Barriers to Team Transition

- Transition between patient navigators
- Medical insurance issues
- Patient's lack of understanding of next steps:
 - Diagnosis
 - Palliative Care
 - Survivorship
 - Hospice/End-of-Life

Supporting a Smooth Care Transition

Barriers	Solutions
Confusion about who continues with care	Identify who gets the handoff
Team members may be misinformed about next steps	Ensure that everyone knows about the transition
Patient may feel that the support system is shrinking	Continue to advocate for the patient



Lesson 5: U.S. Healthcare System, Payment & Financing

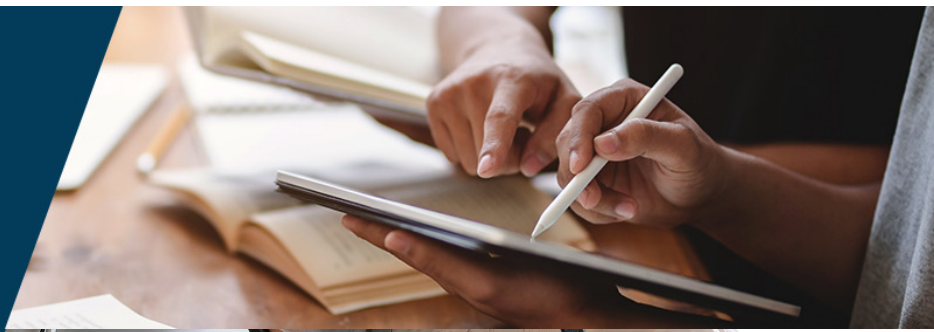
Learning Objectives

1. Compare hospital structures (public, non-profit, private)
2. Describe how cancer care may be structured and delivered
3. Compare inpatient and outpatient care delivery
4. Describe types of care and types of health professionals involved in different types of care
5. Describe how payment and health insurance works
6. Define key insurance terms
7. Describe public and private health insurance options, including patient eligibility



Key Takeaways

- There are three main types of hospital systems: public (funded by government), non-profit (community or religious), and private (investor-owned).
- Cancer care can be delivered in various settings, from free-standing centers to hospital-based programs.
- The distinction between inpatient and outpatient care affects costs and insurance coverage. Inpatient care involves admission to a hospital, while outpatient care includes services like clinic visits and X-rays without admission.
- There are various specialties within the cancer continuum like primary care (first point of contact), urgent care, and long-term care.
- A wide range of healthcare professionals contribute to care, including doctors, nurses, therapists, pharmacists, and social workers.
- Most Americans rely on health insurance to cover medical costs. Key terms to understand include copays, deductibles, premiums, and co-insurance.
- Public programs like Medicare (for seniors and people living with certain disabilities) and Medicaid (for low-income individuals) cover a portion of the population. Private insurance is typically employer-sponsored or obtained through marketplaces.
- The Affordable Care Act (ACA) expanded health insurance coverage, mandated essential health benefits, and provided subsidies for low- and middle-income individuals.



Hospital Systems

Oncology patient navigators work in a variety of settings and need to understand differences between types of hospital systems. A hospital system is a group of hospitals or facilities that work together to deliver services to their communities. Different types of hospital systems have different types of ownership and financial goals.

Public Hospitals

Public hospitals are funded and owned by local, state or federal governments and receive money from the government. Some public hospitals are associated with medical schools.



Non-profit Hospitals

Non-profit hospitals are often community hospitals and are sometimes associated with a religious denomination.



Private Hospitals

Private hospitals are owned by investors, to whom they are accountable.



Cancer Care Delivery⁷³

Cancer care can be delivered in different settings:

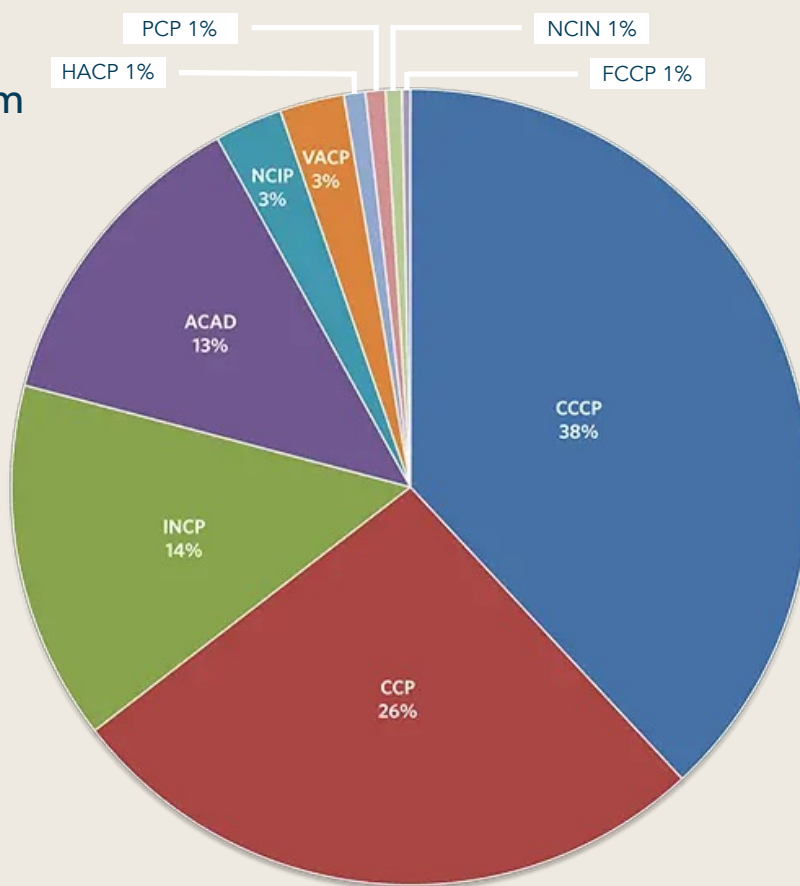
Academic Comprehensive Cancer Program (ACAD) - Provides postgraduate medical education in at least four program areas, including internal medicine and general surgery. The facility sees more than 500 newly diagnosed cancer cases each year.

Community Cancer Program (CCP) - Sees more than 100 but fewer than 500 newly diagnosed cancer cases each year, while a Comprehensive Community Cancer Program (CCCCP) sees 500 or more cases each year.

Free Standing Cancer Center Program (FCCP) – A non-hospital-based program that offers at least one cancer-related treatment, with the full range of diagnostic and treatment services available by referral. There is no minimum caseload requirement for this category.

Hospital Associate Cancer Program (HACP) - Assesses 100 or fewer newly diagnosed cancer cases each year and has a limited range of diagnostic and treatment services available on-site. Other services are available by referral.

Make-up of cancer program categories in the US.



Integrated Network Cancer Program (INCP) - Facilities belong to an owner organization and offer integrated and comprehensive cancer care services. The owner organization is overseen by a centralized governance structure/board and CEO.

NCI-Designated Comprehensive Cancer Center Program (NCIP) - Secures a National Cancer Institute (NCI) peer-reviewed Cancer Center Support Grant and is designated a Comprehensive Cancer Center by the NCI. A full range of diagnostic and treatment services and staff physicians are available.

NCI-Designated Network Cancer Program (NCIN) - Facilities belong to an owner organization and offer integrated and comprehensive cancer care services. The owner organization is overseen by a centralized governance structure/board and CEO. Additionally, the facilities secure a National Cancer Institute (NCI) peer-reviewed Cancer Center Support Grant and are designated a Comprehensive Cancer Center Consortium by the NCI. To be included in the NCIN, all facilities must be included within the NCI grant.

Pediatric Cancer Program (PCP) - A stand-alone facility that provides care to children and adolescents below the age of 18 (a center that cares only for teens and older is excluded). The pediatric facility or pediatric oncology program offers the full range of diagnostic and therapeutic services for pediatric patients. The pediatric facility is required to participate in cancer-related clinical research, including the enrollment of patients in cancer-related clinical trials. There is no minimum caseload requirement for this category.

CoC Pediatric Specialty Accreditation (CoC-PS) - A pediatric oncology program within an existing CoC-accredited facility that provides care to children and adolescents below the age of 18 (a program that cares only for teens and older is excluded). The pediatric oncology program offers the full range of diagnostic and therapeutic services for pediatric patients separate from the adult services. The pediatric oncology program is required to participate in cancer-related clinical research, including the enrollment of patients in cancer-related clinical trials. There is no minimum caseload requirement for this category.

Veterans Affairs Cancer Program (VACP) - Provides care to military veterans and offers the full range of diagnostic and treatment services either on-site or by referral, preferably to CoC-accredited cancer program(s). There is no minimum caseload requirement for this category.









Inpatient and Outpatient Care Delivery

Inpatient - A patient becomes an inpatient starting when they are formally admitted to a hospital with a doctor's order. The last day of their inpatient stay is referred to as 'Discharge Day'.

Outpatient - A patient is an outpatient if they're getting emergency department services, observation services, outpatient surgery, lab tests, X-rays, or any other services at a hospital, clinic or associated facility, and the doctor has not written an order to admit them to a hospital as an inpatient. Most adult cancer care is delivered in an outpatient setting.



Types of Care

-  **Primary Care** - Primary care should be the first place patients go for non-urgent medical care.
-  **Specialty Care** - Care for a patient who has a health problem or illness that requires special knowledge in one medical area.
-  **Emergency Care** - Involves diagnosing and treating life-threatening illnesses or injuries that need immediate attention.
-  **Urgent Care** - Not life-threatening, but is care for an illness or injury that needs immediate attention.
-  **Long-term Care** - Care for someone who is not able to perform daily living activities.
-  **Skilled Nursing Facility** - Can help when patients need help with a mental illness or emotional crisis.
-  **Hospice Care** - Focuses on care to manage symptoms rather than cure a disease toward the end of life.
-  **Mental Health Care** - Can help when patients need help with a mental illness or emotional crisis.

Doctors

- Primary Care Doctors
- Specialists
 - Medical oncology
 - Radiation oncology
 - Surgical oncology
 - Gynecologic oncology
 - Hematology
 - Radiology



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** - The medical field of imaging. Radiologists provide diagnostic services for patients by taking images of the body. Interventional Oncology Radiologists specialize in the diagnosis and treatment of cancer and cancer-related ailments; however, the entire field of Radiologists is not specific to cancer.
- **Pathology** - 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 tissue samples to diagnose cancer.
- **Radiation oncology** - A field focused on providing cancer treatment to patients using radiation.
- **Hematology/oncology** - The specialty that provides chemotherapy treatment to people diagnosed with cancer.
- **Surgery** - A specialty that treats people diagnosed with cancer.

Healthcare Professionals

Advanced Practice Providers <ul style="list-style-type: none">• Physician Assistants (PA)• Nurse Practitioners (NP)• Clinical Nurse Specialists (CNS)• Advanced Practice Nurse (APRN)	<p>PAs and NPs can:</p> <ul style="list-style-type: none">• Perform physical exams, order tests, diagnose illnesses and prescribe medicine, assist in surgery, and provide preventive health care counseling.• Provide patient education and symptom management.• Provide new consults, order chemotherapy, or perform invasive procedures. <p>CNSs can:</p> <ul style="list-style-type: none">• Diagnose and treat acute or chronic illness in an identified population with emphasis on specialist care for at-risk patients and/or populations.• Consult with other nurses and clinicians on complex patient cases.• Provide clinical education for the nursing staff.
Nurses <ul style="list-style-type: none">• Licensed Practical Nurse (LPN)• Registered Nurse (RN)	<p>Nurses work closely with patients. Nurses' jobs and duties depend on their education, area of specialty and work setting. Each of these professions requires specialized training to be able to perform their functions.</p>
Social Workers	<p>Perform assessment, diagnosis, treatment, and prevention of mental illness, emotional, and other behavioral disturbances.</p>

Psychosocial Support

- Mental Health Professionals
 - Psychiatrist
 - Psychologist
 - Social Worker
 - Counselor
 - Marriage/Family Therapist
 - Licensed Clinical Counselor
- Religious Counselors / Chaplains

- Psychiatrists are medical doctors or MDs who diagnose and treat mental, emotional and behavioral disorders. This includes disorders of the brain, nervous system and drugs or chemical abuse. They can prescribe medications.
- Psychologists deal with mental processes, especially during times of stress. Most psychologists do not prescribe medicine, but treat patients with counseling and psychotherapy, or "talk" therapy.
- Social workers help patients and families cope with emotional, physical and financial issues related to an illness.
- Marriage and Family Therapists address a variety of subjects, including childhood counseling, relationship counseling, and divorce counseling.
- Licensed Professional Clinical Counselors work with patients on their mental health needs in a range of areas, including mental or emotional disorders, disabilities, and personal trauma.
- Members of the clergy such as priests, ministers and rabbis provide patients with spiritual support. They may listen to patients, counsel them on religious or spiritual philosophy.

Pharmacists

- Give medicines that are prescribed by a doctor
- Talk about how to use medicines
- Answer questions

Dosimetrists	<ul style="list-style-type: none">• Members of the radiation oncology team• Determine the appropriate type of treatment and dosage of radiation• Design a treatment plan for each patient
Dietitians	<ul style="list-style-type: none">• Registered Dietitian Nutritionists (RDN) are food and nutrition experts• May specialize in oncology nutrition• Provide medical nutrition therapy
Genetic Counselors	<ul style="list-style-type: none">• Assess patient risk for inheriting conditions or illnesses, including some types of cancer• Review genetic test results with patient and families• Support patient decisions based on genetic test results



Technologists and Technicians

Laboratory Technologists	Look for bacteria or parasites, analyze chemicals, match blood for transfusions or test for drug levels in the blood to see how a patient is responding to treatment
Radiation Technologists	Take x-rays, and perform CT (Computed Tomography) scans, MRIs (Magnetic Resonance Imaging) or mammography
Pharmacy Technicians	Prepare prescription medications, perform customer service and perform administrative duties

Therapists and Rehabilitation Specialists

Lymphedema Therapists	Treat lymphedema, which results in swelling and discomfort in the body.
Occupational Therapists	Work with patients who have physical, mental or developmental needs or disabilities
Physical Therapists	Test a patient's strength and ability to move and create a treatment plan
Radiation Therapists	Treat patients using machines that deliver radiation to shrink or destroy cancers
Respiratory Therapists	Treat and care for patients with breathing problems
Speech Therapists	Work with patients who have problems related to speech, communication or swallowing

Social Needs Support

- Health care teams increasingly screen for patients' social needs
- Patients who screen positive are connected to responsive resources
- Resources may be within or outside of the healthcare system, including organizations that provide housing, nutritional or transportation support

Administrative & Support Staff

- Clinic Care Coordinator
- Medical Assistant
- Patient Care Coordinator
- Medical Records Specialists
- Medical Billing Specialists
- Scheduler

Financial Support Staff

- Financial Patient Navigator
- Financial Counselor
- Prior Authorization Specialist

Volunteers

Volunteers are a special support in cancer care. Volunteers work in both administrative and clinical areas and their functions can vary widely. Tasks can include: working in reception areas and gift shops, facilitating wig/bra fittings, filing, escorting patients, providing directions, filing documents, providing rides, making calls, visiting with patients, fundraising, conducting health screening outreach, delivering documents, providing peer support, or assisting with patient support programming.

A Simple Visit

When patients visit their clinician, the visit involves many more people than just the doctor. Here's an example of health care professionals involved in a simple visit:

- Members of the administrative staff schedule the appointment, find the medical record, make a reminder call, greet the person and verify insurance information.
- A nurse or medical assistant records the patient's weight and vital signs, escorts the person to an exam room and records the reason for the visit.
- A patient navigator may help the patient write down questions to ask the doctor; a patient navigator identifies obstacles to coming to treatment appointments and helps the patient identify solutions to address these obstacles.
- The treating clinician may be a doctor, physician assistant or nurse practitioner who examines and talks with the patient to develop a diagnosis and plan of care.
- If a lab or radiology test is ordered, a technician does the test. Administrative staff may help ship out the sample, such as blood, skin, saliva, a lab will perform the analysis and write up the test results. The technician, nurse, or doctor will discuss the results with the patient. If treatment, such as medication is prescribed, a pharmacist fills the prescription.
- Medical billing experts then bill the patient's insurance for the office visit and either the test or the medication.



Health Care Financing⁷⁸

Collection of \$ (from patient and from public health insurance) + Reimbursement to clinicians/hospitals (by private insurance companies, government) = Health care financing

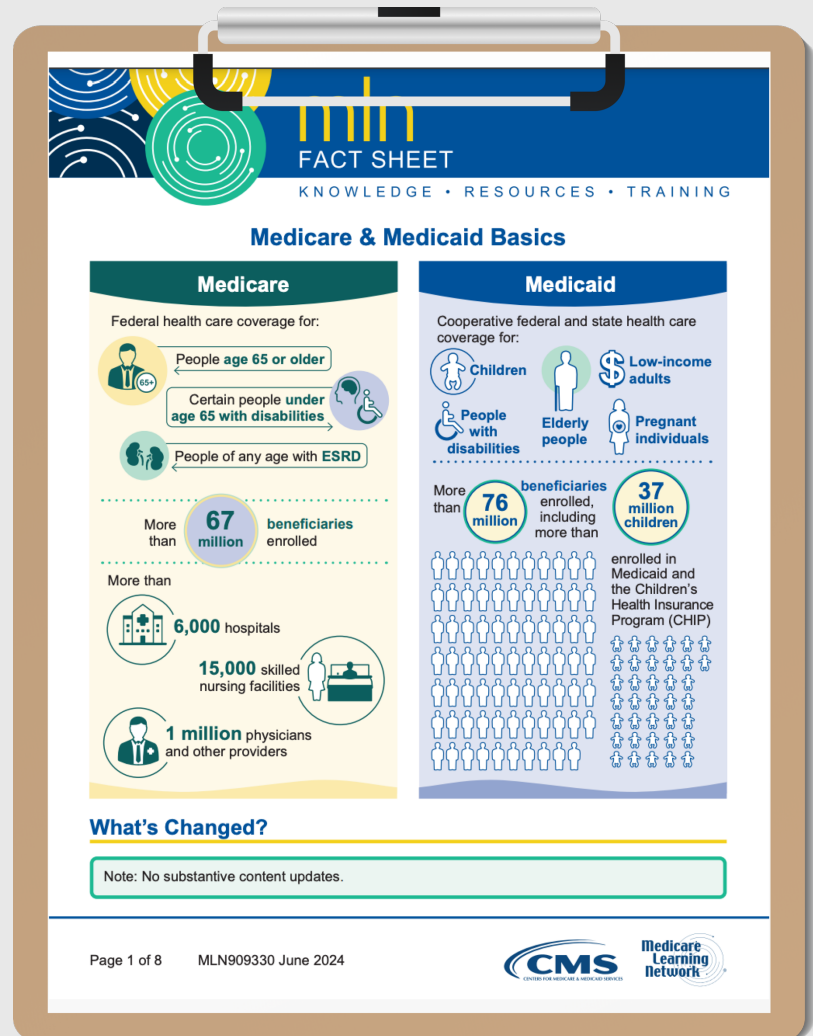
Insurance Terms⁷⁹

- **Copay** - An amount of money that a person with health insurance has to pay at the time of each visit to a doctor or when buying medicine.
- **Co-insurance** - An agreement between the patient and the insurer to both take on risk as well as payment responsibility.
- **Deductible** - The amount a person may owe for health care services that their health insurance or plan covers before their health insurance or plan begins to pay.
- **Premium** - The amount that must be paid for by the patient for a health insurance plan. A patient and/or their employer usually pay it monthly, quarterly or yearly.

Public Health Insurance⁸⁰

Medicare

- Single-payer program administered by the government
- Covers individuals aged 65 and over and some disabled individuals
- Divided into four parts:
 - Medicare A: covers hospital services
 - Medicare B: covers physician services
 - Medicare C: Medicare Advantage
 - Medicare D: offers a prescription drug benefit
- It is financed by:
 - Federal income taxes
 - A payroll tax (employers and employees)
 - Individual enrollee premiums (parts B and D)

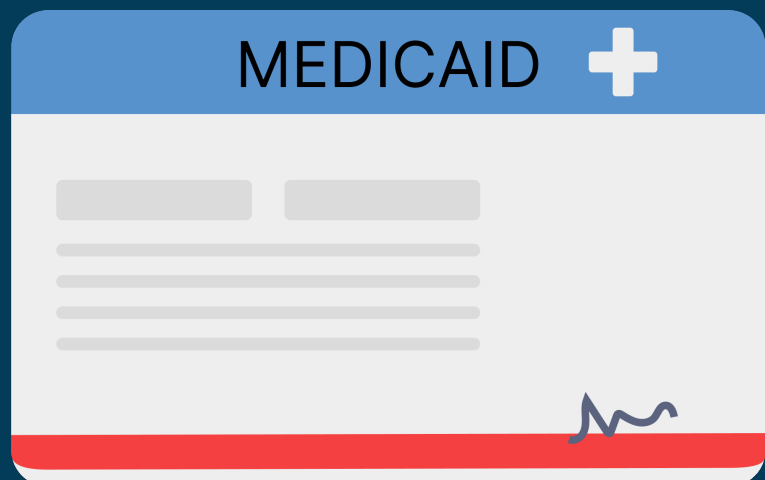


Medicaid

- Financed jointly by the states and the government through taxes
- By law must cover qualifying persons who are pregnant, children, elderly, disabled and parents/caretaker relatives
- States administer the program; each state is different and eligibility criteria may change year to year
- Benefits of the plan include prescription drugs and are fairly comprehensive
- Many clinicians do not accept Medicaid
- The Affordable Care Act gives states the option to expand Medicaid coverage with federal matching dollars

Medicaid in Tribes & Territories⁸¹

- Medicaid is available for American Indians and Alaska Natives and in U.S. territories
- The Center for Medicare and Medicaid Services (CMS) collaborates with the Indian Health Service to provide access to Medicare and Medicaid
- Program offerings and eligibility may vary in territories
 - Territories may use a local poverty level, rather than the federal poverty level, to determine eligibility



Other Public Systems⁸²

Children's Health Insurance Program (CHIP) - Designed in 1997 to cover children whose families make too much money to qualify for Medicaid but make too little to purchase private health insurance.

Veterans Affairs - Health care is delivered in government-owned VA hospitals and clinics. The VA is funded by taxpayer dollars and generally offers extremely affordable (if not free) care to veterans.

Private Health Plans

- Health Maintenance Organization (HMO)
 - Comprehensive services available
 - People can only see HMO doctors and hospitals
 - No or low deductible
 - Small copay
 - Must have a primary care clinician
 - 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
 - Person can choose any doctor or hospital
 - Fewer services may be covered
 - May cost more
- High Deductible Health Plan
 - Lower premiums but higher deductibles
 - Patients can see any doctor or hospital
 - Insurance pays for coverage after high deductible is met

Healthcare and Incarceration^{83,84}

- Correctional facilities are required to provide health services to people who are incarcerated, but provision of care varies widely across states and types of correctional facilities
- Inmates are responsible for their copays and out of pocket costs
- Incarcerated individuals are not eligible for coverage under the Affordable Care Act or Medicaid
- Generally, incarcerated individuals may receive Medicare coverage for Part A (hospitalization) and Part B (physician services), as long as required premiums are paid

The Patient Protection and Affordable Care Act^{85,86}

Commonly called the ACA or “Obamacare” went into law on March 23, 2010

Key points of the Patient Protection and Affordable Care Act

- Requires all health plans sold in new health insurance marketplaces to cover essential benefits
- Makes *US Preventative Services Task Force* A or B recommended cancer screenings and other preventive care available at no cost
- Medicare coverage of a yearly check-up
- Closes the “Donut Hole” in Medicare Part D
- Provides Coverage for clinical trials
- Removes financial limits on care and benefits
- Ends higher charges for people who are ill
- Limits the amount of out-of-pocket costs and deductibles
- Helps people and families with low to moderate incomes buy health insurance
- Covers children to stay on their parent’s insurance until the age of 26
- Ends rescissions (when the insurance company cancels a policy without the patient agreeing)
- Creates health insurance marketplaces
- Gives states the option to cover more low-income, uninsured people through Medicaid
- Makes more information available
- Groups health plans based on level of coverage
- Gives patients new rights to appeal claims that are denied by their insurer



Health Marketplaces (Exchanges)

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

Exchanges are set up in every state and are either run by the state or the federal government

- They can only sell qualified health plans
- They must provide 10 essential health benefits

To qualify for health coverage through the Marketplace, you:

- Must live in the United States
- Must be a U.S. citizen or national, or be a lawfully present non-citizen in the United States
- Can not be currently incarcerated

It is important to note that if someone has Medicare, they are not eligible to use the Marketplace to buy a health or dental plan.

Ten Essential Health Benefits⁸⁷

Under the Affordable Care Act, all individual and small employer health plans must include these 10 essential health benefits:

1. Ambulatory services
2. Emergency services
3. Hospitalization
4. Maternity and newborn care
5. Mental health and substance use disorder services, including behavioral health treatment
6. Prescription drugs
7. Rehabilitative and habilitative services and devices
8. Laboratory services
9. Preventive and wellness services and chronic disease management
10. Pediatric services, including oral and vision care

Lesson 6:

Professional Development and Practice-Based Learning

Learning Objectives

1. Develop and implement a professional development plan, including setting goals and finding opportunities to learn and improve.
2. Create professional development goals based on identified areas for growth.
3. Describe and implement strategies for building trust, performing duties accurately, and managing work efficiently.
4. List organizational, time management, problem-solving, and critical thinking skills to assist people effectively.
5. Identify and use potential information technology tools to enhance efficiency.
6. Identify sources of feedback for improving daily work and professional growth.
7. Develop and implement strategies for giving, receiving, and using feedback constructively.
8. Identify and use tools for dealing with ambiguity and uncertainty in professional settings.
9. Identify and implement self-care strategies for maintaining personal well-being.



Key Takeaways

- Set Specific, Measurable, Achievable, Relevant, Time-bound, Inclusive and Equitable (SMARTIE) goals to track progress and increase confidence.
- Identify areas for growth and create a development plan with specific actions and timelines.
- Utilize various resources like conferences, online courses, and networking to enhance skills.
- Prioritize active listening, respect, and responsiveness to foster strong patient relationships.
- Continuously seek new knowledge and skills to maintain competence in the field of oncology navigation.
- Develop strong organizational, time management, problem-solving, and critical thinking skills.
- Utilize technology tools to increase efficiency and streamline workflows.
- Implement effective workload management strategies, such as prioritizing tasks and delegating when appropriate.
- Actively seek and incorporate feedback from supervisors, peers, and patients.
- Use feedback models like the Feedback Sandwich or Pendleton Model to provide constructive feedback.
- Develop strategies for giving and receiving feedback effectively.
- Cultivate flexibility and adaptability to navigate changing circumstances.
- Employ problem-solving techniques to address challenges and make informed decisions.
- Prioritize self-care strategies like physical activity, healthy eating, and sufficient sleep.
- Recognize and address signs of stress, burnout, and compassion fatigue.
- Build resilience through practices like mindfulness, meditation, and seeking support from colleagues.

Purpose of Goal Setting⁸⁸

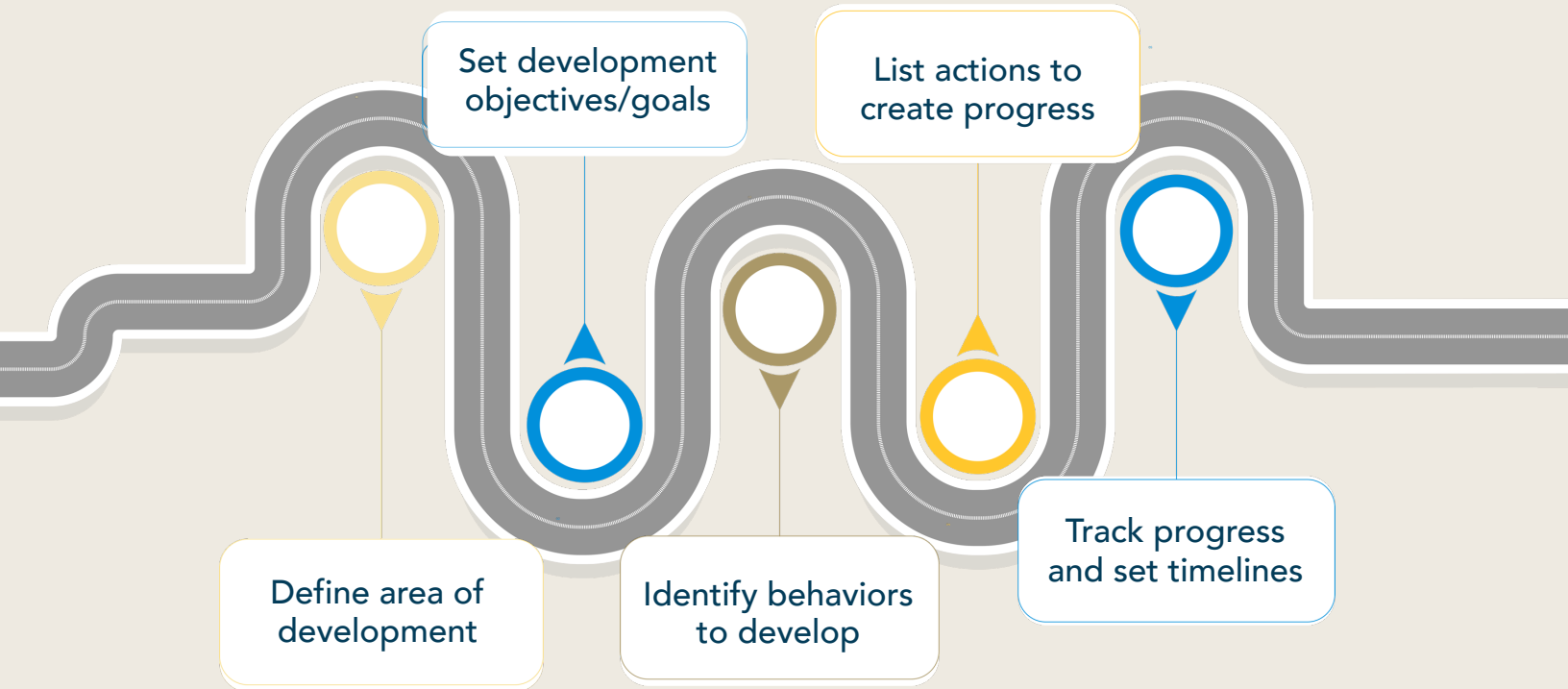


SPECIFIC
MEASURABLE
ACHIEVEABLE
RELEVANT
TIME-BOUND
INCLUSIVE
EQUITABLE

SMARTIE Goals^{89,90}

Specific, Measurable, Achievable, Relevant, Time-bound, Inclusive and Equitable (SMARTIE) goals offer a structured approach to setting clear and effective goals, whether for personal or professional development.

Creating a Professional Development Plan^{91,92}



Sources of New Knowledge

Opportunities to Learn & Develop Professionally⁹³

Professionalism⁹⁴

- Assume personal responsibility for professional development to gain and maintain knowledge in the best interest of patients
- Engage in ongoing professional development to strive for improved competence within their scope of practice
- Reflect on knowledge, skills, and attitudes to identify professional practice gaps and incorporate the principles of professional development and life-long learning to address these gaps
- Seek new knowledge and competence that reflect the current state of oncology navigation and cancer care and promotes critical and future thinking

Building Trust⁹⁵



Administrative Duties of the Patient Navigator⁹⁷

Main Duties

- Being organized
- Managing time
- Problem-solving
- Critical thinking
- Managing workload

Specific Duties

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

Organizational Skills⁹⁸

- Avoid multitasking
- Prioritize tasks
- Delegate tasks
- Communicate clearly
- Be organized
- Plan your projects
- Monitor progress
- Stay focused

Time Management⁹⁹

1. Structure your schedule
2. Time your activities
3. Commit to downtime
4. Be organized





Problem-Solving Skills¹⁰⁰



Critical Thinking Skills¹⁰¹

- **Analyze** - What's the issue?
- **Apply standards** - Where have I seen this before?
- **Critical distinction** - What is the priority?
- **Information seeking** - What don't I know?
- **Logical reasoning** - Why is this the way it is?
- **Predict** - What's going to happen?
- **Transforming knowledge** - What's worked before that I could try again?



Workload Management Daily Questions

To-Do List

1. What tasks must be completed today to directly impact patient care?
2. Is there something I'm doing that could be delegated to someone else, while staying within my scope of practice?
3. Are there responsibilities the patient or family members could take on that would benefit the patient's overall care and autonomy?

Managing Workload Tips¹⁰²

- Actively engaged does not equal productivity
- 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

Tools

- Electronic Health Records (EHR)
- Documentation template
- Navigation software
- Shared data systems
- Patient identification tools
- GW Patient Navigation Barriers and Outcomes Tool or PN-BOT (GW PN-BOT™)

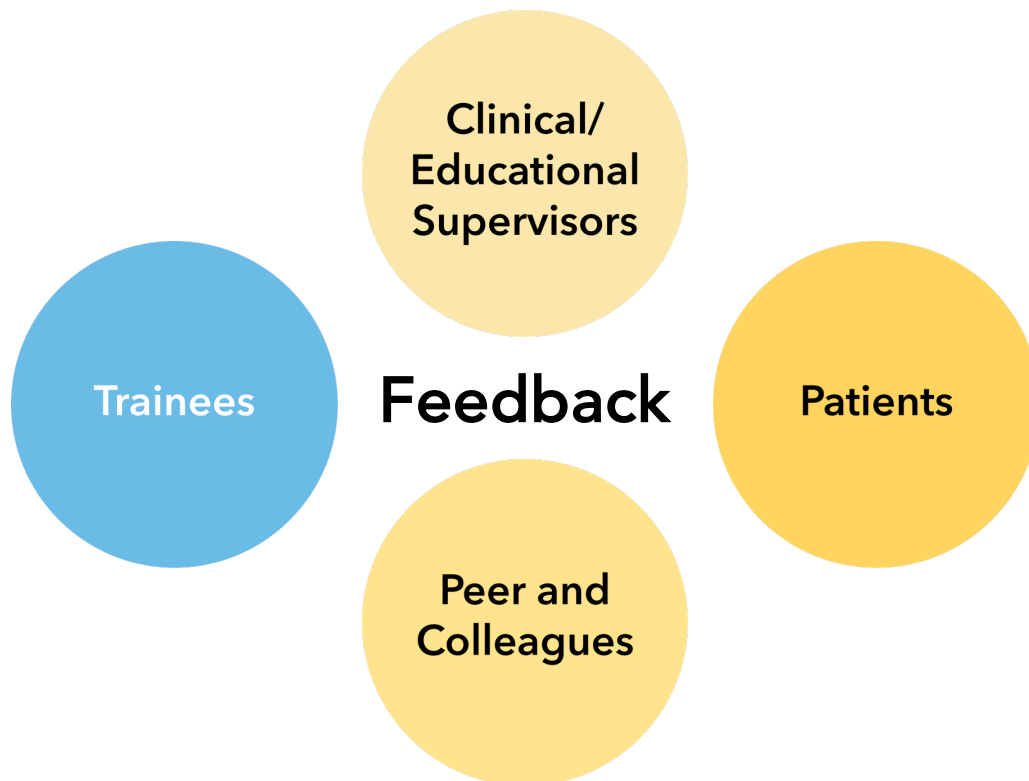
Daily Tips for Success

- Make a daily list of goals
- Check-in and collaborate with your team
- Keep office organized
- Prioritize activities
- Avoid over scheduling
- Communicate with supervisor



Feedback¹⁰³

Feedback is a valuable tool that encourages the recipient to reflect on their performance and use the information to make improvements.



Barriers of Giving Effective Feedback

- Generalized feedback that lacks specific details
- Lack of advice on how to improve
- Fear of upsetting the recipient or damaging the professional relationship
- Resistance or defensiveness from the recipient
- Physical barriers
- Personal agendas
- Lack of respect for the source of feedback
- Lack of confidence in providing feedback



Feedback Models

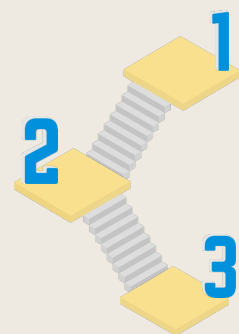
The Feedback Sandwich

This model begins and ends with positive feedback, with areas for improvement placed in the middle. While it can be useful for everyday feedback, overusing this method may reduce its effectiveness, as recipients may begin to anticipate the "but" in the middle.



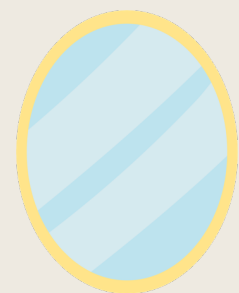
Chronological Feedback

This model involves giving feedback in the order events occurred, allowing the learner to see a step-by-step breakdown of their performance. It works well for short feedback sessions, but in longer sessions, it can become bogged down by details.



Pendleton Model

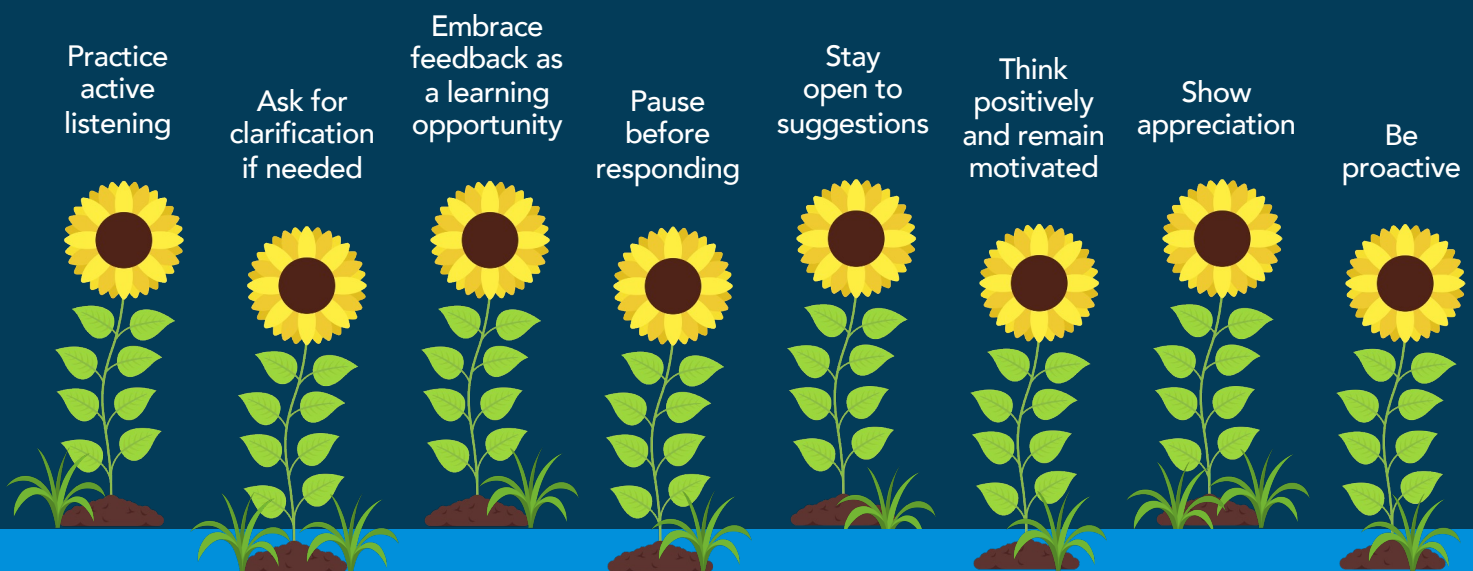
This learner-centered approach fosters conversation and helps the individual reflect on their actions. It begins by asking the learner to highlight what they think went well, then moves into areas for improvement. This method encourages reflection and the creation of an action plan. It aims to prevent defensiveness by focusing on positives first and using open-ended questions.



Principles of Giving Feedback

- Plan in advance
- Be specific
- Provide feedback promptly
- Start gently and encourage self-reflection
- Focus on key points
- Be mindful of nonverbal communication
- Follow up

Principles of Receiving Feedback



Incorporating Feedback into Daily Work

- Take time to write down suggested areas of improvement
- Carefully assess your daily routine and identify areas where you can integrate improvements
- Create notes and reminders
- Set aside time to plan
- Check in frequently with your colleagues or supervisor and communicate any changes or progress you have made

Responding to Ambiguity^{104,105}

- Cope with change
- Practice flexibility to improve your comfort with change
- Make decisions and act without having all the information
- Realize there will be risk and uncertainty
- Create a visual to understand the problem
- Get organized
- Take incremental action
- Dig deeper into the cause of the problem
- Reflect on your emotions
- Seek support








Understanding Stress

Stress is how you respond to a situation, good or bad, that is outside of our usual way of coping. Stress can result from:

- Expectations that are too high
- Situations that cause a conflict between your values and a patient issue or workplace challenge



Physical Symptoms of Acute Stress¹⁰⁶

-  Frequent illness
-  Headaches and muscle tension
-  Changes in eating or sleeping habits
-  Engaging in unhealthy behaviors
-  Emotional symptoms

Burnout¹⁰⁷

Gradual process by which a person detaches from work and other significant roles in response to prolonged stress

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

Health care professionals with burnout adapt to their exhaustion by becoming less empathetic and more withdrawn. Compassion fatigue is a sign they are not getting their needs met, and signs of compassion fatigue are a call to action.

Emotional resilience allows patient navigators to replenish their emotional reserves and respond effectively to the emotional demands of their work.



Managing Stress^{108,109}

1. Grounding
2. Unhooking
3. Acting on values
4. Being kind
5. Making room

Doing What Matters
in Times of Stress:
An Illustrated Guide



Symptoms of Compassion Fatigue

- Difficulty prioritizing or initiating routine tasks
- Difficulty with time management and/or frequent absenteeism or lateness
- Irritability, anxiety, or indecision
- Depression or feelings of hopelessness
- Lower sense of personal accomplishment, or irrationally high self-expectations
- Loss of initiative, energy, and self-care
- Less joy toward people or activities that once evoked happiness
- Exhaustion and physical symptoms, such as headaches, nausea, exhaustion, hypertension, frequent illnesses, gastrointestinal problems, and changes in eating or sleeping habits
- Substance abuse, such as using alcohol, drugs, or food to cope
- Loss of adaptability and inability to relax
- Preoccupation with minor issues or familiar tasks

Qualities of Emotional Resilience:

Ability to self-calm

Self-care practices

Ability to self-replenish

Emotional expressiveness

Nonjudgmental/self-supporting mindset (lack of perfectionism)

Optimism and hope

Hardiness and a sense of coherence

Strong social support network

Self-Care Strategies

Acknowledge and express emotions

Practice self-care: exercise, get enough sleep, practice work-life balance, and follow a healthy diet

Minimize life stress outside of work

Recognize signs of compassion fatigue and burnout across multidisciplinary teams

Seek mentorship and talk with coworkers after particularly challenging encounters

Engage with counseling and behavioral resources as needed

WORK-RELATED STRESS



Support Your Wellbeing¹¹⁰

As oncology patient navigators, balancing the demands of your work with personal well-being is important. A comprehensive approach to self-care is grounded in **purpose**—your reason for doing what you do each day.

Every other component of the graphic shown here supports that central purpose:



Natural Movement: Staying physically active not only improves your health but supports your ability to fulfill your purpose each day, especially when dealing with demanding situations.

Environment: Cultivating a workspace that supports focus and calm can help manage the intensity of your work.

Nutrition: Just as you support people in finding the right care, supporting your body with proper nutrition ensures that you have the energy to do your best work.

Recharge: This refers to ensuring you have enough time to rest, recharge, and maintain a healthy work-life balance.

Support & Belonging: Feeling connected to your colleagues, patients, and community is important in sustaining your emotional resilience.

Prevention: Regular self-care, including stress management and attending to your mental and physical health, acts as preventive care to avoid burnout and compassion fatigue.

Learning Objectives

1. Identify common barriers and solutions to effective communication
2. Identify and use strategies to improve communication
3. Describe tips to help patients improve communication
4. Describe methods to enhance cross-cultural communication
5. Identify and implement conflict resolution strategies
6. Describe strategies for handling difficult conversations
7. Define cultural competency
8. Describe strategies to understand your own potential unconscious biases
9. Describe strategies for dealing with your own biases
10. Compare ways in which diverse individuals are similar to and different from you
11. Identify and implement strategies for communicating with empathy
12. Describe how personal, cultural, ethnic, and spiritual beliefs shape an individual's interpretation and experience of their disease and treatment
13. Demonstrate sensitivity in one's approach to interacting with patients and others
14. Describe and apply Culturally & Linguistically Appropriate Services (CLAS) standards

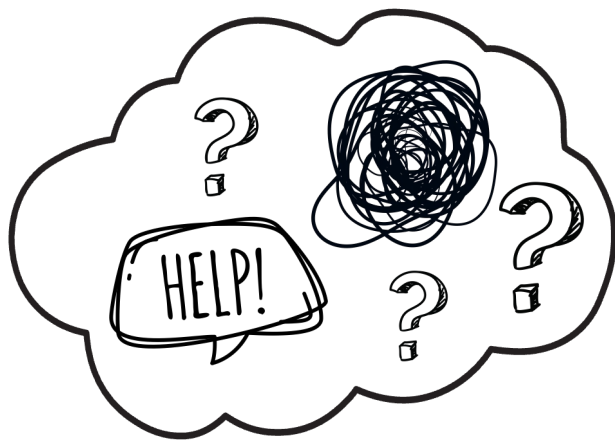
Key Takeaways

- Practice clear and open communication for understanding patient needs and improving health outcomes. It builds trust, reduces anxiety, and enhances adherence to treatment plans.
- Pay attention to both verbal and nonverbal cues, ask open-ended questions, and paraphrase to ensure understanding.
- Understand and respond to patients' emotions, validating their feelings and experiences.
- Respect diverse cultures and beliefs, and tailor communication to individual needs.
- Address conflicts calmly and professionally, focusing on problem-solving and finding common ground.
- Recognize personal biases and work to mitigate their impact on patient interactions.
- Use techniques like open-ended questions, affirmations, reflective listening, and summarizing to empower patients.



Build Rapport¹¹¹

- Clarify your role and how you can help
- Show interest in the person
- Anticipate patient and caregiver feelings
- Normalize the need to ask for help
- Listen to what the other person is saying and use open-ended questions



Communication Strategies¹¹²

Clear communication is essential for understanding your patients' needs and helping them overcome barriers to care.

Active listening:

- Making appropriate eye contact early in the interaction
- Asking open-ended questions
- 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

Reflective listening:

Making statements that capture and return to patients something about what they have just said and/or makes a guess about an unspoken meaning

Effective Communication¹¹³

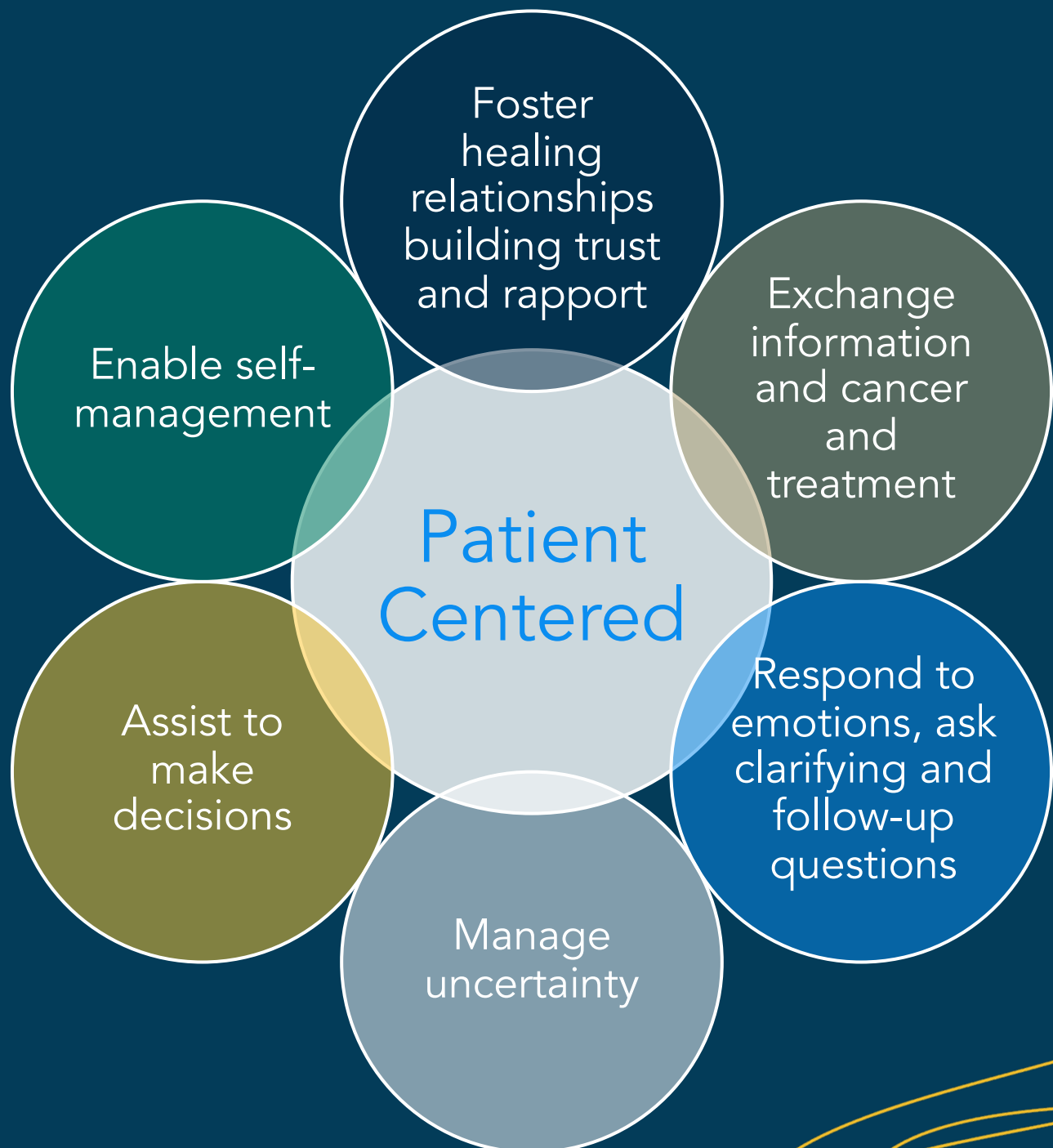
- Communication includes verbal and non-verbal messages
 - Spoken words
 - Written words
 - Body language
 - Listening, not interrupting
- Communication is affected by the physical environment, the people involved, their culture and individual characteristic

Importance of Communication

- Benefits of Good Communication
 - Improves satisfaction
 - Increases quality of life
 - Reduces anxiety
 - Improves symptom control
 - Increases adherence to treatment
 - Enhances clinical trials accrual
 - Improves understanding of disease
 - Improves awareness of prognosis
 - Improves likelihood of care consistent with person's preferences
- Risks of Poor Communication
 - Discontinuity of care
 - Compromises safety
 - Uses resources inefficiently
 - Causes dissatisfaction
 - Reduces adherence to treatment







The National Cancer Institute Patient-Centered Communication Framework^{115,116}







Common Communication Barriers and Solutions¹¹⁷

Common Barriers

-  Physical environment (volume, distractions, privacy)
-  Not listening to the patient
 - Being distracted
 - Judging the patient
 - Information overload
 - Focusing on a personal agenda
-  Misperception of patient's meaning
 - Stereotyping and generalizing
 - Rushing
 - Distorted focus
 - Making assumptions
 - Getting mixed signals
-  Poor verbal communication by navigator
 - Lacking clarity
 - Using stereotypes and generalizations
 - Jumping to conclusions
 - Dysfunctional responses
 - Lacking confidence

Solutions¹¹⁸

-  Quiet, private, non-distracting location
-  Effective listening
 - Stop, look, listen
 - Be empathetic
 - Ask questions
 - Paraphrase
-  Accurate perception
 - Analyze your own perceptions
 - Work to improve them
 - Focus on others
-  Improved verbal communication
 - 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
 - Use affirming responses

Facets of Motivational Interviewing: **OARS**^{119,120}

- Ask **o**pen-ended questions
- Offer **a**ffirmations
- Practice **r**eflective listening
- **S**ummarize the visit

Ambivalence¹²¹

Ambivalence refers to having mixed or uncertain feelings about something. Some patients may feel unsure about their illness and might not be certain about how much information they want or can process.

To address ambivalence, try:

- Exploring the pros and cons of knowing details and not knowing
- Acknowledging the difficulty of a person'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



Open-ended Questions¹²²

- 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

Open-ended Question Starters

Tell me about...

To what extent...

What does...

Help me understand...

How did you...

What, if any...

Affirmations

- I appreciate that you are willing to meet with me today.
- You are clearly a very resourceful person to cope with such difficulties for so long.
- Thank you for sharing that with me.
- That's a good suggestion.
- I've enjoyed talking with you today.
- You are such a great advocate for yourself.
- It can be hard to do something for yourself, so I applaud you for taking time to do something that makes you feel good.
- Thank you for trusting your team to help you through this journey.

Summarizing

A summary restates the key parts of the conversation. The summary may include:

- Thoughts
- Concerns
- Plans
- Reflections

A summary can be useful in a number of ways. It can help the person:

- Recall the conversation
- Think of new ideas
- Plan their next steps
- Feel more confident about moving forward
- Reinforce conversation
- Show you've been listening



Supporting Open Communication¹²³

- Build trust
- Facilitate communication
- Address concerns
- Address individual factors

Tips for Patient Communication Coaching¹²⁴

Encourage
them to be
assertive

Express your
feelings

Help them
use "I"
messages

Teach them
active
listening

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



Conflict Resolution¹²⁵

- Work at talking about the issues
- Recognize the value of the conflict
- Recognize conflict is a spiral and you can change the direction of the spiral
- Emphasize common goals
- Check perceptions
- Use competent communication techniques
- Agree to disagree
- Attack the problem, not the person



Primary Strategies

Flight

Avoiding conflict and hoping it will go away

Fight

Using authority, rights or force to attempt to prevail over others

Unite

Talking with other people to develop solutions that will satisfy mutual interests, some result that they all can "live with"

Difficult Conversations

You may encounter difficult conversations when dealing with:

- High emotions
- Challenging or demanding
- Family member confrontations
- Disappointing information

To navigate difficult conversations, try:

- Validating patient fear
- Encouraging the patient to talk with the doctor about concerns and questions
- Seeking to connect patient with appropriate health care professional
- Being empathetic, without physical touch
- Remaining firm when necessary
- Using active and reflective listening strategies
- Remaining non-judgmental



How to Break Bad News Using **SPIKES**¹²⁶

S – Setting up the interview

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

P – Perception

- What is the patient's understanding of the situation?

I – Invitation

- Assess patient preference for information

K – Knowledge and information to the patient

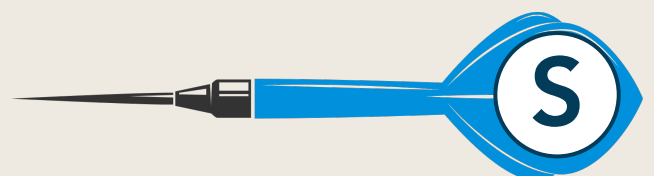
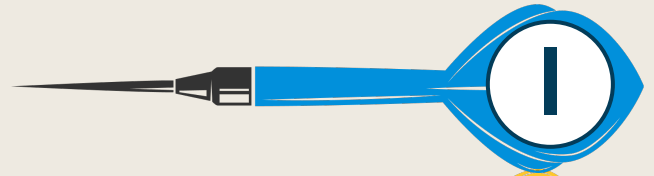
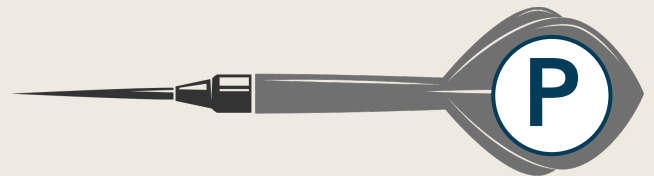
- Avoid excessive bluntness
- Give information in small chunks, and check for understanding
- Use plain, non-technical language

E – Access Emotions with Empathic responses

- Observe patient's reaction
- Allow for silence
- Use empathic statements

S – Strategy & Summary

- Check for understanding
- Make an action plan



Cultural Competency¹²⁷

Cultural competency emphasizes the need for healthcare professionals to be aware of, and responsive to, cultural perspectives and backgrounds of patient and family preferences, values, and that cultural traditions, language, and socioeconomic conditions are respected.

- Cultural Competency
 - Builds knowledge and skills
 - A fixed goal that can be achieved
- Cultural Humility
 - A commitment to self-reflection, self-critique, and an openness to learn from others
 - An ongoing development

Acknowledge the Influence of Culture¹²⁸

Many factors, such as a person's personal, cultural, racial, ethnic, and spiritual beliefs significantly impact their life and their healthcare decisions. As a culturally sensitive navigator, you must acknowledge and respect these influences, using your understanding of a person's beliefs, attitudes, and behaviors to guide your interactions.

Culture can influence how your patients interact with you in a variety of ways. For example:

- | | |
|-------------------|-------------------------|
| • Health beliefs | • Religious beliefs |
| • Family customs | • Dietary customs |
| • Healing customs | • Interpersonal customs |

It's also important to remember that culture is not limited to just religious, racial, or ethnic groups. Communities like the Deaf and LGBTQI+ (lesbian, gay, bisexual, transgender, queer/questioning, intersex, and other sexual and gender minorities) have distinct cultural perspectives as well.

Personal and Cultural Barriers

Gender & Family Dynamics

- Preference for healthcare professionals gender
- Women may need husband's permission (patriarchal cultures)
- Adult children may make decisions for elderly parents (indigenous cultures)

Belief Systems & Cultural Norms

- Fear of questioning authority
- Seek religious/spiritual guidance before treatment
- Belief in non-Western medicine
- Opposition to surgery or placing foreign objects in the body
- Touch and eye contact may be considered inappropriate

Shame, Mistrust, and Acceptance

- Shame or fear of not having children/getting married
- Mistrust from LGBTQI+ individuals toward the healthcare system
- Difficulty accepting illness

Linking Communication to Health Outcomes

COMMUNICATION

PATIENT SATISFACTION

ADHERENCE

HEALTH OUTCOMES

Implicit Bias & Health Disparities¹²⁹

- Bias is the evaluation of something or someone that can be positive or negative, and implicit or unconscious bias is when the person is unaware of their evaluation
- Explicit bias implies that there is awareness that an evaluation is taking place
- Implicit (or unconscious) bias is when the person is unaware of their evaluation

Gaining Cultural Knowledge¹³⁰

Cultural Awareness

Individuals engage in self-examination of their own beliefs, values, prejudices, and communication patterns.



Cultural Knowledge

Individuals expand their understanding and familiarity with the cultural characteristics of different groups.



Cultural Sensitivity

Healthcare professionals develop empathy and a deeper awareness of others' differences, fostering understanding and showing respect for diverse cultural perspectives.



Cultural Implementation

Applying cultural knowledge in practice.



Assess Your Self-Awareness

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?"



Examine Your Biases

1. Keep a journal
2. Role-play difficult situations with colleagues
3. Record and review your encounters with patients with permission
4. Observe how colleagues work with similar patients

Strategies for Dealing with Your Own Biases¹³¹

Bias: Person has a high Body Mass Index

- Stereotype replacement - Acknowledge your bias. Think about why you made that assumption about their weight and how to avoid it in the future.
- Individuation - Take some time to get to know your patient as an individual.
- Counter-stereotypic imaging - Picture the individuals that you know who may be overweight or received a cancer diagnosis despite eating healthy and exercising.
- Perspective taking - Imagine yourself living what your patient has experienced.
- Increasing opportunities for contact - Actively seek to interact with different groups of people.

Strategies for Communicating with Empathy¹³²

1

Agenda setting

2

Questioning and history taking

3

Recognize a patient's empathic opportunity

4

Work toward a shared understanding

5

Empathically respond to the patient's emotions

6

Facilitate coping and connect to social support

7

Close the conversation

The EMPATHY Model¹³³



Eye contact

Muscle of facial expression

Posture

Affect

Tone of voice

Hearing the whole person

Your response



Effective Communication Strategies for Navigating Cultural Differences¹³⁴

1

Speak slowly and clearly

5

Avoid negative or leading questions

2

Give encouragement

6

Consider writing things down

3

Avoid slang, idioms, and sayings

7

Take turns speaking and actively listening

4

Ask one question at a time

8

Summarize and repeat what has been said

The RESPECT Model of Cross-Cultural Communication¹³⁵

Rapport

- Attempt to connect on a personal level
- Ask questions to understand 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 within the context of their culture
- Verbalize acknowledgement and legitimize the patient's feelings

Support

- Offer support in ways that are meaningful to the patient's background
- Involve family members/caregivers as desired
- Reassure the patient that your role is to provide assistance

Partnership

- Be flexible with regard to control dynamics
- Negotiate roles when necessary
- Value the patient's perspective as equally as the healthcare professional's perspective

Explanations

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

Cultural Competence/Humility

- Acknowledge any biases you may have and take proactive steps to educate yourself about the patient's cultural background
- Approach each patient as a unique individual
- Practice self-reflection to recognize your own limitations
- Engage in an ongoing process of self-evaluation and critique

Trust

- Take the necessary time and consciously work to establish trust

RESPECT

LEARN Model: Overcoming Obstacles in Cross-Cultural Communication

L

Listen to the patient, encourage the patient to talk with you, be open and non-judgmental.

E

Explain to the patient your perception of the problem.

A

Acknowledge differences AND similarities in your perception and the patient's perception.

R

Recommend solutions to the problem that involve the patient.

N

Negotiate the action plan that accounts for the patient's cultural needs and preferences.

Lesson 8:

Shared Decision-Making and Building Trust

Learning Objectives

1. Define shared decision-making and explain its benefits
2. Identify strategies to access patient desire and capacity in the decision-making process
3. Describe barriers to patient decision making and adherence to treatment-plan
4. Describe strategies for shared decision-making
5. Describe how to encourage active patient participation in decision-making
6. Explain how to determine patient preferences and priorities for treatment and ways to support patients in discussing preferences and priorities with clinician
7. Explain how to evaluate patient decision-making process in alignment with desired level of engagement
8. Define self-management and health promotion resources

Key Takeaways

- Shared decision-making is a collaborative process that empowers patients to actively participate in healthcare decisions.
- Assessing patient desire and capacity for decision-making is crucial, considering factors like culture, personal preference, health literacy, and emotional state.
- Effective communication is essential, especially for patients with low literacy or limited English proficiency.
- Addressing barriers to treatment adherence requires understanding factors like comorbidities, denial, and side effects, and implementing strategies to improve adherence.
- Supporting self-management empowers patients to take control of their health by providing education, practical support, and encouraging healthy behaviors.

Shared Decision-Making¹³⁷

Shared decision-making is a process in which patients are involved as active partners with the clinician in clarifying acceptable medical options and in choosing a preferred course of clinical care.

It can increase:

- 👍 Patient knowledge
- 👍 Patient adherence to treatment
- 👍 Patient and provider satisfaction
- 👍 Quality of life
- 👍 Individualized treatment
- 👍 Positive outcomes

It can decrease:

- 👎 Anxiety
- 👎 Missed appointments
- 👎 Cost of healthcare

Assessing Desire for Decision-Making¹³⁸

Assessing the capacity and desire of a patient and their caregivers to participate in their health management involves many factors.

- **Culture:** Patient navigators must be culturally sensitive when working with patients and their families. They should recognize and confront cultural biases, generalizations, and values.
- **Personal Preference:** Not all patients want to engage in decision-making, while some patients want to be involved in every decision.
- **Health Literacy:** Health literacy can significantly impact a patient's desire to participate in decision-making. Patient navigators should deliver information in an accessible and understandable way, using plain language and check for comprehension.
- **Emotional State:** Patients who are experiencing high levels of stress, anxiety, or depression may feel overwhelmed by the responsibility of making decisions.
- **Social Support:** The presence or absence of a supportive network can influence a patient's engagement in decision-making. Patients with strong support systems may feel more empowered to participate, while those without adequate support may need additional encouragement and assistance from healthcare professionals.
- **Medical Condition:** The patient's overall health and the severity of their condition can also affect their desire and ability to engage in decision-making.



Assessing Capacity for Decision-Making^{139,140}

Literacy: People with low literacy may struggle with reading, writing, speaking, or computing, which can affect their ability to solve problems. When working with patients with low literacy, tailor your approach to enhance their understanding.

Health Literacy: Health literacy is distinct from general literacy. While literacy refers to the ability to read and write and make sense of numbers, health literacy involves understanding health information and how to apply it to one's health and health care decisions.

Language: When working with patients who speak a different language from their physician, interpretation services are needed. In the U.S., most care is delivered in English, with some exceptions. For people with Limited English Proficiency (LEP), interpretation services in the patient's native language can facilitate effective communication and patient understanding.

Physical Condition and Environment: Factors such as comorbidities, pain, limited mobility, poor lighting, room temperature, and noise levels can distract a patient and add to their anxiety or fear, hindering their engagement in healthcare. A patient who is experiencing housing instability, an unsafe home environment or transitioning homes may also have lower capacity for shared-decision making.

Medical Trauma: Mistrust and fear have deep rooted history for some populations and may impact a person's capacity and desire to be engaged with the healthcare team. Medical trauma can also be rooted in a person's history of difficult procedures, past disappointing outcomes, and perceptions with previous care.

Learning Style: Patient navigators should use strategies from multiple learning styles to accommodate a patient's needs and check for comprehension.



Communication Considerations¹⁴¹

To provide culturally responsive care, it's essential to consider factors such as language, family structure, and religion or spirituality:

- Age
- Gender and sexuality
- Race and ethnicity
- Socioeconomic status
- Language
- Family structure
- Religion/spirituality

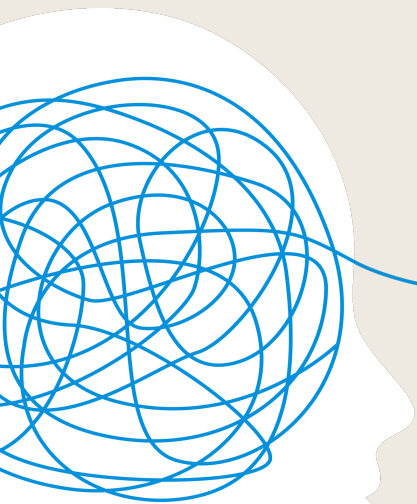
Assessing Lower Literacy^{142,143}



Clues That Your Patient May Have Lower Literacy

- ☐ Incomplete or poorly completed paperwork
- ☐ Difficulty completing health forms or questionnaires
- ☐ Missed appointments
- ☐ Nervousness, confusion, frustration or indifference in complex learning situations
- ☐ Points to text when reading
- ☐ Makes excuses not to read on the spot

Using Plain Language¹⁴⁴



Keep paragraphs and sentences short and simple.

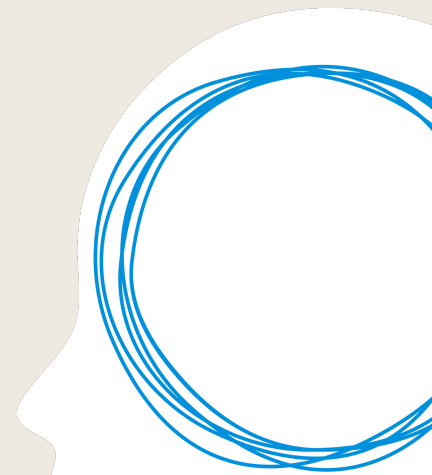
Use familiar language.

Use the active voice.

Define complex terms.

Use everyday examples.

Write in a friendly, conversational tone.



Limited English Proficiency (LEP)¹⁴⁵

Interpreter services are required by law and policy guidance:



Treatment Adherence & Self-Management¹⁴⁶

The extent to which a person's behavior—taking medication, following a diet and/or executing lifestyle changes, corresponds with agreed recommendation from a health care provider.¹⁴⁷

Barriers to Treatment Adherence

- Comorbidities: dementia/Parkinson disease
- Denial of cancer diagnosis
- Psychiatric illness
- Substance dependency (alcohol, drugs)
- The change treatment has on normal daily routines
- Not understanding treatment (appointment) instructions
- Forgetting the treatment
- Lack of immediate treatment effect and misconceptions about the treatment effect
- Therapy-related side-effects
- The treatment equipment itself (e.g. comfort of the mask needed for treatment radiation)

Essential Steps of Shared Decision-Making¹⁴⁸

- Seek your patient's participation
- Help your patient explore and compare treatment options
- Assess your patient's values and preferences
- Reach a decision with your patient
- Evaluate your patient's decision

Learning Styles: VARK Strategy¹⁴⁹

Visual

(pictures, charts, videos)

Auditory

(listening – verbal information)

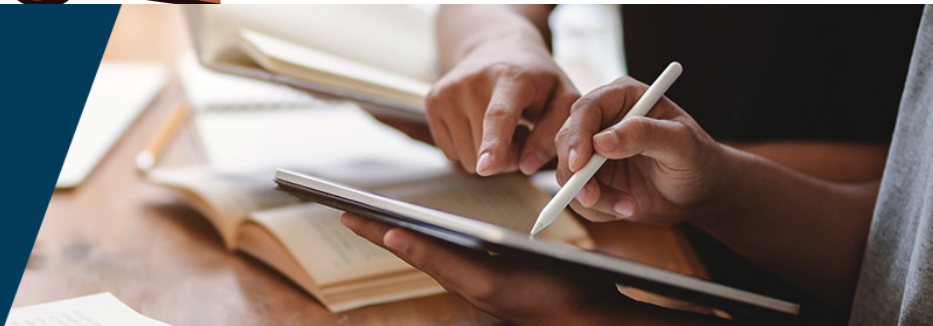
Read or write

(written words)

Kinesthetic

(hands-on learning)

Seek Patient Participation¹⁵⁰



Discussing Treatment Options & Preferences

- Understand what patients need to make informed decisions, and their goals and values
- Coordinate with clinicians
- Use decision aids and tailored information
- Communicate effectively
- Respect patient autonomy
- Return to the **5As**
(Ask, Assess, Advise, Assist, Arrange)¹⁵¹

A

Ask

A

Assess

A

Advise

A

Assist

A

Arrange

Accessing Values

- 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 (pictures, charts, videos), auditory (verbal information), written words, or kinesthetic (hands-on learning)
- How much information would you like to have about your diagnosis or treatment?
- How would you like us to reach out to you?
 - Give examples of text message, phone, email, or patient portal.
- Who are the key people in your support system, and how would you like them involved in your care?



Medical Trauma¹⁵²

While a patient may or may not directly have medical trauma, it's important to recognize the historical and ongoing impact of medical trauma on various communities. This awareness helps us provide more compassionate and culturally sensitive care.

MEDICAL TRAUMA

- Race-Based Medical Trauma
- Gender-Based Medical Trauma
- Forced Assimilation and Boarding Schools
- Indian Health Service (IHS) and Healthcare Disparities
- Forced Sterilization and Reproductive Coercion
- Ethical Violations in Research
- Cultural Insensitivity and Discrimination

Evaluating Patient Decisions¹⁵³

After a patient has reached a decision about treatment and the support services they want to receive, you need to evaluate your patient's understanding and decisions. It is common for patients to think that they understand the information provided to them, while not fully comprehending all of it.

- Check for understanding
- Patient and caregiver explains diagnosis and repeats back plans

Supporting Patients in the Decision-Making Process¹⁵⁴

- Deliver education
- Offer psychosocial support
- Encourage lifestyle modifications
- Enhance communication and decision-making support
- Facilitate care
- Translate medical information into plain language
- Provide ongoing support and encouragement
- Facilitate practical support
- Promote independence



Treatment Plan¹⁵⁵

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.

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

Barriers to Treatment Adherence

- Fail to fill prescriptions
- Disbelief that the medication was necessary or effective
- Unable to afford the medication
- Not wanting to take the medication
- Not wanting to change their behavior
- A desire to avoid the side effects of treatment
- Disbelief about the severity of their condition
- A perception of being too busy or too stressed to follow the treatment plan
- A feeling of being incapable of changing their behavior
- Uninvolved in treatment plan creation



Adhering to Treatment¹⁵⁷

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

Self-Management^{158,159}

Self-management encompasses various domains of health and functioning, leading to diverse outcomes. Increased patient self-management has been shown to significantly improve overall patient outcomes and quality of life.

Increases/Improves

- Emotional and mental health
- Self-confidence

Patient



Decreases

- Pain
- Nausea
- Fatigue
- Hopelessness

Typical Self-Management Tasks¹⁶⁰

- Tracking symptoms
- Scheduling doctors' appointments and lab visits
- Taking medications as prescribed
- Adopting healthy behaviors
- Determining what to do when symptoms cause problems

Lesson 9:

Patient Advocacy

Learning Objectives

1. Describe the terms advocacy and self-advocacy
2. Implement strategies for advocating for your patient
3. Describe components of self-advocacy
4. Assess patient capacity to advocate for themselves
5. Support personal empowerment to help patients and caregivers advocate for themselves
6. Identify strategies to support the patient's ability to advocate for themselves and communicate with the medical team
7. Describe strategies for advocating for quality patient care and optimal patient systems

Key Takeaways

- By actively supporting patients' needs and preferences, healthcare professionals can improve patient satisfaction and outcomes.
- When patients are actively involved in their care, they experience improved health outcomes, increased satisfaction, and a stronger sense of autonomy.
- By providing knowledge, fostering assertiveness, and developing essential skills, healthcare professionals can equip patients to effectively navigate the healthcare system.
- Understanding a patient's strengths, weaknesses, and needs allows for targeted interventions to enhance their ability to advocate for themselves.
- Effective communication is fundamental to patient advocacy and self-advocacy.
- System-level advocacy is necessary to create a healthcare environment that supports patient needs.

Patient-Provider Communication¹⁶¹

In a patient-centered communication model, patients are encouraged to express their wants, needs, and preferences with their entire care team. A care team may include:

- | | |
|---|--|
|  Medical oncologist |  Nurses |
|  Surgical oncologist |  Allied health care practitioners |
|  Radiation oncologist |  Research team members |
|  Advanced practice providers |  Patient support team members |



Definitions¹⁶²



Advocacy is the act or process of supporting a cause or proposal.

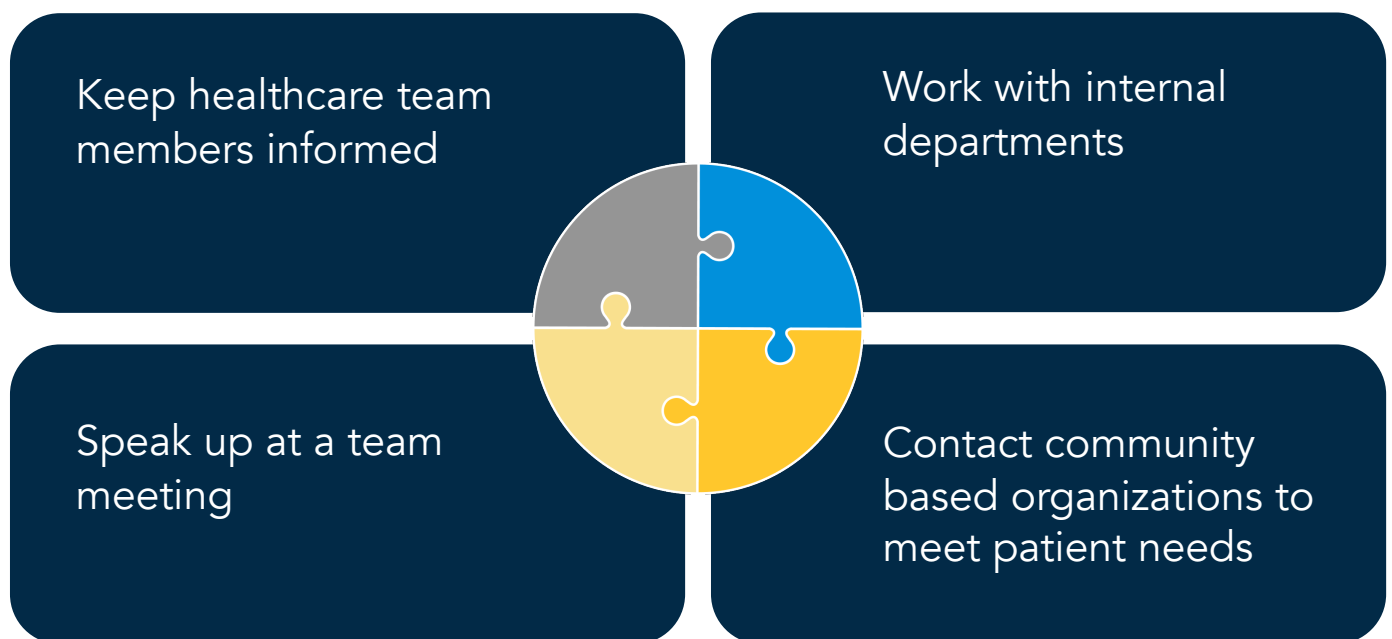
A **patient advocate** is a person who helps guide a patient through the healthcare system. This includes help going through the screening, diagnosis, treatment, and follow-up of a medical condition, such as cancer.

Self-advocacy is patient behavior to get their preferences, needs, and values met in the face of a challenge.

Strategies for Advocating for Your Patient

- Assess patient abilities, strengths and needs
- Determine when to advocate
- Build strong partnerships with clinicians while working toward system improvement to support patient-centered care
- Provide patients with the best evidence-based care that includes treatment options, decision-making tools, culturally and health literacy appropriate educational materials, and full disclosure of cost, side effects, and impact on quality of life
- Display confidence and assertiveness

Strategies to Advocate for Patients¹⁶⁴



Examples

- Write appeal letters
- Call utilities company

System Advocacy

- Speak up at tumor boards about patient needs
- Talk with doctors about common issues you see
- Convene a meeting with all of the relevant team members to collectively identify solutions
- Contribute to a state comprehensive cancer coalition
- Volunteer with local, regional and national cancer advocacy organizations
- Call state or national representatives to advocate for patient-centered programs and standards



Engagement Behavior Framework¹⁶⁵

This framework provides an overview of ways that patients can self-advocate to support their health and benefit from their care. Patients can:

- Seek good health care
- Communicate with their doctors
- Participate in their treatment planning
- Promote their health
- Organize their health care using various tools and resources
- Get preventative health care
- Pay for their health care
- Plan for their health care
- Plan for end-of-life care
- Make informed treatment decisions
- Seek knowledge about their health

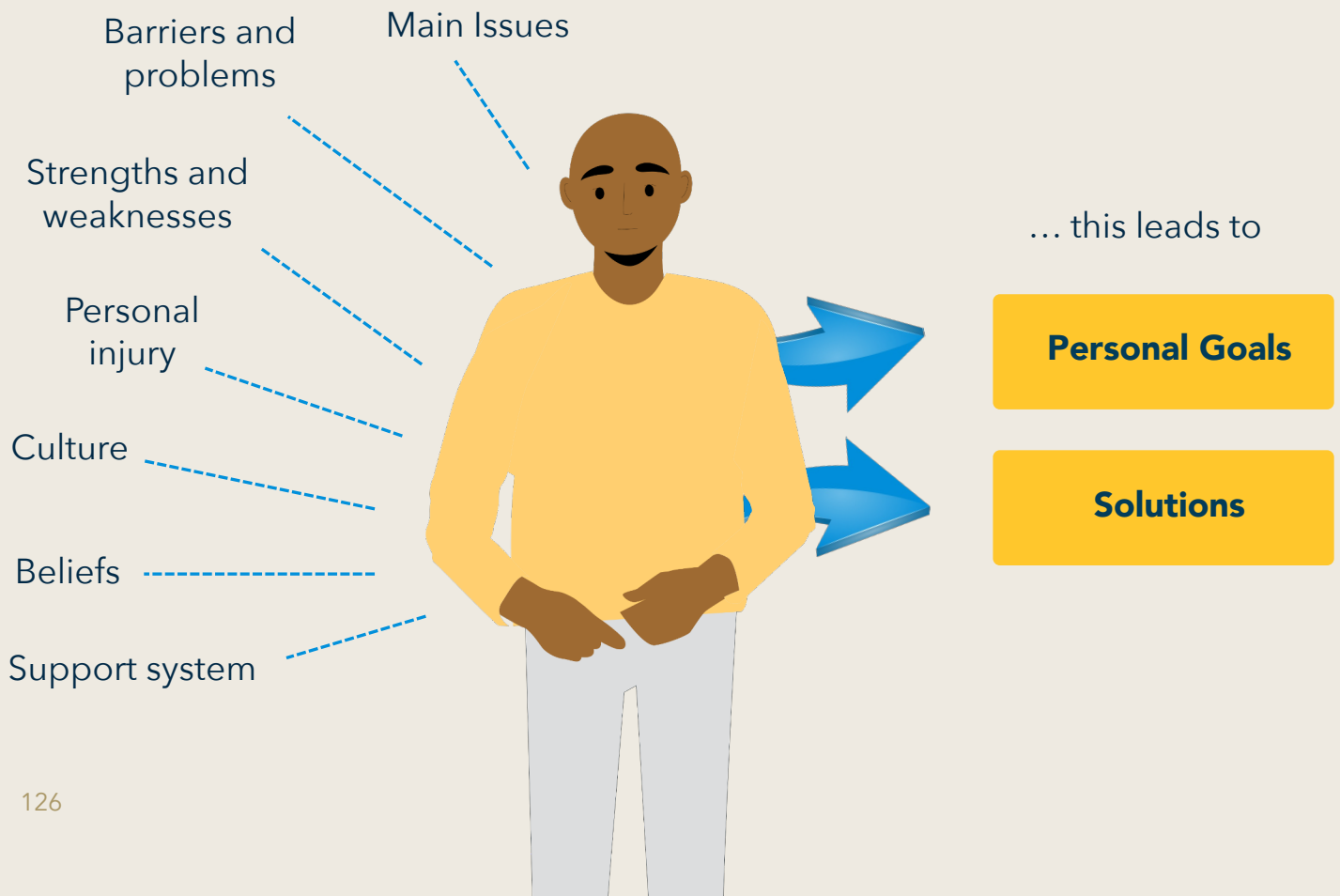
Outcomes of Patient Self-Advocacy¹⁶⁶

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



Learning About the Patient

Evaluate and understand a patient's...



Assessing 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 to advocate?

Does the patient have access to support?



Supporting Patient Empowerment¹⁶⁷





Strategies to Support the Patients' Ability to Advocate

Patient navigators can help patients to:

- Seek information
- Engage clinicians
- Talk to family and caregivers
- Organize preferences and priorities
- Use resources

Self-Advocacy Tools to Support Patients¹⁶⁹

- Checklist of questions to ask clinicians
- Checklist of items and documents to take to appointments
- List of local resources, such as support groups or financial and legal counsel
- Information packets

Basic Elements of Self-Advocacy¹⁶⁸

Informed Decision-Making

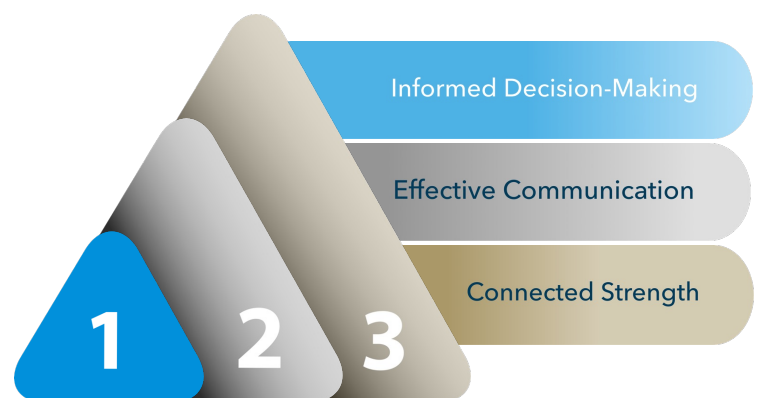
- Access health information
- Recognize opportunities to make decisions
- Weigh risks and benefits of various options
- Make decisions based on priorities

Effective Communication

- Ask questions
- Share opinions and preferences
- Discuss personal experiences
- Openly communicate concerns

Connected Strength

- Seek support from others
- Provide support to others
- Share their experience of cancer with others
- Raise awareness about cancer



Helping Patients Contact Organizations¹⁷⁰

Patients share the responsibility of finding and using resources and may need to directly contact organizations as well. Patient Navigators should assist the patients to:

- Prioritize who to contact
- Write things down
- Create a way to be organized

Helping Patients with Limited English Proficiency

- Find language-concordant services when possible
- Work with or find interpreter services
- Enlist family members, friends and neighbors to make calls in English and provide other support as appropriate
- Identify agencies that the patient can visit in person



Maintain Communication with the Patient

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

Lesson 10:

Addressing Barriers to Care with Strengths-based Community and Individual Assessments

Learning Objectives

1. Describe potential barriers to care that patients may encounter
2. Describe the purpose and navigator role in community needs assessments
3. Identify strategies to conduct a community needs assessment
4. Create a resource directory
5. Evaluate resources for appropriateness
6. Describe a framework to assess patient's strengths and assist patients
7. Identify strategies to remain neutral and non-judgmental
8. Determine and prioritize challenges to accessing care with a patient
9. Describe and apply strategies for helping patients cope with a cancer diagnosis
10. Identify situations in which clinical referral is required



Key Takeaways

- Recognize diverse barriers patients may face, such as physical, emotional, and financial limitations, is important for providing effective care. Addressing these barriers can improve patient adherence to treatment plans and overall health outcomes.
- Conduct community assessments helps identify specific needs and gaps in healthcare services. This information can be used to tailor interventions and allocate resources effectively, ensuring that the community's unique needs are met.
- Focus on a patient's strengths empowers them and fosters a positive mindset, which can significantly impact their ability to cope with illness and adhere to treatment plans.
- Have a non-judgmental approach builds trust and rapport with patients, encouraging open communication and honest self-disclosure. This can lead to better patient engagement and improved health outcomes.
- Work collaboratively with patients to identify and address barriers empowers them to take ownership of their health and make informed decisions.
- Assist patients in accessing necessary resources, such as financial assistance, transportation, and support groups, can alleviate stress and improve access to care.
- Teach patients effective coping strategies helps them manage stress, anxiety, and other emotional challenges associated with illness. This can enhance their quality of life and improve their ability to adhere to treatment plans.
- Identify situations that require clinical referral ensures that patients receive the appropriate level of care and support. Early intervention can prevent complications and improve overall health outcomes.
- Recognize the significant role of caregivers and providing them with support can improve patient outcomes and reduce caregiver burden.

Barriers and Facilitators to Care^{171,172}

Physical

- Pain
- Physical comfort and mobility
- Comorbidities
- Side-effects from treatment

Informational

- Decision-making
- Procedure & treatment understanding
- Resources
- Health literacy

Emotional

- Mistrust
- Anger
- Despair
- Fear & anxiety

Psychological

- Self-worth
- Body image & sexual health
- Coping
- Anxiety
- Depression

Social

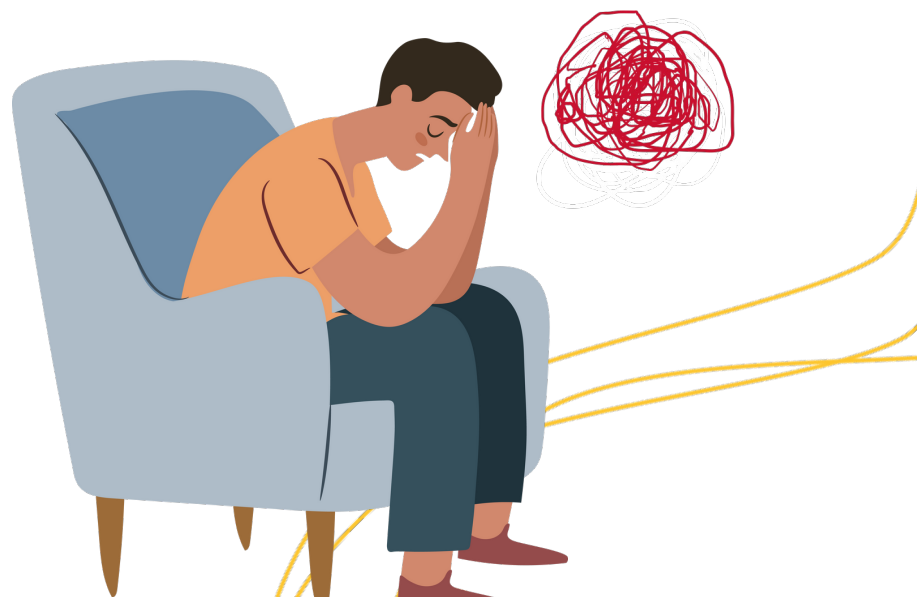
- Family dynamics
- Community reactions
- Work/school relationships
- Stigma & shame

Spiritual

- Meaning
- Beliefs
- Values
- Hopelessness/despair

Practical

- Finances
- Transportation
- Housing & basic needs
- Language & cultural barriers
- Work & insurance challenges



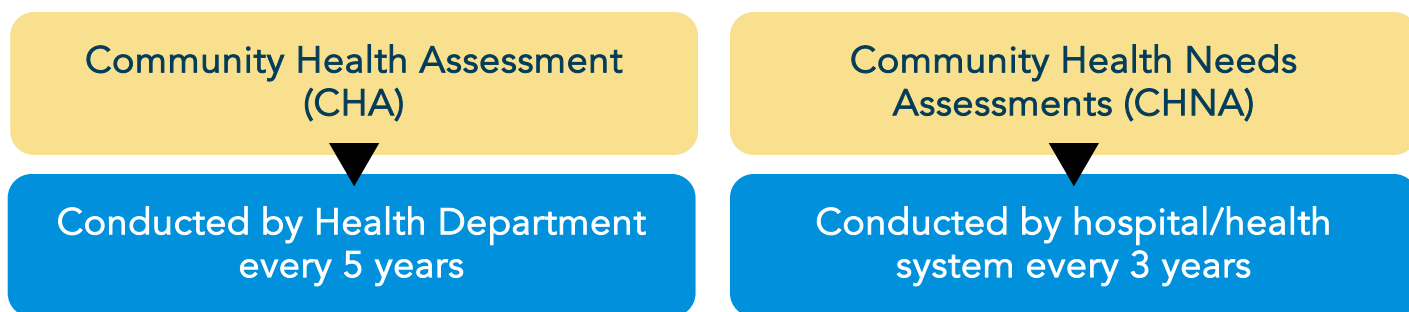
Where to Start?

To be well-informed and efficiently assist patients, navigators must understand:

- The make-up of the community and its local resources
- The make-up of the health system, its policies and resources
- The strengths and weaknesses of the support in the community, system and be able to identify resources or strategies to cover gaps

Community Assessments^{173,174}

Community assessments aim to collaborate and prioritize their communities' most significant health needs and implement strategies to address those needs.



Benefits Include:¹⁷⁵

- Improved organizational and community coordination and collaboration.
- Increased knowledge about public health and the interconnectedness of activities.
- Strengthened partnerships within state and local public health systems.
- Identified strengths and weaknesses to address in quality improvement efforts.
- Baselines on performance to use in preparing for accreditation.
- Benchmarks for public health practice improvements.

Roadmap for Assessing Barriers to Care¹⁷⁷

Step 1 - Conduct Analysis of Cancer Care Barriers

Review and analyze strengths and barriers within your cancer program.

Resources:

- Cancer Quality Improvement Program (CQIP) reports
- Patient satisfaction surveys
- Patient focus groups
- State cancer registry data and cancer program data
- Local and regional population health resources
- Community Needs Assessment
- Analysis of unique features within cancer program or state

Step 2 - Identify Barriers to Cancer Care

Identify barriers specific to your cancer program. Barriers can be patient-, clinician-, or system-level.

Examples:

- Specific population challenges to accessing care
- Implicit bias
- Gaps in community resources
- Policies and procedures that do not provide affirming care environments

Step 3 - Implement Strategies to Address Barriers

Leverage community resources to address barriers to care. Consider partnering with local community-based organizations.

Examples:

- Collaborate with local community health centers to sponsor a cancer screening event
- Find a local gym that offers American College of Sports Medicine/American Cancer Society-certified exercise trainers

Step 4 - Modify or Enhance Process

Assess process and short-term outcomes. Discuss ways to modify or enhance your process.

Tips for evaluating:

- Access your program at regular intervals
- Refer to your logic model and evaluation plan

Identifying Resources¹⁷⁸

Engage patients to help them identify their own strengths and personal network resources. This includes connections with family and friends. Next, explore local community resources, followed by state, regional, and national assets that can support patient needs.

Individual assets

- Talk to patients to identify strengths

Network assets

- Include patients' friends and families

Local community assets

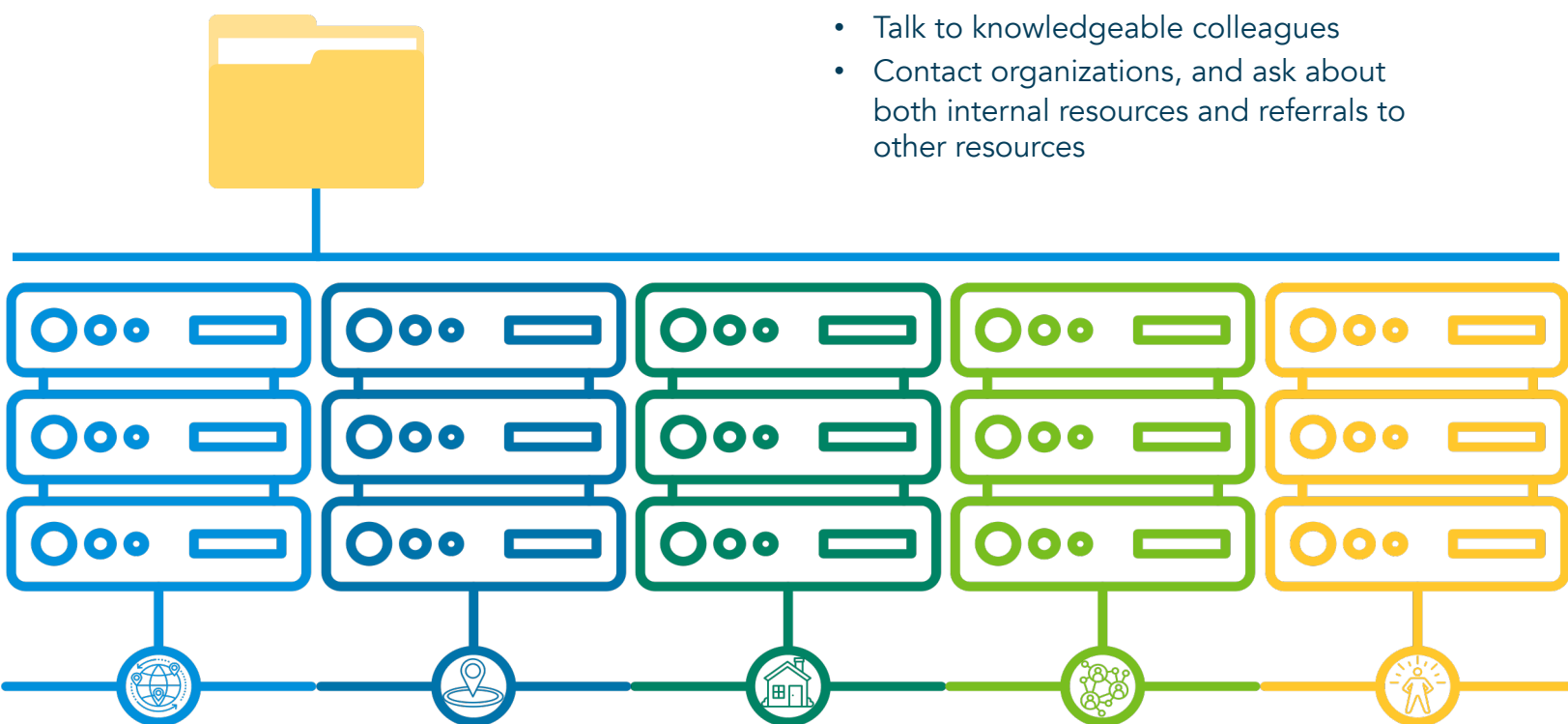
- Talk to key community members
- Talk to knowledgeable colleagues
- Scan local news sources
- Contact local organizations

State or regional assets

- Become familiar with state-level public benefits
- Scan internet and directories
- Talk to knowledgeable colleagues, network with other patient navigators across your area
- Contact organizations, and ask about both internal resources and referrals to other resources

National organization/federal assets

- Become familiar with public benefits
- Search the web, scan directories
- Talk to knowledgeable colleagues
- Contact organizations, and ask about both internal resources and referrals to other resources





Asset Mapping^{179,180}

Helps you identify and visualize helpful resources

Assets can be:

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



Making an Inventory of Local Organizations¹⁸¹

- Examine published materials
- Contact local institutions
- Contact opinion leaders and individuals



Make a Resource Directory

- Identify personal, network and community assets
- Interview individuals from reputable organizations
- Look for resources at local, state and national levels
- Include resources to meet basic needs in addition to disease-specific resources
- Complete resource directory form(s)
- Compile in a notebook or enter in database and use existing resource directories
- It is important to list eligibility requirements for any program and refer patients to resources they are eligible for to save time and distress

Evaluate Resources¹⁸²

Evaluate resources routinely for:

- Credibility
- Usefulness to patients
- Literacy level and language
- Accessibility
- Reliability

Is the resource you found a good fit for your patient?

- Does your patient want the resource?
- Is your patient eligible to receive the resource?
- Is your patient the intended audience for the resource?
 - Reading level, health literacy, culture, language, amount of information desired
- Can your patient feasibly access the resource?

Assessing Resources for Credibility

Sponsorship

- Who sponsors the site? Can you easily identify the site sponsor?
- What is the mission of the sponsoring organization?
- What bias may the organization bring to the information provided on their site?

Timeliness

How up to date is the site or resource?

Information

- Information should be factual. You should be able to verify the facts from a primary information source such as professional literature or other websites.
- Information represented as an opinion should be clearly stated and the source should be identified as a qualified professional or organization.
- Information should support, not replace, the doctor-patient relationship.

Audience

- The website should clearly state whether the information is intended for the consumer or the health professional.
- The design of the site should make selection of one area over the other clear to the user.

Privacy

Respect the privacy and confidentiality of personal data submitted to the site.

Financial Disclosure

The website should fully disclose funding sources.

Getting Ready to Contact the Organization

1. Know what you are asking for

- What assistance does the patient need?
- What is the patient's time frame?
- What information will the patient need to know?

2. Know who you are calling

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

3. Be persistent!

Contacting the Organization



Introduce yourself



Concisely state the need



Make sure you are talking to
the right person



Elaborate on details if needed



Ask key questions

Maintaining Relationships with Organizations

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

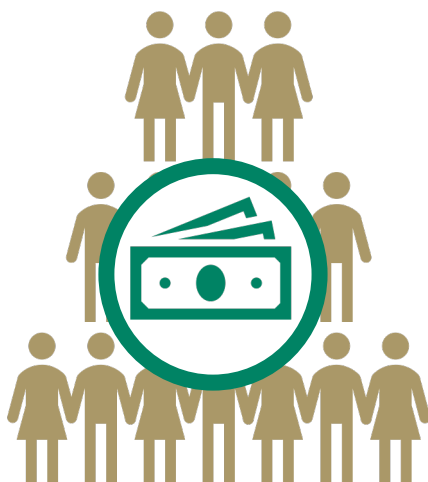
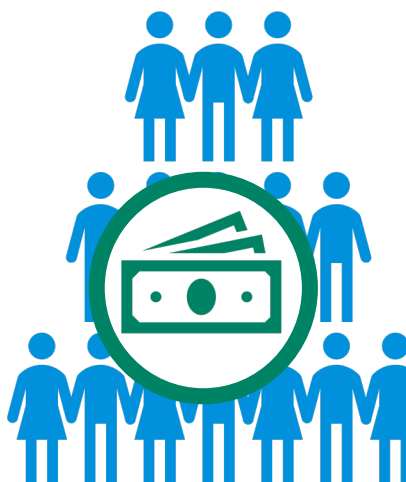


Stewardship of Resources

Don't overuse
resources

Prioritize resources
across patients

Ensure patients get
the most relevant
and helpful
resources for them



The 5 A's framework^{183,184}

A strategy to remove barriers to care and ensure patients have the support they need.



1. Ask
2. Assess
3. Advise
4. Assist
5. Arrange

Ask and Assess

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

Listen

Patient expresses
worries, fear,
concern, anger

Look

Expression of
doubt or anger,
disinterest

Clarify

You sound worried
that you will not be
able to...

Ask

What may make it
difficult to attend
your appointment?

Strengths-based Approach¹⁸⁵

- Assumes people have capacity to grow
- Relies on identifying patient strengths
- Has great potential to facilitate behavior change for chronic disease management
- Emphasizes these strengths to promote recovery and well-being

Remaining Non- Judgmental¹⁸⁶

- Not taking sides
- Active listening
- Not assigning value
 - Focus on understanding the patient's perspective
 - Reassure the patient that you're not there to persuade them one way or another
 - Reflect back what the patient says, without labeling it as good or bad
 - Assist the patient in considering the pros and cons of their decision, without pushing for a specific outcome

Elicit-Provide-Elicit¹⁸⁷

Elicit

- Ask the patient to tell you what they know

Provide

- With permission, provide your patient with new and additional information

Elicit

- Ask the patient for thoughts on what has been said



Advise

When you advise patients, you are helping to come up with a plan to meet their needs.

To develop a plan:

- Prioritize needs
- Involve patient in problem solving
- Focus will be on available resources to meet the patient's needs

Problem-Solving Cycle¹⁸⁸

You can guide patients in developing their own problem-solving skills by following these steps.

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

Assist

Once a plan has been developed to address the patient's barriers and needs, the next step is to begin assisting in its implementation.

- Assess patient understanding of treatment plan and options
- Assist the patient with making a list of questions
- Offer to help connect the patient with a clinician to have questions answered



Removing Barriers

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"> • Be empathetic • 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

Arrange

Implement the Action Plan and Follow-Up

- Document with the patient what tasks will be done, who will do them and what the deadline will be.
- Contact the patient by phone to offer reminders and update them on progress.
- Follow up during the next meeting with the patient.

When You Cannot Find Resources

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

What if you are not able to solve the problem with the patient?

You will not be able to solve every patient problem or address every barrier.

- May need additional coaching or counseling
- Bring in a colleague with the patient's permission
- With permission, bring in a counselor or a social worker to work with the patient



Finding Mental Health Support¹⁸⁹

Patient navigators do not diagnose or provide counseling. If you notice signs of generalized anxiety disorder or depression in a patient, refer them to their clinical oncology team or connect them with a mental health specialist, such as a licensed counselor, psychologist, or psychiatrist

Generalized anxiety

Excessive or out of control worry that hinders daily function (6+ months).

Signs and symptoms include:

- 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. Signs and symptoms include:

- 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.

Patient Navigator Role¹⁹⁰

A patient navigator should:

- 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

A patient navigator should **NOT**:

- 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





Patients Cope Differently Across a Spectrum



- | | | |
|--|--|--|
| <ul style="list-style-type: none">• Cannot discuss diagnosis, prognosis or emotions• Cope by avoidance, denial, venting and focusing on present and treatment options• May require referral for counseling | <ul style="list-style-type: none">• Comprehend situation, emotionally disconnected from prognosis• May be in touch with emotions but cannot express feelings• Intellectually and emotionally connected | <ul style="list-style-type: none">• Discuss prognosis openly, balance possibility of death with realistic hopes• Feel more resilient or able to be more present |
|--|--|--|

Coping Strategies¹⁹¹

Problem Focused - Aim to remove/reduce stressor or increase resources to manage it:

- Take control
- Seek information
- Weigh pros & cons

Emotion-Focused - Aim to regulate emotional distress:

- Talk to support persons
- Distract self
- Keep busy
- Ignore/deny
- Prepare self for the worst
- Think positively
- Pray

Mixed

Assist Patients to Choose Coping Strategies¹⁹²

Active Problem-Focused Strategies

- Seek information
- Set goals
- Make decisions
- Resolve conflicts
- Request help

Passive Problem-Focused Strategies

- Behavioral avoidance (not doing anything about stressor)
- Cognitive avoidance (denial, ignoring stressor)



Strategies for Uncontrollable Stressors

Active Problem-Focused Strategies

- Reappraise the situation (reframe thoughts)
- Exercise, massage, walks, meditation, relaxation
- Accept negative emotions
- Talk with support persons

Passive Problem-Focused Strategies

- Smoking, over or under eating, heavy drinking, substance abuse
- Not caring for self (missing meds, doctor appointments, low hygiene)
- Keeping feelings inside

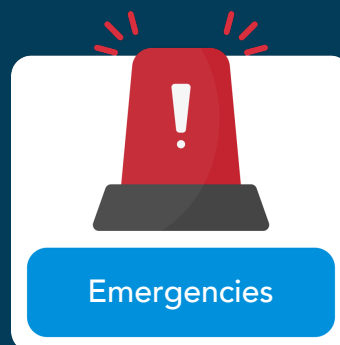
When to Refer to a Mental Health Specialist

- 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 themselves or others

Caregiver Concerns¹⁹³

- Encourage patients to bring a caregiver with them to their appointments for support and to help them write down questions and answers about their care
- Remember that caregivers need support, too
- Help caregivers find ways to rejuvenate and care for themselves, so they can continue to care for the patient
- CancerCare provides free support for caregivers
- Refer to Social Worker

When to Refer to a Clinician



Learning Objectives

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

Key Takeaways

- Autonomy, beneficence, non-maleficence, and justice guide ethical decision-making in healthcare.
- A structured approach to ethical dilemmas involves recognizing the issue, gathering facts, evaluating options, making a decision, and reflecting on the outcome.
- Strong relationships are built on respect, confidentiality, active listening, and clear communication.
- Patients have the right to privacy, informed consent, quality care, and respectful treatment.
- HIPAA protects patient privacy by regulating the use and disclosure of health information.
- Healthcare providers have a duty to warn, report abuse, and address patient self-harm.
- Dual relationships can compromise professional boundaries and should be avoided.
- Navigators must be aware of and manage potential conflicts of interest that may arise.
- Maintaining clear boundaries is essential to ensure the well-being of both the patient and the navigator.



What is Ethics?^{194,195}

Ethics is the formal study of morality from a wide range of perspectives and in healthcare based on four principles:

Autonomy

The ability to decide for oneself.

Beneficence

More than just avoiding doing harm. It is that of doing the best for another.

Nonmaleficence

The practice of refraining from causing harm or preventing intentional harm from occurring.

Justice

Actions that provide fairness or address the perception of what a person or community deserves.

Ethics does not equal:¹⁹⁶

- Emotions
- Religion
- Law
- Culture
- Science



Five Approaches to Ethical Behavior¹⁹⁷

Utilitarian approach focuses on the outcomes, aiming to choose actions that produce the most good and the least harm.

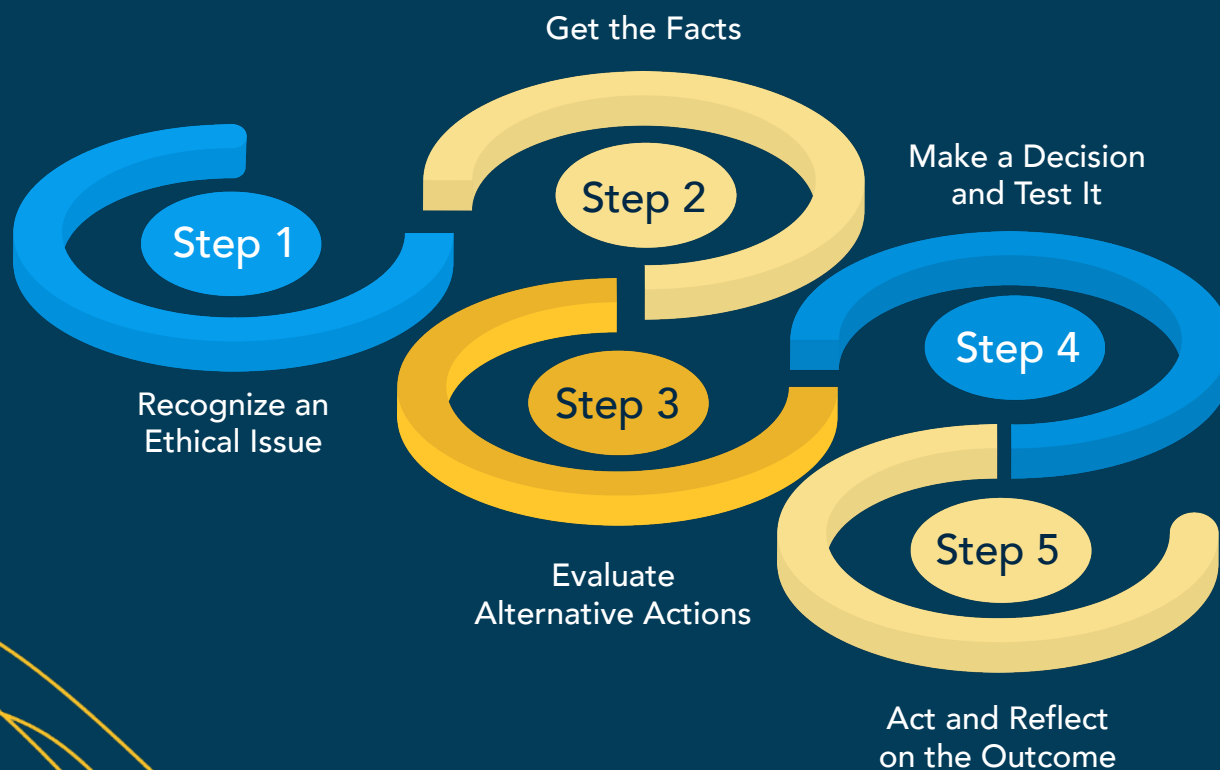
Rights approach is grounded in the belief that we must respect the inherent rights of others.

Fairness or justice approach emphasizes treating everyone equally, unless there is a valid and ethical reason to treat someone differently.

Common good approach highlights the interconnectedness of all people and encourages actions that promote respect and compassion, especially for the vulnerable.

Virtue approach suggests that ethical decisions should be guided by universal virtues, such as honesty, fairness, courage, compassion, and prudence.

Framework for Ethical Decision-Making¹⁹⁸



Ethics in the Healthcare System¹⁹⁹

- Respect the rights, dignity and safety of patients
- Respect clinician judgments
- Provide optimal clinical care to each patient
- Avoid imposing risks and burdens on patients
- Understand and address health inequalities
- Conduct continuous learning activities that improve the quality of clinical care and health care systems
- Contribute to the common purpose of improving the quality and value of clinical care and health care systems

Building Strong Ethical Relationships with Patients²⁰⁰

- Be clear about your role up front
- Keep patient information private
- Be patient with patients
- Listen actively and reflectively
- Focus on the patient
- Provide accurate information



Understanding Professional Boundaries with Patients²⁰¹

Boundaries distinguish a professional relationship from a social/personal relationship.

Establishing clear limitations helps to:

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

Actions outside professional boundaries:

- Giving patients your personal cell phone number
- Trying to be the patient's friend
- Sharing personal information
- Giving and receiving gifts/factors
- Making physical contact/touch

Strategies for maintaining professional boundaries:

- Use a strengths-based approach
- Refer to another professional

Blurring Boundaries²⁰²

- 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

Being a Navigator is Different from Being a Friend

Navigators:

- Represent society's support for the patient
- Are trained to give that support effectively
- Are a temporary relationship

A Caring Relationship is...

Reciprocal (mutual) in terms of empathy.

- The Navigator understands the emotions that the patient is feeling, which gains the patient's trust and creates a sense of commitment in the Navigator.

Not mutual in focus

- The focus for the Patient Navigator is other-directed
- The focus for the patient is **self-directed**

Not reciprocal in perspective

- The perspective for the Patient Navigator is **external**
- The perspective for the patient is **internal**



Evaluating Your Behavior²⁰³

- What are my intentions?
- What are the likely intended or perceived consequences of my actions?
- Do I have any bias?
- Is my professional relationship being maintained?



Conflicts of Interest²⁰⁴

When the needs or interests of a navigator impact the navigator's abilities to act professionally and focus on the needs of the patient.

- Dual relationships
- Receiving commissions for sales of products recommended to patients
- Loyalty to employer clashes with best interests of patient or ethical obligations

Dual Relationships are formed in settings where you are seen as a professional but want to participate as a peer.²⁰⁵



Social relationships,
including online



Business-related
relationships



Financial
relationships

The Ethical Dilemma of Dual Relationships

- Impact your patient's progress
- Impact your ability to competently perform your duties
- Could violate your patient's confidentiality
- Lead to unrealistic expectations

How to Address Dual Relationships

- Be aware of risk
- Seek help from a supervisor
- When in doubt, ask

Managing Conflict of Interest²⁰⁶

- Consult your supervisor and research any policies and procedures your organization may have in place
- Actively avoid any situations that could be compromising
- Take steps to remedy the situation
- 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

Medical Liability and its Implications²⁰⁷

Acting outside of your scope of practice can have significant consequences, depending on the nature of the issue, your institution's policies, and state laws. Understand both your organization's policies and state laws regarding medical liability. Make sure to discuss these with your supervisor to ensure you fully understand your responsibilities.



Patient Rights & Responsibilities^{208,209}

Patients have the right to:

- ☒ See their healthcare records and get accurate and easy to understand information
- ☒ Choose their doctors and plans
- ☒ Access emergency services
- ☒ Be part of treatment decisions
- ☒ Be treated with respect and without discrimination
- ☒ Have their health information kept private
- ☒ Complain about their healthcare



Patient Responsibilities:

- ☒ Patients are responsible for their own health
- ☒ Patients must disclose information relevant to their health and healthcare
- ☒ Patients are financially and administratively responsible
- ☒ Patients must be respectful of others

Informed Consent²¹⁰

A patient must 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
- Their own rights as a patient
- Who to contact if they have questions or feel they have been mistreated



Informed consent dictates that health care teams may not withhold health status information from patients.

Opportunities to Support Patient Rights



Health Insurance Portability and Accountability Act (HIPAA)²¹¹

Created in 1996 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
- Describes how healthcare 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

Privacy Issues in a Technology Age²¹²

New technologies require wider consideration of ways to preserve patient privacy.

Patient preferences and perceptions can help guide new approaches to privacy.



Who is Subject to HIPAA

- Health plans
- Health care clearinghouses
- Health care teams who transmit claims in electronic form
- Medicare prescription drug card sponsors

Who is Not Subject to HIPAA

- Employers
- Life insurance companies
- Workers' compensation carriers
- Schools and school districts
- State agencies
- Law enforcement agencies
- Municipal offices

Guidelines for Protecting Health Information

Guideline 1

Use only the minimum information needed to do your job.

Guideline 2

If in doubt about giving information, get patient authorization.

Guideline 3

Keep patient health information secure.

Legal Obligations



Duty to Warn

Defined by the National Conference of State Legislatures, duty to warn is a mandatory obligation for certain professionals to report any suspicion that a patient may pose a threat to themselves or others. The specifics of this law vary by state and may include civil and criminal protections for the professional involved.²¹³



Abuse Reporting Rules

Healthcare professionals are mandated to break patient confidentiality and report any suspected abuse or neglect. Become familiar with the local and state laws and reporting agencies. Talk with your supervisor about the organization's process for reporting abuse.²¹⁴



Patient Self-harm Disclosure

When a patient expresses harmful intentions or suicidal thoughts, it is your duty to immediately notify the doctor or your supervisor. It is not the patient navigator's role to assess a patient's intention to harm themselves, simply to report.²¹⁵

Lesson 12:

Program Evaluation and Quality Improvement

Learning Objectives

1. Describe importance of program evaluation
2. Describe potential roles for the patient navigator in evaluating programs
3. Identify opportunities for quality improvement based on metrics
4. Identify and implement strategies for quality improvement
5. Describe value of patient navigation to different interest holders
6. Summarize patient navigation role and responsibility to different interest holders

Key Takeaways

- Program evaluation is important for clarifying and improving programs, demonstrating effectiveness, securing funding, reporting value to administration, advocating for the program, meeting accreditation requirements, and addressing patient needs.
- Patient navigators play a significant role in data collection, analysis, and reporting. They can gather information on patient demographics, diagnoses, barriers addressed, time spent on tasks, and patient acuity.
- Implementing quality improvement strategies, such as the PDSA cycle, can help identify and address areas for improvement in patient flow, communication, and resource utilization.
- Understanding the specific needs of the community is essential for tailoring patient navigation services and addressing barriers to care.

Definitions²¹⁶

Program

A program is a group of resources and activities used together to fulfill one or more purposes.

Program Evaluation

The systematic collection and analysis of information about some or all aspects of a program to guide judgments or decisions.

Interest Holders

Organizations, groups or individuals who have the power to influence your program, have a political interest in your program, or would be affected by your program's evaluation or outcomes.



Why Program Evaluation?



Common Areas for Improvement²¹⁸

- Workflow integration
- Communication across healthcare team
- Planning and implementation
 - Revising workflows for efficiency
 - Incorporating quality improvement strategies
 - Building a business case for patient navigation
- Funding stability



Program Evaluation Answers These Questions

Does the program improve organization and clinical outcomes?

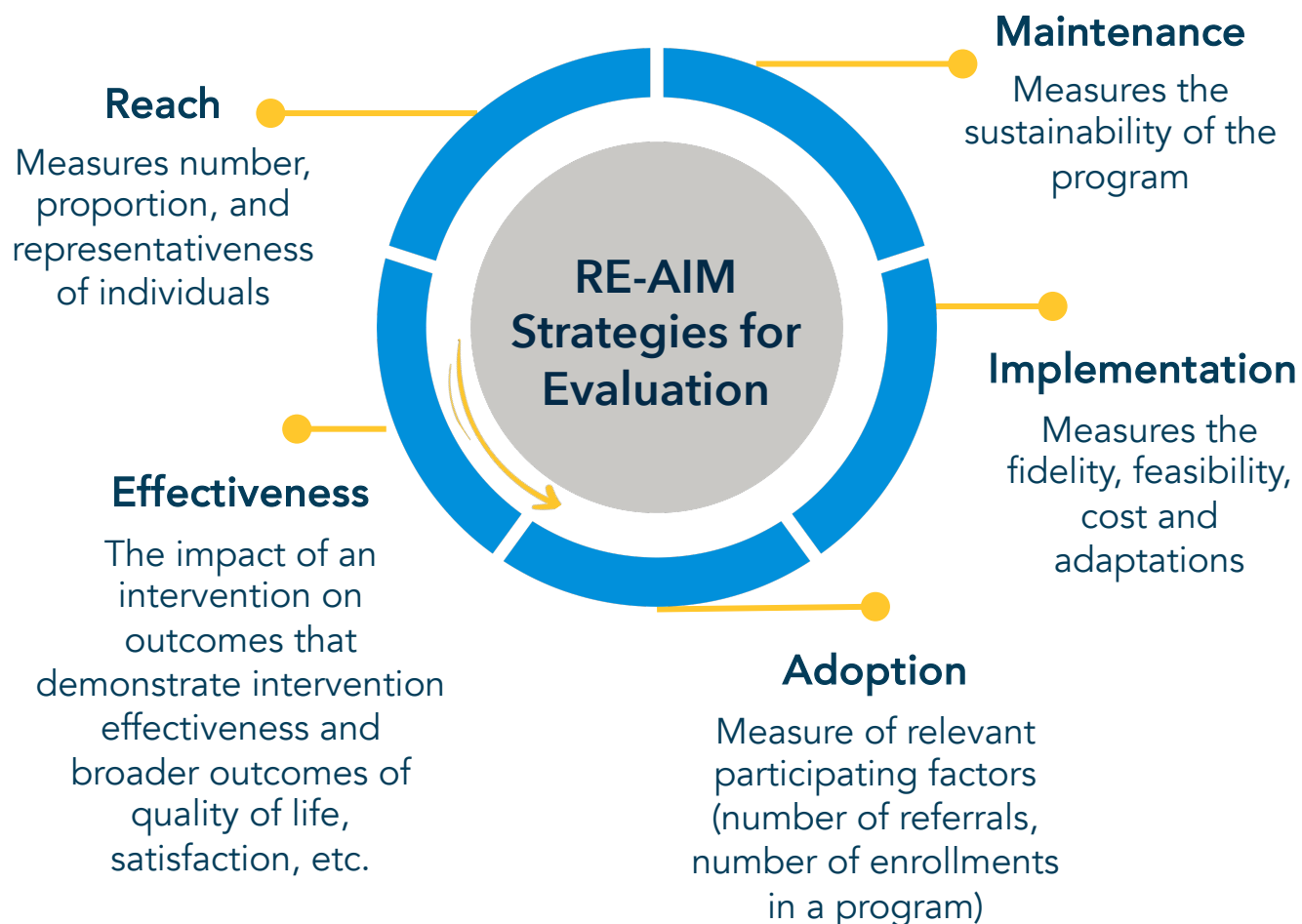
What can be changed to make the program more effective and improve outcomes?

Does the program support/improve the patient experience?

Does the program demonstrate value to the organization?



RE-AIM Strategies for Evaluation^{219,220}



Formative Evaluation

World Health Organization Patient Navigation Formative Evaluation Approach²²²

Step 1

Identify and engage stakeholders

Step 2

Conduct a situational analysis

Step 3

Identify priority areas for patient navigation policies and develop supporting procedures, processes and guidelines

Step 4

Assess human resource capacity to perform

Step 5

Identify financing mechanisms

Step 6

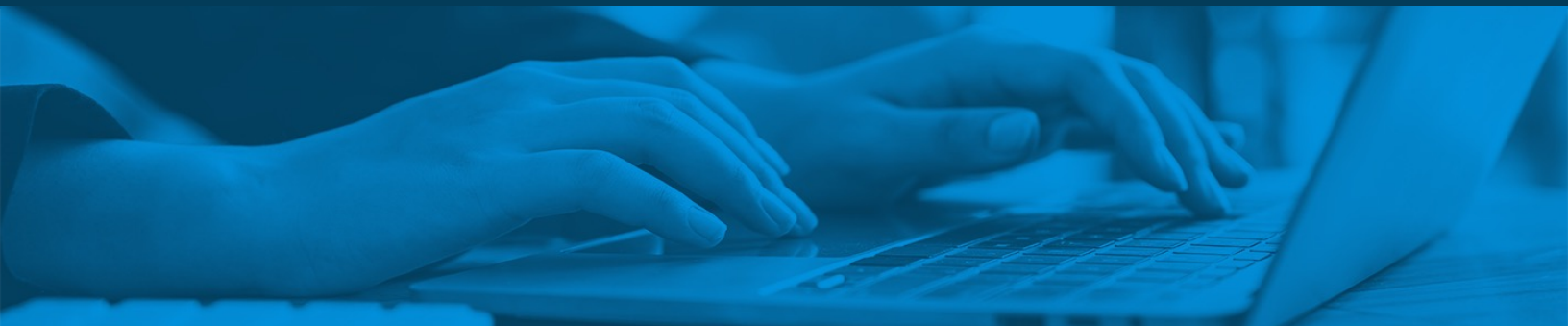
Implement and pilot the patient navigation program

Step 7

Adapt to local context and cultural perspective

Step 8

Monitor, evaluate, and learn



Patient Navigator Role in Program Evaluation

Data Collection

- Patient Demographics
- Patient Diagnosis and Staging
- Types of barriers addressed
- Time spent for various tasks
- Patient acuity

Document

Data Analysis

- Identify and describe trends
- Identify areas for improvement

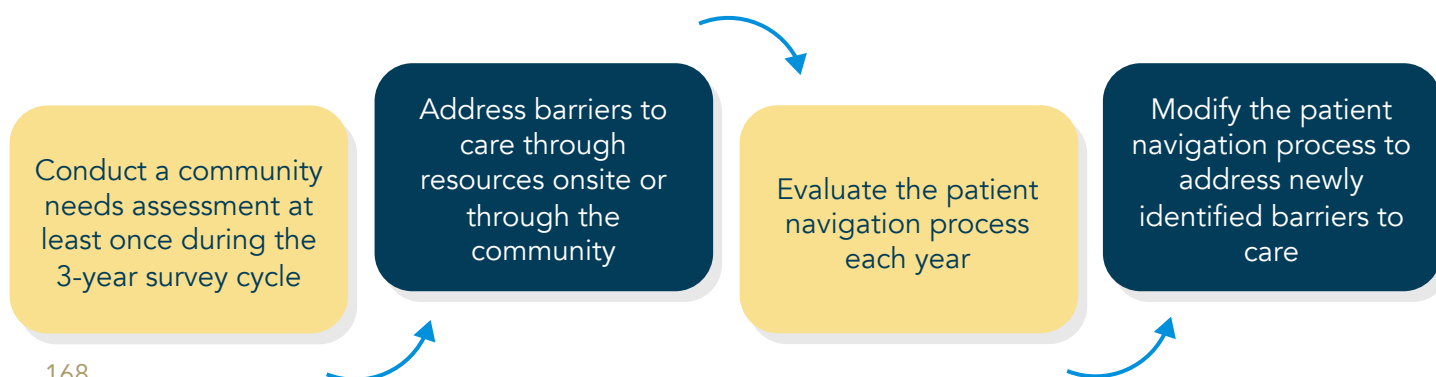
Explain with data

Data Reporting

- Community needs assessment data
- Report for interest holders
- Presentations

Report out

Commission on Cancer Addressing Barriers to Care Standard^{223,224}



A **Community Needs Assessment** is a means of identifying and describing community health needs so you can gain information and make informed choices about patient and community needs.

Steps of Community Needs Assessment²²⁵

1

Define the scope

2

Collect information

3

Review and analyze
the data

4

Report on and
share the data

Process Evaluation

- What was done?
- How was the program implemented?
- Was the program implemented as planned?
- How satisfied are patients or health care team members?
- How can we demonstrate program implementation even before outcomes have been attained?

Outcome Evaluation

The change(s) that your program will bring in your populations of focus or social condition (*not the program itself*).

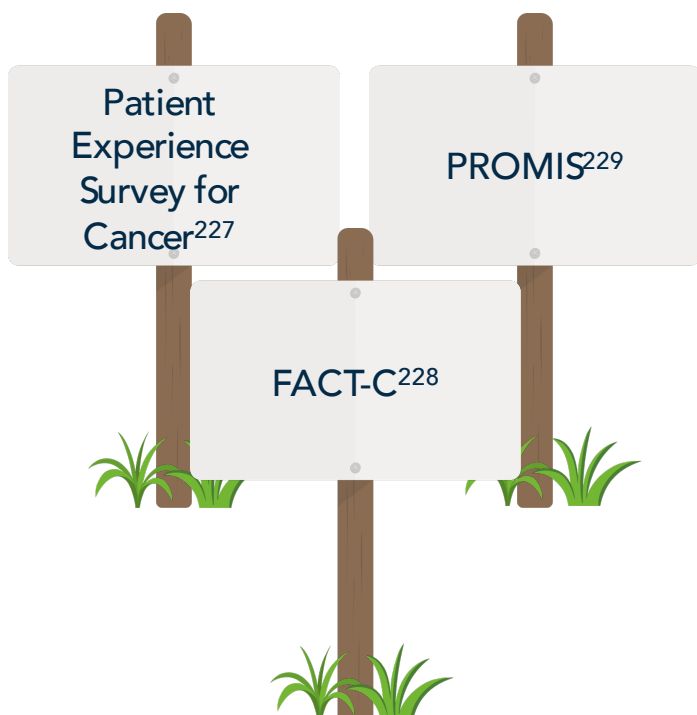
- Was our program effective?
- How did the program impact the patient?
- What evidence demonstrates that our administrators, funders, etc. should continue to support and fund the program?

Evaluation Metrics²²⁶

METRICS EXAMPLE	MEASUREMENT TASK EXAMPLES
Barriers to Care	Measure the number and list the specific barriers to care identified by navigator each month
Time from diagnosis to treatment	Measure the number of business days from date pathology results were delivered to initial treatment
Health Economics	Measure the number of navigated patients readmitted to the hospital at 30, 60, 90 days
Psychosocial Support	Measure number of navigated patients referred to support network per month
Survivorship	Measure number of navigated patients referred to palliative care per month
Patient Advocacy	Measure number of navigated patients per month whose preferred learning style was discussed during intake
Professional Development	Measure percentage of new hires who have completed navigator core competencies training
Quality Improvement	Measure patient experience of patient satisfaction results per month using survey

Validated Measures

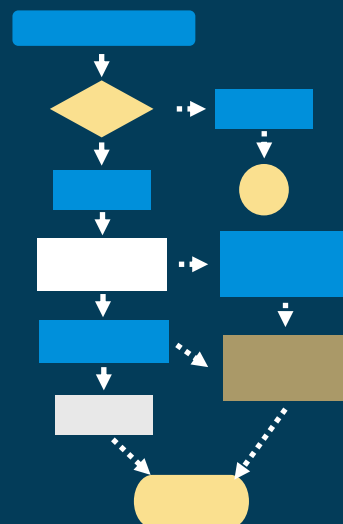
Validated measures have been tested to make sure they measure what they are supposed to measure.



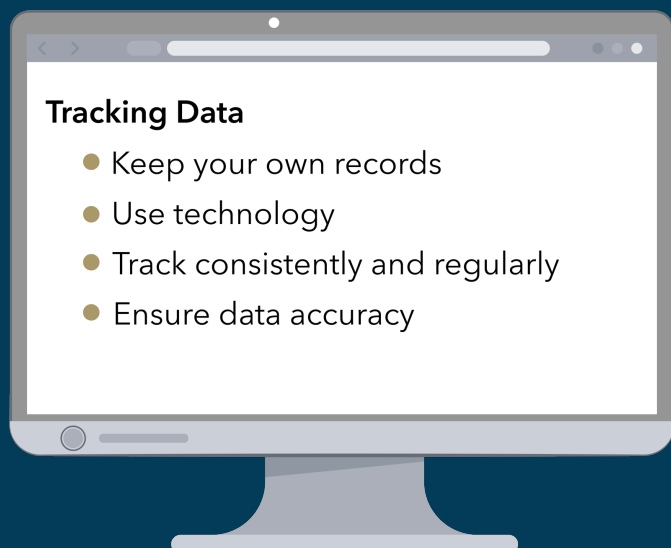
Quality/Process Improvement (Q/PI)

Understand the problem

- Use a patient Flow/Process Map²³⁰

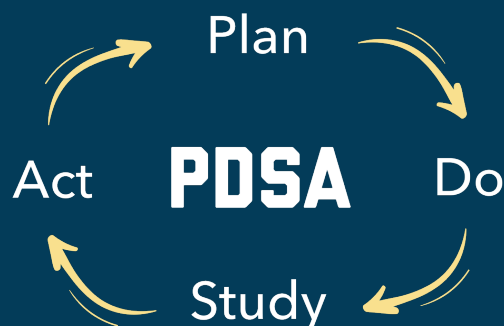


Tracking Data



Plan for change

- Use the Plan, Do, Study, Act (PDSA) Model²³¹



Q/PI Process Mapping

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?

Q/PI Tools: Patient Flow

- A. How long does it take to get a diagnosis?
- B. When does a patient navigator meet patients?
- C. What support or info do patients need at diagnosis?

- A. What does survivorship care mean for a particular patient?
- B. Who helps transition patients to survivorship care, if appropriate?
- C. What information needs do patients have to improve self-management?
- D. What resources are available to improve patient self-management, self-efficacy and quality of life?

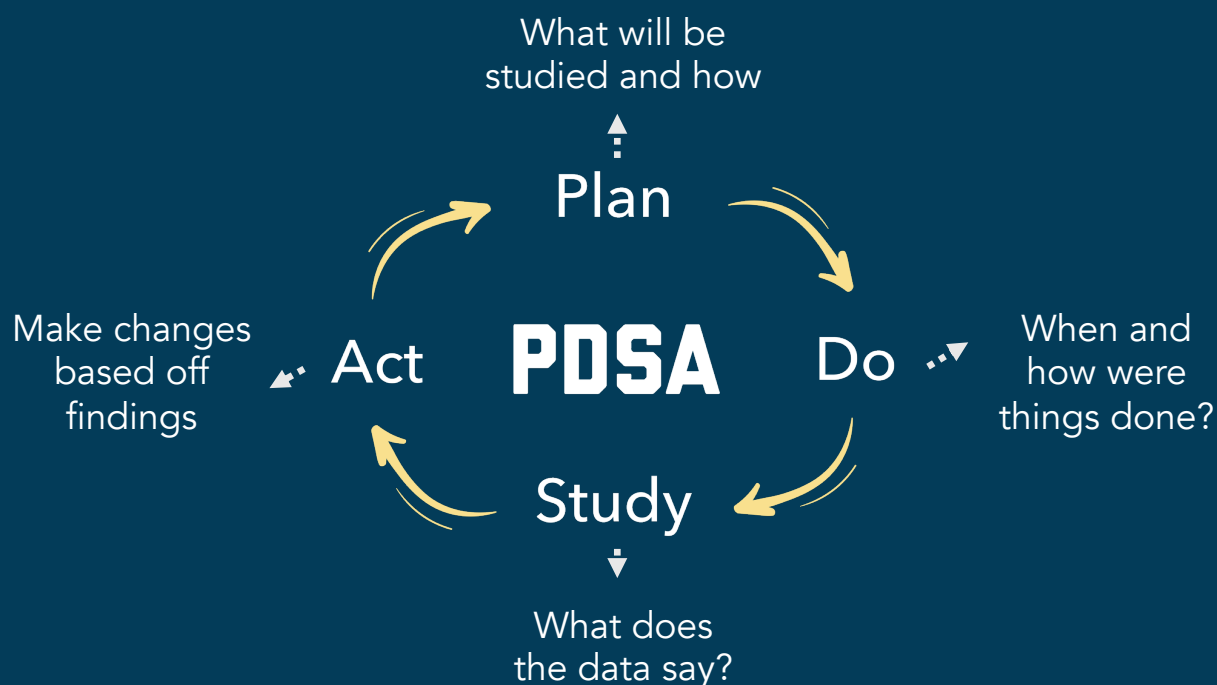


- A. How long does it take for patients to get test results?
- B. What are the biggest barriers?

- A. How long does it take for patients to start treatment?
- B. How many patients miss appointments and why?
- C. What administrative barriers do patients face?



Planning for Change: PDSA Cycle



Showing Value and Presenting Program Information²³²

- Have a prepared elevator speech about your program and role that is short, compelling, has an action item and is tailored to the interest holder (e.g., based on the what the navigator does for clinicians v. patients v. other colleagues)
- Items to highlight in an elevator speech may include reduction in no-show rates, a new program implementation, patient satisfaction, or reducing barriers for unique patient situations.

Lesson 13

Clinical Trials

Learning Objectives

1. Define clinical trials
2. Identify the risks and benefits of clinical trials
3. Describe strategies for helping patients understand clinical trials
4. Identify resources for patients on how to learn more about clinical trials

Key Takeaways

- Clinical trials are research studies that investigate new ways to prevent, diagnose, and treat cancer.
- Clinical trials provide valuable data that lead to new treatments, improved treatment strategies, and a better understanding of cancer.
- Understanding the different types of trials helps patients and healthcare clinicians identify suitable options based on individual needs and circumstances.
- Navigators play an important role in increasing clinical trial participation.
- Navigators help address barriers to enrollment, such as transportation, cost, and lack of awareness, particularly for underserved populations.
- Openly discussing risks and benefits, and providing clear and understandable information, is essential for building trust and encouraging informed decision-making.



Clinical Trials²³⁴

What is the purpose of a clinical trial?

- New ways to find, prevent, and treat cancer
- Help doctors improve patients' quality of life



Why are clinical trials important?

- Add to our knowledge of cancer
- Help improve future cancer care
- Play a role in cancer research
- Move science forward

Types of Clinical Trials²³⁵

Study Type	Who Can Join	Study Goals
Treatment Clinical Trials	People with cancer	Tests new medicines, surgical procedures, and combining current treatments
Prevention Clinical Trials	People who had cancer in the past, and healthy volunteers*	Examines how to reduce risk of getting cancer or the return of cancer
Screening Clinical Trials	Healthy volunteers	Find new ways to detect cancer before it causes symptoms and when it may be easier to treat
Supportive Care Clinical Trials	People with cancer	Explores ways to improve quality of life in people who have or had cancer
Observational Studies	People with cancer and healthy volunteers	Follows participants over time to collect health information and analyze data; no treatment is given

Common Questions about Clinical Trials²³⁶

- **Why are clinical trials important?**
Improve people's health and make medical advances
- **Who pays for the clinical trials?**
Study sponsor, insurance company, Medicare, patient
- **Who are the people involved in a clinical trial?**
Doctors, nurses, navigators, pharmacists, researchers, others
- **What do clinical trials study?**
Prevention, screening, diagnosis, treatment, quality of life
- **Can a patient get paid to be in a clinical trial?**
Sometimes
- **Do patients in a clinical trial still see their own doctor?**
Yes
- **Can a patient leave a clinical trial after it starts?**
Yes
- **If a patient chooses not to participate in a clinical trial, will they be treated differently?**
No
- **Can some patients get a placebo or "sugar pill" instead of real treatment?**
This is possible, but very rare. Patients will ALWAYS receive the standard of care as part of the control group. The clinical trial is designed to test a new approach compared to the usual approach.
- **Who can join clinical trials?**
Each clinical trial has different eligibility criteria
- **Why do clinical trials need a variety of people to participate?**
So, we know that a treatment works on people with different characteristics
- **Why is it important to include underserved patients in clinical trials?**
So, we know whether treatment options work for that population
- **Why are navigators important to underserved communities?**
To address the barriers that help underserved patients join and stay in a clinical trial



What is a randomized study?²³⁷

In a randomized study, participants are placed into groups by chance. This random assignment is often done by a computer to ensure fairness and objectivity.

In some studies, neither the patient nor the doctor knows which treatment is being given. This is known as a double-blind study, where both the patient and clinician are unknown to the treatment assignment to eliminate bias in how the results are observed and reported.

Clinical Trial Participation²³⁸

- Participation in clinical trials is voluntary
- Federal laws protect the rights of research participants
- Patients can leave a clinical trial at any time
- Clinical trials are not right for everyone

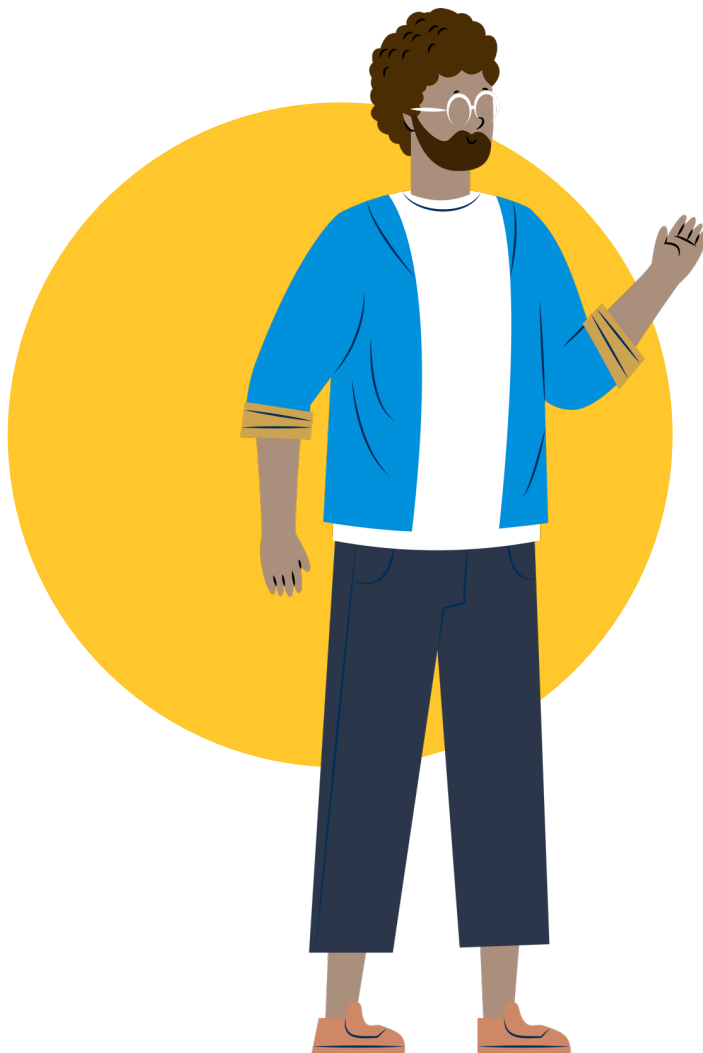


Why do patient navigators need to know about clinical trials?^{239,240,241,242}

- The percentage of adults who participate in clinical trials is only 7.1%²⁴³
- Patients may not seek out or learn about clinical trials independently
- Navigators offer a way to improve clinical trials recruitment because of rapport with patients
- Navigators help address barriers to clinical trial enrollment and adhesion

Clinical Trials for Adolescent and Young Adult (AYA)²⁴⁴

- Only 17% of AYAs were aware of clinical trials
- Among those who knew of clinical trials, 68% enrolled
- Reasons for not enrolling include:
 - Clinician factors, such as treatment setting and physician attitudes and knowledge
 - Patient factors, including educational, employment and family responsibilities
 - System factors, such as age restrictions, regulatory barriers, lack of developmentally appropriate facilities

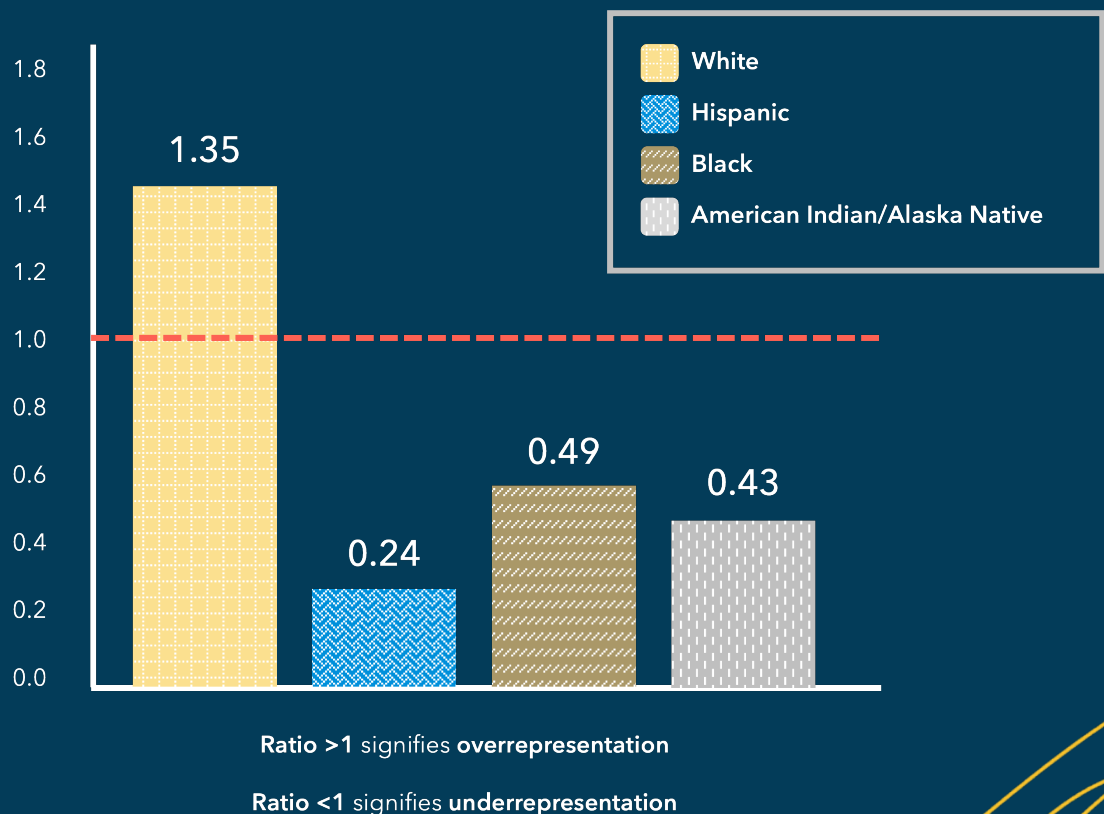


Disparities in Clinical Trials²⁴⁵

- Over the last 10 years clinical trials have engaged less diverse participants
- Patients and doctors are often not informed or aware of relevant clinical trials
- Patient navigators can address barriers to cancer trial participation among people who are unrepresented and medically underserved

Analysis of Precision Oncology Clinical Trial Representation in the U.S.

In a 2023 analysis of 93 precision oncology clinical trials with 5,867 participants, representation of racial and ethnic minorities was calculated using the ratio of the actual number of enrolled cases to the expected number of cases based on their corresponding U.S. population.



Barriers and Facilitators for Diversity in Clinical Trials²⁴⁶

Individual Level

Barrier (Patient)	Solution
Transportation	Transportation vouchers, decentralized trials, Special arrangements with Uber/Lyft, ACS Road to Recovery, Gas cards, Parking reimbursement
Cost	Financial navigation, decentralized trials
Caregiver burden	Support system, decentralized trials
Time toxicity	Extended clinic hours, decentralized trials, coordinated visits
Language	Use of interpreters, clinical team members who speak language of patients
Education	Patient education, Assessment of information for appropriate literacy level
Health literacy	Patient education, Visual aids, Information in language of the patient, Assessment of information for appropriate literacy level
Lack of awareness	Patient and family education

Barrier (Doctor)	Solution
Lack of awareness	Education and training
Implicit bias	Education and training, representation of underserved populations in clinical leadership
Cultural insensitivity	Cultural humility training, exposure to people with different lived experiences, representation of underserved populations in clinical leadership, learning about other cultures

Barriers and Facilitators for Diversity in Clinical Trials²⁴⁶

Institutional/Structural Level

Barrier	Solution
Lack of clinical trial sites	Increase clinical trial site locations
Complicated informed consent process	Patient navigation
Eligibility criteria	Expand criteria based on real-world data
Medical distrust or mistrust	Identifying and reducing structural bias Representation of underserved communities in clinical care leadership Patient navigation and community outreach/engagement



Clinical Trial Risks and Benefits²⁴⁷

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
- More doctor visits, procedures or tests
- Potential extra expenses, like travel, housing and childcare costs

Benefits

- The trial may help researchers learn more about cancer and help people in the future
- Participants may be the first to access a new study treatment before it is widely available
- The research team will carefully watch patients, adding an extra layer of care
- Patients in a clinical trial may be the first to benefit from new treatments

Protections for Patients²⁴⁸

- Ethical guidelines outlined in the Belmont Report.
 - **Respect for persons:** All participants should be treated with dignity and respect.
 - **Beneficence:** Researchers must aim to maximize benefits and minimize risks for participants.
 - **Justice:** The benefits and burdens of research must be distributed fairly among participants.
- Scientific Review
- Strict Research Protocols
- Informed Consent: The rules around informed consent are strict, ensuring that patients fully understand the clinical trial. For non-English-speaking patients, the informed consent form must be provided in their native language.
 - Purpose of trial
 - What will happen
 - Benefits and risks
 - Patient rights
 - Language accessible

What is the process for the patient?²⁴⁹

1. If a particular clinical trial is an option for a patient, the patient's doctor should talk with them more about the clinical trial to answer medically related questions.
2. The process of helping the patient understand the clinical trial is called Informed Consent.
3. Once enrolled in a clinical trial, the patient will receive either the new treatment or a treatment that is already available.
4. If the treatment is effective, patients may be able to continue the treatment after the clinical trial.



In Clinical Trials, Patient Navigators...²⁵⁰

DO

- Increase patient interest
- Reduce barriers

MAY

- Explain clinical trials

DO NOT

- Encourage patients to join clinical trials
- 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
- Connect patients to clinical coordinator
- Written information
- Review written materials with patients in their native language
- Write down medical term definitions
- Consult with clinical coordinator for answers



Common Patient Concerns

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



Learning Objectives

1. Describe the value of patient navigation to patients, communities, healthcare clinicians, and health systems
2. Describe the value of patient navigation in moral, performance, and economic terms

Key Takeaways

Patient navigation can:

- Enhance patient care by improving patient satisfaction, care coordination, and quality of life.
- Lead to improved cancer screening rates, reduced late-stage diagnoses, and minimized health disparities.
- Lead to increased cancer screening uptake, faster treatment initiation and diagnostic resolutions, improved shared decision-making, and better care coordination.
- Benefit healthcare systems by reducing unplanned hospital admissions and readmissions, shorter hospital stays, fewer ER visits, reduced missed appointments, improved patient retention, and increased market competitiveness.
- Reduce the significant economic burden associated with racial/ethnic disparities in cancer, including premature deaths and lost productivity.



Benefits of Patient Navigation

Patient navigation can improve patient experience and outcomes, clinician experiences, and health system value.

For Patients²⁵³

- Improved patient satisfaction with care
- Improved care coordination
- Improved quality of life

For Communities²⁵⁴

- Improved cancer screening rates to help find cancer early
- Reduced late-stage diagnoses
- Reduced health disparities

For Healthcare Clinicians

- Increased cancer screening uptake
- Reduced time to treatment initiation
- Reduced time to diagnostic resolution
- Improved shared decision-making
- Improved care coordination
- Increased adherence to surveillance

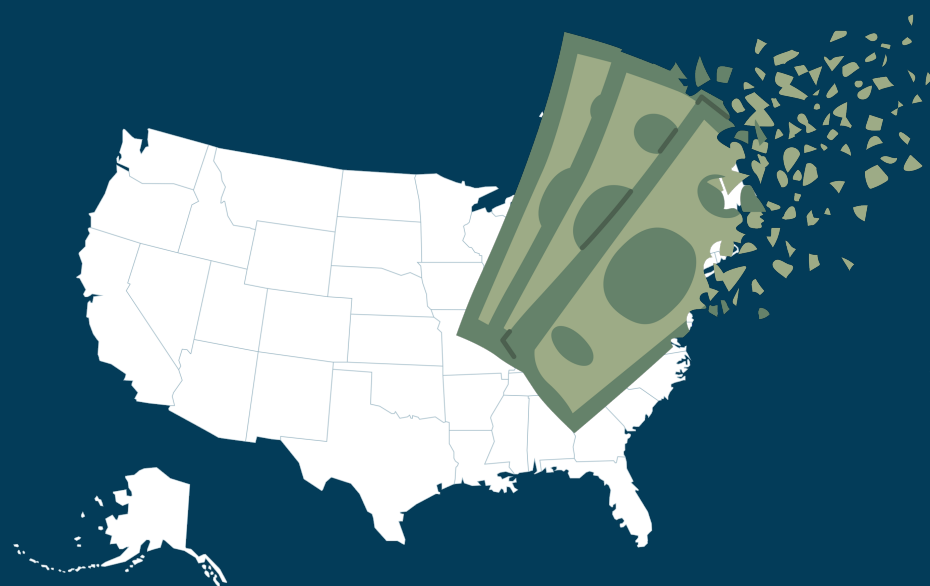


For Healthcare Systems²⁵⁵

- Fewer unplanned hospital admissions and readmissions
- Reduced length of hospital stays
- Reduced Emergency Department visits
- Fewer missed appointments
- Improved patient retention
- Less outmigration and loss to follow up
- Increased market competitiveness
- Increased downstream revenue
- Meets several Commission on Cancer Standards²⁵⁶
- Compliance with the National Accreditation Program for Breast Centers.²⁵⁷

Patient Navigation Makes Economic Sense²⁵⁸

Racial/ethnic disparities in cancer cost an estimated annual \$193 billion in premature death and \$471.5 million in lost productivity in the United States in 2018.



Health
disparities cost
\$193 billion in
2018 in the U.S.

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