THIRD EDITION
MAY 2026

Patient-Centered Oncology Navigation Toolkit

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CHAPTER ONE

Introduction

First of its Kind: SHARE Cancer Support Navigation Curriculum Toolkit

The SHARE Cancer Support Navigation Curriculum Toolkit is the first of its kind to provide resources any cancer program will need to create or revise an evidence-based navigation program. It includes all the rich work completed by all the national oncology organizations that support and have created standards for navigation. The toolkit is not all-inclusive, with every resource in oncology navigation, but it provides a significant example of evidence-based, validated tools and best practices.

The curriculum toolkit will provide step-by-step the critical components for an oncology navigation program, including:

- Choosing the correct model of navigation for your program
- Creating job descriptions and role delineation based on the oncology national practice standards and core competencies
- Provide example intake assessment tools and process maps/workflows
- Communicating across the continuum with the patient, providers, and multidisciplinary team
- Orientation and training guidelines and checklists
- Review of national oncology accreditation programs and standards that apply to a navigation program
- Utilization of evidence-based screening tools
- Providing appropriate interventions and follow-up with the patient and their caregivers
- Review of documentation standards, metrics, reports, and dashboards
- Review the roles of the multidisciplinary team and coordination with community resources
- Review national evidence-based oncology resources
- Utilizing technology to support the role of the navigator and provide additional resources for the patients and their caregivers
- Discussion on the 2022 CPT Codes for Oncology Navigation Services and the 2024 CMS federal reimbursement for Principal Illness Navigator

The SHARE Cancer Support Navigation Curriculum Toolkit will align with the national oncology organizations and best practices for the patient, social work, and nurse navigator models. This curriculum will support navigation in all settings, such as community cancer centers, academic cancer centers, community health centers, nonprofit community partners, and oncology providers (hospital and private settings) for individuals of all ages diagnosed with cancer.

Definition of Navigation

The Professional Oncology Navigation Taskforce has defined oncology navigation 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 prediagnosis through all phases of the cancer experience.

Sources:
Oncology Nursing Society. 2017 Oncology Nurse Navigator Core Competencies. www.ons.org/sites/default/files/2017-05/2017_Oncology_Nurse_Navigator_Competencies .pdf. 2017.
Association of Oncology Social Work. Scope and Standards of Practice. https://aosw.org/publications-media/scope-of-practice.

National Association of Social Workers. Standards for Social Work Practice in Healthcare Settings. Washington, DC: National Association of Social Workers; 2016.

History of Oncology Navigation

Patient navigation has evolved as a strategy to improve outcomes in vulnerable populations by eliminating barriers to timely diagnosis and treatment of cancer and other chronic diseases. In 1989, the American Cancer Society held "National Hearings on Cancer in the Poor". The hearings were led by the President of the Society and were conducted in seven American cities. The testimony was primarily by poor Americans of all racial and ethnic groups who had been diagnosed with cancer. Based on these hearings, the American Cancer Society issued its "Report to the Nation on Cancer in the Poor."

Source: Cancer and the socioeconomically disadvantaged: a summary of the American Cancer Society Report to the Nation. Cancer J Clin 1989; 39:263–95.

The report concluded that the most critical issues confronting poor people with cancer are as follows:

- Poor people face substantial barriers to obtaining cancer care and often do not seek care if they cannot pay for it.
- Poor people and their families often make extreme personal sacrifices to obtain and pay for care.
- Fatalism about cancer is prevalent among the poor and may prevent them from seeking care.
- Cancer education programs are often culturally insensitive and irrelevant to many poor people.
- Poor people endure greater pain and suffering from cancer than other Americans.

These findings led to the concept of patient navigation. The nation's first patient navigation program was initiated by Freeman in 1990 at a public hospital in Harlem, New York. The original program focused on the critical window of opportunity to save lives from cancer by eliminating barriers to timely care between the point of suspicious finding and the resolution of the finding by diagnosis and treatment. The aim was to diminish the extremely high breast cancer death rate in a population of poor Black women, half of whom had presented with late-stage breast cancer.

Commonly experienced barriers to timely care in Harlem were:

- Poor people face substantial barriers to obtaining cancer care and often do not seek care if they cannot pay for it.
- Poor people and their families often make extreme personal sacrifices to obtain and pay for care.
- Fatalism about cancer is prevalent among the poor and may prevent them from seeking care.

Source: Cancer Epidemiol Biomarkers Prev (2012) 21 (10): 1614–1617. https://doi.org/10.1158/1055-9965.EPI-12-0982, para 6.

Dr. Freeman's program was highly successful in increasing breast cancer screening, identification of early-stage breast cancer, and increasing survival rates in Black women. This incredible work created the foundation for international oncology navigation programs.

Oncology Continuum of Care Overview

Regardless of the model, the oncology navigator must understand the phases in the continuum of care. The navigator's role is to prepare the patient and their caregivers for their cancer journey through education, from prevention to survivorship or end-of-life services.

Figure 1: Cancer Continuum

(1) Prevention	(2) Cancer Screening	(3) Diagnosis	(4) Treatment	(5) Survivorship	(6) End of Life
• Diet/exercise • Sun exposure • Alcohol • Tobacco control • Chemo prevention	• Pap test • Mammogram • PSA/DRE • Fecal occult • Blood test • Colonoscopy • Awareness of cancer risks, signs, and symptoms	• Oncology/surgery consultation • Tumor staging • Patient counseling and decision-making • Clinicial trials • Informed decision-making	• Chemotherapy • Surgery • Radiation • Symptom management • Psychosocial • Maintenance therapy	• Long-term follow-up/surveillance • Manage late effects • Rehabilitation • Coping • Health promotion • Prevention • Palliative care	• Support patient and family • Hospice • Informed decision-making

Source: Adapted from http://cancercontrol.cancer.gov/od/continuum.html.

Understanding Your Navigation Program Needs Based on the Continuum of Care.

When assessing at what time the navigator makes initial contact with the patient in the continuum of care, it is vital to identify patient needs for your patient population. In some programs, the navigator contacts the patient before their first appointment to identify any specific barriers/needs and educate the patient and their caregiver about the roles of the oncology team. The navigator will also provide appropriate interventions to ensure a timely and coordinated initial visit with the provider. Other programs prefer to follow patients from diagnosis to post-treatment, again assessing barriers/needs, providing appropriate interventions, and transitioning them to an internal or community survivorship program.

Models of Navigation

Several different models of oncology navigation include the oncology nurse navigator, social work navigator, patient navigator (nonclinical), or a hybrid model, which is defined as a mixture of models.

Oncology Navigation Standards of Professional Practice, The Professional Oncology Navigation Task Force defines navigation as:

> **Clinical Navigator/Oncology Nurse Navigator:** A professional registered nurse with oncology-specific clinical knowledge who offers individual assistance to patients, 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.
>
> **Source:** Oncology Nursing Society. 2017 Oncology Nurse Navigator Core Competencies. www.ons.org/sites/default/files/2017-05/2017_Oncology_Nurse_Navigator_Competencies.pdf. 2017.

Clinical Navigator/Oncology Social Work Navigator: 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 patients, families, and caregivers to help overcome healthcare system barriers. Using the social work process, an oncology social work 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.

Source: March 2022 • Vol 13 • No 3 • JONS-online.com

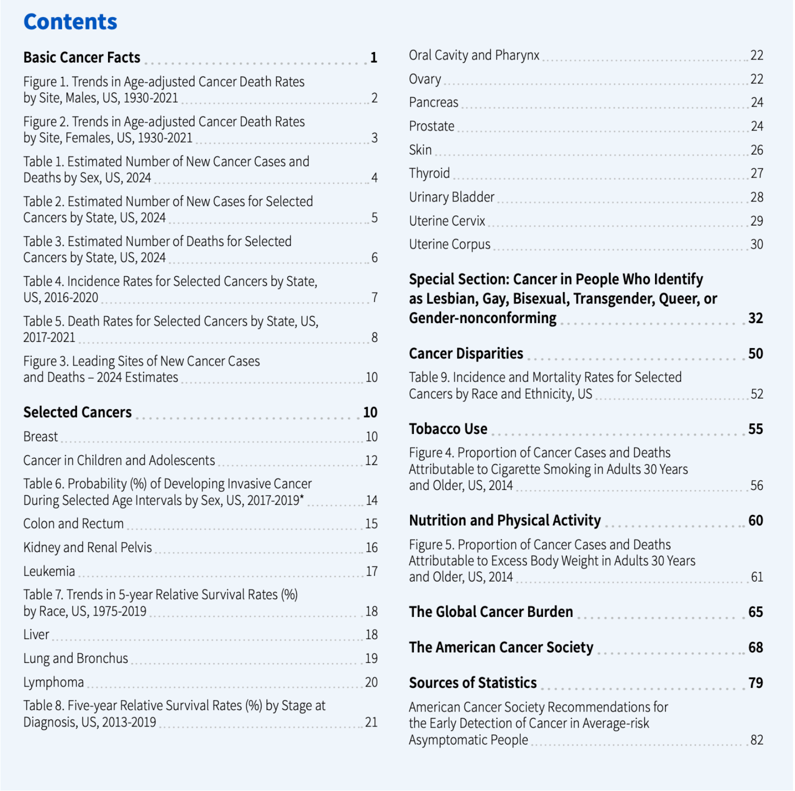
Oncology Patient Navigator: A professional who provides individualized assistance to patients and families affected by cancer to improve access to healthcare services. A patient navigator may work within the healthcare system at the point of screening, diagnosis, treatment, or survivorship across the 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.

Source: March 2022 • Vol 13 • No 3 • JONS-online.com

Implementing a Navigation Program: Choosing the Correct Model

Choosing the correct model is vital to ensuring a successful program at your cancer center and, more importantly, for the patient population serviced in your area. The first element to review is the patient population demographics for your state and any specific regional information from your tumor registry. This information can be retrieved from your hospital system's annual report, tumor registry, the American Cancer Society's Facts and Figures, or the National Cancer Institute Surveillance, Epidemiology, and End Results (SEER) Program.

Figure 2: The Table of Contents for the ACS Facts and Figures



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Source: https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/2024-cancer-facts-figures.html

Example questions to ask about your patient population include:

- What is the breakdown of your patient population, age, race/ethnicity, etc.?
- What is the education level of your population?
- What is the average income of your population?
- What is the reading level of your population?
- What are the top cancer diagnoses of your population?
- What are the barriers to accessing medical care for your population?
- What are the social determinants of health concerns for your population?
- Other

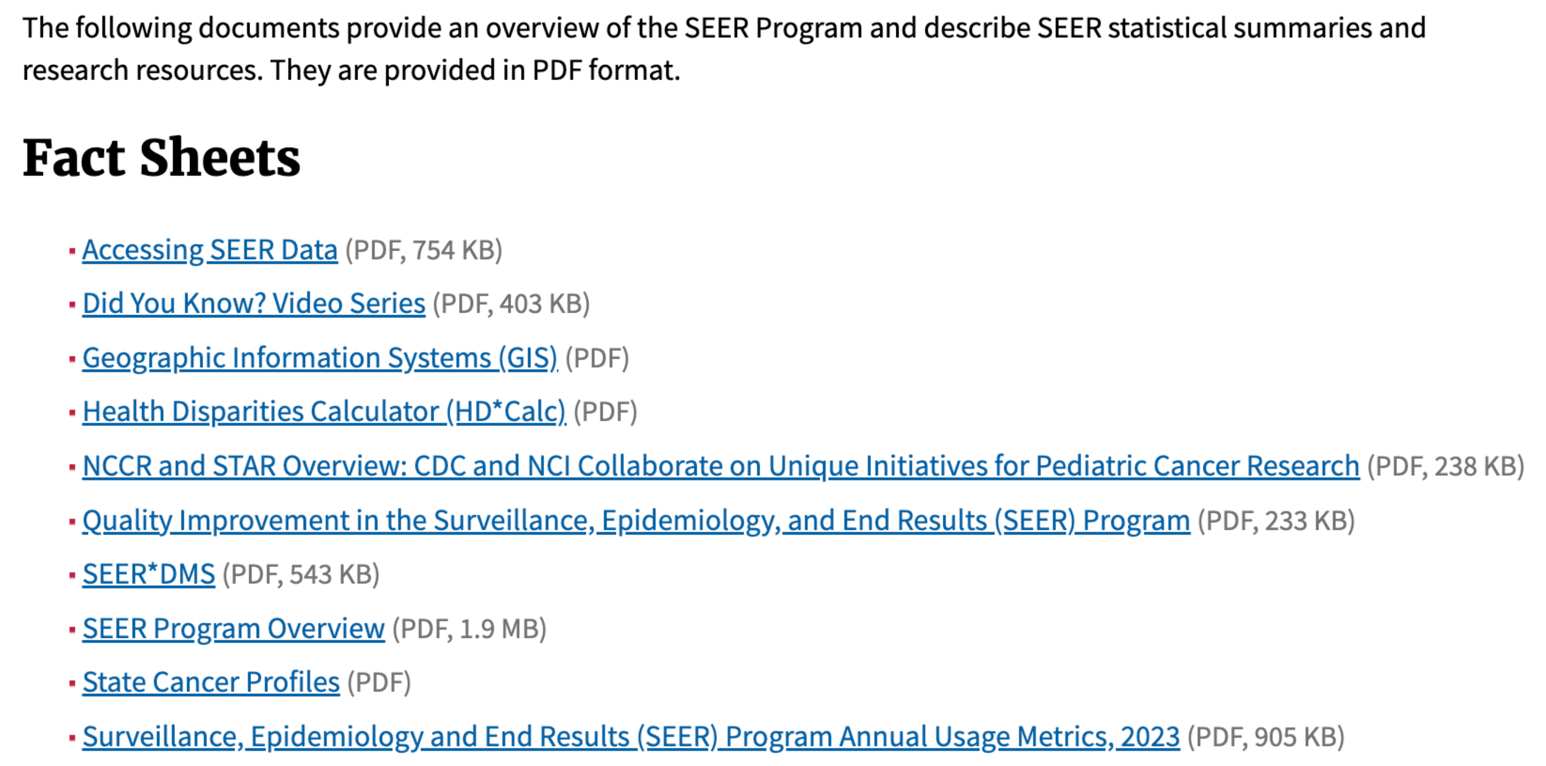
These questions can assist with your navigation model because they will help identify your patients' specific needs. For example, if they are lower in income, they may have barriers related to finances, transportation, and child/elder care, to name a few. Review the barriers identified for your patient population and assess the level of the navigator you must have for your program; will your cancer program require a clinical navigator or a nonclinical navigator?

It is also essential to review the goals of your navigation program with your key stakeholders, including your providers and administrators. The specific responsibilities of the navigator need to be identified (refer to Chapter Two on practice standards). Does your program want to include clinical education and assessments? If yes, then a nurse navigator model may be more appropriate. If the program aims only to identify and remove medical and psychosocial barriers, then a patient (nonclinical) navigator may be more appropriate. The nonclinical navigator must refer any medical discussions to the appropriate physician and their office staff.

Another idea for researching your program model is hosting a patient and caregiver focus group. Ask your current and past patients and caregivers what their specific needs across the continuum were and where they needed additional guidance or resources.

The pediatric, adolescent, and young adult populations will have different needs. Refer to the evidence-based resources below to support your program (refer to Chapter Five for specific resources available for these populations).

Figure 3: National Cancer Institute Surveillance, Epidemiology, and End Results (SEER) Program SEER Fact Sheets



The following documents provide an overview of the SEER Program and describe SEER statistical summaries and research resources. They are provided in PDF format.

Fact Sheets

- Accessing SEER Data (PDF, 754 KB)
- Did You Know? Video Series (PDF, 403 KB)
- Geographic Information Systems (GIS) (PDF)
- Health Disparities Calculator (HD*Calc) (PDF)
- NCCR and STAR Overview: CDC and NCI Collaborate on Unique Initiatives for Pediatric Cancer Research (PDF, 238 KB)
- Quality Improvement in the Surveillance, Epidemiology, and End Results (SEER) Program (PDF, 233 KB)
- SEER*DMS (PDF, 543 KB)
- SEER Program Overview (PDF, 1.9 MB)
- State Cancer Profiles (PDF)
- Surveillance, Epidemiology and End Results (SEER) Program Annual Usage Metrics, 2023 (PDF, 905 KB)

Source: https://seer.cancer.gov/about/factsheets/

CHAPTER TWO

Fundamentals of Navigation

Oncology Navigator Core Competencies and Practice Standards

Researching and reviewing the national oncology navigation organizations is a must for creating a solid program with clear and appropriate job descriptions and role delineation. National oncology navigation organizations have created core competencies, practice standards, and knowledge domains. The navigator's job description must include these competencies and practice standards, and the oncology multidisciplinary team must be aware of these practice standards.

National Oncology Navigation Organizations include:

- Oncology Nursing Society (ONS)
- Academy of Oncology Nurse and Patient Navigators (AONN+)
- Association of Oncology Social Work (AOSW)
- National Association of Social Workers (NASW)
- Professional Oncology Navigation Taskforce (PONT)
- American Cancer Society National Navigation Roundtable (ACS NNRT)
- Association of Pediatric Hematology/Oncology Nurses (aphon)
- Oncology Financial Navigator Core Competencies
    - Association of Community Cancer Centers (ACCC)
    - George Washington Cancer Center (GW)

Figure 4: National Oncology Navigation Organizations

National Organization	Website
Oncology Nursing Society (ONS) Core Competencies	https://www.ons.org/sites/default/files/2024-10/onn-competencies-final.pdf
Academy of Oncology Nurse and Patient Navigators (AONN+) Knowledge Domains	https://aonnonline.org/toolkits
Professional Oncology Navigation Taskforce Standards of Practice	https://aosw.org/wp-content/uploads/2023/08/Oncology-Navigation-Standards.pdf Scan this QR code to access the Oncology Navigation Standards of Professional Practice
American Cancer Society (ACS) National Navigation Roundtable Job Roles	https://navigationroundtable.org/resource/patient-navigation-job-roles-by-levels-of-experience-workforce-development-task-group-national-navigation-roundtable
George Washington Cancer Center Patient Navigation Core Competencies	https://cme.smhs.gwu.edu/gw-cancer-center-/content/new-oncology-patient-navigator-training-fundamentals
Association of Oncology Social Work (AOSW)	https://aosw.org/resources/scope-and-standards-of-practice/
National Association of Social Workers (NASW)	https://www.socialworkers.org/Practice/Practice-Standards-Guidelines
Association of Pediatric Hematology/Oncology Nurses	https://www.aphon.org/

The websites listed in the table provide extensive information on navigation resources; review these websites for up-to-date information.

Core Competencies of the Financial Navigator

The literature reflects that financial concerns for our patients and their caregivers are the number one problem for oncology patients. The ability to assist our patients in this area has helped elevate the role of the financial navigator. The financial navigator has the tools and resources to assess the patient's concerns and provide interventions or discussions on managing their financial concerns.

Association of Cancer Care Centers (ACCC) Resources on Financial Toxicity or Financial Distress.

General Information About Financial Toxicity (Financial Distress) and Cancer Treatment

Key Points

- Financial toxicity describes a patient's problems related to the cost of medical care.
- Several studies show that people with cancer and survivors are more likely to have financial toxicity than people without cancer.
- The level of financial toxicity you may have will depend on several factors in your household.
- Cancer treatment can affect your ability to work and pay your bills.

Financial Toxicity

Source: https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-hp-pdq

Excellent resources are available through the Academy of Oncology Nurse and Patient Navigators, the Association of Cancer Care Centers, and George Washington University for the financial navigator.

Figure 6: Financial Navigation Organizations

National Organization	Website
Academy of Oncology Nurse and Patient Navigators	https://www.aonnonline.org/financial-navigation
Association of Cancer Care Centers (ACCC)	https://www.accc-cancer.org/home/learn/financial-advocacy/guidelines https://www.accc-cancer.org/acccbuzz/blog-post-template/accc-buzz/2021/09/28/accc-unveils-new-tool-for-financial-advocates
Association of Community Cancer Centers (financial navigator bootcamp)	https://www.accc-cancer.org/education-and-resources/financial-navigation/boot-camp
George Washington University	https://financialaid.gwu.edu/resources

Navigation Intake and Referrals to the Navigation Program

The main goal with referrals to the navigation program is to identify the patient as soon as possible in their cancer journey. Referrals to the navigation program can be generated from high-risk cancer screening programs, outreach/screening activities in the community, pathology reports, inpatient admissions, and emergency room visits. Pathology reports are one of the best opportunities to identify the patients early in the continuum. As many cancer programs become more automated, pulling a report from the tumor registry or the pathology department becomes easy. This report should contain the following elements: patient name, address, date of birth, phone number, physician name and phone number, cancer diagnosis, pathology, and stage. When identifying the patient early in the continuum, coordinate with the surgeon or appropriate physician so that the patient is aware of their diagnosis before contacting the patient.

Navigation Referrals

- Keep the referral process straightforward, such as using EMR/electronic referral systems. This will help streamline the process and make it more manageable for everyone involved.
- Create a script for the navigator to introduce themselves and the navigation program.
- Provide a patient welcome packet, treatment journal, or patient portal to provide frequently asked question decision aid and disease site-specific patient educational material.
- Create referral guidelines to ensure that referrals are only accepted for patients in active cancer treatment.

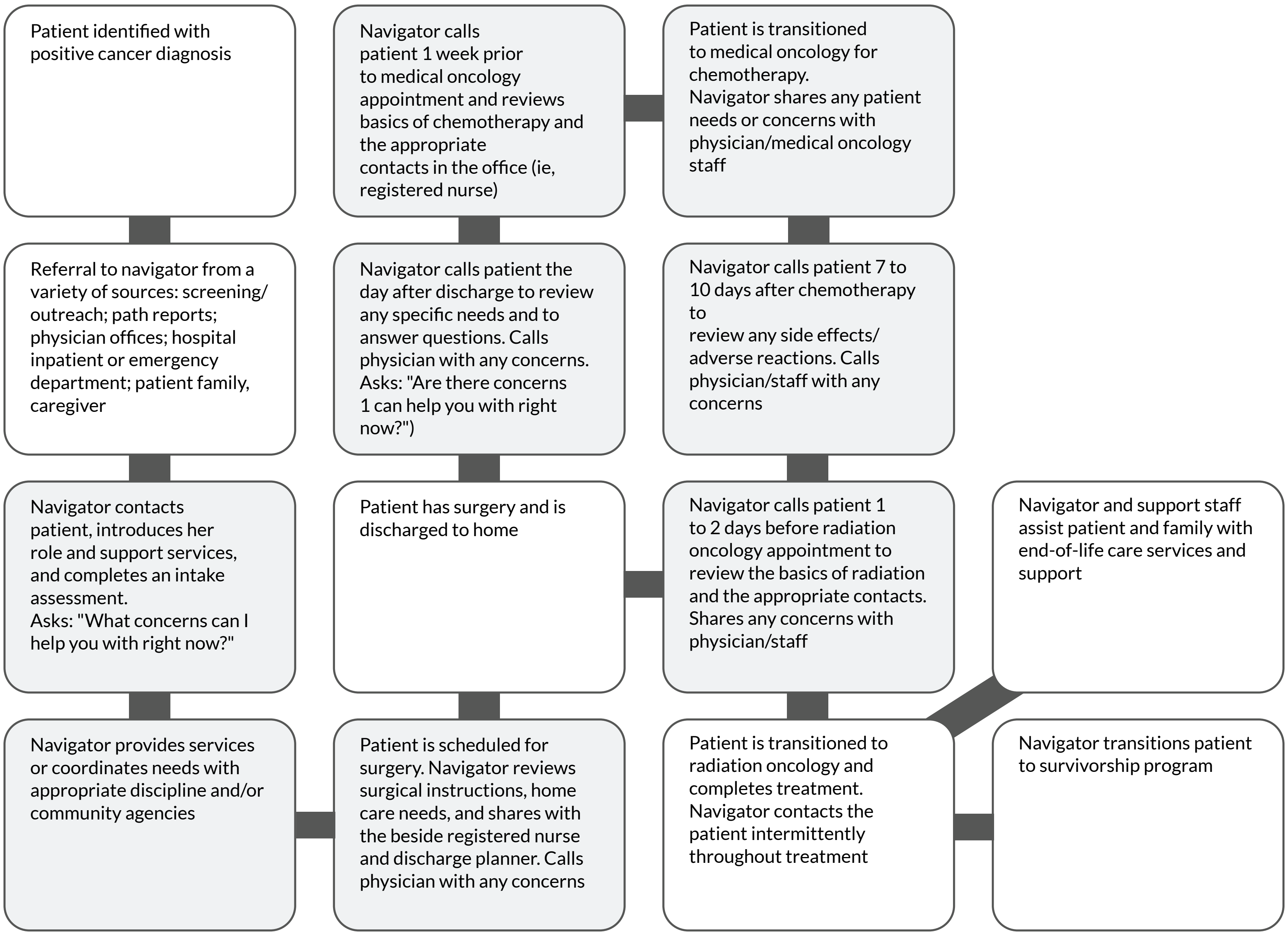
Example Introductory Script for the Navigator

Good morning, Mrs. Smith, my name is ______; I am your navigator (use the correct navigator title, i.e., nurse, patient, social work, financial, community, etc.) I work very closely with Dr. ______; she/he requested I contact you to review my role and the services available to you and your family (or caregiver). My role is to help you understand your treatment plan, review any specific barriers or concerns and coordinate any services needed during your cancer treatment. My phone number is XXX-XXX-XXXX. I will send you some educational materials in the mail or on the patient portal. Is there anything I can help you with right now? Please do not hesitate to call if I can assist you and your family in any way. Thank you, and I look forward to assisting you and your family.

Navigation Algorithm/Process Map

A process map/algorithm visualizes the navigator flow across the patient continuum of care. This navigation algorithm featured in this section is overly simplified but reviews the patient flow from the time of screening through survivorship or end of life. It illustrates how the navigator coordinates and assesses the needs of patients, families, and caregivers across the continuum.

Figure 5: Example of Workflow Diagram



Source: Stusowski T. Value-Based Cancer Care: Creating Partnerships Between Oncology Nurse Navigators and Oncology/Hematology Physician Practices. Presented at: 24th Association of Cancer Executives Annual Meeting: January 28-30, 2018. Portland, OR.

Managing Patient Transitions Across the Continuum

Managing and coordinating the care of the patient and caregiver across the continuum sounds simple. Still, most programs don't share patient information as well as they perceive that they do. Communicating the assessments, needs, and barriers of the patient and caregivers with the appropriate departments, support staff, and MD offices is essential. The goal is to increase communication among the healthcare team and decrease duplication for the patient. Look for any opportunity to decrease duplication for the patient. The navigator continues to assess for psychosocial and medical barriers and provide interventions to coordinate appropriate referrals with the support staff or other healthcare team members.

Process Mapping Exercise Goals

- Identify the earliest entry point for the patient into the navigation program. This will ensure timely support.
- Provide a comprehensive assessment or psychosocial distress screening utilizing an evidence-based validated tool.
- Based on the assessment, provide support services or referrals to appropriate disciplines. Remember to follow-up with the patient to assess the intervention's outcome.
- Communicate with your multidisciplinary team to coordinate care for the patient and their caregivers.
- Clarify the navigator and multidisciplinary team roles and actively seek opportunities to collaborate and enhance patient and caregiver care.
- Create performance improvement projects from gaps/barriers identified in the process map/algorithm to enhance the patient experience and multidisciplinary team process.

Multidisciplinary Team Communication

Communication is essential. Remember, one of the goals of the navigation program is to increase communication among the healthcare team, therefore decreasing duplication for the patient. The healthcare team comprises physicians, their office staff, and other support staff such as social workers, dietitians, genetic counselors, pastoral care, financial assistants, and the rehabilitation team. In the inpatient setting, the healthcare team might include bedside nurses, discharge planners, and rehabilitation therapists, to name a few. Ultimately, the healthcare team is anyone or any department involved with the oncology patient's plan of care.

Routes of Communication

The navigator needs to establish how the team wants to receive updates on the patient. It is also imperative to discuss what type of information is vital to communicate among the team.

Team communication could occur by:

- Verbal updates
- Multidisciplinary team meetings
- Tumor conferences
- Electronic medical record/plan of care
- Email if secure/safe
- Patient Portal

What to Communicate

- Medical and psychosocial barriers to care and interventions, such as transportation, financial concerns, etc.
- Results of psychosocial distress screening and the results of the intervention
- If the patient calls with new signs, symptoms, or side effects/adverse reactions. (Teach the patient reportable signs and symptoms and when to call their physician)
- Navigation metrics and outcomes
- Changes in the navigation workflow or processes
- New internal or community resources
- Updates with CoC or NAPBC standard

CHAPTER THREE

Orientation, What Must Be Included

Through the years, the role of the navigator has become more established with the incorporation of practice standards/core competencies, documentation standards, and evidence-based metrics. The best practice standard for the navigator is that they should have some experience in the oncology field so they have a solid foundation for the journey of a cancer patient. There are essential orientation components that must be included in the navigation orientation program.

The following list is an example of what should be included in the orientation. This orientation checklist can be applied to the entire navigation team (multidisciplinary team).

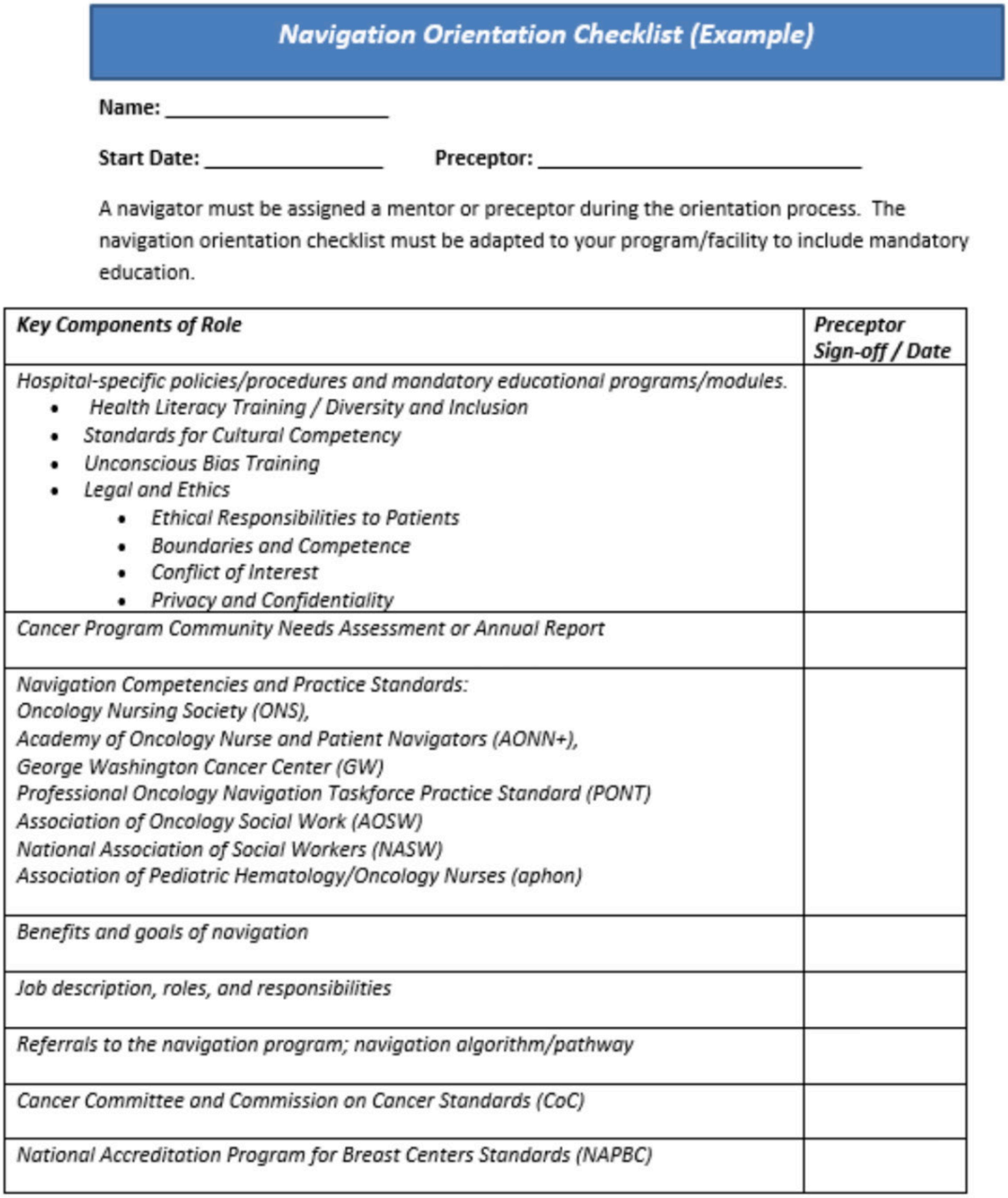
- Hospital or Program Specific Mandatory Education Classes/Modules
- Cancer Program and Hospital System Annual Report
- Navigation Core Competencies, Knowledge Domains, and Practice Standard
- Navigation Referrals, Intake Process and Workflows
- Job Descriptions/Role Delineation
- Process Maps or Navigation Workflows
- Shadow Experience with Cancer Program Staff and Departments
- Review of Internal and Community Resources
- Evidence-Based Patient Assessment Tools
- Communication and Managing Transitions with the Multidisciplinary Team
- Navigation Evidence-Based Metrics
- Commission on Cancer and National Accreditation of Breast Programs Standards
- Patient and Caregiver Educational Materials and Frequently Asked Questions Guide
- Support Groups and Educational Programs
- Tumor Conference Responsibilities (if applicable)
- Multidisciplinary Consults (if applicable)
- EMR Documentation Standards
- Oncology Navigation Professional Organizations
- Health Literacy Training / Diversity and Inclusion
- Standards for Cultural Competency
- Unconscious Bias Training Legal and Ethics
- Ethical Responsibilities to Patients
- Boundaries and Competence
- Conflict of Interest
- Privacy and Confidentiality

A navigation orientation checklist must be created, and the navigator must be assigned a preceptor or mentor during and after the formal orientation process. The orientation checklist can also be modified as an annual checklist.

The navigation leadership must inform the team about new navigation elements related to practice standards, metrics, and oncology practices, such as clinical trials, treatment standards, survivorship, palliative care, or end-of-life services or resources.

The following is an example orientation checklist that can be modified to meet the needs of your navigation program.

Figure 7: Navigation Checklist Example



Navigation Orientation Checklist (Example)

Name: ____________________

Start Date: ________________ **Preceptor:** _____________________________

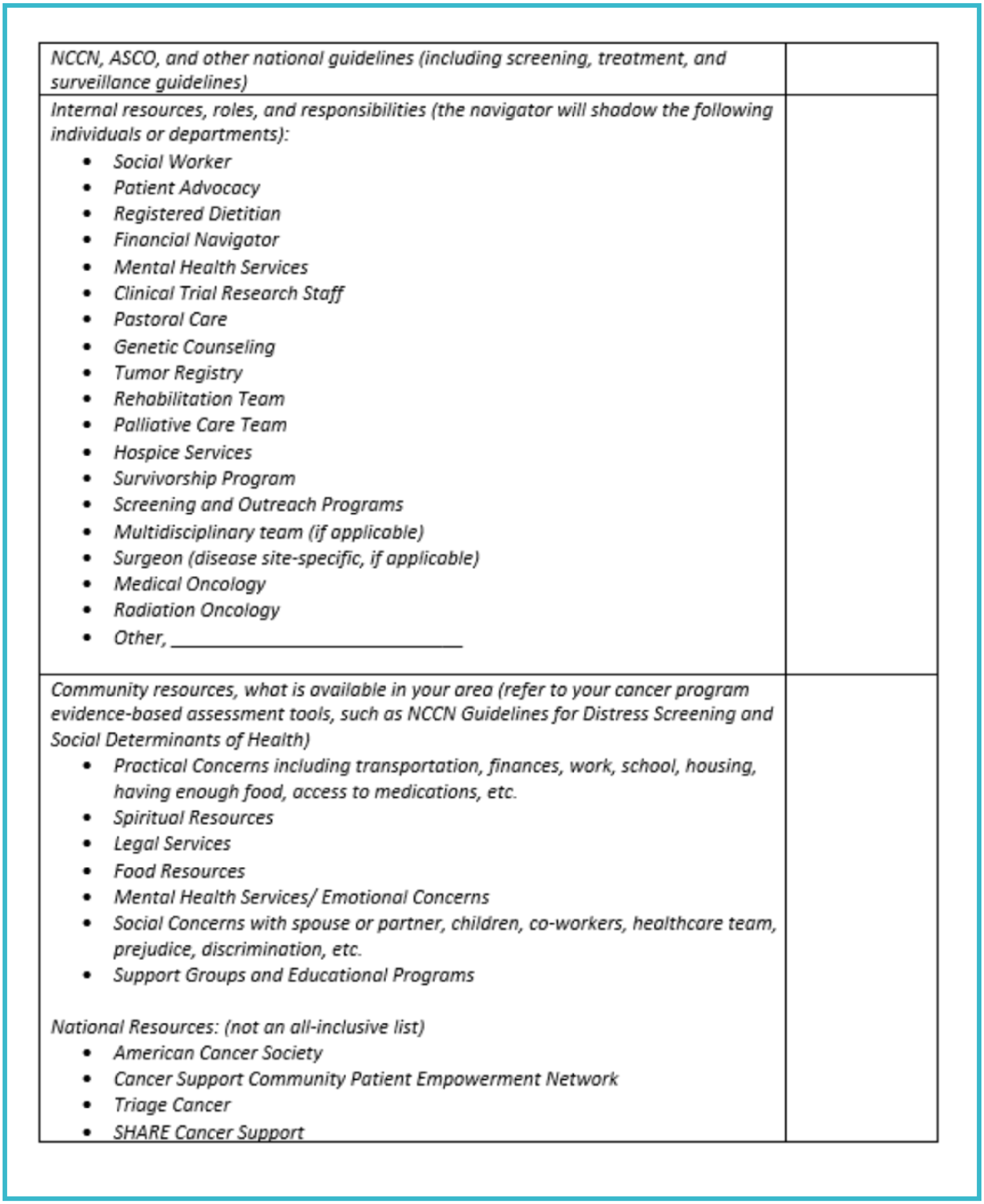
A navigator must be assigned a mentor or preceptor during the orientation process. The navigation orientation checklist must be adapted to your program/facility to include mandatory education.

Key Components of Role	***Preceptor Sign-off / Date***

Hospital-specific policies/procedures and mandatory educational programs/modules.
• *Health Literacy Training / Diversity and Inclusion*
• *Standards for Cultural Competency*
• *Unconscious Bias Training*
• *Legal and Ethics*
  • *Ethical Responsibilities to Patients*
  • *Boundaries and Competence*
  • *Conflict of Interest*
  • *Privacy and Confidentiality*	

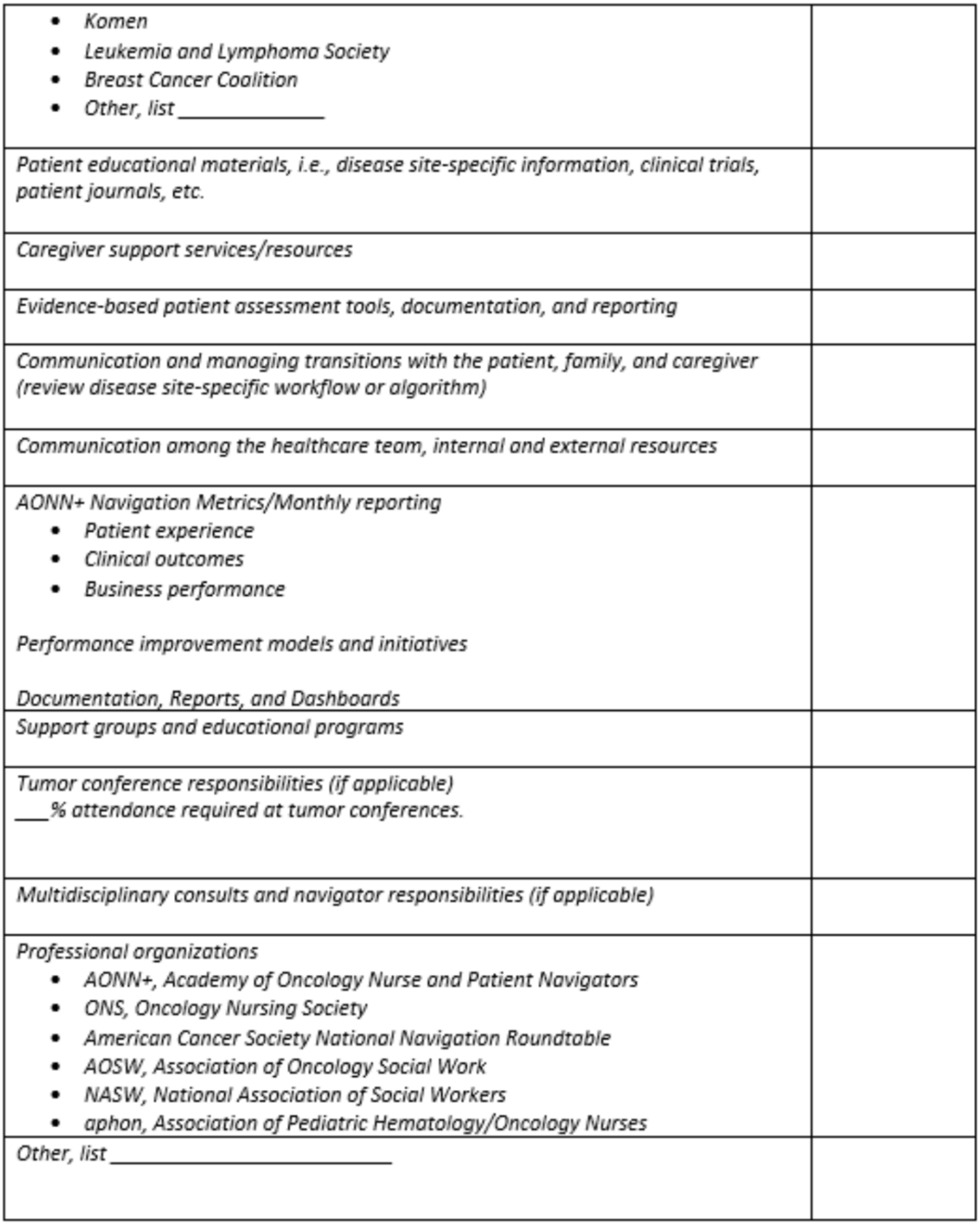
Cancer Program Community Needs Assessment or Annual Report	
Navigation Competencies and Practice Standards: *Oncology Nursing Society (ONS),* *Academy of Oncology Nurse and Patient Navigators (AONN+),* *George Washington Cancer Center (GW)* *Professional Oncology Navigation Taskforce Practice Standard (PONT)* *Association of Oncology Social Work (AOSW)* *National Association of Social Workers (NASW)* *Association of Pediatric Hematology/Oncology Nurses (aphon)*	
Benefits and goals of navigation	
Job description, roles, and responsibilities	
Referrals to the navigation program; navigation algorithm/pathway	
Cancer Committee and Commission on Cancer Standards (CoC)	
National Accreditation Program for Breast Centers Standards (NAPBC)	

Figure 7: Navigation Checklist Example (CONT.)



NCCN, ASCO, and other national guidelines (including screening, treatment, and surveillance guidelines)	
Internal resources, roles, and responsibilities (the navigator will shadow the following individuals or departments): • *Social Worker* • *Patient Advocacy* • *Registered Dietitian* • *Financial Navigator* • *Mental Health Services* • *Clinical Trial Research Staff* • *Pastoral Care* • *Genetic Counseling* • *Tumor Registry* • *Rehabilitation Team* • *Palliative Care Team* • *Hospice Services* • *Survivorship Program* • *Screening and Outreach Programs* • *Multidisciplinary team (if applicable)* • *Surgeon (disease site-specific, if applicable)* • *Medical Oncology* • *Radiation Oncology* • *Other, ______________________________*	
Community resources, what is available in your area (refer to your cancer program evidence-based assessment tools, such as NCCN Guidelines for Distress Screening and Social Determinants of Health) • *Practical Concerns including transportation, finances, work, school, housing, having enough food, access to medications, etc.* • *Spiritual Resources* • *Legal Services* • *Food Resources* • *Mental Health Services/ Emotional Concerns* • *Social Concerns with spouse or partner, children, co-workers, healthcare team, prejudice, discrimination, etc.* • *Support Groups and Educational Programs* *National Resources: (not an all-inclusive list)* • *American Cancer Society* • *Cancer Support Community Patient Empowerment Network* • *Triage Cancer* • *SHARE Cancer Support*	

Figure 7: Navigation Checklist Example (CONT.)



• Komen • Leukemia and Lymphoma Society • Breast Cancer Coalition • Other, list ______________	
Patient educational materials, i.e., disease site-specific information, clinical trials, patient journals, etc.	
Caregiver support services/resources	
Evidence-based patient assessment tools, documentation, and reporting	
Communication and managing transitions with the patient, family, and caregiver (review disease site-specific workflow or algorithm)	
Communication among the healthcare team, internal and external resources	
AONN+ Navigation Metrics/Monthly reporting • Patient experience • Clinical outcomes • Business performance Performance improvement models and initiatives Documentation, Reports, and Dashboards	
Support groups and educational programs	
Tumor conference responsibilities (if applicable) ___% attendance required at tumor conferences.	
Multidisciplinary consults and navigator responsibilities (if applicable)	
Professional organizations • AONN+, Academy of Oncology Nurse and Patient Navigators • ONS, Oncology Nursing Society • American Cancer Society National Navigation Roundtable • AOSW, Association of Oncology Social Work • NASW, National Association of Social Workers • aphon, Association of Pediatric Hematology/Oncology Nurses	
Other, list ___________________________	

CHAPTER FOUR

Oncology National Standards Relevant to Navigation

National oncology standards exist for cancer programs and for navigation programs. Your program may not participate in national accreditation programs, however, these standards provide guidance and best practice.

Commission on Cancer (CoC) Standards

The CoC is a consortium of professional organizations dedicated to improving cancer patient's survival and quality of life through standard-setting, prevention, research, education, and the monitoring of comprehensive quality care. This section outlines three CoC standards directly relatable to a navigation program:

This section will also cover the CoC specifications for program fulfillment and the rating scale the CoC uses to assign a “Compliant” vs. “Non-Compliant” rating for each standard.

Standard 8.1: Addressing Barriers to Care

A navigation team is established to identify barriers to care for patients with cancer and implement a process to overcome the identified barrier.

Definition and Requirements:

Navigation Team

Each calendar year, the cancer committee identifies a navigation team to address barriers to care. Each year, the navigation team identifies at least one patient, system, or provider-based barrier to accessing health and psychosocial care their cancer patients face and develops and implements a plan to address the barrier.

The navigation team may include professionals specializing in psychosocial care, financial assistance, nurse navigation, or any specialty deemed appropriate by the cancer committee. Representatives from the community, including an American Cancer Society or patient representative, may be part of the navigation team.

Cancer Barriers Analysis

The navigation team reviews and analyzes the strengths and barriers of the cancer program. Resources for identifying strengths and barriers include, but are not limited to:

- Cancer Quality Improvement (CQIP) reports
- Cancer patient satisfaction surveys
- Patient focus groups
- Use of state cancer registry data compared to your cancer center data
    - Are you treating the leading cancers that occur in your area?
    - Are you reaching vulnerable populations?
- Population health resources form public health work done locally and regionally
- Community Needs Assessment
- Analysis of unique features of your institution and state (i.e., affordable or adequate lodging for patients receiving care at a rural facility)

Identification of Barriers

Programs determine the frequency and format of the navigation team meetings. This team must meet separately from the full cancer committee meeting. Each calendar year, the team identifies barriers specific to the cancer program and chooses one to focus on for the upcoming year. Examples include but are not limited to:

- Gaps in community resources
- Identified populations in need
- Uninsured or underinsured
- Healthcare professional shortages

Each calendar year, the navigation team provides a report to the cancer committee. The report must state:
- What barrier was chosen
- What resources/processes were utilized to identify and address the barrier
- Metrics related to outcomes of reducing the chosen barrier
- Plans for the upcoming year

Specifications by Category
All programs fulfill this standard as written

Documentation
Submitted with Pre-Review Questionnaire:
- Minutes and any relevant documentation from the navigation team meetings
- Cancer committee minutes documenting the navigation team's report to the cancer committee

Measures of Compliance

Compliance: Each calendar year, the program fulfills the compliance criteria:
1. The cancer committee identifies a navigation team
2. The navigation team identifies at least one barrier to focus on for the year and resources and processes to address the barrier
3. At the end of the year, the navigation team evaluates the resources and processes adopted to address the barrier to care and identifies strengths and areas for improvement
4. The navigation team reports all required information to the cancer committee once each year

Noncompliance: The program does not fulfill one or more of the compliance criteria.

Standard 5.3 Psychosocial Distress Screening

Psychosocial services are available on-site or by referral. Each calendar year, the cancer committee implements a policy and procedure for providing and monitoring psychosocial distress screening and referral for psychosocial care. The psychosocial service coordinator evaluates and documents the psychosocial distress process and reports the findings to the cancer committee.

Definition and Requirements:

Psychosocial Policy and Procedure
Services that address physical, psychological, social, spiritual, and financial needs that result from a cancer diagnosis must be available on-site or by referral with an established policy and procedure in place to inform patients how to access them.

Psychosocial Distress Screening
Cancer programs must implement a policy and procedure for psychosocial distress screening for cancer patients. The process identifies psychological, social, financial, and behavioral issues that may interfere with a patient's treatment plan and adversely affect treatment outcomes. It also provides patients identified with distress with the appropriate resources and/or referral for psychosocial needs.

Timing of Screening
Cancer patients must be screened for distress at least one time during the patient's first course of treatment. Additional screenings may be provided per cancer program or healthcare provider discretion but are not required by this standard.

The following patients are not included in compliance with this standard:
- Biopsy only or class of "00" patients
- Patients who are admitted to the hospital with a history of cancer but for non-cancer-related issues
- Inpatients with a current diagnosis of cancer who are treated for a non-cancer issue and do not receive cancer treatment

Method
The mode of administration (patient questionnaire or clinician-administered questionnaire) is determined by the cancer committee and may be tailored to the practice's workflow. Medical staff, including medical assistants, nurses, social workers, and physicians, who administer or interpret the screening tool must be properly trained.

The policy and procedure must address the sites of service where screening occurs, including at the CoC-accredited facility and/or with designated providers (for example, the office of medical oncologists and/or radiation oncologists affiliated with the CoC program). The policy and procedure must include processes for assessment and treatment (on-site or referral) appropriate for the source of distress identified by the screening, including the psychosocial, physical, spiritual, and mental health resources available to patients on-site or by referral.

Tools
The cancer committee selects and approves the psychosocial distress screening tool to be administered. Preference is given to standardized, validated instruments or tools with established clinical cutoffs. The cancer committee determines the cutoff score used to identify distressed patients.

Direct clinical contact is required for patients whose results exceed the defined cutoff score identified in the policy and procedure, even when screening is completed electronically. Direct clinician contact means discussing with the patient face to face, by telephone or telemedicine.

Assessment and Referrals
If the distress screening results indicate clinical evidence of moderate or severe distress, a member of the patient's oncology team (physician, nurse, social worker, psychologist, and/or contracted mental health professional) must assess the patient to identify the problems initiating the distress. This assessment will confirm the distress screening results and identify the appropriate referrals as needed.

Documentation
The policy and procedure document the screening process, timing of screening, identified tools, and distress level triggering a referral to services.

The distress screening(s) results, referrals for care provision, and any follow-up are documented in the patient's medical record to facilitate integrated, high-quality care.

The Psychosocial Services Coordinator is required to oversee this activity and report to the cancer committee each year. Reports must include one year's worth of data.

The annual psychosocial services summary must include, but is not limited to:
- Number of patients screened
- Number of patients referred for distress resources or further follow-up
- Where patients were referred (on-site or by referral)

Specifications by Category
All programs fulfill this standard as written.

Documentation
Submitted with Pre-Review Questionnaire
- Policies and procedures that ensure patient access to psychosocial services either on-site or by referral
- The psychosocial distress screening policy and procedure
- The annual psychosocial services summary that documents all required elements
- Cancer committee minutes that document discussion of the process and tools providing, monitoring, and evaluating the psychosocial distress screen

Measure of Compliance
Compliance: Each calendar year, the cancer program fulfills all the compliance criteria:
1. Policies and procedures are in place to ensure patients have access to psychosocial services either on-site or by referral.

2. The cancer committee implements a policy and procedure that includes all requirements for providing and monitoring psychosocial distress screening and referral for psychosocial care.
3. Cancer patients are screened for psychosocial distress at least once during the first course of treatment.
4. The psychosocial distress screening process is evaluated and documented, and the psychosocial services coordinator reports the findings to the cancer committee. The coordinator's report includes all required elements and is documented in the cancer committee minutes.

Noncompliance: The program does not fulfill one or more of the compliance criteria each calendar year.

Standard 4.9, Survivorship Program

The cancer committee oversees developing and implementing a survivorship program designed to meet the needs of cancer patients treated with curative intent.

Definition and Requirements:
The cancer program has a survivorship care program in place that includes the following elements documented in a written plan;

- Designated director of the survivorship care program who must be a member of the cancer committee
- An identified team responsible for the development of survivorship care delivery models and activities
- A survivorship program that addresses the needs of a cancer survivor through care and consultative services provided either on-site or by referral
- A survivorship program report describing the program and its planned future development. The report will be presented to the cancer committee, with discussion, annually. It also includes a status update on the previous reports' planned improvement(s)
  - Patients who are admitted to the hospital with a history of cancer but for non-cancer-related issues
  - Inpatients with a current diagnosis of cancer who are treated for a non-cancer issue and do not receive cancer treatment

Survivorship and Follow-up Care
The care of cancer survivors is an ongoing activity. Cancer survivors may require services shortly after treatment completion or many years after. Therefore, ongoing care, as determined by the individual patient's needs, will be provided with appropriate interventions to mitigate the complications of the patient's cancer and treatment toxicities. The survivorship program addresses this continuing need.

Components of the Survivorship Program
Survivorship Program Team: Leadership and Personnel
The cancer committee appoints a director of the survivorship program who is responsible to the cancer committee for the development and execution of the survivorship program. The Survivorship Program Director is a required member of the cancer committee.

The Survivorship Program Director will develop a team. Members may include physicians, advanced practice providers, nurses, social workers, nutritionists, physical therapists, and others in similar positions.

The survivorship program team evaluates and develops the program. Programs determine the frequency and format of the survivorship team meetings, which must be held separately from the full cancer committee meeting.

Target Population
The survivorship program is established to meet the needs of cancer survivors. While definitions of survivors include those from diagnosis through their lifespan, including those with metastatic disease, the CoC focuses on the development of services for patients treated with curative intent. Additional activities reaching the broader group of cancer survivors are encouraged but not required under this standard.

Services

Cancer survivors need a variety of services dependent on their diagnosis, the treatment they receive, comorbidities, and personal needs. These may include but are not limited to:

- treatment summaries and survivorship care plans
- screening for cancer resources
- screening for new cancers
- physical therapy
- nutritional services
- psychological support
- cardiac consultation

Some of these services are required and outlined in other standards for CoC accreditation. They should be available to all cancer patients, including those undergoing diagnostic evaluation, treatment, and post-treatment survivorship care. The survivorship program policy and procedure include a comprehensive list of services available for cancer survivors. Services may be available on-site or by referral.

Treatment Summaries and Survivorship Care Plans

The CoC recommends and encourages that patients receive a treatment summary and survivorship care plan (SC)) but delivery of such plans is not a required component of this standard.

Delivery of SCPs may be utilized as one of the services offered to survivors to meet the requirements of this standard. If so, the program defines the population that should receive care plans. Suggested components of the treatment summary and SCP are outlined in the reference below. (Mayer et. al.)

Annual Review of the Survivorship Program

Each year, the cancer committee reviews the activities of the survivorship program. Of the services provided to the cancer program's survivorship population, the cancer program chooses three services for an in-depth review. For each of the three chosen services, the report includes:

- The estimated number of patients impacted by each of the chosen services
- The cancer site impacted by each of the chosen services
- Resources/processes utilized to enhance each of the chosen services
- Identification of opportunities for improvement for each of the chosen services and plans for implementing improvements

Specifications by Category

All programs fulfill this standard as written.

Documentation

Submitted with Pre-Review Questionnaire

- Policy and procedure defining the survivorship program requirements
- Cancer committee minutes that document the required yearly evaluation of the survivorship program

Measure of Compliance

Compliance: Each calendar year, the program fulfills all the following compliance criteria:

1. The cancer committee identifies a survivorship program team, including its designated director and members
2. The survivorship program is monitored and evaluated. A report is given to the cancer committee, contains all required elements, and is documented in the cancer committee minutes

Noncompliance: The program does not fulfill one or more of the compliance criteria each calendar year.

National Accreditation Programs for Breast Centers (NAPBC) Standards

About the NAPBC

The National Accreditation Program for Breast Centers (NAPBC) is a quality program at the American College of Surgeons, assisted by representatives from other national professional organizations focused on breast health. The NAPBC is dedicated to the improvement of quality outcomes for patients with breast disease and breast cancer through the implementation of multidisciplinary care guided by evidence-based accreditation standards and comprehensive professional and patient education.

Standard 5.8: Patient Navigation

Rationale
Individuals undergoing treatment for breast disease or breast cancer are generally unfamiliar with the numerous phases of care and the associated decision-making related to each that must be made as they traverse the patient's journey. Navigation professionals serve as a resource and ally in this stressful time.

Definition and Requirements:
Patient navigation begins at the time of patient presentation to the NAPBC-accredited program and continues beyond treatment. Patient navigation is integral to the patient journey as it assists with care transitions, continuity, and communication between the treatment team members.

A protocol must be developed and implemented to address patient navigation throughout the patient journey. For example:
- The patient has a point of contact (the navigation professional(s)) from the moment of diagnosis onward
- Facilitation of timely transitions between surgery and medical oncology treatment
- Assistance with addressing survivorship and surveillance throughout treatment
- Alerting the radiation oncology team if a patient cannot complete chemotherapy and finishes treatment early

Evaluation by the Breast Program Leadership Committee (BPLC)
During each accreditation cycle, the BPLC must review and assess:
- The protocol for patient navigation

As barriers to compliance with this standard are identified, the accredited program must address them.

The BPLC evaluation and discussion must be documented in the BPLC meeting minutes.

Documentation
Submitted with Pre-Review Questionnaire
- Required protocol
- BPLC meeting minutes documenting the required evaluation

Documentation uploaded into the Pre-Review Questionnaire must have all protected health information removed. Programs are expected to follow local, state, and federal requirements for all accreditation standards for patient privacy, risk management, and peer review. These requirements vary from state to state.

Measure of Compliance
The NAPBC-accredited program fulfills all compliance criteria:
- A protocol is developed and implemented to address patient navigation throughout the patient journey
- The BPLC evaluation is completed and documented in the BPLC meeting minutes once each accreditation cycle

5.15 Survivorship Standard

Rationale
Patients with breast disease or breast cancer are at risk for complications and symptoms that can delay other treatments and interfere with recovery. Identifying and controlling these symptoms are essential to promote compliance with continued therapies and restore the patient's sense of normalcy. After treatment, some patients need assistance and guidance to help them return to their "new normal." Other patients may see their diagnosis as a "wake-up call" to improve their overall health. NAPBC-accredited programs promoting a healthy lifestyle will decrease patient risk for disease recurrence and improve the patient's post-cancer well-being.

Definition and Requirements:
The NAPBC-accredited program must use evidence-based guidelines to develop and implement a protocol addressing persistent symptoms, functional issues, and social and behavioral determinants of health for maximizing symptom management, physical function, and social well-being among patients with breast disease or breast cancer. Evidence-based guidelines include those provided by the ACSM, APTA, ONS, ACS, NCCN, and ASCO.

Examples of evidence-based guidelines include, but are not limited to, the following:
- Referral to local or online exercise programs
- Referral to a social worker if psychosocial distress remains elevated post-treatment
- Referral to outpatient rehabilitation if specific functional complaints arise
- Referral to outpatient rehabilitation for evaluation and treatment for lymphedema, as needed
- Use of a lymphedema prevention program, including regular symptom assessment and clinical evaluation using objective measurements of lymphedema, such as bioimpedance spectroscopy

The protocol must also address how patients with breast disease or breast cancer are connected to evidence-based elements of breast cancer recovery.
- For example, ensuring that breast cancer survivors receive referrals to exercise programming at follow-up appointments
- For services that are not available on-site, the treatment team must help facilitate patient access to needed resources

It is recommended, but not required, that a written summary of treatment and associated survivorship recommendations is provided to the patient and the patient's primary care provider. Patients must be encouraged to maintain a relationship with their primary care provider, who is informed about the care the patient received, and potential side effects the patient may encounter.

Evaluation by the Breast Program Leadership Committee (BPLC)
During each accreditation cycle, the BPLC must review and assess:
- The protocol for following evidence-based guidelines to address persistent symptoms, functional issues, and social and behavioral determinants of health, for maximizing symptom management, physical function, and social well-being among patients with breast disease or breast cancer
- Barriers to maximizing wellness of patients with breast disease or breast cancer after treatment

As barriers to compliance with this standard are identified, they must be addressed by the NAPBC-accredited program.

The BPLC evaluation and discussion must be documented in the BPLC meeting minutes.

Documentation
Reviewed On-Site
- The site reviewer will evaluate preselected medical records to confirm compliance with this standard, including:
  - Persistent symptoms are queried and addressed according to evidence-based guidelines
  - Social and behavioral health is assessed regularly and addressed according to evidence-based guidelines

Submitted with Pre-Review Questionnaire
- Required protocol
- BPLC meeting minutes documenting the required evaluation

Documentation uploaded into the Pre-Review Questionnaire must have all protected health information removed. Programs are expected to follow local, state, and federal requirements for all accreditation standards for patient privacy, risk management, and peer review. These requirements vary from state to state.

Measure of Compliance
The NAPBC-accredited program fulfills all compliance criteria:
- A protocol is developed and implemented to address patient navigation throughout the patient journey
- The BPLC evaluation is completed and documented in the BPLC meeting minutes once each accreditation cycle.

7.1 Quality Measures Standards

Definition and Requirements:
The National Accreditation Program for Breast Centers (NAPBC) requires accredited programs to treat patients with breast disease or breast cancer in accordance with all nationally accepted quality measures. The NAPBC approves such nationally accepted quality measures based on determining the need for quality or accountability regarding a specific aspect of breast care. All approved quality measures must be reviewed and implemented by the NAPBC-accredited program. The NAPBC determines the timeline for implementation and the expected compliance rate for all new quality measures. The Breast Program Leadership Committee (BPLC) must monitor the accredited program's adherence to all required quality measures.

If adherence to any required quality measure falls below its expected rate of compliance, a corrective action plan must be developed and implemented to improve performance. The corrective action plan must document how the NAPBC accredited program will investigate and resolve all barriers affecting a required quality measure that falls below its expected rate of compliance.

Programs with no cases eligible for assessment in an approved quality measure are exempt from demonstrating compliance with the requirements for that individual quality measure.

Evaluation by the BPLC
Each calendar year, the BPLC must review and assess:
- Compliance with all required quality measures
- Development and implementation of corrective action plans for all quality measures that fall below the expected rate of compliance

The BPLC evaluation and discussion must be documented in the BPLC meeting minutes.

Source: https://accreditation.facs.org/accreditationdocuments/NAPBC/Standards/Optimal_Resources_for_Breast_Care_2024.pdf

CHAPTER FIVE

Addressing Barriers to Care, Interventions, and Follow-Up

Addressing Barriers to Care and Interventions

As reviewed in the prior chapter on national oncology standards and included in the definition of an oncology navigator, identifying medical and psychosocial barriers across the continuum of care is vital. Barriers must be identified utilizing an evidence-based validated tool. This tool, per CoC, is to be administered early in the continuum of care, and best practice standards demonstrate that discussing barriers with the patient and their caregivers will allow for early and successful interventions, resulting in better outcomes.

When assessing and providing interventions, referrals and Follow-up must occur which includes,

- Referrals to appropriate disciplines based on identified barriers
- Follow-up with patient and caregiver regarding interventions provided
- Communicating with the healthcare team barriers and interventions

Evidence-Based Validated Tools

There are exceptional tools available for navigation programs that are evidence-based, validated, and considered best practice. This chapter will provide a short list of example tools, such as,

- NCCN Psychosocial Distress Screening Tool
- PROMIS (adult, pediatric, parental, health condition-specific, and symptom-specific)
- Edmonton Symptom Assessment System Tool
- PH2 and PH9 Depression Screening
- Functional Assessment of Cancer Therapy – General (FACT-G)

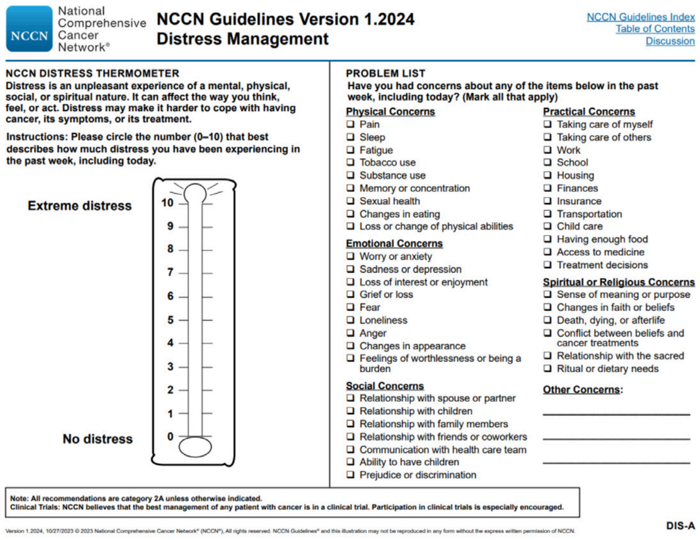
There are many tools to evaluate for your program; create a navigation multidisciplinary committee to discuss which tool will be best for your program and patient population.

The following is a limited review of some of the most widely used evidence-based validated tools.

NCCN Psychosocial Distress Thermometer Tool (2024 Version)

According to the NCCN Distress Management Tool, distress is an unpleasant mental, physical, social, or spiritual experience that can affect how you think, feel, or act. It may make it harder to cope with cancer, its symptoms, or its treatment. This tool is the most widely used patient reportable tool in the world. The tool is excellent for conversing with your patients while building trust and providing appropriate resources based on the responses.

Figure 8: NCCN Guidelines Distress Management



National Comprehensive Cancer Network®

NCCN Guidelines Version 1.2024
Distress Management

NCCN Guidelines Index
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Discussion

NCCN DISTRESS THERMOMETER

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.

PROBLEM LIST

Have you had concerns about any of the items below in the past week, including today? (Mark all that apply)

Physical Concerns
☐ Pain
☐ Sleep
☐ Fatigue
☐ Tobacco use
☐ Substance use
☐ Memory or concentration
☐ Sexual health
☐ Changes in eating
☐ Loss or change of physical abilities

Emotional Concerns
☐ Worry or anxiety
☐ Sadness or depression
☐ Loss of interest or enjoyment
☐ Grief or loss
☐ Fear
☐ Loneliness
☐ Anger
☐ Changes in appearance
☐ Feelings of worthlessness or being a burden

Social Concerns
☐ Relationship with spouse or partner
☐ Relationship with children
☐ Relationship with family members
☐ Relationship with friends or coworkers
☐ Communication with health care team
☐ Ability to have children
☐ Prejudice or discrimination

Practical Concerns
☐ Taking care of myself
☐ Taking care of others
☐ Work
☐ School
☐ Housing
☐ Finances
☐ Insurance
☐ Transportation
☐ Child care
☐ Having enough food
☐ Access to medicine
☐ Treatment decisions

Spiritual or Religious Concerns
☐ Sense of meaning or purpose
☐ Changes in faith or beliefs
☐ Death, dying, or afterlife
☐ Conflict between beliefs and cancer treatments
☐ Relationship with the sacred
☐ Ritual or dietary needs

Other Concerns:
____
____
____

Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

DIS-A

PROMIS Tools

PROMIS includes over 300 physical, mental, and social health measures for use by the general population and individuals with chronic conditions.

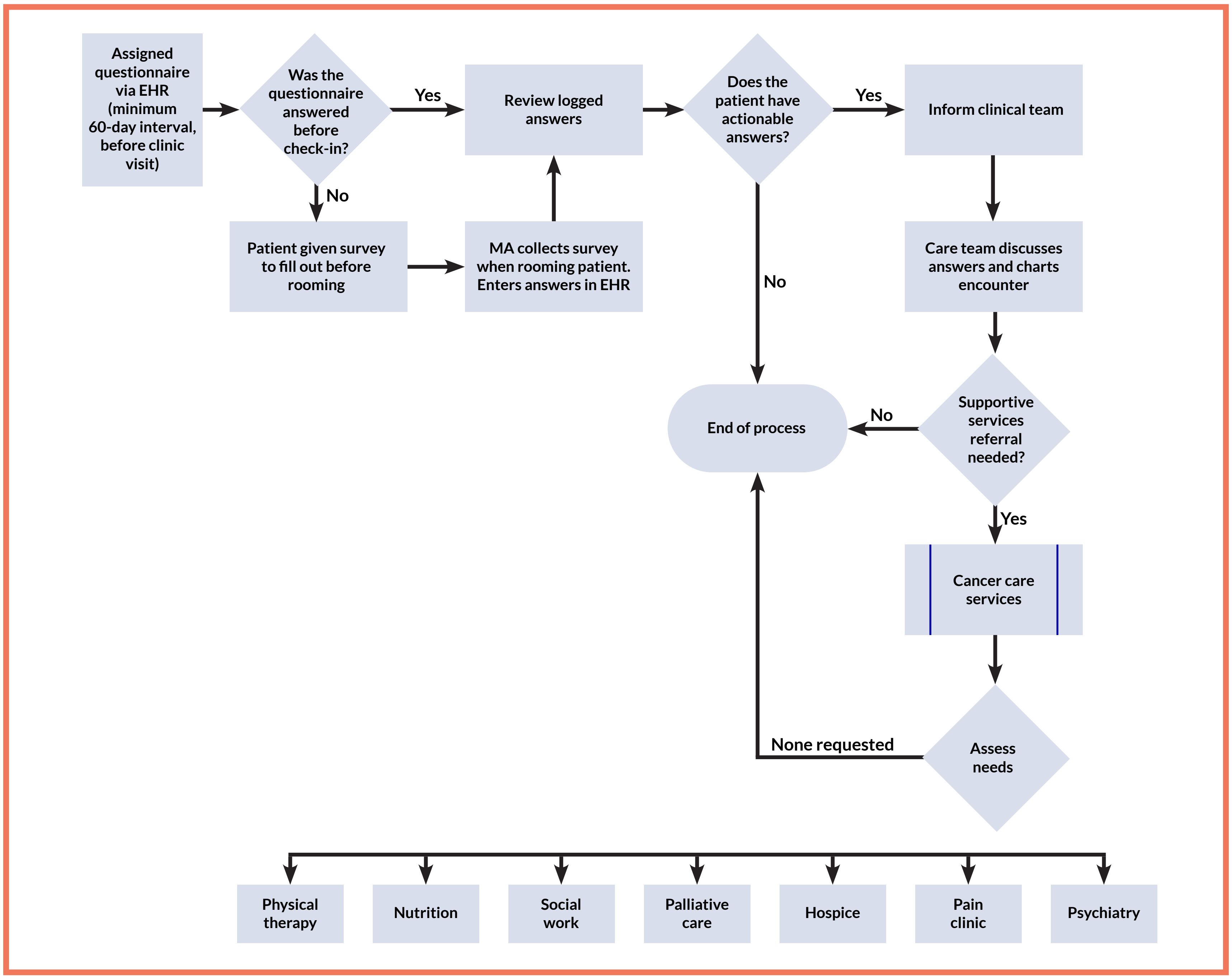
Disease-Specific PROMIS Measures

Some PROMIS measures were constructed by selecting a subset of items from a PROMIS item bank that are particularly relevant to individuals living with a specific health condition. Sometimes, these measures added new items.

Workflow for PROMIS-Ca

The workflow of implementing the PROMIS questionnaire as a tool for distress screening started with medical assistants assessing its completion and reviewing for a positive screen on the questionnaire. If a patient had any such responses, the clinical team was informed, with the recommendation for supportive service referral. EHR, electronic health record; MA, medical assistant; PROMIS, Patient-Reported Outcomes Measurement Information System.

Figure 9: PROMIS-Ca Workflow



Translations
There are many available translations.

Types of Measures
PROMIS measures include item banks, short forms, and computer adaptive tests (CATs).

Item banks are collections of carefully selected and tested items all measuring the same construct. Any subset of items can be administered and produce a score on the same metric. In some administration platforms, an item bank defaults to being administered as a computer adaptive test. Item banks are not intended to be administered in their entirety. Short forms are subsets of items selected from a larger collection of items (e.g., from an item bank). A short form usually generates a single score for a construct. Sometimes short forms are called fixed length forms or fixed forms.

Scales are complete collections of scored items to be administered in their entirety. Profiles measure multiple constructs through a fixed collection of short forms or CATs. Pools are collections of related items not intended to produce a summary score but to be used as single items.

Source: https://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis

Assessment Tool for the Financial Navigator

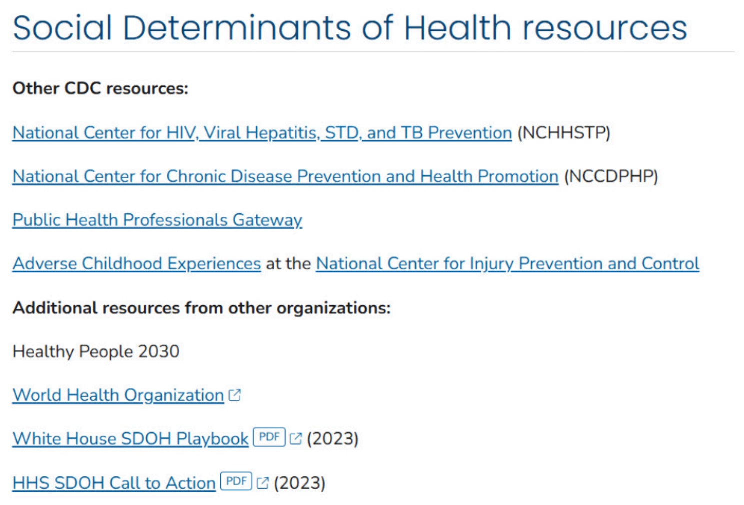
There is no universal standard for financial toxicity screening. However, the COmprehensive Score for financial Toxicity (COST) measure, a 7-item self-report measure, can help assess financial toxicity (de Souza et al., 2017).

Source: https://pmc.ncbi.nlm.nih.gov/articles/PMC5298039/

The Importance of Understanding and Assessing Social Determinants of Health

The Centers for Disease Control (CDC) states that social determinants of health (SDOH) are nonmedical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age. These forces and systems include a wide set of forces and systems that shape daily life, such as economic policies and systems, development agendas, social norms, social policies, and political systems. CDC has adopted this definition from the World Health Organization.

Figure 10: CDC's Social Determinants of Health Resources



Social Determinants of Health resources

Other CDC resources:

National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)

National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)

Public Health Professionals Gateway

Adverse Childhood Experiences at the National Center for Injury Prevention and Control

Additional resources from other organizations:

Healthy People 2030

World Health Organization

White House SDOH Playbook PDF (2023)

HHS SDOH Call to Action PDF (2023)

Source: https://www.cdc.gov/about/priorities/why-is-addressing-sdoh-important.html#:~:text=Addressing%20differences%20in%20SDOH%20accelerates%20progress%20toward%20health,either%20genetic%20factors%20or%20access%20to%20healthcare%20services

Evidence-based and Best Practice Social Determinants of Health Screening Tools

https://www.aafp.org/dam/AAFP/documents/patient_care/everyone_project/hops19-physician-form-sdoh.pdf

https://prapare.org/the-prapare-screening-tool/

https://www.cms.gov/priorities/innovation/Files/worksheets/ahcm-screeningtool.pdf

https://sirenetwork.ucsf.edu/sites/default/files/2021-02/BMC-THRIVE.pdf

Evidence-Based Pediatric Oncology Resources

Figure 11: List of Evidence-Based Pediatric Oncology Resources

National Organization	Website
The American Childhood Cancer Organization	https://www.acco.org/
Children's Oncology Group (COG) Guidelines:	https://www.childrensoncologygroup.org/ https://childrensoncologygroup.org/cog-supportive-care-endorsed-guidelines
Clinical Practice Guidelines in Oncology	https://pubmed.ncbi.nlm.nih.gov/37549914/
NIH, National Cancer Institute	https://www.cancer.gov/types/childhood-cancers

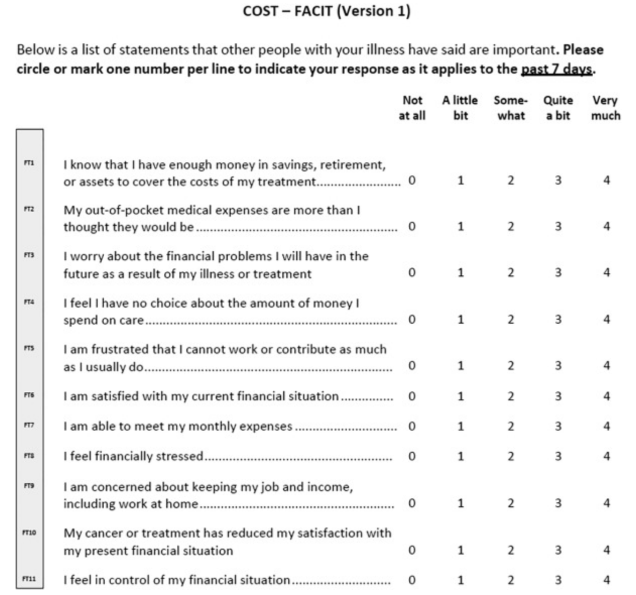
This selection from the NCCN Guidelines for Adolescent and Young Adult (AYA) Oncology focuses on considerations for the comprehensive care of AYA patients with cancer. Compared with older adults with cancer, AYA patients have unique needs regarding treatment, fertility counseling, psychosocial and behavioral issues, and supportive care services. The complete version of the NCCN Guidelines for Adolescent and Young Adult (AYA) Oncology addresses additional aspects of caring for AYA patients, including risk factors, screening, diagnosis, and survivorship.

Source: https://www.accc-cancer.org/home/learn/comprehensive-cancer-care-services/aya-resources

Assessment Tool for the Financial Navigator

There is no universal standard for financial toxicity screening. However, the COmprehensive Score for financial Toxicity (COST) measure, a 7-item self-report measure, can help assess financial toxicity (de Souza et al., 2017).

Figure 12: COmprehensive Score for financial Toxicity (COST) - Functional Assessment of Chronic Illness Therapy (FACIT)



COST – FACIT (Version 1)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

		Not at all	A little bit	Some-what	Quite a bit	Very much
FT1	I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment	0	1	2	3	4
FT2	My out-of-pocket medical expenses are more than I thought they would be	0	1	2	3	4
FT3	I worry about the financial problems I will have in the future as a result of my illness or treatment	0	1	2	3	4
FT4	I feel I have no choice about the amount of money I spend on care	0	1	2	3	4
FT5	I am frustrated that I cannot work or contribute as much as I usually do	0	1	2	3	4
FT6	I am satisfied with my current financial situation	0	1	2	3	4
FT7	I am able to meet my monthly expenses	0	1	2	3	4
FT8	I feel financially stressed	0	1	2	3	4
FT9	I am concerned about keeping my job and income, including work at home	0	1	2	3	4
FT10	My cancer or treatment has reduced my satisfaction with my present financial situation	0	1	2	3	4
FT11	I feel in control of my financial situation	0	1	2	3	4

Source: https://pmc.ncbi.nlm.nih.gov/articles/PMC5298039/figure/cncr30369-fig-0001/

Program Connects Adolescents and Young Adults to Quality Cancer Care

From puberty to leaving home, starting a career, and navigating adult relationships, adolescents and young adults can feel like they're facing a seemingly unending stream of challenges. Now imagine adding cancer to that mix.

Every year, almost 90,000 of these adolescents and young adults (AYAs)—generally defined as people between the ages of 15 and 39—receive a cancer diagnosis. And this group of patients often needs extra help navigating the complexities of cancer care.

Source: https://www.cancer.gov/news-events/cancer-currents-blog/2024/aya-cancer-program-expands-quality-care

ACCC, Adolescent and Young Adult (AYA) Resources

National Comprehensive Cancer Network (NCCN) Guidelines define an adolescent and young adult (AYA) oncology patient as an individual between 15 and 39 years of age at the time of initial diagnosis. These guidelines state that AYAs develop different cancers than other age groups; this patient population also has unique needs around treatment and survivorship.

According to NCCN, more than 700,000 AYAs are diagnosed with cancer annually in the U.S., accounting for 5 out of 100 new cancer diagnoses and 2 out of 100 cancer deaths.

The American Cancer Society calls attention to issues that can uniquely affect young adults with cancer, including:

- Delays in diagnosis
- Communication challenges with providers unaccustomed to treating patients in this age range
- Financial issues, including lack of or limited insurance coverage
- Social and emotional concerns specific to adolescents and young adults

Several recent studies report a continued increase in diagnosis of colorectal cancer in individuals younger than age 50 in the U.S., and that younger adults are being diagnosed with more advanced disease.

A recent observational study by Sung and colleagues found increased risk of obesity-linked cancer in the younger adult population. Researchers found that individuals born around 1985 had a 2 to 5 times increased risk for kidney, gallbladder, pancreatic, and endometrial cancers—almost double the risk for colorectal cancer and about 1.5 times the risk for multiple myeloma--compared to those born around 1950.

Sources:
Virostko J, Capasso A, Jankeelov TE, Goodgame B. Recent trends in the age at diagnosis of colorectal cancer in the US National Cancer Data Base, 2004-2015. Cancer. 2019;125(21):3828-3835.

Siegel RL, Miller KD, Fedewa SA, et al. Colorectal cancer statistics, 2017. CA Cancer J Clin. 2017;67:177-193.

American Cancer Society: Key statistics for colorectal cancer. Available at cancer.org/colon-rectal-cancer/about/key-statistics.html.

Sung H, Siegel RL, Rosenberg PS, Ahmedin J. Emerging cancer trends among young adults in the USA: analysis of a population-based cancer registry. Lancet Pub Health. 2019;4(3):PE137-E147.

Explore resources from ACCC to help cancer care providers better serve the unique needs of AYA patients with cancer:

https://www.accc-cancer.org/home/learn/comprehensive-cancer-care-services/aya-resources

LGBTQI+

LGBTQ+ | An acronym for “lesbian, gay, bisexual, transgender and queer” with a "+" sign to recognize the limitless sexual orientations and gender identities used by members of our community.

Source: https://www.hrc.org/resources/glossary-of-terms

Access to Care and Medical Mistrust
Currently, there is medical mistrust and decreased access to care for the LGBTQI+ community. They include a lack of healthcare provider knowledge about LGBTQI+ disparities and how to care for these populations, legislative prohibitions on care for these populations, and biases both unconscious and conscious.

Medical Trauma
- 20% of LGBTQI+ people avoid healthcare due to fear or disrespect and discrimination
- 1 in 3 transgender people report educating providers about appropriate healthcare
- 48% of transgender people have at least one negative experience within the last year

Decrease Access to Care
- 20% of LGBTQI+ people live in 9 states where it is legal to refuse care
- Less cancer screening
- Experience more disparities in chronic disease /long-standing health conditions.

Examples of Reputable Resources: NIH collection of SOGI data, SafeZone training, HRC, Fenway Health, WPATH, USCF Transgender Guidelines

Source: https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf

Out

The National Cancer Survey is a survey for LGBTQI+ cancer survivors. The National LGBT Cancer Network works to improve the lives of LGBT cancer survivors and those at risk by:

- EDUCATING the LGBT community about our increased cancer risks and the importance of screening and early detection
- TRAINING healthcare providers to offer more culturally competent, safe, and welcoming care
- ADVOCATING for LGBT survivors in mainstream cancer organizations, the media, and research

Source: https://cancer-network.org/out-the-national-cancer-survey/

Taking An Affirming History

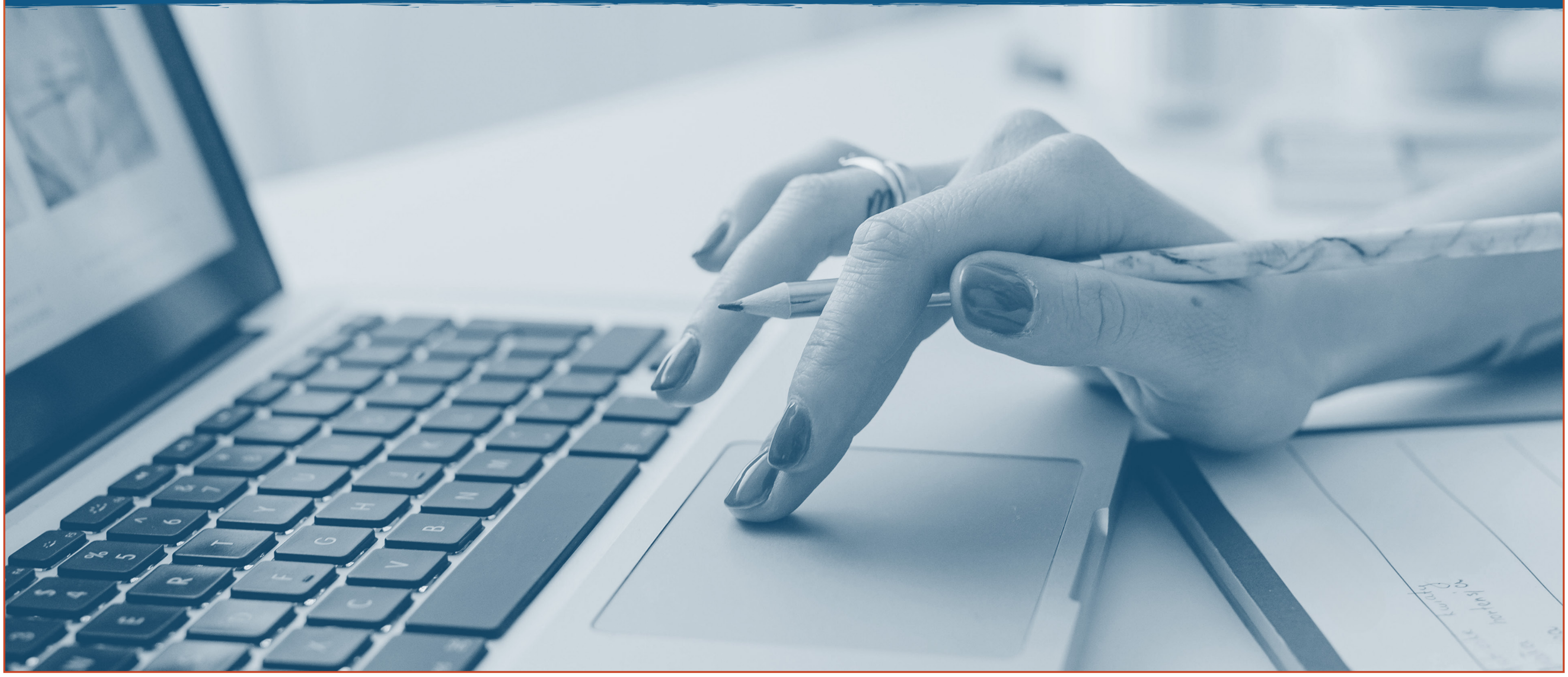
It is essential to meet the patients where they are and provide a safe environment for education and support. This may include:

- Create a welcoming physical environment with visual depictions of a safe environment: pins, signs with non-discrimination statements specifically protecting LGBTQI+ patients, brochures of same-sex couples, people who have different gender expressions; magazines popular in LGBTQI+ communities, i.e., Go Magazine (Lesbian NYC mag)
- Considerate front-line staff – security to desk attendants, environmental staff – with training
- Avoid honorifics
- Consider putting this further on the list: Start with the patient fully clothed
- Use open-ended questions
- Do not make assumptions or shy away from difficult topics
- Mirror the patient's language for themselves and their bodies
- Discuss what exams/tests involve ahead of time and ask the patient if they have any concerns
- Organs dictate a person's exam and testing, not gender identity

Source: AONN+ Annu al Conference, 2024, LGBTQI+: Navigating the Healthcare Experience, Al Asante-Facey MBA, PA-C, Associate Director, Advanced Practice Providers in SubSpecialty Medicine & Supportive Care, Memorial Sloan Kettering Cancer Center, Kelly Haviland, PhD, RN, MSN, FNP-BC, TGNB-C (she/her), Advanced Practice Provider Manager, Professional Development
Advanced Practice Providers, LGBTQI+ Clinical Consultant

CHAPTER SIX

Documentation, Reporting, Metrics, and Performance Improvement



Documentation Standards

Navigation documentation standards are a critical and essential responsibility of the navigator. The navigator's goal is to comprehensively assess the patient's understanding of their disease, treatment, barriers to medical and psychosocial care, interventions, and follow-up. The optimal and best practice standard for documentation is to create discreet reportable fields in the program's documentation system, whether EPIC, Cerner, another navigation-specific platform, or an Excel spreadsheet. The narrative section of the navigator's documentation should be minimal, with most of the focus on reportable fields to report demographics, barriers, interventions, metrics, and outcomes.

The Academy of Oncology Nurse & Patient Navigators (AONN+) developed 35 separate and unique measurements—or metrics—to help you prove the effectiveness of your navigation program and measure its progress. Each metric is backed by evidence from medical literature and is designed to assist navigators in assessing their programs regarding clinical outcomes, patient experience, and return on investment of the navigation program itself. It is not only for the navigation program; the metrics can also help support the cancer program.

But how do navigators implement metrics? How do you select a metric, or metrics, that apply to the goals and needs of your institution? How do you collect the data? What do you do with the data once collected? To help navigators with these questions, AONN+ and the American Cancer Society created the Navigation Metrics Toolkit.

This Toolkit is a digital resource that guides users through selecting, implementing, reporting on, and utilizing the AONN+ navigation metrics. To access it, visit https://AONNonline.org/toolkit.

Sources:
https://www.accc-cancer.org/docs/Documents/acccbuzz/0217-jons-whitepaper

https://jons-online.com/issues/2017/may-2017-vol-9-no-5

Metrics and Dashboards and Reporting Outcomes to Key Stakeholders

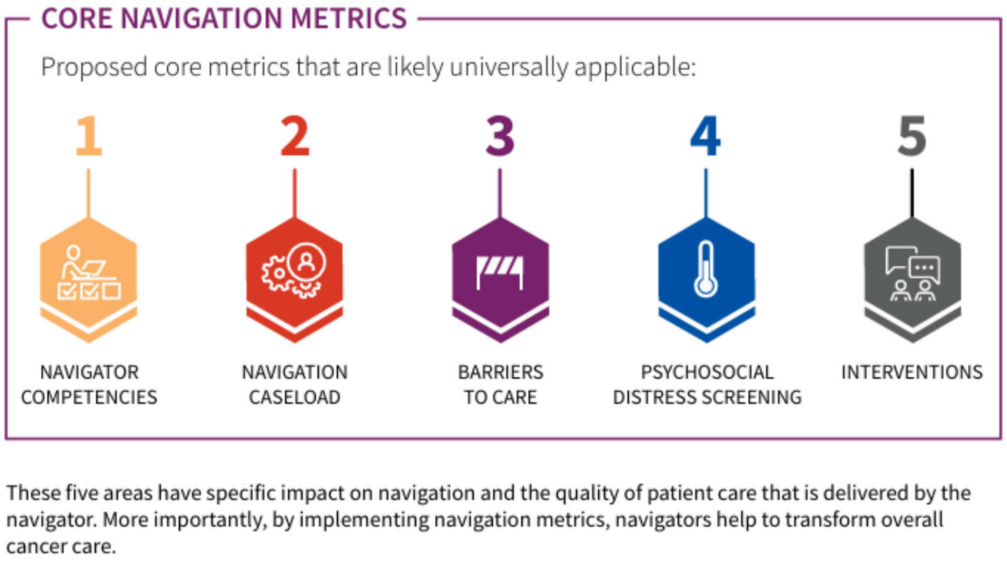
Identifying key metrics to collect and report is a team effort; AONN+ 35 evidence-based navigation metrics in the categories of patient experience, clinical outcome, and return on investment. These metrics are available in the article Academy of Oncology Nurse & Patient Navigators Announces Standardized Navigation Metrics.

Source: https://jons-online.com/issues/2017/may-2017-vol-9-no-5

The AONN+ metrics can be utilized by any navigation model in any setting. The metrics support navigation core competencies and practice standards, national oncology accreditation standards (CoC, NAMPBC), and value-based cancer care.

The first-of-its-kind navigation metric IRB study identified five core metrics that every program should collect; these metrics are directly related to the navigation definition.

Figure 13: Core Navigation Metrics



These five areas have specific impact on navigation and the quality of patient care that is delivered by the navigator. More importantly, by implementing navigation metrics, navigators help to transform overall cancer care.

When collecting metrics in the electronic medical record, marry the metric topic with the definition of the metrics. For example:

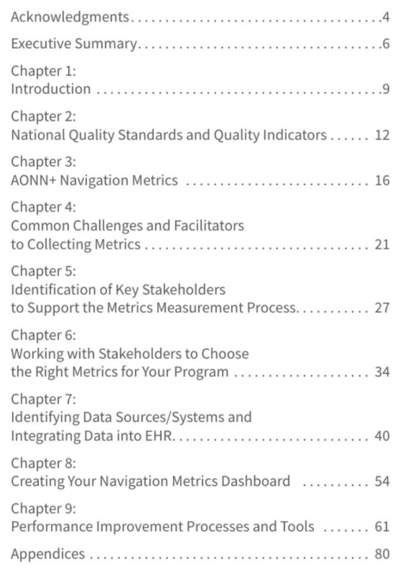
Figure 14: Psychosocial Support, Assessment

Psychosocial Support, Assessment		
Metric	**Definition**	**Patient Experience (PE), Clinical Outcomes (CO), Return on Investment (ROI)**
Psychosocial Distress Screening	Number of navigated patients per month who received psychosocial distress screening at a pivotal medical visit* with a validated tool**	PE, CO
Social Support Referrals	Number of navigated patients referred to support networks per month	PE, CO, ROI
*Pivotal medical visit definition: Period of high distress for the patient when psychosocial assessment should be completed. **Define various validated tools as examples: FACT, NCCN Psychosocial Distress Screening Thermometer.		

It is essential to ensure that the navigators understand the definition so they can collect the metrics similarly.

AONN+, with support from the American Cancer Society, has created a Navigation Metrics Implementation Toolkit. This toolkit reflects the current recommendations from AONN+, recommendations from the IRB metric study and best practices gleaned from navigators and navigation experts across the nation. The toolkit guides navigators on selecting, implementing, reporting, and utilizing navigation metrics as they engage in quality/performance improvement and strategic decision-making. his toolkit was developed to make it easier for navigators to start that journey and to provide additional momentum for programs that are already on their way.

Figure 15: Navigation Metrics Implementation Toolkit



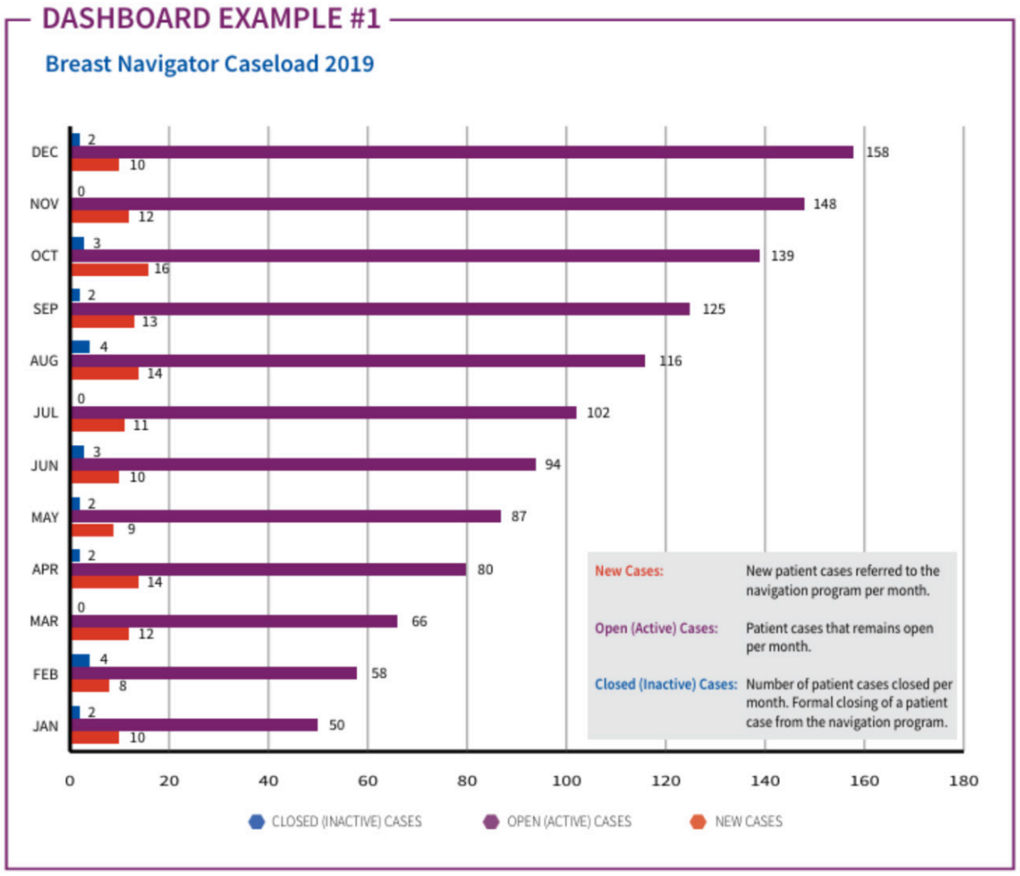
Metrics Reports and Dashboards are mandatory for administrators and key stakeholders to demonstrate the success and sustainability of the navigation program. Metric outcomes also need to be shared with your navigation team, cancer committee, other departments, and physicians, to name a few.

When creating a dashboard, keep these principles in mind:

1. Don't try to place all the information on the same page; prioritize simplicity so that the most relevant information can be contained in a single page.(See examples below)
2. Choose relevant key performance indicators (select measures that have been identified through consensus as meaningful by key stakeholders within the cancer program, in the sense that they will drive performance on important initiatives)
3. Provide context in terms of improvement or declines in performance or some other benchmark
4. Make it easy to understand
5. Choose your layout carefully.
6. Don't use too many color
7. Use the right type of charts (e.g., line charts, bar charts, pie charts
8. Use interactive data if possible, allowing user to drill down to details for each type of can
9. Be consistent with labeling and format
10. Don't be afraid to change the way the dashboard looks if it is not working for the end user (test dashboard before officially rolling it out)

For some example dashboards, refer to Chapter 8 in the AONN+ Navigation Metrics Toolkit.

Figure 16: Dashboard Example 1



New Cases: New patient cases referred to the navigation program per month.

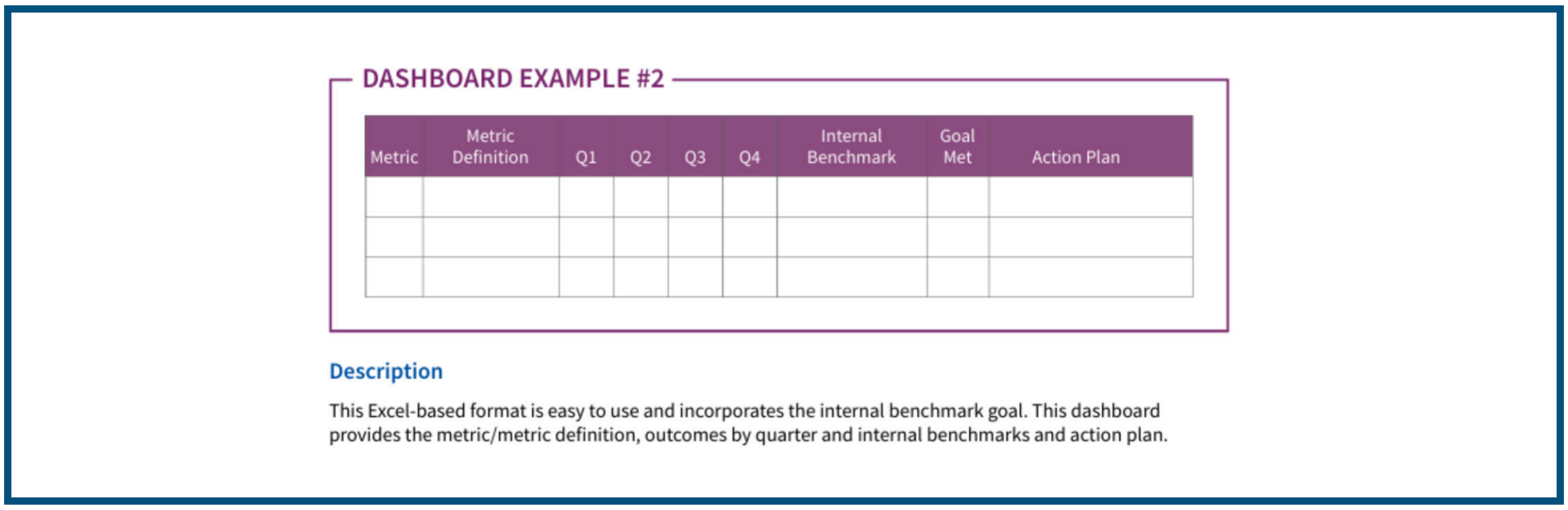
Open (Active) Cases: Patient cases that remains open per month.

Closed (Inactive) Cases: Number of patient cases closed per month. Formal closing of a patient case from the navigation program.

Description

This bar graph dashboard is an easy-to-read approach to reporting metrics information on caseloads, barriers to care, interventions and clinical trial education. The graph was created using Excel data.

Figure 17: Dashboard Example 2



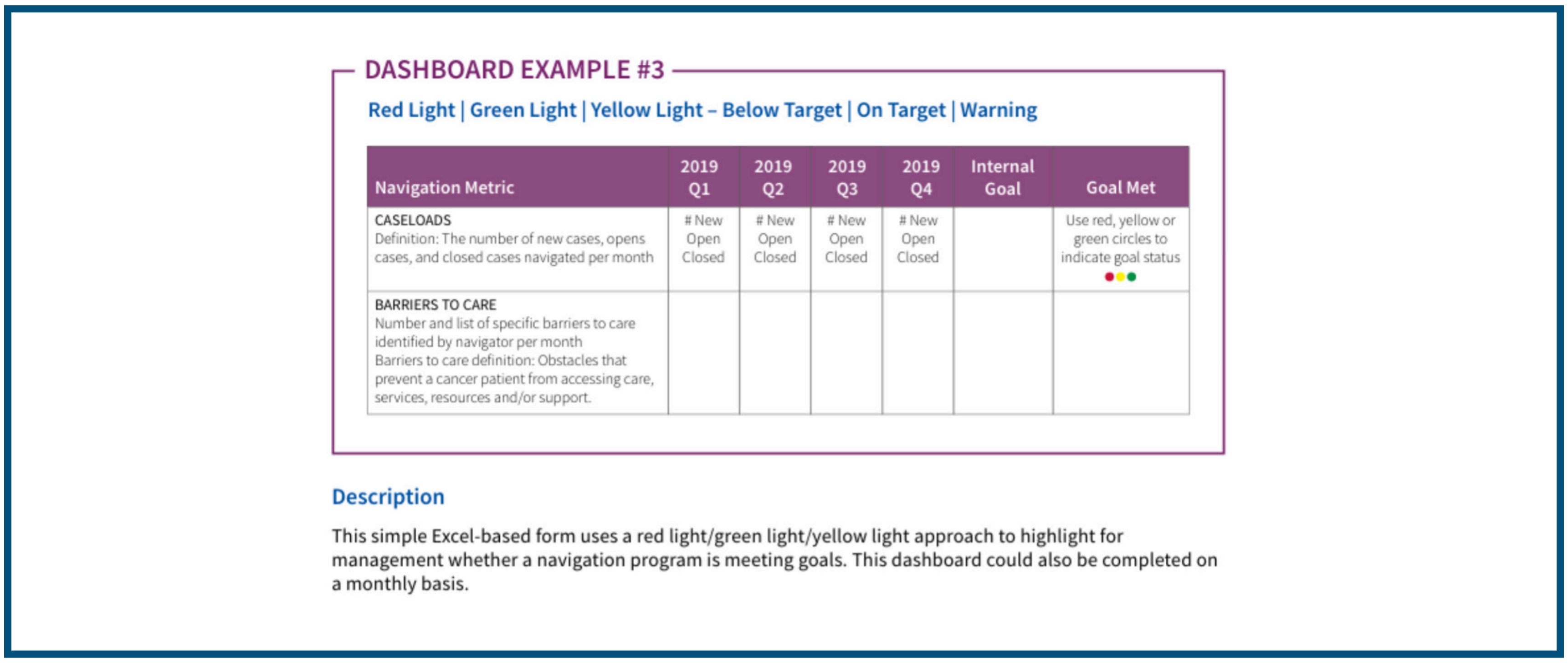
DASHBOARD EXAMPLE #2

Metric	Metric Definition	Q1	Q2	Q3	Q4	Internal Benchmark	Goal Met	Action Plan

Description

This Excel-based format is easy to use and incorporates the internal benchmark goal. This dashboard provides the metric/metric definition, outcomes by quarter and internal benchmarks and action plan.

Figure 18: Dashboard Example 3



DASHBOARD EXAMPLE #3

Red Light | Green Light | Yellow Light – Below Target | On Target | Warning

Navigation Metric	2019 Q1	2019 Q2	2019 Q3	2019 Q4	Internal Goal	Goal Met
CASELOADS Definition: The number of new cases, opens cases, and closed cases navigated per month	# New Open Closed	# New Open Closed	# New Open Closed	# New Open Closed		Use red, yellow or green circles to indicate goal status ●●●
BARRIERS TO CARE Number and list of specific barriers to care identified by navigator per month Barriers to care definition: Obstacles that prevent a cancer patient from accessing care, services, resources and/or support.						

Description

This simple Excel-based form uses a red light/green light/yellow light approach to highlight for management whether a navigation program is meeting goals. This dashboard could also be completed on a monthly basis.

Value-Based Cancer Care

Metric synergy can be created by reviewing national oncology standards (CoC, NAPBC), and value-based metrics such as alternative payment models (APMs), merit incentive programs (MIPs), enhancing the oncology care model (EOM), as well as the quality oncology physician initiative (QOPI). The navigation program should meet with key stakeholders to identify the needs of the cancer program and decide on navigation metrics. A detailed crosswalk of national standards and indicators can be found at June 2018 • Vol 9 • No 6 • JONS-online.com.

Reporting Outcomes to Key Stakeholders:

The navigation team must report the metrics and outcomes to keystakeholders which include administrators, providers, and the cancer committee. Internal or national external benchmarks should be included in your reports and dashboards. If outcomes are not as desired a performance improvement plan must be created and monitored.

Performance Improvement

Metrics outcomes may not meet your expectations upon initiation; do not be disappointed with the program or team. This is a fantastic opportunity to create a performance improvement plan. Share your results with your team, discuss the current process for the metric, and discuss opportunities to enhance the metric outcome. Document your discussion using a simple tool such as the PDSA tool.

The Plan, Do, Study, Act (PDSA) cycle is an iterative, four-stage problem-solving model used to improve a process or implement change. It is a systematic series of steps for continuously gaining valuable learning and knowledge to improve a product or process.

Stages in the PDSA Cycle:

Plan

Plan a change. Under this stage, you define the objective and subsequently intend to answer all the other questions. The planning stage implies to:

- Identify the problem
- Analyze the problem
- Clarify goals and objectives
- Define success
- Identify key team players
- Plan strategies, putting a plan into action

Do

In this stage, components of the plan are implemented, such as developing a product or service. The Do stage implies:

- To start implementation of the action plan
- To collect the data
- To design appropriate tools to implement changes
- To perform appropriate activities

Study

Outcomes are monitored to test the plan's validity against the goal and objectives. The study stage implies to:

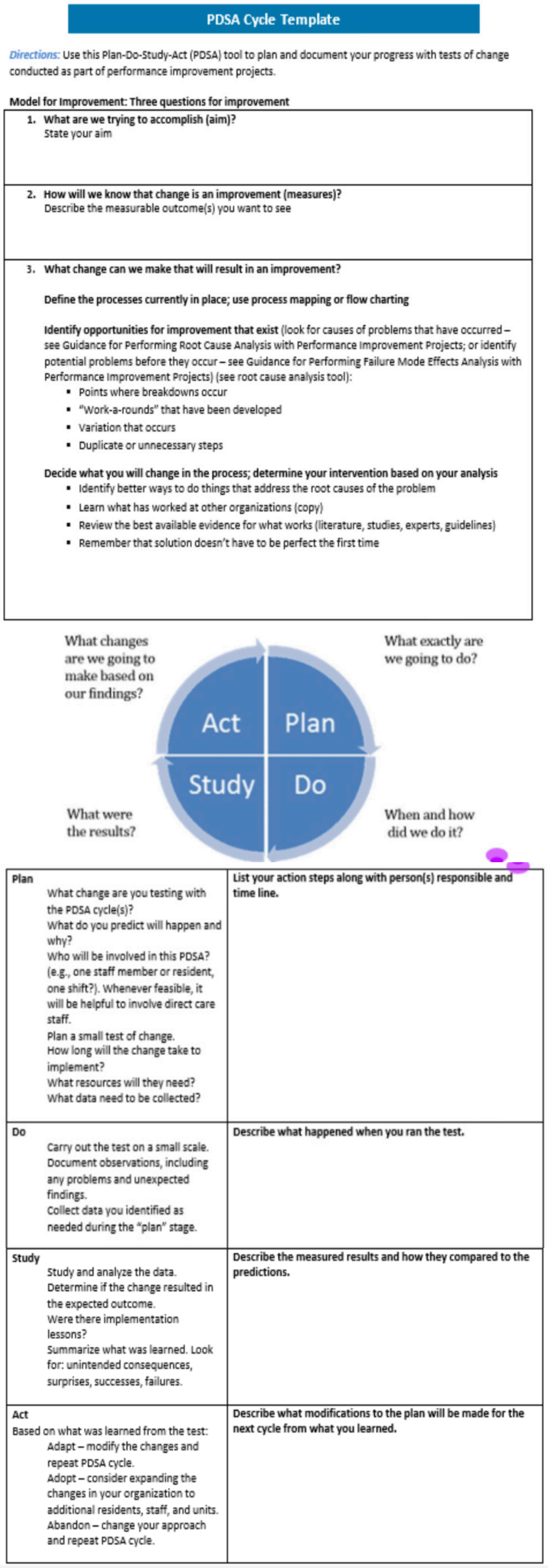
- Analyze the data collected
- Ensure the plan is working
- Identify and remove bottlenecks

Act

The Act step ends the cycle by integrating the learning generated by the entire process. Act stage implies to:

- Communicate the results and determine if the plan worked
- Adjust the goals to meet the objectives, change methods, or even reformulate a theory altogether

Figure 19: PSDA Cycle Template



PDSA Cycle Template

Directions: Use this Plan-Do-Study-Act (PDSA) tool to plan and document your progress with tests of change conducted as part of performance improvement projects.

Model for Improvement: Three questions for improvement

1. **What are we trying to accomplish (aim)?**
   State your aim
2. **How will we know that change is an improvement (measures)?**
   Describe the measurable outcome(s) you want to see
3. **What change can we make that will result in an improvement?**

   Define the processes currently in place; use process mapping or flow charting

   Identify opportunities for improvement that exist (look for causes of problems that have occurred – see Guidance for Performing Root Cause Analysis with Performance Improvement Projects; or identify potential problems before they occur – see Guidance for Performing Failure Mode Effects Analysis with Performance Improvement Projects) (see root cause analysis tool):
   - Points where breakdowns occur
   - "Work-a-rounds" that have been developed
   - Variation that occurs
   - Duplicate or unnecessary steps

   Decide what you will change in the process; determine your intervention based on your analysis
   - Identify better ways to do things that address the root causes of the problem
   - Learn what has worked at other organizations (copy)
   - Review the best available evidence for what works (literature, studies, experts, guidelines)
   - Remember that solution doesn't have to be perfect the first time

What changes are we going to make based on our findings?

What exactly are we going to do?

What were the results?

When and how did we do it?

Plan What change are you testing with the PDSA cycle(s)? What do you predict will happen and why? Who will be involved in this PDSA? (e.g., one staff member or resident, one shift?). Whenever feasible, it will be helpful to involve direct care staff. Plan a small test of change. How long will the change take to implement? What resources will they need? What data need to be collected?	**List your action steps along with person(s) responsible and time line.**
Do Carry out the test on a small scale. Document observations, including any problems and unexpected findings. Collect data you identified as needed during the "plan" stage.	**Describe what happened when you ran the test.**
Study Study and analyze the data. Determine if the change resulted in the expected outcome. Were there implementation lessons? Summarize what was learned. Look for: unintended consequences, surprises, successes, failures.	**Describe the measured results and how they compared to the predictions.**
Act Based on what was learned from the test: Adapt – modify the changes and repeat PDSA cycle. Adopt – consider expanding the changes in your organization to additional residents, staff, and units. Abandon – change your approach and repeat PDSA cycle.	**Describe what modifications to the plan will be made for the next cycle from what you learned.**

Source: whatissixsigma.net › plan-do-study-act. https://whatissixsigma.net/plan-do-study-act/#:~:text=The%20Plan%20do%20study%20act%20is%20an%20iterative%2C,the%20continuous%20improvement%20of%20a%20product%20or%20process

CHAPTER SEVEN

Support Staff Roles in the Cancer Center, Resources, and National Guidelines

Knowing your multidisciplinary team's roles will provide additional support for your patients and their caregivers. The entire team needs to be aware of the roles and responsibilities of each discipline and utilize evidence-based assessment/screening tools to provide a smooth transition for the patient and their caregiver. For the navigator orientation, include shadowing opportunities with the oncology support staff and departments.

It is also essential to discuss the roles of your team members and community partners with your patients, so they understand all the resources available to them during and after their cancer journey. Many programs create a welcome packet or online resources to describe the program and the team's roles and responsibilities.

Create standing meetings with your multidisciplinary team to provide updates on the navigation program, such as a review of metrics, processes, patient education materials, new practice standards, role delineation, and workflows.

Some of the team members will include:

- Surgeons
- Medical Oncologist
- Radiation Oncologist
- Social Workers
- Financial Navigator/Counselor Responsibilities
- Psychologist
- Registered Dietician
- Genetic Counselor
- Palliative Care
- Integrative Therapy
- Other: any department included in the coordination of care for the oncology patient
- Community and National Organization Partners

Community Resources and Guidelines

As per the navigation definition, the navigator, regardless of the navigation model, needs to assess the patient's medical and psychosocial barriers and provide appropriate interventions; these interventions will include internal cancer program/hospital resources, community resources, and national resources.

The navigator and the multidisciplinary team must stay current on resources. The team can be updated at the regularly scheduled team meetings. The team should also meet with their community partners to keep informed on new support and educational programs and coordinate any activities. A repository of resources should be created, and an individual assigned or a volunteer/intern should review the repository to ensure the resources are still available.
Resources should be available:

- Reputable websites and evidence-based guidelines, for example, the American Cancer Society (ACS), National Comprehensive Cancer Network (NCCN), and National Cancer Institute (NCI), just to name a few
- Different languages
- Appropriate reading level
- Address different learning styles, for example, instructional vs. visual (videos)

CHAPTER EIGHT

Navigation Reimbursement

Navigation Reimbursement

Reportable CPT Codes for Oncology Navigation Services

Note: CPT coding guidance for these services uses the terms "qualified healthcare professional and "clinical staff." These terms are specifically defined within the CPT code set as indicated in the following definitions:

> A "physician or other qualified healthcare professional" is an individual who is qualified by education, training, licensure/regulation (when applicable) and facility privileging (when applicable) who performs a professional service within his/her scope of practice and independently reports that professional service. These professionals are distinct from 'clinical staff.' A clinical staff member is a person who works under the supervision of a physician or other qualified healthcare professional and who is allowed by law, regulation, and facility policy to perform or assist in the performance of a specified professional service but who does not individually report that professional service. Other policies may also affect who may report specific services.

Principal care management (PCM) services codes in the CPT Evaluation and Management (E/M) section are reportable for clinical navigation services, including oncology navigation services. Codes 99424-99427, which were established in 2022, represent services that "focus on the medical and/or psychological needs manifested by a single, complex chronic condition expected to last at least three months and includes establishing, implementing, revising, or monitoring a care plan specific to that single disease," and are not limited to use with oncology patients. Complete information on their intent and use was featured in the January 2022 issue of CPT Assistant. These codes are part of the broader care management services group, which also includes chronic care and complex chronic care management services.

PCM services are provided under the direction of a physician or other QHP or may be provided personally by a physician or other QHP to a patient residing at home or in a domiciliary, rest home, or assisted living facility. The physician or other QHP provides or oversees the management and/or coordination of care management services, which include establishing, implementing, revising, or monitoring the care plan; coordinating the care of other professionals and agencies; and educating the patient or caregiver about the patient's condition, care plan, and prognosis.

These services help improve coordination of care, reduce avoidable hospital services, decrease overutilization of services, improve patient engagement, and decrease care fragmentation due to decentralized patient throughput.

Codes 99424 and 99425 may be reported when a physician or other QHP personally provides the service; while codes 99426 and 99427 may be reported when services are provided by clinical staff under the direction of a physician or other QHP.

 # 99424 Principal care management services, for a single high-risk disease, with the following required elements:

- one complex chronic condition expected to last at least 3 months, and that places the patient at significant risk of hospitalization, acute exacerbation/decompensation functional decline, or death
- the condition requires development, monitoring, or revision of diseasespecific care plan,
- the condition requires frequent adjustments in the medication regimen and/or the management of the condition is unusually complex due to comorbidities,
- ongoing communication and care coordination between relevant practitioners furnishing care;

first 30 minutes provided personally by a physician or other qualified healthcare professional, per calendar month

#+ 99425 each additional 30 minutes provided personally by a physician or other qualified healthcare professional, per calendar month (List separately in addition to code for primary procedure)

(Use 99425 in conjunction with 99424)

(Principal care management services of less than 30 minutes duration in a calendar month are not reported separately)

► (Do not report 99424, 99425 in the same calendar month with 90951- 90970, 99374, 99375, 99377, 99378, 99379, 99380, 99426, 99427, 99437, 99439, 99473, 99474, 99487, 99489, 99490, 99491) ◄

(Do not report 99424, 99425 for service time reported with 93792, 93793, 98960, 98961, 98962, 98966, 98967, 98968, 98970, 98971, 98972, 99071, 99078, 99080, 99091, 99358, 99359, 99366, 99367, 99368, 99421, 99422, 99423, 99441, 99442, 99443, 99605, 99606, 99607)

 # 99426 Principal care management services, for a single high-risk disease, with the following required elements:

- one complex chronic condition expected to last at least 3 months, and that places the patient at significant risk of hospitalization, acute exacerbation/ decompensation, functional decline, or death,
- the condition requires development, monitoring, or revision of disease specific care plan,
- the condition requires frequent adjustments in the medication regimen and/or the management of the condition is unusually complex due to comorbidities,
- ongoing communication and care coordination between relevant practitioners furnishing care;

first 30 minutes of clinical staff time directed by physician or other qualified healthcare professional, per calendar month.

#+ 99427 each additional 30 minutes of clinical staff time directed by a physician or other qualified health care professional, per calendar month (List separately in addition to code for primary procedure)

(Use 99427 in conjunction with 99426)

(Principal care management services of less than 30 minutes duration in a calendar month are not reported separately)

(Do not report 99427 more than twice per calendar month)

► (Do not report 99426, 99427 in the same calendar month with 90951-90970, 99374, 99375, 99377, 99378, 99379, 99380, 99424, 99425, 99437, 99439, 99473, 99474, 99487, 99489, 99490, 99491) ◄

(Do not report 99426, 99427 for service time reported with 93792, 93793, 98960, 98961, 98962, 98966, 98967, 98968, 98970, 98971, 98972, 99071, 99078, 99080, 99091, 99358, 99359, 99366, 99367, 99368, 99421, 99422, 99423, 99441, 99442, 99443, 99605, 99606, 99607)

CPT PCM Codes: Reporting Frequency

How often can PCM codes be reported? When reporting PCM services, note that each code in this subsection is reported only when a full 30 minutes of time is spent providing the service during a calendar month. It would not be appropriate to report these codes if less than 30 minutes are spent providing the service. The following table was established in the CPT 2022 code set to illustrate appropriate reporting of these codes. See Table 1 for reporting CPT PCM codes based on total time utilized during a calendar month.

Figure 20: Reporting CPT PCM Codes Based on Total Time

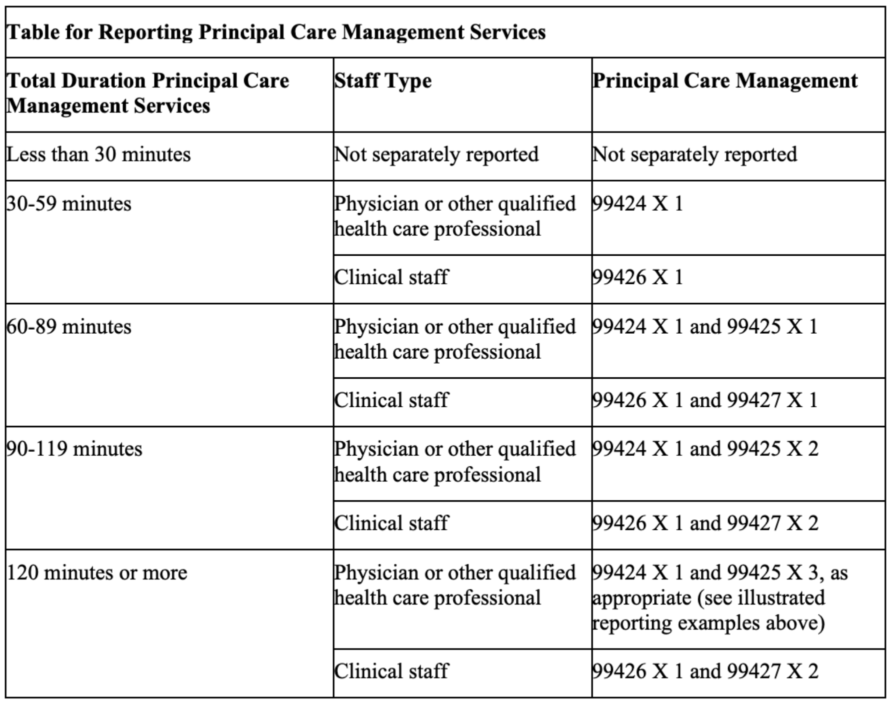


Table for Reporting Principal Care Management Services

Total Duration Principal Care Management Services	Staff Type	Principal Care Management
Less than 30 minutes	Not separately reported	Not separately reported
30-59 minutes	Physician or other qualified health care professional	99424 X 1
	Clinical staff	99426 X 1
60-89 minutes	Physician or other qualified health care professional	99424 X 1 and 99425 X 1
	Clinical staff	99426 X 1 and 99427 X 1
90-119 minutes	Physician or other qualified health care professional	99424 X 1 and 99425 X 2
	Clinical staff	99426 X 1 and 99427 X 2
120 minutes or more	Physician or other qualified health care professional	99424 X 1 and 99425 X 3, as appropriate (see illustrated reporting examples above)
	Clinical staff	99426 X 1 and 99427 X 2

Source: CPT® Assistant Special Edition: November Update / Volume 33 • 2023
https://www.ama-assn.org/system/files/cpt-assistant-oncology-navigation-codes.pdf

In addition to Figure 20, refer to parenthetical notes, which provide guidance to direct and restrict the reporting of these codes in conjunction with each other or in conjunction with other services when provided over the same or overlapping time. For example, the phrase “in the same calendar month” in the parenthetical notes indicates that the codes should not be reported together in the same month under any circumstances. Note that PCM services may be reported by multiple clinicians for a given patient in a calendar month, in contrast to chronic care management services, which are limited to one clinician in each calendar month. For more detailed reporting guidelines, refer to the CPT 2024 code set.

Reporting Patient Navigation Services for Non-Clinical Staff Using CMS G-Codes

On November 2, 2023, CMS’ Medicare Physician Payment Schedule Final Rule for 2024 introduced four new Healthcare Common Procedure Coding System (HCPCS) G-codes (G0023, G0024, G0140, G0146). Codes G0023 and G0024 were created for principal illness navigation (PIN) services provided by certified or trained auxiliary personnel under the direction of a physician or other practitioner: these personnel may include a patient navigator or certified peer specialist. It is important to note the differences in the required time for reporting G-codes compared to CPT’s PCM codes 99425-99427. For example, CPT code 99426 is reported for the first 30 minutes of clinical staff time, while code G0023 is for the first 60 minutes of time. Codes G0140 and G0146 were created specifically to describe PIN services provided by peer support (PS) specialists around behavioral health conditions. PIN services are designed to help patients identify and connect with appropriate clinical and support resources.

These changes will be effective January 1, 2024. Users should review additional details on these changes within the Final Rule on the CMS website at https://www.federalregister.gov/publicinspection/current.

Reporting Summary

To report oncology navigation services using CPT PCM codes and HCPCS PIN codes, see Figure 21, which provides a reporting summary of these codes.

Figure 21: Reporting CPT PCM Codes Based on Total Time

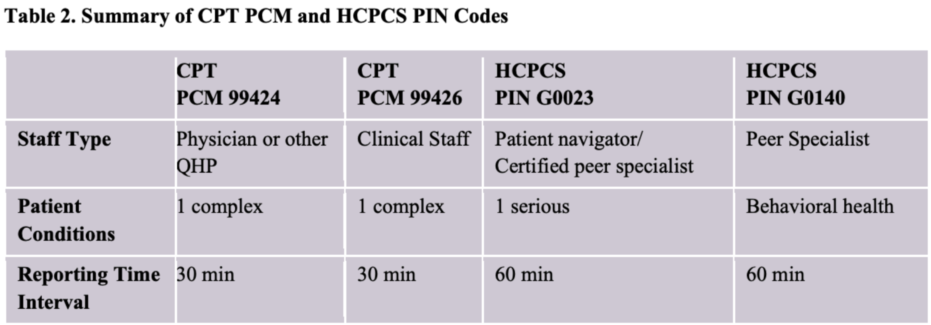


Table 2. Summary of CPT PCM and HCPCS PIN Codes

	CPT PCM 99424	CPT PCM 99426	HCPCS PIN G0023	HCPCS PIN G0140
Staff Type	Physician or other QHP	Clinical Staff	Patient navigator/ Certified peer specialist	Peer Specialist
Patient Conditions	1 complex	1 complex	1 serious	Behavioral health
Reporting Time Interval	30 min	30 min	60 min	60 min

Source: CPT® Assistant Special Edition: November Update / Volume 33 • 2023
https://www.ama-assn.org/system/files/cpt-assistant-oncology-navigation-codes.pdf

Principal Illness Navigation (PIN)

The Centers for Medicaid and Medicare (CMS) announced the reimbursement of navigation services in January 2024.

CMS created four new service codes describing PIN services that auxiliary personnel, including care navigators or peer support specialists, may perform incidental to the professional services of a physician or other billing practitioner under general supervision. Two codes describe PIN services, and two codes describe Principal Illness Navigation-Peer Support (PIN-PS) services, which are intended more for patients with high-risk behavioral health conditions and have slightly different service elements that better describe the scope of practice of peer support specialists. In general, where we describe aspects of PIN, it also applies to PIN-PS unless otherwise specified.

The billing practitioner initiates PIN services during an initiating visit addressing a serious high-risk condition, illness, or disease with these characteristics:

One serious, high-risk condition and for PIN-PS, a serious, high-risk behavioral health condition expected to last at least three months that places the patient at significant risk of:

- Hospitalization
- Nursing home placement
- Acute exacerbation or decompensation
- Functional decline or death

A condition that requires the development, monitoring, or revision of a disease-specific care plan and may require frequent adjustment in the medication or treatment regimen or substantial assistance from a caregiver

Examples of a serious, high-risk condition, illness, or disease include:

- Cancer
- Chronic obstructive pulmonary disease
- Congestive heart failure
- Dementia
- HIV/AIDS
- Severe mental illness
- Substance use disorder

A healthcare practitioner initiates PIN services during an initial visit, during which they identify the medical necessity of PIN services and establish an appropriate treatment plan. The same practitioner bills for the subsequent PIN services that auxiliary personnel provide. The billing practitioner personally performs initiating visits, including:

- E/M visit, other than a low-level E/M visit done by clinical staff
- A Medicare AVW provided by a practitioner who meets the requirements to furnish subsequent PIN services
- CPT code 90791 (Psychiatric diagnostic evaluation) or the Health Behavior Assessment and Intervention (HBAI) services that CPT codes 96156, 96158, 96159, 96164, 96165, 96167, and 96168 describe

You must see a patient for a PIN initiating visit before furnishing and billing PIN services. We created PIN services for auxiliary personnel like patient navigators and peer support specialists to provide navigation in treating a serious, high-risk condition or illness. These services help guide the patient through their course of care, including addressing any unmet social needs that significantly limit the practitioner's ability to diagnose or treat the condition. PIN services include items like:

- Health system navigation
- Person-centered planning
- Identifying or referring patient and caregiver or family, if applicable, to supportive services
- Practitioner, home, and community-based care coordination or communication
- Patient self-advocacy promotion
- Community-based resources access facilitation

The billing practitioner or auxiliary personnel may provide PIN services following an initiating visit during which the billing practitioner addresses the serious, high-risk condition. During this initiating visit, the billing practitioner establishes the treatment plan, specifies how PIN services are reasonable and necessary to help accomplish that plan, and establishes the PIN services as incidental to their professional services. Auxiliary personnel can perform the subsequent PIN services.

Since there isn't a Medicare benefit for paying navigators and peer support specialists directly, we'll pay for their services as incidental to the services of the healthcare practitioner who directly bills Medicare. The auxiliary personnel may be external to, and under contract with, the practitioner or their practice, such as through a CBO that employs navigators, peer support specialists, or other auxiliary personnel, if they meet all "incident to" requirements and conditions for payment of PIN services.

Auxiliary personnel must meet applicable state requirements, including licensure. In states with no applicable requirements, auxiliary personnel providing PIN services must be trained or certified in the competencies of:

- 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

Developing an appropriate knowledge base, including specific certification or training on the serious, high-risk condition, illness, or disease being addressed. For PIN-PS services (HCPCS codes G0140 and G0146), if no applicable state requirements exist, the training must be consistent with the National Model Standards for Peer Support Certification published by the Substance Abuse Mental Health Services Administration (SAMHSA). This is the most universally recognized standard for peer support specialists in the country and was developed and maintained by SAMHSA, which has expertise in this area.

The billing practitioner or the auxiliary personnel under supervision must get advance patient consent before providing PIN services and annually thereafter. Consent can be written or verbal, so long as you document it in the patient's medical record. Explain to the patient that cost sharing will apply.

The billing practitioner can't furnish PIN services more than once per practitioner per month for any single serious high-risk condition. This avoids duplication of PIN service elements when utilizing the same navigator or billing practitioner. Don't concurrently bill PIN and PIN-PS services for the same serious, high-risk condition.

We currently make separate payments under the PFS for a number of care management and other services that may include aspects of navigation services. Those care management services focus heavily on clinical, rather than social, aspects of care. You can furnish PIN services in addition to other care management services if you:

- Don't count time and effort more than once
- Meet requirements to bill the other care management services
- Perform services that are medically reasonable and necessary

The billing practitioner or auxiliary personnel don't necessarily need to perform these services in person. We expect that many service elements will involve direct patient contact, especially for PIN-PS services, and that they may be most impactful when provided in person.

We finalized the following PIN service codes:

G0023: Principal illness navigation services by certified or trained auxiliary personnel under the direction of a physician or other practitioner, including a patient navigator, 60 minutes per calendar month, in the following activities:

- Person-centered assessment, performed to understand better the individual context of the serious, high-risk condition
  - Conducting a person-centered assessment to understand the patient's life story, strengths,
  - needs, goals, preferences, and desired outcomes, including understanding cultural and
  - linguistic factors and including unmet SDOH needs (that aren't separately billed)
  - Facilitating patient-driven goal setting and establishing an action plan
  - Providing tailored support as needed to accomplish the practitioner's treatment plan
- Identifying or referring the patient (and caregiver or family, if applicable) to appropriate supportive services

- Practitioner, home- and community-based care communication
    - Coordinating receipt of needed services from healthcare practitioners, providers, and facilities; home- and community-based service providers; and caregiver (if applicable)
    - Communicating with practitioners, home-and community-based service providers, hospitals, and skilled nursing facilities (or other healthcare facilities) regarding the patient's psychosocial strengths and needs, functional deficits, goals, preferences, and desired outcomes, including cultural and linguistic factors
    - Coordination of care transitions between and among healthcare practitioners and settings, including transitions involving referral to other clinicians; follow-up after an emergency department visit; or follow-up after discharges from hospitals, skilled nursing facilities, or other healthcare facilities
    - Facilitating access to community-based social services (e.g., housing, utilities, transportation, food assistance) as needed to address SDOH need(s)
- Health education - helping the patient contextualize health education provided by the patient's treatment team with the patient's individual needs, goals, preferences, and SDOH need(s), and educating the patient (and caregiver if applicable) on how to best participate in medical decision-making
- Building patient self-advocacy skills so that the patient can interact with members of the healthcare team and related community-based services (as needed) in ways that are more likely to promote personalized and effective treatment of their condition
- Healthcare access/health system navigation
    - Helping the patient access healthcare, including identifying appropriate practitioners or providers for clinical care and helping secure appointments with them
    - Providing the patient with information/resources to consider participation in clinical trials or clinical research as applicable
- Facilitating behavioral change as necessary for meeting diagnosis and treatment goals, including promoting patient motivation to participate in care and reach person-centered diagnosis or treatment goals
- Facilitating and providing social and emotional support to help the patient cope with the condition, SDOH need(s), and adjust daily routines to meet diagnosis and treatment goals better
- Leveraging knowledge of the serious, high-risk condition and/or lived experience when applicable to provide support, mentorship, or inspiration to meet treatment goals

G0024: Principal illness navigation services, additional 30 minutes per calendar month (List separately in addition to G0023)

G0140: Principal illness navigation - peer support by certified or trained auxiliary personnel under the direction of a physician or other practitioner, including a certified peer specialist; 60 minutes per calendar month, in the following activities:

- Person-centered interview, performed to understand better the individual context of the serious, high-risk condition
- Conducting a person-centered interview to understand the patient's life story, strengths, needs, goals, preferences, and desired outcomes, including understanding cultural and linguistic factors, including unmet SDOH needs (that aren't billed separately)
- Facilitating patient-driven goal setting and establishing an action plan
- Providing tailored support as needed to accomplish the person-centered goals in the practitioner's treatment plan
    - Identifying or referring the patient (and caregiver or family, if applicable) to appropriate supportive services
    - Practitioner, home, and community-based care communication
- Assisting the patient in communicating with their practitioners, home-and community-based service providers, hospitals, and skilled nursing facilities (or other healthcare facilities) regarding the patient's psychosocial strengths and needs, goals, preferences, and desired outcomes, including cultural and linguistic factors
- Facilitating access to community-based social services (e.g., housing, utilities, transportation, food assistance) as needed to address SDOH need(s)
- Health Education
    - Helping the patient contextualize health education provided by the patient's treatment team with the patient's individual needs, goals, preferences, and SDOH need(s), and educating the patient (and caregiver if applicable) on how to best participate in medical decision-making
    - Building patient self-advocacy skills so that the patient can interact with members of the healthcare team and related community-based services (as needed) in ways that are more likely to promote personalized and effective treatment of their condition

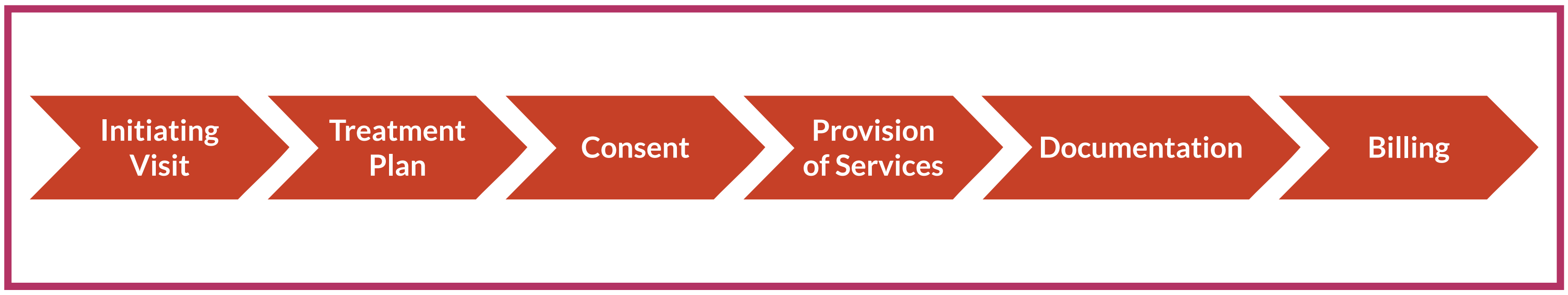
- Developing and proposing strategies to help meet person-centered treatment goals and supporting the patient in using chosen strategies to reach person-centered treatment goals
- Facilitating and providing social and emotional support to help the patient cope with the condition, SDOH need(s), and adjust daily routines to meet person-centered diagnosis and treatment goals better
- Leveraging knowledge of the serious, high-risk condition and/or lived experience when applicable to provide support, mentorship, or inspiration to meet treatment goals

G0146: Principal illness navigation - peer support, additional 30 minutes per calendar month (List separately in addition to G0140)

Source: file:///C:/Users/tstru/OneDrive/Documents/ACS%20NNRT/CMS-2024-Final-Rule.pdf

CMS Principal Illness Navigator Readiness Assessment

Figure 22: Process of Providing PIN Services



Who Can Receive PIN Services

- Medicare patient
- Who has a “serious high-risk condition”
- Expected to last at least 3 months
- Places patient at “significant risk of hospitalization, nursing home placement, acute exacerbation/decomposition, functional decline or death”
- Requires disease-specific care plan and may require frequent adjustment in medication or treatment regimen or substantial assistance from a caregiver

Figure 23: PIN Readiness Assessment Checklist

Service Assessment	Compliant Y/N	Comments
Initial Visit with Provider • Visit types: Evaluation and management (E/M) visit; annual wellness visit, psychiatric diagnostic evaluation, or visit involving health behavior • Assessment and Intervention services • Visit elements: Establish medical necessity, develop a treatment plan		

Figure 23: PIN Readiness Assessment Checklist (Cont.)

Service Assessment	Compliant Y/N	Comments
Consenting • Written or verbal • Documented in the patient's medical record • Must explain that cost-sharing applies • Must be obtained annually • Can be obtained by auxiliary personnel		
Categories of Services • Person-centered assessment • Identifying or referring the patient (and caregiver or family) to appropriate supportive services • Practitioner, home, and community-based care coordination • Health Education • Building patient self-advocacy skills • Healthcare access/health system navigation • Facilitating behavioral change as necessary for meeting diagnosis and treatment goals • Facilitating and providing social and emotional support • Leveraging knowledge of the condition and/or lived experience when applicable to provide support, • mentorship, or inspiration to meet treatment goals		
Documentation **Billing practitioner must document in the medical record:** • Time spent providing PIN services • Activities performed by auxiliary personnel • How activities are related to the treatment plan • Identified SDOH needs, if present		
Billing PIN Services **G0023:** PIN services by certified or trained auxiliary personnel under the direction of a physician or other practitioner, including a patient navigator; 60 minutes per calendar month, in the following activities… **G0024:** Principal Illness Navigation services, additional 30 minutes per calendar month Billing process (how is this documented and submitted for reimbursement)		
Additional Comments /Concerns 1. Compliance Dept 2. 3. 4. 5. 6. 7. 8. 9. 10.		

Source: ACS NNRT, Pursuing Patient Navigation Policy Landscape. American Cancer Society National Navigation Roundtable Fall 2023 Call to Action Series

Document Request for PIN Readiness Assessment

- Caseloads and navigator assignments
- Job description/including navigator training/certification
- Process maps/algorithm (if available)
- PIN consent (if available)
- Navigator's PIN documentation/screenshots
    - Evidence-based screening tools for barrier identification, social determinants of health, and interventions provided
    - Metrics and Dashboards
- Billing guidelines and process (if available)

Interview Questions

Navigation Lead (Manager/Director)

- Analytic cases per year, disease site, and stage?
- Caseloads and navigator assignments?
- Navigation model and support staff?
- Role delineation of navigators and support staff?
- Navigation intake and flow across the continuum (referrals from MDs, key points of contact with the patient)?
- Assessment tools for distress screening and social determinants of health (policies/procedures, who completes the assessment, who the assessment is shared with on the multidisciplinary team, and where the assessment documentation is housed)?
- EMR and documentation of assessments (screenshots).
- Navigation reports and metrics (dashboards).

Navigation Team

- What does navigator training consist of? What national organization is utilized for training and certification?
- What is the current navigation point of entry and workflow for the oncology patient?
- What are the roles and responsibilities of the navigators?
- What is the consenting process for PIN?
- Does a checklist exist to support PIN guidelines?
- When is distress and SDoH screening completed? What tools are utilized? How is this documented in EPIC?
- What metrics are collected?
- How is documentation submitted to the billing/coding department?

Billing and Coding Team

- Understanding of the PIN guidelines and billing codes.
- What is the PIN process? (initial visit > treatment plan > referral to navigation dept. > navigator consenting > services provided/assessment/education/documentation > billing/coding dept.)
- What concerns have arisen due to PIN reimbursement?
- Audit process for billing/coding of PIN services? (submission to reimbursement)
- Reporting revenue associated with PIN.

Navigation Reimbursement Resources

Figure 24: List of Navigation Reimbursement Resources

National Organization	Website
AONN+ Navigation Reimbursement Resources	https://www.aonnonline.org/navigation-reimbursement-resources
CPT Assistant Guide	https://www.ama-assn.org/practice-management/cpt/cpt-coding-support-cpt-assistant
Principal Illness Navigation & Principal Care Management Codes FAQ	https://navigationroundtable.org/wp-content/uploads/NNRT-PIN-PCM-Codes-FAQ_05.23.2024.pdf
American Cancer Society National Navigation Roundtable	https://navigationroundtable.org/

CHAPTER NINE

Incorporating Technology

As navigation programs become more incorporated into cancer programs, it is a fact that programs will never have enough navigators for every new cancer patient. That being said, technology will provide an opportunity to expand the navigation program's resources. Asking the patient about their access and comfort level with technology is an important question during the initial discussion with your patient. The navigator can provide a list of free evidence-based applications that can provide education and support.

Oncology Evidence-Based Applications and Platforms

When assessing technology for your patients and caregivers, review platforms incorporating evidence-based tools to support the patient and their caregivers. Review the ability to navigate the platform, reading level, incorporation of patient education, and psychosocial support resources.

What are the Needs of Oncology Patients and Their Caregivers?

Criteria For Evaluating Apps:

- Consider the parent organization/company that funded the app development
- Consider content sources (who is writing the content, how often is it updated, evidence-based/based in research)
- Privacy policies (esp. with uploading medical records)
- Evaluate reviews in app stores

Technology Intervention Guide/Ideas:

- Education and tutorials are a must
- Give the caregiver a role in visits and assistance with any/all technology or applications
- Apps geared to caregivers to alleviate anxiety and additional stress
- Content on apps and anything created for technology must be at the appropriate grade reading level
- It must be patient-centered technology and applications. Instead of trying to force patients to communicate with us using the system tools, understanding how patients communicate and feel comfortable and designing ways to bridge the gaps and get them comfortable
- Interactive, versatile with various learning styles, for example, instructional, visual/videos

Above all, do the features help patients/survivors/caregivers to:

- Regain a sense of control
- Find trustworthy information and resources
- Provide connection to self and others
- Reduce/manage anxiety and fear
- Validate feelings/experiences
- Feel better

When assessing technology, look for opportunities to incorporate screening tools to support the role of the navigator, for example, patient-reported assessment tools such as the NCCN distress screening or social determinants of health screening. The patient could self-identify their concerns/barriers with alerts sent to the navigator. Resources for interventions could be included for patients who are comfortable with technology. Technology will never replace the human connection; however, patients are becoming empowered to research their specific needs related to their cancer journeys.

In conclusion, SHARE Cancer Support hopes you found this toolkit helpful in creating or revising your navigation program. The navigator's commitment to their patients and caregivers is a tremendous responsibility that will provide great trust for their journey during and after treatment. Thank you for all you do every day.

Tricia Strusowski, MS, RN, and SHARE Cancer Support

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A special thank you to the many participants of the 2023-2024 SHARE Cancer Support Navigation Workstream who provided valuable input and feedback about the navigator's role and that of their multidisciplinary support team.

Navigation Curriculum Toolkit Implementation Assistance:

If you would like additional assistance with developing or redesigning your navigation program, an experienced oncology patient navigator can provide step-by-step guidance. Fees will be discussed upon referral.

Contact **patientnavigation@sharecancersupport.org** for more information.

Scan to email SHARE's
Patient Navigation Program