Implementing the Commission on Cancer Standard 8.1: Addressing Barriers to Care

A Road Map for Comprehensive Cancer Control Professionals and Cancer Program Administrators

January 2021
INTRODUCTION

Welcome to Implementing the Commission on Cancer Standard 8.1: Addressing Barriers to Care. We developed this road map to support comprehensive cancer control (CCC) professionals and cancer program administrators from hospitals, treatment centers and other facilities to fulfill the requirements for this standard. The purpose of this road map is to guide CCC professionals and administrators in identifying and addressing barriers to accessing health and/or psychosocial cancer care for cancer patients.

This road map for Implementing the Commission on Cancer Standard 8.1: Addressing Barriers to Care is an update of the previous resource for Implementing the Commission on Cancer Standard 3.1: Patient Navigation Process. Although the 2020 Commission on Cancer (CoC) standards do not specifically require conducting a Community Needs Assessment (CNA) or establishing a patient navigation process, this road map includes guidance on conducting a CNA, which can be a useful approach to identifying barriers to cancer care. Additionally, patient navigation can be used as a means to address barriers facing patients, caregivers, and communications in a cancer program’s catchment area. Therefore, guidance and resources on patient navigation are included in this road map.

Funding for this project was generously provided by the Centers for Disease Control and Prevention (CDC) in response to technical assistance requests by comprehensive cancer control stakeholders to help cancer control coalitions help their cancer center members meet CoC standards.

HOW TO USE THIS ROAD MAP

If you are a CCC professional, use this road map to:
- Identify CoC cancer programs in your region and disseminate this resource
- Provide technical assistance and training in public health strategy development, research and evaluation
- Connect CoC cancer programs with data sources

If you are a cancer center program administrator, use the road map to help you:
- Identify barriers to care and determine potential solutions to reduce cancer disparities
- Identify resources available to assist patients in need
- Work with your CCC partners to address identified gaps in resources

If you need technical assistance or would like more information, please contact us at cancercontrol@gwu.edu.

Viewing this PDF in Google Chrome? Use “Ctrl+Click” on links to open them in a new tab.
ACKNOWLEDGMENTS AND CONTRIBUTORS

GW Cancer Center Staff Contributors

Dao Duong, MPH  
Technical Assistance Coordinator, Comprehensive Cancer Control

Liza Fues, JD  
Technical Assistance Coordinator, Comprehensive Cancer Control

Mohammad Khalaf, MPH  
Senior Manager, Comprehensive Cancer Control

Mandi Pratt-Chapman, MA, PhD  
Associate Center Director for Patient-Centered Initiatives & Health Equity

Content Reviewers

The George Washington University (GW) Cancer Center would also like to thank Erin DeKoster (American College of Surgeons), Connie Bura (American College of Surgeons) and Holly Frye (George Washington University Cancer Center Comprehensive Cancer Control Technical Assistance Steering Committee) for providing feedback on a draft of the resource.

ABOUT THE GW CANCER CENTER

The GW Cancer Center is a collaboration between the GW Hospital, the GW Medical Faculty Associates, and the GW School of Medicine and Health Sciences to expand GW’s efforts in the fight against cancer. The GW Cancer Center also partners with the Milken Institute School of Public Health at GW and incorporates all existing cancer-related activities at the university, serving as a platform for future cancer services and research development.

Our vision is a cancer-free world through groundbreaking research, innovative education and equitable care for all.

ABOUT THE COMPREHENSIVE CANCER CONTROL PROJECT

The GW Cancer Center has received funds from the Centers for Disease Control and Prevention (CDC) since 2013 to provide technical assistance and training (TAT) to CDC’s National Comprehensive Cancer Control Program (NCCCP) grantees and their partners. This road map is delivered under project year three of the five-year DP18-1805 Cooperative Agreement: “Building Cancer Control Capacity: Scaling Evidence to Practice to Advance Health Equity”. To learn more, visit www.CancerControlTAP.org.

FUNDING ACKNOWLEDGMENT

This work was supported by Cooperative Agreement #NU58DP006461-03 from CDC. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.
Implementing the Commission on Cancer Standard 8.1 Addressing Barriers to Care
A Road Map for Comprehensive Cancer Control Professionals and Cancer Program Administrators

CONTENTS
Introduction ............................................................................................................................................ ii
How to Use This Road Map ...................................................................................................................... ii
Acknowledgments and Contributors ..................................................................................................... iii
About the GW Cancer Center ................................................................................................................. iii
About the Comprehensive Cancer Control Project .................................................................................. iii
Funding Acknowledgment ...................................................................................................................... iii
Road Map for Implementing CoC Standard 8.1: An Overview .............................................................. 5
About Commission on Cancer Standard 8.1: Addressing Barriers to Care ......................................... 6
Step 1: Conduct Analysis of Cancer Care Barriers ..................................................................................... 8
Step 2: Identify Barriers ........................................................................................................................... 9
Step 3: Implement Strategies to Address Prioritized Barrier ................................................................. 12
Step 4: Modify or Enhance the Process to Address Prioritized Barrier .................................................... 14
Step 5: Report to Cancer Committee ..................................................................................................... 14
Resources .............................................................................................................................................. 15
References ............................................................................................................................................ 20
Appendix A: Conducting a Community Needs Assessment .................................................................. 21
Patient Population and Health Disparities ............................................................................................ 21
Appendix B: Establishing a Patient Navigation Process ......................................................................... 23
STEP 1: Conduct Analysis of Cancer Care Barriers

Review and analyze strengths and barriers within your cancer program. Resources for identifying strengths/barriers may include:

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

STEP 2: Identify Barriers to Cancer Care

Identify barriers specific to your cancer program and choose one to focus on for the upcoming year. Barriers can be patient-, provider-, or system-level. Examples include:

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

STEP 3: Implement Strategies to Address Prioritized Barrier

- Leverage community resources to address prioritized barrier to care
- Consider partnering with local community-based organizations

STEP 4: Modify or Enhance Process(es) to Address Prioritized Barrier

- Identify strengths and areas for improvement
- Map root causes of challenges and smoother care processes for patients

STEP 5: Report to Cancer Committee

Elements of Report will include:

- Barrier prioritized
- Resources/processes utilized to identify and address barrier
- Metrics related to outcomes of reducing this barrier
ABOUT COMMISSION ON CANCER STANDARD 8.1: ADDRESSING BARRIERS TO CARE

The CoC Accreditation Committee establishes standards for hospitals, treatment centers and other facilities seeking accreditation to improve the quality of patient care across the cancer continuum. These standards aim to ensure that cancer programs within these facilities offer their patients a full range of services and access to community-based resources. The CoC Accreditation Committee outlines these standards in *Optimal Resources for Cancer Care (2020 Standards)*.

**Documentation**

- Documentation is submitted with pre-review questionnaire
- Cancer committee minutes document submission of required report to cancer committee

**Compliance**

To fulfill the main criteria for CoC accreditation, your program must meet the following compliance criteria for each calendar year:

1. “The cancer committee identifies at least one barrier to focus on for the year and identifies resources and processes to address the barrier”
2. “At end of year, the cancer committee evaluates the resources and processes adopted to address the barrier to care and identifies strengths and areas for improvement”
3. The cancer committee minutes must include all required elements

*(CoC, 2019, p. 77)*
Begin with conducting a cancer care barrier analysis

Identify which populations experience cancer health outcome disparities and barriers to care faced by those populations

Prioritize a barrier to care experienced by those populations

Identify internal and external resources available to address barrier

Develop processes that draw on resources to address barrier

Monitor process throughout year

Evaluate

Review findings and identify areas of ongoing improvement

Choose a new barrier or enhance process to address same barrier

Sample Strategy for Meeting Commission on Cancer Standard 8.1

Adapted from strategy to meet CoC Standard 3.1 from Cancer Program Standards: Ensuring Patient-Centered Care, 2016 Edition (Mercurio, 2016)
STEP 1: CONDUCT ANALYSIS OF CANCER CARE BARRIERS

Review and analyze strengths and barriers of your cancer program. The 2020 CoC standard 8.1 does not specifically require conducting a Community Needs Assessment (CNA). However, a CNA can be used as a resource to analyze existing program strengths and weaknesses. For a guide on developing a CNA, please refer to Appendix A.

Example Resources for Analysis

- Cancer Quality Improvement Program (CQIP) reports
- Cancer patient satisfaction scores
- Patient focus groups
- State registry cancer data
- Cancer program data
- Population health resources (local and regional)
- Community Needs Assessment (CNA)
- Analysis of unique features of cancer program and/or state

Compare your cancer program data to regional and national data to identify areas where your program needs additional effort to meet or exceed national/regional trends. Determine if your cancer program is treating people diagnosed with the most common cancers that occur in your area. Additionally, determine if historically underserved populations are being reached to the same degree that White, heterosexual, and/or higher income populations are.

Conduct confidential interviews or focus groups with patients and caregivers to identify barriers to care.

Below are some potential data sources that can help inform your analysis.

<table>
<thead>
<tr>
<th>Local/Site-Specific Sources</th>
<th>Community or Regional Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patient navigators</td>
<td>• Community health needs assessments by non-profit hospitals or departments of health</td>
</tr>
<tr>
<td>• Community outreach coordinators</td>
<td>• Community health improvement plans by government entities</td>
</tr>
<tr>
<td>• Breast and Cervical Cancer Early Detection Program coordinators</td>
<td>• Susan G. Komen regional needs assessment community profiles</td>
</tr>
<tr>
<td>• Cancer program administrators</td>
<td>• Hospital and clinic annual reports</td>
</tr>
<tr>
<td>• Tumor/cancer registries</td>
<td>• Tumor/cancer registries</td>
</tr>
<tr>
<td>• Cancer committee minutes</td>
<td>• Cancer committee minutes</td>
</tr>
<tr>
<td>• Other local resources</td>
<td>• Other local resources</td>
</tr>
</tbody>
</table>
State Sources
- State health policy and plan agencies (e.g., Florida’s Agency for Healthcare Administration, D.C.’s Department of Health Care Finance)
- Division of Vital Records from departments of health
- State cancer surveillance data (e.g., Behavioral Risk Factor Surveillance System)
- Cancer control state profiles

National and Multi-Level Sources
- CDC Cancer Data and Statistics
- National Cancer Institute (NCI) State Cancer Profiles
- National Institute of Health (NIH) Surveillance, Epidemiology and End Results (SEER)
- American Cancer Society (ACS) Cancer Facts and Figures
- American College of Surgeons National Cancer Database
- National Academy of Medicine
- U.S. Census Bureau
- Cancer Control P.L.A.N.E.T.
- Robert Wood Johnson 500 Cities Project

STEP 2: IDENTIFY BARRIERS TO CANCER CARE

Identify barriers to care from various sources and choose one to focus on. Barriers may be patient-centered, provider-centered or health system-centered (CoC, 2019). Determine potential solutions to reduce cancer disparities.

The table below provides some examples of identified barriers, as well as actions and solutions that could be used to address them. Please note that this is not an exhaustive list and could look different from the barriers faced by your organization and patient population.

TIP #2
Use the American Society for Quality’s Impact Effort Matrix to help prioritize barriers and decide which to address.

TIP #3
Barriers specific to cancer care may include access to risk reduction and cancer screening services, not just cancer treatment, post-treatment and supportive care services.
<table>
<thead>
<tr>
<th>IDENTIFIED BARRIERS</th>
<th>EXAMPLES</th>
<th>POTENTIAL ACTIONS</th>
<th>POTENTIAL SOLUTIONS</th>
</tr>
</thead>
</table>
| Logistical          | • Transportation issues  
                    • Lack of childcare | • Identify patients who require transportation to medical care or support services within or outside their community  
                    • Identify patients who require childcare | *Transportation (within community):*  
                    • Work with local Medicaid managed care organizations on improvements to transportation vendor availability  
                    • Work with ride sharing companies (e.g., Lyft) to pay for rides for patients  
                    • Engage local churches or non-profit organizations  
                    • Identify local or national resources that provide financial assistance for transportation and create an instructional document for patients on how to access these resources (e.g., American Cancer Society (ACS’s) Road to Recovery)*  
                    *Transportation (outside of community):*  
                    • Utilize ACS’s Hope Lodges* or Ronald McDonald Houses* for children  
                    • Develop a hotel partner program  
                    • Work with administrators of telemedicine services to provide care |
| Economic            | • Lack of insurance or under-insurance  
                    • High co-pays or deductibles  
                    • Prescription medication costs  
                    • Financial and legal issues | • Assess financial and legal issues faced by patients during and after treatment  
                    • Have navigators document barriers | • Provide financial counseling and navigation services to all patients diagnosed with cancer  
                    • Work with local insurance exchange navigators or safety net insurers to enroll eligible patients  
                    • Screen patients for financial assistance eligibility and navigate them to co-pay and other patient assistance programs  
                    • Develop support initiatives such as medical-legal partnerships  
                    • Provide ACS’s National Cancer Information Center (NCIC) with information about resources in your community and refer patients to NCIC |

* Services may be currently suspended or restricted due to COVID-19 pandemic
| Cultural and Linguistic | • Lack of culturally or linguistically competent services  
• Patient mistrust or negative perception of health care providers  
• Systems that perpetuate structural racism  
• Assess cultural and linguistic competency of services and providers  
• Understand cultural background(s) of patient population  
• Review policies and procedures to determine if they result in an unanticipated burden on some populations  
• Adopt the [Office of Minority Health’s National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care](https://www.hhs.gov/ash/ohpop-health-initiative/guidance/cultural-competency/standards Nh.html)  
• Ensure access to in-person or telephone medical interpreter services on demand  
• Conduct culturally humble community outreach  
• Change policies and processes that disproportionately burden people historically discriminated against |
| Communication | • Low health literacy  
• Lack of knowledge about wellness behaviors  
• Lack of knowledge about resources or events  
• Unclear provider explanations to patients  
• Track and document communication issues  
• Assess patient understanding of treatment plan and available resources  
• Collaborate with on-site or community wellness group to offer support groups  
• Ensure access to patient navigators  
• Ensure educational materials meet health literacy standards for readability (e.g., reading grade level should be 5th grade or below)  
• Provide materials in the languages of patients seen in the clinic  
• Provide patients with worksheets to prioritize questions for their health care team  
• Improve provider communication skills through training and practice-based learning |
| Provider-Centered | • Perceptions or attitudes, including implicit bias  
• Time constraints and demand for health care services  
• Administrative barriers  
• Assess providers’ perceptions, time constraints and other administrative barriers, like excessive paperwork  
• Measure patient satisfaction and identify opportunities to improve patient-provider interactions  
• Use resources from the [American Medical Association](https://www.ama-assn.org) or other organizations to reduce administrative burden associated with prior authorization programs from insurers  
• Work directly with managed care organizations to reduce referral burden  
• Prioritize diversity of background and perspective in the workforce to optimize peer-to-peer learning |
STEP 3: IMPLEMENT STRATEGIES TO ADDRESS PRIORITIZED BARRIER

Design processes to leverage existing community resources. A list of potential local and national resources is provided on page 15 of this document.

Consider partnering with local community-based organizations to address prioritized barrier to cancer care. For example, you could collaborate with a local community health center to sponsor a cancer screening event or find a local gym that offers American College of Sports Medicine/American Cancer Society-certified exercise trainers. You could also refer patients to online support groups or financial assistance resources depending on the nature of the selected barrier.

Another option may be to design a patient navigation process that offers individualized assistance to patients, caregivers and families to help them overcome a selected barrier. For more guidance on establishing a patient navigation process, please refer to Appendix B.

Revisit the potential actions and solutions you identified and align them with the resources you mapped. Gaps in resources may become apparent during this process. Create an action plan that includes specific, measurable, achievable, realistic and time-bound (SMART) objectives. Refer to the table below for examples of SMART objectives.

Prioritize objectives that:

- Promote policy, systems or environmental improvements within your facility
- Implement evidence-based cancer screening and risk reduction programs
- Focus on the populations experiencing the greatest cancer incidence, mortality or quality of life disparities in your service or catchment area
- Create impactful, continuing education programs for providers
- Promote a holistic view of wellness for survivors
- Provide holistic survivorship care that includes ongoing screening, surveillance, long-term and late effects monitoring, health promotion, service referral, and care coordination
- Support cancer programs/facilities in achieving CoC accreditation

Document strategies under each objective and include output and outcome metrics. These data will allow you to identify areas of quality improvement and steps for addressing issues. The table below includes examples of SMART objectives for several identified barriers.

TIP #4
Perform internal and external resource mapping to help think through existing resources within your facility or community that may be of assistance as you develop your processes.

The GW Cancer Center’s Action4PSEChange.org site lists several tools to assist in mapping resources and compiling data.

TIP #5
Identify key stakeholders and their needs. This helps determine who else could be impacted by your program or process.
<table>
<thead>
<tr>
<th>IDENTIFIED BARRIERS</th>
<th>SMART OBJECTIVE EXAMPLES</th>
</tr>
</thead>
</table>
| **Logistical**           | • Implement program with community partner to provide # of patients with free transportation services for cancer treatment by mm/dd/yyyy  
                           |   • Work with Medicaid or other payer to initiate pilot program for emergency transportation services for outpatient visits in order to reduce visits to emergency department % by mm/dd/yyyy  
                           |   • Extend weekday or weekend hours for radiation oncology and medical oncology clinics by mm/dd/yyyy  |
| **Economic**             | • Identify existing in-hospital financial resources and partner with safety net clinics to develop a financial navigation resource guide for patients and caregivers by mm/dd/yyyy  
                           |   • By mm/dd/yyyy, designate a financial navigator to assist patients with financial assistance applications and insurance appeals  
                           |   • Catalog co-pay and financial assistance programs from pharmaceutical companies and non-profit agencies to support eligible patients by mm/dd/yyyy  
                           |   • Conduct a fundraising campaign to create patient assistance fund with $ by mm/dd/yyyy      |
| **Cultural and Linguistic** | • Sponsor one evening or weekend patient support group for # Spanish-speaking patients diagnosed with cancer for three six-week sessions by mm/dd/yyyy  
                           |   • Provide education to # clinicians on the importance of providing interpretation services for patients whose first language is not English and model access to interpretation resources by mm/dd/yyyy  
                           |   • Contract to provide medical interpretation services for oncology patients by mm/dd/yyyy  
                           |   • Hire certified medical interpreters for patients speaking top three languages after English by mm/dd/yyyy  
                           |   • Require cultural competency training that goes beyond knowledge checks to self-reflection and personal action planning |
| **Communication**        | • Implement training to # primary care providers who have patients who have a history of cancer to improve care coordination with oncologists by mm/dd/yyyy  
                           |   • Contract with communication expert to facilitate workshop for oncologists to enhance patient-provider communication by mm/dd/yyyy  
                           |   • Provide patients with resources to encourage self-advocacy and to ask for clarification when information is confusing |
| **Provider-Centered**    | • Implement and evaluate # evidence-based, provider-focused culturally sensitive care workshops for oncologists and navigators to increase their skills in providing culturally sensitive care by mm/dd/yyyy  
                           |   • Create and implement a strategic plan to prioritize hiring a diversity of providers in terms of sociodemographic background and cultural and professional perspectives |
STEP 4: MODIFY OR ENHANCE THE PROCESS TO ADDRESS PRIORITIZED BARRIER

At the end of each year, the cancer committee evaluates resources and processes adopted to address the barrier to cancer care. Identify strengths and areas for improvement. For the evaluation, assess process and short-term outcomes. Discuss with the cancer committee ways to modify or enhance your process. Some tips for evaluating your process include:

- “Assess your program at regular intervals (e.g., quarterly)
- Refer back to your logic model and evaluation plan
- Keep in mind what stakeholders value and if the information you provide to them is aligned with those values (e.g., cost savings, revenue generated, increased patient satisfaction)” (Willis et al., 2016, p. 33)

Your program will then choose a new barrier to focus on (or justify the need to continue working on the same barrier) at the first meeting of the next year. If the same barrier is chosen two years in a row, update your resources and progress made to address resource gaps and document any changes. When you identify a barrier to prioritize during the next term, create SMART objectives and strategies or modify strategies that have not been successful. Assigning metrics to these strategies will prepare you for the end-of-year evaluation to measure how well your program did to address the barrier. Based on your initial evaluation results, redirect resources as needed and document your approach.

STEP 5: REPORT TO CANCER COMMITTEE

Each calendar year, the cancer committee minutes must document a report that includes the following elements:

- What barrier was prioritized as an area of focus
- What resources/processes were utilized to identify and address the prioritized barrier
- Metrics related to outcomes of reducing prioritized barrier

(CoC, 2019, p. 77)
RESOURCES

Administrative

- **Reducing Administrative Barriers to Care**: This resource from the American Medical Association helps patients and physicians ease burdens of prior authorizations and other arduous barriers to care.

Commission on Cancer Standard 8.1

- **Optimal Resources for Cancer Care (2020 Standards)**: New accreditation standards developed by the Commission on Cancer. Website also includes crosswalk comparing 2016 standards to the 2020 standards as well as videos and slides breaking down each chapter.

Communication and Marketing

- **CancerCare Publications**: Written by experts, these easy-to-read booklets and fact sheets from CancerCare provide reliable information on cancer-related topics.

- **Cancer Information in Other Languages**: This resource from the American Cancer Society offers information about cancer including prevention, early detection, treatment and managing side effects in 14 languages in addition to English.

- **Guide to Making Communication Campaigns Evidence-Based**: This guide from the GW Cancer Center is a companion text to the *Communication Training for Comprehensive Cancer Control Professionals 102* course. While it is intended as a resource on cancer control communication, Lesson 2.1 contains useful information on *Conducting a Systematic Community Assessment*.

- **National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care**: The National CLAS Standards from the Office of Minority Health aim to improve health care quality and advance health equity by establishing a framework for organizations to serve the nation’s increasingly diverse communities.

Community Needs Assessment (CNA)

Appendix A was developed through examining several existing cancer-specific CNAs, including:

- **Moffitt Cancer Center Community Health Needs Assessment 2016**: This cancer-specific community health needs assessment includes data collected from local and national sources, as well as primary data from key informant interviews and focus groups with community residents.

- **University of Vermont Medical Center Cancer Community Needs Assessment Report**: This 2016 report highlights three specific community needs in cancer care and aligns them with the 2020 Vermont State Cancer Plan goals.
• **University of Connecticut Community Needs Assessment**: This 2016 community needs assessment identifies disparities in cancer care and resources, explores current medical system barriers, and addresses patient navigation services within the towns of Connecticut.

• **University of North Carolina Community Cancer Needs Assessment**: This 2017 report was conducted through an analysis of available data identifying cancer disparities, cancer risk factors and barriers to care throughout North Carolina. The document also reviews current cancer navigation and survivorship processes and resources within the NC Cancer Hospital.

**Financial/Legal**

• **Cancer Financial Assistance Coalition (CFAC)**: CFAC is a coalition of organizations helping patients diagnosed with cancer manage their financial challenges.

• **National Cancer Information Center (NCIC)**: The National Cancer Information Center from the American Cancer Society provides information and support to those facing cancer. Trained cancer information specialists are available via phone, live chat, or video chat and provide accurate, up-to-date cancer information to patients, family members and caregivers and connect them to valuable services and resources in their communities.

• **National Center for Medical-Legal Partnership**: This project aims to improve the health and well-being of people and communities by leading health, public health and legal sectors in an integrated, upstream approach to combating health-harming social conditions.

**Patient Navigation Competencies, Scope of Practice and Program Planning**

• **Advancing the Field of Cancer Patient Navigation: A Toolkit for Comprehensive Cancer Control Professionals**: This toolkit from the GW Cancer Center was developed to guide states in advancing patient navigation. This resource can be used to educate and train patient navigators, provide technical assistance to members of comprehensive cancer control coalitions, build navigation networks at the state level and identify policy approaches to sustain patient navigation.

• **Core Competencies for Non-Clinically Licensed Patient Navigators**: These competencies from the GW Cancer Center can be used by health care professionals and institutions considering qualifications for patient navigators.

• **Executive Training on Navigation and Survivorship**: This interactive online program from the GW Cancer Center teaches the nuts and bolts of patient navigation and clinical survivorship program development and implementation. Target audiences include administrators, comprehensive cancer control practitioners, nurses, physicians, patient navigators, social workers and others. The companion guide, **Executive Training on Navigation and Survivorship: Finding Your Patient Focus - Guide for Program Development** can also be used as a standalone resource for creating and maintaining navigation programs.
• **How Are We Doing? How to Evaluate Your Patient Navigation Program:** Developed by the Patient Navigator Training Collaborative, this toolkit is designed to help patient navigation program managers identify goals, identify what measures can be tracked to help determine if goals are being met, create data collection tools and conduct basic descriptive analysis.

• **Job Task and Knowledge Area Analysis:** This form from the National Consortium of Breast Centers helps describe the knowledge areas and job tasks for assisting patients, caregivers and survivors throughout the continuum of care.

• **Navigation Matrix Tool:** This tool from the National Cancer Institute can be used to assist in building a stronger navigation process. This form can be used to assess an individual tumor site or an entire program or process.

• **Navigator Responsibilities and Core Functions:** This resource from the Association of Community Cancer Centers provides a sample list of patient navigator responsibilities and job functions designed to be adapted to meet your program’s specific resources, community needs and strategic objectives.

• **Oncology Nurse Navigator Core Competencies (2017):** These role-specific core competencies from the Oncology Nursing Society are designed for a variety of oncology nursing responsibilities. They provide the fundamental knowledge, skills and expertise required for nurses to perform proficiently in their roles.

• **Oncology Patient Navigator Training: The Fundamentals:** This competency-based training from the GW Cancer Center uses interactive web-based presentations to discuss evidence-based information and case studies to prepare patient navigators to effectively address barriers to care for cancer patients and survivors. The Guide for Patient Navigators provides a supplement to the Oncology Patient Navigator Training as you move through the course.

• **Patient Navigation Barriers and Outcomes Tool (PN-BOT™):** This free, Excel-based data entry management and reporting product from the GW Cancer Center is designed for oncology patient navigation programs. Navigation programs can use the PN-BOT™ to document, track and generate simple reports.

• **Scope of Practice in Oncology Social Work:** This resource from the Association of Oncology Social Work provides a list of common goals and functions for oncology social workers.

• **Standardized Navigation Metrics and Standardized Evidence-Based Oncology Navigation Metrics for All Models: A Powerful Tool in Assessing the Value and Impact of Navigation Programs:** Developed by the Academy of Oncology Nurse and Patient Navigators (AONN+) Standardized Metrics Task Force, this tool includes a set of universal, research-supported metrics to measure the impact of navigation programs. It consists of eight domains in which to measure patient experience, clinical outcome, and business performance or return on investment.
Policy, Systems and Environmental Change

- **Action for PSE Change Tool**: This no-cost online tool from the GW Cancer Center helps comprehensive cancer control professionals, coalitions and communities with improving health across the cancer continuum. It also features tips on how to use and visualize cancer data for reporting purposes.

- **The Community Guide**: An independent panel of public health and prevention experts from the Department of Health and Human Services (the Community Preventive Services Task Force) is responsible for collecting these evidence-based interventions to help you select programs to improve health and reduce disease. Search by topic and choose policy development, environmental change or other relevant terms under “strategy.”

- **Advancing Patient-Centered Care Survivorship Care Toolkit**: The GW Cancer Center developed this toolkit to support training and technical assistance from Comprehensive Cancer Control Programs/Coalitions to health care providers/organizations in order to improve patient-centered cancer survivorship care in their state, tribe or territory. All parts of this toolkit can be adapted to fit program specific needs. These tools are intended to serve as a starting point to help address reported care needs of post-treatment cancer survivors.

Survivorship, Rehabilitation and Supportive Care Resources

- **ACS Guidelines for Diet and Physical Activity**: These guidelines from the American Cancer Society cover cancer prevention but may also be useful general guidelines for cancer survivors.

- **Cancer Support Groups**: These online, telephone and face-to-face support groups from CancerCare can provide support and connection for cancer survivors.

- **Cancer Survivorship E-Learning Series for Primary Care Providers**: This continuing education program from the GW Cancer Center provides a forum to educate primary care providers who may have patients who are cancer survivors about how to better understand and care for survivors in the primary care setting.

- **LIVESTRONG at the YMCA**: This 12-week physical activity program is designed to get cancer survivors back on their feet.

- **Survivorship Care Guidelines**: Clinical survivorship care guidelines are available from the American Cancer Society for colorectal cancer, prostate cancer, head and neck cancer and breast cancer (in partnership with the American Society for Clinical Oncology).
Transportation/Lodging†

- **Hope Lodge**: Each Hope Lodge from the American Cancer Society offers cancer patients and their caregivers a free place to stay when their best hope for effective treatment may be in another city.

- **Road to Recovery**: This program from the American Cancer Society provides transportation to and from treatment for people with cancer who do not have a ride or are unable to drive themselves.

- **Ronald McDonald House**: These houses provide lodging for families so they can stay close by their hospitalized child at little to no cost.

† Transportation/Lodging resources may be suspended or restricted due to COVID-19 pandemic
REFERENCES


APPENDIX A: CONDUCTING A COMMUNITY NEEDS ASSESSMENT

One of the resources that may be helpful in identifying a cancer program’s strengths and barriers is to conduct a community needs assessment (CNA). A CNA typically includes the following:

- The cancer program’s target community and/or local population
- Health disparities in cancer incidence and mortality (can be influenced by race, ethnicity, gender, underserved groups and socioeconomic status)
- Cancer risk factors specific to population (i.e., tobacco use, diseases, obesity)
- Barriers to care (patient-centered, provider-centered or health system-centered)
- Available resources to address barriers (i.e., patient navigation programs)
- Program challenges (i.e., gaps in available resources to address barrier)
- Strategies to reduce cancer burden

In your CNA, you can describe your facility and the characteristics of your program’s comprehensive cancer care program.

Description of facility

- Number of beds
- Specialized, cancer-related programs offered (e.g., transportation, financial assistance)
- Reputation in cancer care
- Number of cancer patients served, cancer case volume
- List of accreditations

Comprehensive cancer care characteristics

- Range of cancer-related clinical services and equipment
- Multidisciplinary team approach, coordinated care
- Clinical trials information and new treatment options
- Prevention and detection programs, including education and support services by partner organizations

PATIENT POPULATION AND HEALTH DISPARITIES

If you choose to establish a patient navigation process, it may be helpful to describe your patient population, as well as cancer-related health disparities that may exist within the population.
Population(s) served and/or patient characteristics

- Catchment area, including geographic boundaries and characteristics (e.g., urban, suburban, rural)
- Socioeconomic characteristics (e.g., median household income, housing security, health insurance rate, average education level/quality of public schools, food insecurity, languages spoken, immigration status, employment status, poverty level, availability of affordable housing and public transportation, homelessness)
- Race/ethnicity
- Age
- Behavioral and psychosocial health characteristics such as tobacco use rates, alcohol/substance abuse rates and/or mental illness rates
- If available and relevant, include chronic disease incidence or comorbidity rates of obesity, heart disease, diabetes and/or respiratory disease

Cancer burden

- Cancer screening rates
- Cancer survival rates, including 5-year survival rate and/or 10-year survival rate
- Cancer incidence among patient population by diagnosis, age, gender, ethnicity, socioeconomic status or zip code (if data are available)
- Cancer mortality among patient population by diagnosis, age, gender, ethnicity, socioeconomic status or zip code (if data are available)

It may be helpful to look beyond facility-based patient data. Compare your cancer program data with national and regional level data as well. Collect data that will allow you to address barriers in the community for patients not seeking care.
APPENDIX B: ESTABLISHING A PATIENT NAVIGATION PROCESS

If you choose to establish a patient navigation process, you can design a process that offers individualized assistance to patients, caregivers and families to help them address barriers to care. Staff that provide navigation services to patients may be referred to as nurse navigators, social workers, patient navigators, peer navigators, outreach staff, patient representatives, nurses or case managers. Community health workers are also important allies for navigators in order to reach diverse communities where they live, work, play and pray. These terms are not always fully distinguished, which can create confusion about the roles of different types of navigators (Willis et al., 2016).

Regardless of a navigator’s title, your cancer program’s navigation process should help patients, caregivers and families address barriers by linking them to the resources you mutually identify, including internal sources of resilience, individual support networks, service providers and community-based organizations. Visit the resources page to review competencies and scope of practice for different types of navigators.

Below are useful steps taken from Willis et al. (2016, p. 32) that could be useful to you as you establish a patient navigation process in your setting:

- The cancer program’s community and local population
- Health disparities (numerous factors can contribute to disparities in cancer incidence and death rates such as race, ethnicity, gender, underserved groups and socioeconomic status)
- Barriers to care, which may include patient-centered, provider-centered or health system-centered barriers
- Resources available to overcome barriers on-site or by formal referral
- Gaps in the availability of resources to overcome barriers

The CNA must define/identify:
- The cancer program’s community and local population
- Health disparities (numerous factors can contribute to disparities in cancer incidence and death rates such as race, ethnicity, gender, underserved groups and socioeconomic status)

Once you have designed your patient navigation process, revisit and update the resources you have identified. Gaps in resources may become apparent during this process. Implementation of your navigation process should be based on your needs assessment and will be refined through ongoing evaluation (Willis et al., 2016).

As you prepare your report to the cancer committee, consider including the following in addition to the required items mentioned in Step 5:

- Outline the background, role and appropriate scope of practice for patient navigators at your facility and define roles of staff providing navigation-related services.
- Describe the navigation process – who will address identified barrier(s) and how?
- Evaluate how the patient navigation process identifies and tracks barriers to care
- Provide a list of recommendations or action steps to address barriers that still exist
AONN+ Metrics Initiative provides a tool to measure the success of a navigation process or program’s patient experience, clinical outcomes and business performance or return on investment. For more information, visit the Standardized Evidence-Based Oncology Navigation Metrics for All Models: A Powerful Tool in Assessing the Value and Impact of Navigation Programs. Most of these metrics are embedded in the no-cost Patient Navigation Barriers and Outcomes Tool™ (PN-BOT)™.

Finally, discuss your report with the cancer committee and reach consensus regarding the process.