



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

EXECUTIVE TRAINING ON NAVIGATION AND SURVIVORSHIP: FINDING YOUR PATIENT FOCUS

Guide for Program Development



THE GEORGE
WASHINGTON
UNIVERSITY
WASHINGTON, DC

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WELCOME

The George Washington University (GW) Cancer Institute's Center for the Advancement of Cancer Survivorship, Navigation and Policy (caSNP) is committed to advancing patient navigation and cancer survivorship efforts locally and nationally through training, research, policy analysis, outreach and education. One of our goals is to equip health care professionals with the skills and resources needed to improve care for people affected by cancer across the care continuum. With a growing emphasis on delivering high-quality, patient-centered care, many health care professionals are responding to the need to transform the cancer care delivery system by developing evidence-based navigation and survivorship programs.

When we set out to develop the GW patient navigation and survivorship programs, we realized that there was little guidance or consensus on approaches. We did what many health care professionals have done: We sought out everyone we could find who already had programs to identify best practices. We also looked to the literature to learn about the latest research and other promising strategies. As we talked with more and more professionals, it became clear that many people were struggling with program development and would benefit from the lessons learned that we collected.

In 2010 we launched the *Executive Training on Navigation and Survivorship* to facilitate the implementation of navigation and survivorship programs across the country. With feedback from participants, we have continued to improve the training over the past three years. In 2012 we added a new component to the training – this comprehensive guide that distills the lessons we have learned over the course of several years and continue to refine with the latest information. In 2014, through a cooperative agreement with the Centers for Disease Control and Prevention, we first provided the training in an online format at no charge to make sure as many people have access to the content as possible.

This *Guide for Program Development* and the accompanying *Program Development Workbook* were developed to efficiently and effectively walk you through the process of program planning. We have included background information, tools and resources along with short activities to help with program design, implementation, evaluation and sustainability. Each activity is fully customizable, so when you have completed each of them, you will have a tailored plan for your program.

We hope that you find this *Guide* and corresponding *Workbook* beneficial in your program development endeavors, leading to improvements in quality cancer care and in the lives of those affected by cancer.

Sincerely,



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About GWCI

Founded in 2003, the GW Cancer Institute integrates and coordinates the broad spectrum of cancer-related activities across the GW campus and among its affiliated partners. In collaboration with the [GWU Hospital](#) and the [GW Medical Faculty Associates](#), the Institute ensures outstanding patient care and support from screening through treatment to survivorship and end-of-life. The Institute leads biomedical and population-based research and collaborates with the [Katzen Cancer Research Center](#) on clinical research. The Institute has deep roots into the Washington, DC community and sets standards for patient-centered care through its [Center for the Advancement of Cancer Survivorship, Navigation and Policy](#).

The vision of the GW Cancer Institute is to set the standard for patient-centered care and eliminate cancer health disparities. The mission of the GW Cancer Institute is to ensure access to quality, patient-centered care across the cancer continuum through community engagement, patient and family empowerment, health care professional education, policy advocacy and collaborative multi-disciplinary research. For more information, visit www.gwcancerinstitute.org.

About caSNP

The Center for the Advancement of Cancer Survivorship, Navigation and Policy (caSNP) is committed to advancing patient navigation and cancer survivorship efforts locally and nationally through training, research, policy analysis, outreach and education. The Center offers:

- Interactive online trainings through its Online Academy
- A monthly newsletter full of resources and tools to support patient-centered care
- A regular webinar series with experts in navigation and survivorship
- Research opportunities to advance the fields of navigation and survivorship

Disclaimer

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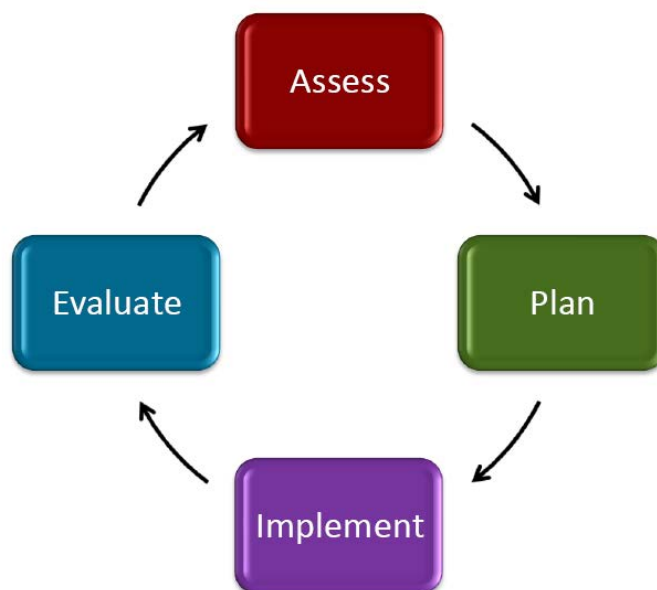
Permission was granted to use the templates/tools incorporated in the *Guide* solely for educational and training purposes and/or were publically available. We thank those organizations for their contributions.

How to Use the Program Development Guide

The GW Cancer Institute developed the free, web-based Executive Training on Navigation and Survivorship. The training contains 3 main components:

- Interactive learning modules walk you through important concepts in program implementation.
- The *Guide for Program Development* provides an overview of important content for building and sustaining navigation and survivorship programs and provides tips and tools that we have gathered over several years. We consider it to be the textbook for the course. Each learning module reviews content from and builds upon the *Guide*.
- The *Program Development Workbook* includes customizable activities that, when completed, help you create a project plan for your navigation and/or survivorship program. Each learning module reviews the activities and provides guidance for completing them.

The *Guide for Program Development* is structured around the Program Development Cycle below. These four main sections are designed to guide you through the program planning process from assessment through evaluation. In each section you will find content color coded to match the cycle. More information about the program development cycle is covered in the interactive learning modules available at www.gwcancerinstitute.org.



Based on our experience, we recommend starting at the beginning of the *Guide* and looking through each section, even if you do not think it is relevant to your program. Many of our training participants realize during the training that they may have missed a key step in program implementation and note that they find more of the content beneficial than they may have originally thought.

We update the *Guide* content frequently to include new information and make sure the content is relevant. If you have suggestions for additional material to include, please email us at caSNP@gwu.edu. Our goal is to make this as useful as possible for as many health care professionals as possible, so we welcome your feedback.

Defining Cancer Survivorship

The State of Cancer Survivorship

Advances in technology and cancer treatment have led to an increase in cancer survival. However, with the increase in survival, there is a critical need to provide quality follow-up care to patients post-treatment to address late and long-term effects of cancer and its treatment. Cancer survivorship – the phase of the cancer continuum after completion of active treatment – is increasingly receiving attention. The large number of cancer survivors is expected to rapidly grow in the next several years with the aging of the baby boomer population. According to the American Cancer Society (ACS), approximately 14.5 million Americans are alive with a history of a cancer diagnosis, and this number is expected to grow to 19 million by 2024.¹ Several national reports on survivorship have identified the need to improve post-treatment care,^{2,3,4} and new care standards are being developed to include the survivorship phase by organizations such as the American College of Surgeons' Commission on Cancer and the Association of Community Cancer Centers.

Studies by ACS, LIVESTRONG and others document survivors' many physical/medical, psychological, social, spiritual, financial and informational needs and concerns and indicate that the current standard of care does not adequately address these issues. Change requires a cultural shift in the way care is delivered, however there are many challenges that may inhibit such change, including:⁵

- A fragmented delivery system
- Lack of awareness by both survivors and providers of the late effects of cancer and its treatment
- Lack of/suboptimal communication
- Lack of survivorship standards of care and clinical guidelines
- Limited capacity for delivering care
- Lack of agreement on who should provide care
- Diverse survivorship populations
- Need for patient and provider education
- Uncertainty about the right care delivery models

Despite these challenges, much progress has been made toward improving follow-up care in a short period of time. An increasing number of survivorship programs are addressing the needs of cancer survivors; a small but growing body of research is documenting survivorship needs and risks; and resources for providers and survivors are increasingly available. Several national initiatives are helping to lead this movement to improve cancer survivorship care.

The National Cancer Survivorship Resource Center (The Survivorship Center), a collaboration between ACS and the GW Cancer Institute funded by a 5-year cooperative agreement with the Centers for Disease Control and Prevention, launched in September 2010. The goal of The Survivorship Center is to shape the future of cancer survivorship care and improve the quality of life of cancer survivors as they transition from treatment to recovery. Some of the primary activities include:

- Development of clinical follow-up care guidelines for primary care providers
- Primary care provider training and education through the *Cancer Survivorship E-Learning Series for Primary Care Providers*
- Creation of survivor and provider resources, including the *Life After Treatment Guide* and the *Prescription for Cancer Information, Moving Beyond Patient Satisfaction: Tips to Measure Program Impact Guide*
- White paper on *Cancer Survivorship: A Landscape Analysis*

In September 2011, The Survivorship Center sponsored the **LIVESTRONG** Essential Elements of Survivorship Care Meeting in Washington, DC to develop expert consensus around the essential elements of survivorship care.⁶ These elements are evolving but provide guidance based on the latest evidence and expert consensus for designing programs that best meet the needs of cancer survivors.

In early 2012, the National Cancer Institute launched its Grid Enabled Measures (GEM) Care Planning Initiative to identify and build consensus on target measures for use in studies of survivorship care planning.⁷ Through GEM, an interactive website that fosters collaboration and communication, registered participants can identify key constructs and tools for measuring those constructs. Other users can then rate and comment on the measurement tools. Once the high-priority process and outcome measures for use in studies of survivorship care planning have been identified, researchers can increase the use of shared measures across studies to help inform care planning strategies.

A major facilitator in increasing the number of survivorship programs, the Commission on Cancer (CoC) announced a new patient-centered Survivorship Care Planning standard that must be phased in by 2015.⁸ Because CoC-accredited institutions care for the majority of cancer patients in the United States, this standard has the potential to significantly impact survivorship care. Standard 3.3 requires that a survivorship care plan is prepared by the oncology providers and given to the patient upon completion of treatment.

Through these concerted national efforts, the field of cancer survivorship is gaining momentum. The progress is promising but much more needs to be done to identify the best care models and strategies for improving the lives of those affected by cancer.

National Cancer Survivor Concerns

Several large national studies have explored patient-reported survivorship concerns. These studies demonstrate cancer survivors' ongoing needs across several domains after treatment has ended. The data can be helpful for raising awareness in your institution about the need to improve post-treatment care.

American Cancer Society's (ACS) Cancer Survivor Studies

The ACS Behavioral Research Center has launched several studies that are collectively referred to as the Studies of Cancer Survivors (SCS). The studies are meant to look at diverse cancer survivors beyond academic centers and follow survivors beyond the 5-year mark to identify long-term issues and assess adjustment over time.⁹ Table 1 illustrates the severity of some of the top concerns experienced by cancer survivors in the SCS.

LIVESTRONG Survey

In 2006 and 2010, **LIVESTRONG** conducted surveys to assess the post-treatment concerns of cancer survivors. The chart below lists some of the common physical, emotional and practical issues experienced by survey respondents in the 2010 survey.¹⁰ Although the sample is made up of a higher proportion of female, younger and white respondents than the general survivor population, the data clearly indicates that many survivors are not receiving help for many commonly experienced issues. Table 2 demonstrates some of the top physical, emotional and practical concerns experienced by cancer survivors in the study. This study was conducted again in 2012.

TABLE 1: SURVIVOR CONCERNS¹⁰

| Description | A Severe Problem (%) | Somewhat of a Problem (%) | Not a Problem (%) |
|---|----------------------|---------------------------|-------------------|
| Less physically able to have sexual intercourse | 17.2 | 30.1 | 52.7 |
| Feeling fearful that my illness will return | 14.5 | 53.8 | 31.7 |
| Fatigue, loss of strength | 12.8 | 52.7 | 34.5 |
| Concern about relapsing | 10.9 | 53.8 | 35.3 |
| Sleep difficulties | 10.1 | 42.7 | 47.2 |
| Fear about the future | 10.1 | 46.9 | 43 |
| Uncomfortable with changes in my physical appearance | 7.5 | 32.7 | 59.9 |
| Being less able to provide for the financial needs of my family | 7.5 | 19.6 | 72.9 |
| Not being able to change jobs for fear of losing my health insurance coverage | 7.2 | 11.1 | 81.7 |
| Continued major problems with my health | 7.1 | 31.2 | 61.7 |
| Having difficulties in making long-term plans | 6.5 | 31 | 62.5 |
| Difficulty in meeting my medical expenses | 6.5 | 18.8 | 74.7 |
| Difficulty in obtaining adequate insurance | 6.1 | 12.6 | 81.3 |
| Feeling vulnerable | 5.2 | 32.6 | 62.2 |
| Difficulties in pursuing the career of my choice | 5.1 | 11.5 | 83.4 |

TABLE 2: SURVIVOR CONCERNS AND RECEIPT OF HELP

| Concern | % Experienced | % Experienced Who Did NOT Receive Help |
|--|---------------|--|
| Physical: 91% experienced one or more physical concerns | | |
| Energy | 59 | 56 |
| Concentration | 55 | 83 |
| Sexual Functioning | 46 | 71 |
| Neuropathy | 42 | 60 |
| Pain | 34 | 37 |
| Emotional: 96% experienced one or more emotional concerns | | |
| Fear of Recurrence | 80 | 66 |
| Grief and Identity | 68 | 75 |
| Personal Appearance | 62 | 67 |
| Family Member Risk | 51 | 70 |
| Sadness and Depression | 51 | 59 |
| Practical: 75% experienced one or more practical concerns | | |
| School Issues | 73 | 50 |
| Employment Issues | 45 | 56 |
| Debt | 27 | 67 |
| Insurance | 18 | 70 |

Defining Navigation

The State of Patient Navigation

Patient navigation was pioneered in the 1990s by Dr. Harold Freeman as a way to reduce cancer disparities among the poor in Harlem, New York.¹¹ Though originally designed to assist women through screening, diagnosis and treatment of cancer, the positive results of the intervention have led to expansion across the entire cancer continuum with replication of the program across the country and in various diseases such as diabetes,¹² heart disease¹³ and HIV/AIDS.¹⁴

The National Cancer Institute (NCI) describes patient navigation as the support and guidance provided to persons with abnormal screenings or new cancer diagnoses, including overcoming challenges and barriers to accessing the health care system in a culturally competent manner.¹⁵ Patient navigation can include not only patients but also providers, families and caregivers, and it can extend throughout the cancer continuum from prevention and screening through post-treatment survivorship.¹⁶

As patient navigation programs have flourished across the nation, patient navigators vary in education, skill set, role and responsibility. Patient navigators can include non-clinically licensed navigators (sometimes called lay navigators) and clinically licensed navigators such as a social worker or nurse navigators with a specialized focus. The GW Cancer Institute recently published an article describing the similarities and differences across these navigator types.¹⁷ Despite the varying roles, the main responsibility of patient navigators is to guide the patient through the health care system and eliminate barriers to care.¹⁸ Examples of barriers to care may include:¹⁹

- Geographic location of the clinic, center or hospital
- Financial services and insurance coverage
- Transportation and child care issues
- Lost wages
- Language and cultural issues
- Health belief systems
- Mistrust between patient and provider

Patient navigators can also connect patients with resources and support services, coordinate and schedule appointments, provide a link between the patient and physician, assist with medical paperwork and reduce fear and anxiety.²⁰ As patient navigation programs have been used to reduce race and ethnic disparities within the health care system, each program is tailored to a specific population centered on the goal of removing barriers to care and facilitating access to care.

In 2011, the Commission on Cancer (CoC) released new standards that will require CoC-accredited programs to provide patients access to patient navigation services by 2015 guided by a community needs assessment.²¹ Institutions may also be compelled to develop patient navigation programs to stay competitive with other facilities and provide comprehensive patient services.

Challenges in the field of patient navigation include lack of reimbursement for services, role confusion with other providers and lack of standardized training programs. However, patient navigation continues to grow and be regarded as a valuable patient service for removing barriers to care and improving patient outcomes.

TIMELINE OF IMPORTANT EVENTS THAT HAVE SHAPED NAVIGATION AND SURVIVORSHIP

| | |
|---------|--|
| 1989/90 | <ul style="list-style-type: none"> •ACS releases <i>Report to the Nation: Cancer in the Poor</i> •Harold P. Freeman invents the concept of Patient Navigation |
| 2004 | <ul style="list-style-type: none"> •CDC and LIVESTRONG produce <i>A National Action Plan for Advancing Cancer Survivorship</i> •President's Cancer Panel publishes <i>Living Beyond Cancer: Finding a New Balance</i> |
| 2005 | <ul style="list-style-type: none"> •IOM releases <i>From Cancer Patient to Cancer Survivor: Lost in Transition</i> •President Bush signs into law the Patient Navigator Outreach and Chronic Disease Prevention Act •NCI/ACS fund nine sites for the Patient Navigation Research Program |
| 2006 | <ul style="list-style-type: none"> •CMS funds six demonstration projects to study patient navigation |
| 2007 | <ul style="list-style-type: none"> •IOM releases <i>Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs</i> |
| 2008 | <ul style="list-style-type: none"> •HRSA funds six patient navigation demonstration projects •U.S. Surgeons General collective issues <i>National Call to Action on Cancer Prevention and Survivorship</i> |
| 2010 | <ul style="list-style-type: none"> •CDC funds National Cancer Survivorship Resource Center •Affordable Care Act passes •Patient Navigation Leadership Summit takes place |
| 2011 | <ul style="list-style-type: none"> •Patient Navigation measures are described in <i>Cancer</i> Supplement •LIVESTRONG Essential Elements meeting achieves consensus on survivorship care elements |
| 2012 | <ul style="list-style-type: none"> •New CoC Standards go into effect, to be phased in by 2015 •New CMS "S" codes for treatment planning and care coordination •First results of NCI-funded Patient Navigation Research Program published |
| 2013 | <ul style="list-style-type: none"> •The GW Cancer Institute leads an effort to delineate roles across community health workers, non-clinically licensed patient navigators (sometimes called lay navigators) and clinically licensed navigators •Launch of the <i>Cancer Survivorship E-Learning Series for Primary Care Providers</i> •PCORI funds GW Cancer Institute study to evaluate survivorship models |
| 2014 | <ul style="list-style-type: none"> •The GW Cancer Institute leads submission to include Patient Navigator in the Office of Management and Budget's Standard Occupational System •The GW Cancer Institute develops the first-ever consensus-based competencies for non-clinically licensed patient navigators •The first-ever large-scale environmental scan of survivorship practices is completed |

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ASSESS

Identifying the Need

Section Overview

In this section you will learn how to conduct a needs assessment that includes various stakeholders. After completing this section you will be able to:

1. Identify the different components of a needs assessment.
2. Determine which components are most important for your needs assessment.
3. Develop a needs assessment that is customized for your institution and patient population.
4. Utilize needs assessment tools to identify patient needs, assess organizational capacity and identify internal and external resources.

Related Workbook Activities:

Activity 1: Defining your Patient Population

Activity 2: Determining Patient Flow

Activity 3: Conducting an Institutional Analysis

Activity 4: Internal and External Resource Mapping

Activity 5: Assessing Stakeholder Needs

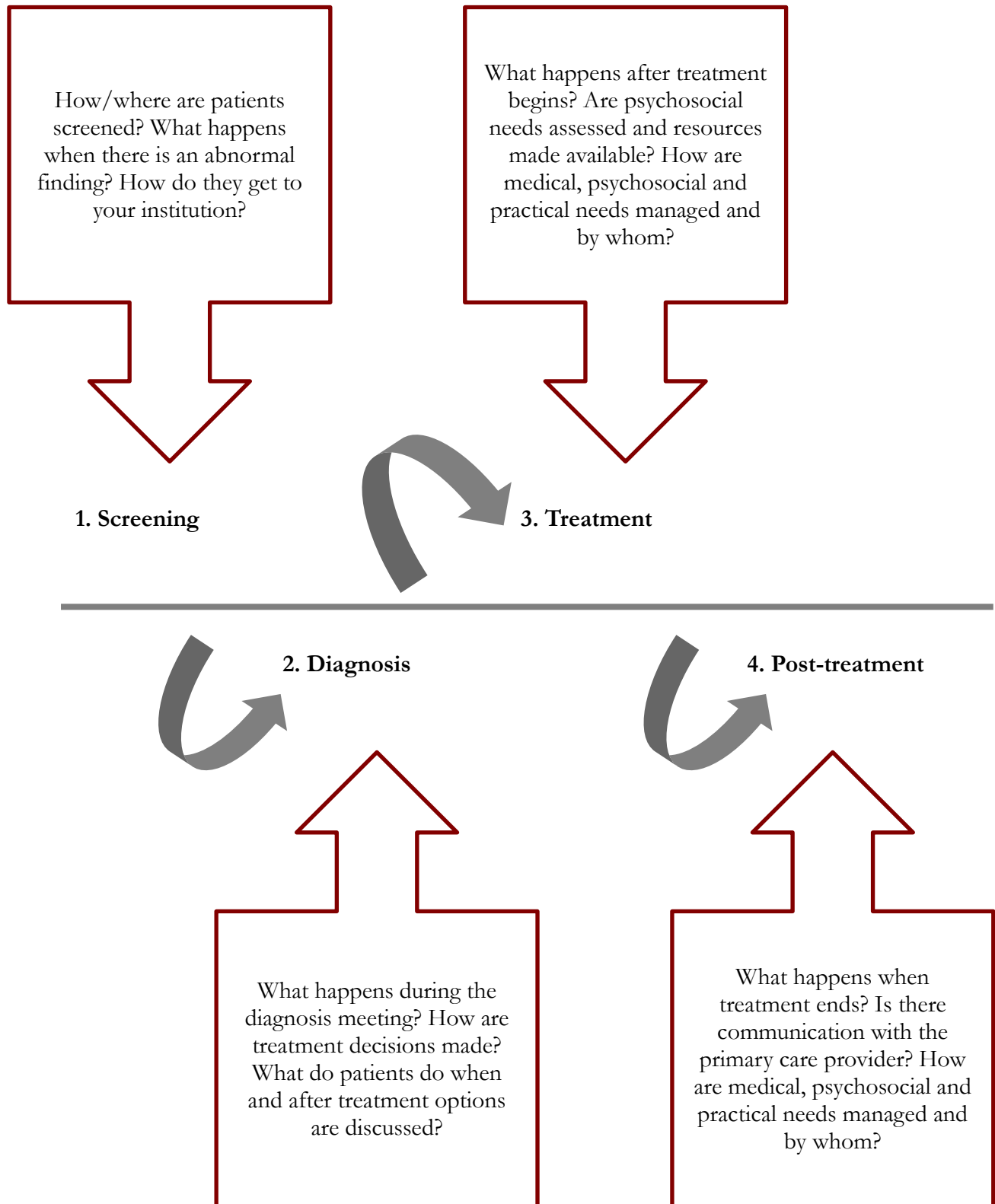
Conducting a Needs Assessment: Process Overview

A needs assessment is a critical tool for identifying the gap between current and ideal conditions and for identifying barriers and challenges to develop a program responsive to the needs of your patients and your institution's priorities. It will help you assess the needs and beliefs of different stakeholders to inform your program development and refinement. The needs assessment is divided into steps with accompanying *Workbook* activities 1-5 that will guide you through developing and implementing the assessment.

Defining Your Patient Population

Before you create or enhance a program you will need to understand your patient population and their needs to best serve patients.

- **Defining your Patient Population** enables you to establish an overview of your patient population and some of the key barriers your population faces. This can help you identify what information you already know and what additional information you need to gather. Your institution may have compiled some of this information, or you may need to look at available city or state data. Examples of data sources include:
 - State Cancer Registry
 - State Cancer Plan
 - [American Cancer Society Facts and Figures](#)
 - [Center for Disease Control and Prevention's U.S. Cancer Statistics](#)
 - National Cancer Institute
 - [Center to Reduce Health Disparities](#)
 - [Surveillance, Epidemiology and End Results \(SEER\)](#)
 - [Cancer Mortality Maps](#)
 - [State Cancer Profiles](#)
 - [U.S. Census Bureau](#)
- **Determining Patient Flow** helps you understand how patients move through your institution and at which points they need the most assistance. This will help you visualize the steps that are needed to achieve your program goal. Once you have determined the current patient flow and areas of improvement, you can repeat this step as necessary to create the ideal patient flow. The following is an example of patient flow.

FIGURE 1: PATIENT FLOW

Conducting an Institutional Analysis

When creating a program you will need to understand your institution and the factors that support or hinder program development so that you can plan accordingly and achieve optimal program success.

- **Institutional Analysis** guides you through understanding your institution's Strengths and Weaknesses as well as external Opportunities and Threats (known as a SWOT analysis). It is a way to determine how your program can be successful given your institutional situation. Below are some questions to consider when conducting a SWOT analysis.

Strengths/Weaknesses:

- What human resources, such as staff and volunteers, are available (e.g., oncologist, nurse, social worker, psychiatrist and dietitian)? Is there a program champion?
- What are the physical resources that can be leveraged for the program (e.g., location, building, equipment)? Is space an issue?
- Where do the financial resources come from (e.g., government, philanthropy, earned revenue)? Is there a sustainable funding stream?
- What is our reputation in the community? What are we most known for?
- Does our program have internal support from upper management (e.g., clinicians, administration)?

Opportunities/Threats:

- What are the future trends in our field that we can take advantage of (i.e., CoC Standards, Affordable Care Act, ACCC guidelines)?
- Have there been changes in the physical, emotional and financial needs of the patient population?
- Are there legal requirements or billing issues that pose an issue?
- Are there any local or national economic, political or societal issues that may impact our work?

Identifying Internal and External Resources

The following will help you to identify the resources that are available both within and outside your organization to assist with program development and implementation.

- **Internal and External Resource Mapping** helps you think through existing resources *within your institution* as well as *within your community* that may be available to assist your program. Internal resources can include people, services or physical items or other resources that you may not have considered. National and community-based organizations may have resources that can be leveraged to improve your program.
 - **Internal:** clinical and administrative staff, space, program champion, funding and other departments
 - **External:** national and local organizations, grants or donations and services available in the community

Gathering Key Stakeholder Data

After you have assessed your institutional situation, you may need to collect additional information from different stakeholders to fill in information you may not already have. Not only do you need to understand what patients need, but you also need to understand the perspective of providers and staff as well as community organizations.

- **Stakeholder Needs Assessment** helps you identify your assessment goals, how to conduct the assessment, a timeline for completion, who will be responsible for conducting it, who the target audience is, how you will reach them and what questions you will ask them. Examples of types of stakeholders are outlined below.
 1. **Patient/Survivor/Caregiver Needs Assessment:** Some of this information may already exist in the form of patient satisfaction surveys, intake forms or other previous evaluation.
 2. **Provider/Staff Needs Assessment:** This audience can also identify additional patient needs or services that may be of value. Understanding their perspective and how they might approach solving problems not only helps with program design, but it also can help create buy-in, which is one of the barriers many program creators face.
 3. **Community Group Needs Assessment:** You may want to seek additional information from the community organizations you identified in your external resource map about which needs they believe need to be addressed, what services they provide and how you may collaborate to best utilize resources.

Potential Questions for Your Patient/Survivor/Caregiver Needs Assessment

These questions are provided as a tool to help you create your own needs assessment. You can pull from, modify or add to these questions for use within your patient population, but it is important that you adjust the questions based on your institution. For example, if you ask what services patients might want, you need to make sure that you can include those services in your program. Remember to keep these assessments short, avoid asking complex questions and only ask one question at a time. *If you plan to use data from your survey for external presentations, you will need to have it reviewed and approved by an Institutional Review Board and attain consent from patients who complete the survey. This review is not necessary if you use survey data only to inform the development of your program.*

Use this section to gather information about who is taking your survey.

On what date were you or your loved one diagnosed? _____

At what age were you or your loved one diagnosed? _____

What type of cancer were you or your loved one diagnosed with? _____

What type of health insurance do you or your loved one have?

None Private Medicaid Medicare Other: _____

When did you or your loved one's treatment end? _____

Use this section to identify what services are needed

Please indicate whether any of the following prevent you from getting to all your appointments

- Child/elder care Finances
 Transportation needs Other _____
 Job responsibilities

How would you rate the care you received at **<Insert Institution Name>?**

Poor Average Excellent

Are you familiar with the role of a patient navigator?

Yes No

If yes, please describe how you think this person could benefit you:

Do you have difficulty obtaining your medicines due to finances? Yes No

Do you feel there is a language barrier between you and your provider? Yes No

What services and information would be most helpful to you?

- | | |
|--|--|
| <input type="checkbox"/> A treatment plan | <input type="checkbox"/> Help with scheduling appointments |
| <input type="checkbox"/> Asking for help | <input type="checkbox"/> Identifying treatment options |
| <input type="checkbox"/> Communicating with my employer | <input type="checkbox"/> Identifying treatment preferences |
| <input type="checkbox"/> Communicating with your medical team | <input type="checkbox"/> Information about clinical trials and other treatment options |
| <input type="checkbox"/> Communication with my family and friends about my diagnosis and treatment | <input type="checkbox"/> Information about completion of treatment |
| <input type="checkbox"/> Communication with my healthcare team | <input type="checkbox"/> Information at diagnosis |
| <input type="checkbox"/> Coping with a cancer diagnosis | <input type="checkbox"/> Information during the treatment decision making process |
| <input type="checkbox"/> Coping with physical changes | <input type="checkbox"/> Information during treatment |
| <input type="checkbox"/> Coping with work issues | <input type="checkbox"/> Information for family/caregivers |
| <input type="checkbox"/> Counseling for psychological or practical issues | <input type="checkbox"/> Language assistance |
| <input type="checkbox"/> Dealing with emotional effects of cancer | <input type="checkbox"/> Managing distress |
| <input type="checkbox"/> Dealing with employment issues | <input type="checkbox"/> Managing side effects |
| <input type="checkbox"/> Dealing with financial issues | <input type="checkbox"/> Managing stress |
| <input type="checkbox"/> Dealing with insurance issues | <input type="checkbox"/> Managing treatment side effects |
| <input type="checkbox"/> Dealing with school issues | <input type="checkbox"/> Meeting others with cancer |
| <input type="checkbox"/> Education about community resources | <input type="checkbox"/> Nutrition and healthy living |
| <input type="checkbox"/> Education about my cancer | <input type="checkbox"/> Nutrition information |
| <input type="checkbox"/> Employment/career/job counseling | <input type="checkbox"/> Someone to go with me to my appointments |
| <input type="checkbox"/> Exercise information | <input type="checkbox"/> Spirituality: finding meaning |
| <input type="checkbox"/> Fitness and exercise | <input type="checkbox"/> Talking to family and children about cancer |
| <input type="checkbox"/> Genetic counseling | <input type="checkbox"/> Tips for caregivers |
| <input type="checkbox"/> Healthy behaviors | <input type="checkbox"/> Transportation assistance |
| <input type="checkbox"/> Help dealing with insurance company | <input type="checkbox"/> Understanding the timeframe for making decisions |
| <input type="checkbox"/> Help getting insurance | <input type="checkbox"/> Your cancer treatment |
| <input type="checkbox"/> Help with coordination of appointments and communication with providers | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Help with financial issues | |

I understand my treatment plan and how side effects from my treatment will be managed.

Strongly agree Agree Not sure Disagree Strongly disagree

I understand my plan for follow up care and health related screenings.

Strongly agree Agree Not sure Disagree Strongly disagree

Which of the following topics would you be interested in learning about related to cancer survivorship?

- | | |
|---|--|
| <input type="checkbox"/> Nutrition | <input type="checkbox"/> Smoking cessation |
| <input type="checkbox"/> Safe exercise | <input type="checkbox"/> Estate planning/living wills |
| <input type="checkbox"/> Employment issues | <input type="checkbox"/> Complementary/alternative therapies |
| <input type="checkbox"/> Emotional issues | <input type="checkbox"/> Stress reduction |
| <input type="checkbox"/> Communication skills | <input type="checkbox"/> Financial issues |

Potential Questions for Your Provider/Staff Needs Assessment

These questions are provided as a tool to help you create your own needs assessment. You can pull from, modify or add to these questions for use within your patient population, but it is important that you adjust the questions based on your institution. For example, if you ask what services patients might want, you need to make sure that you can include those services in your program. Remember to keep these assessments short, avoid asking complex questions and only ask one question at a time. *If you plan to use data from your survey for external presentations, you will need to have it reviewed and approved by an Institutional Review Board and attain consent from patients who complete the survey. This review is not necessary if you use survey data only to inform the development of your program.*

Use this section to identify the background of the providers answering the questions.

What is your professional background (MD, RN, SW, etc.)? _____

In which department do you work? _____

How do providers feel about patient navigation and survivorship?

Are you aware of the new American College of Surgeons' Commission on Cancer accreditation standards that require establishment of a patient navigation process that is regularly modified or enhanced based on a community needs assessment?

Yes No

Are you aware of the new American College of Surgeons' Commission on Cancer accreditation standards that require a treatment summary be given to a patient by the oncology team as they transition off of treatment?

Yes No

How important do you believe it is to meet the American College of Surgeons' Commission on Cancer accreditation requirements? (select one)

Not important Somewhat important Very important Not sure

Do you believe it would be beneficial for your patients to develop/improve patient navigation and/or survivorship services at your institution? (circle one)

Yes No

If no, why not? _____

How do you define patient navigation?

How do you define survivorship?

How would you rate how well your institution addresses post-treatment needs of cancer survivors?

Excellent Good Average Poor Not at all

What types of services and program components are needed?

Who should be included in discussions about developing/improving a patient navigation program?

What types of survivorship services do you believe are most critical for your patients? (select all that apply)

Clinical Services

- Endocrinology
- Fertility
- Genetic counseling
- Gynecology
- Integrative medicine
- Neurology
- Nutrition counseling
- Patient navigation
- Psychiatry
- Rehabilitation
- Other _____

Additional Services

- Art therapy
- Educational workshops
- Exercise program
- Financial assistance
- Support groups
- Transition class
- Transportation assistance
- Vocational/career counseling
- Other _____

At what point(s) in the continuum do you think patients are most in need of care coordination and support services? (select all that apply)

- Prior to entering the healthcare system
- At time of screening
- At time of suspicious finding
- At time of diagnosis
- Throughout treatment
- Follow up care after treatment
- At all points
- Other (please specify)

Are there particular types of patients you believe are most in need of patient navigation services?
Patients who:

- Are at a particular stage of treatment (specify)
- Have a particular type of cancer (specify)
- Have a particular prognosis (specify)
- Face cultural barriers (specify)
- Do not have health insurance
- Other

| | |
|---|--|
| <p>What are the primary functions you would like the navigator to fulfill? Please rank them with 1 being the most important.</p> | |
| <ul style="list-style-type: none"> — Community education — Patient education — Care coordination — Resource referral | <ul style="list-style-type: none"> — Financial assistance (insurance, copays) — Financial counseling — Psychosocial support — Other (please specify) |
| <p>What other activities would you like the navigator to be involved in? Please rank them with 1 being the most important.</p> | |
| <ul style="list-style-type: none"> — QI/PI activities — Community outreach — Educational programs — Screenings | <ul style="list-style-type: none"> — Staff education programs — Survivorship program — Help set up program(s) by disease state(s) — Other (please specify) |
| <p>If you need to refer a patient out for support services, what are some of the local resources you utilize?</p> | |
| <p>How would you rate the patient level of <i>informational</i> preparedness prior to medical appointments?</p> <p> <input type="checkbox"/> Very good <input type="checkbox"/> Good <input type="checkbox"/> Average <input type="checkbox"/> Poor </p> | |
| <p>How would you rate the patient level of <i>emotional</i> preparedness prior to medical appointments?</p> <p> <input type="checkbox"/> Very good <input type="checkbox"/> Good <input type="checkbox"/> Average <input type="checkbox"/> Poor </p> | |
| <p>How would you prefer to work with a patient navigator?</p> <p> <input type="checkbox"/> Share functions with the navigator <input type="checkbox"/> Delegate functions to the navigator <input type="checkbox"/> N/A- Coordinate care without assistance of a navigator </p> | |

What do you believe are the reasons patients miss appointments?

- | | |
|---|--|
| <input type="checkbox"/> Financial constraints | <input type="checkbox"/> Lack of insurance |
| <input type="checkbox"/> Apprehension about appointment | <input type="checkbox"/> Too busy |
| <input type="checkbox"/> Don't believe they are necessary | <input type="checkbox"/> Other |
| <input type="checkbox"/> Lack of transportation | |

What outcomes do you think are most important to track?

- | | |
|--|---|
| <input type="checkbox"/> Number of patients navigated | <input type="checkbox"/> Access to clinical care |
| <input type="checkbox"/> Number of patient interactions | <input type="checkbox"/> Adherence to medical recommendations |
| <input type="checkbox"/> Patient retention rates | <input type="checkbox"/> Health care utilization |
| <input type="checkbox"/> Patient satisfaction scores | <input type="checkbox"/> Access to supportive care |
| <input type="checkbox"/> Physician/staff satisfaction scores | <input type="checkbox"/> Self-efficacy |
| <input type="checkbox"/> Timeliness of care indicators | <input type="checkbox"/> Health knowledge and literacy |
| <input type="checkbox"/> Barriers removed | <input type="checkbox"/> Health behaviors |



AN IN-DEPTH LOOK

CASE STUDY ON BEST PRACTICES IN NAVIGATION: COMMUNITY NEEDS ASSESSMENT

Program Type: Patient Navigation

Organization Description:

- Academic medical center with approximately 400 licensed beds, located in the mid-west.
- The rationale for creating this particular needs assessment was to address the ACoS Commission on Cancer’s “Patient Navigation” standard.
- The program’s and state’s Cancer Registries provided a great starting point for data collection. Since we work very closely with the Kentucky Cancer Program, we already had a firm understanding of our state’s health challenges from a public health perspective.

Approach:

- Spearheaded by program’s quality coordinator with support from the program’s VP of Operations.
- The program’s quality coordinator collected and aggregated the data, with the exception of the Registry data, for which she enlisted our Lead Registrar to assist. The coordinator started with querying our program’s Registry data to determine the top five analytic cases, by site, seen at our facility for years 2006-2010. She also queried the top counties in which our patients resided for those same years.
- Using CDC data, she compared our state’s top 10 cancer sites (male and female, all races) incidence and mortality with the U.S.’s top 10 cancer sites (male and female, all races) incidence and mortality.
- She then broke down the age-adjusted invasive cancer incidence and mortality by the counties that are contiguous to ours, using the Kentucky Cancer Registry’s data. Then collected demographic data regarding known cancer risk factors (e.g., prevalence of smoking; prevalence of obesity; lack of physical activity; prevalence of binge drinking; etc.) from these same counties, using the database available at kentuckyhealthfacts.org.
- After aggregating and organizing these data into tables, it was presented to the Cancer Committee “as is” to not bias the committee members’ perspectives. Immediately, the physicians identified the same trends noticed by the coordinator. Though we were certainly aware of these trends already from collaborative work with public health agencies and various research projects, this project instilled a sense of urgency related to our disproportionate burden of lung cancer.
- At the time, low-dose CT lung screening had not yet received much support from the scientific community. As a result of this needs assessment, for 2012, the Cancer Committee decided to facilitate the creation of a pulmonary nodule clinic, and we also started offering low-cost, low-dose CT lung screening to the public. In addition, we more aggressively promoted a free, evidence-based smoking cessation program in our community.

Challenges and Solutions:

- The challenge was limiting the scope of data to collect and analyze. There are so many data available online that you need to be reminded, “You are not an epidemiologist; this project doesn’t have to include everything!” It’s important that whoever is charged with performing the needs assessment is given such reassurance and is reminded to keep it simple. Approach this project with “broad strokes” and realize not every nuance of the data has to be examined.

Lessons Learned:

- There is a wealth of data readily available online to anyone who wants it.

Successes:

- The opening of the multidisciplinary pulmonary nodule clinic was a real triumph and was possible because our program has heartily embraced the multidisciplinary clinic model for many years now.

Results to Date:

- As above, the report was presented to the Cancer Committee.
- We developed a formalized process for incidental pulmonary nodule findings discovered in our ER to be referred to the newly-created Pulmonary Nodule Clinic.
- We adopted evidence-based criteria for determining which patients were high-risk/appropriate for low-dose CT lung screening.
- Since these projects were executed last year, we have diagnosed and treated several patients with early stage lung cancers.

**ONLINE RESOURCES**

Association of Community Cancer Centers [Patient Navigation Program Pre-Assessment Tool](#)

Commission on Cancer [best practices on Standard 3.1 Patient Navigation Process](#)

Southern Rural Development Center's [Mapping the Assets of Your Community: A Key Component for Building Local Capacity](#)

PLAN

Survivorship and Navigation Programs in Practice

Section Overview

In this section you will explore case studies from individuals who have developed and implemented survivorship and navigation programs. After completing this section you will be able to:

1. Develop SMART goals and objectives.
2. Identify best practices for navigation and/or survivorship programs.
3. Identify potential program components and strategies.

Related Workbook Activities:

Activity 7: Developing SMART Program Goals

Activity 8a: Designing Your Survivorship Program

Activity 8b: Designing Your Patient Navigation Program

Developing SMART Program Goals

Goals represent the quantifiable target that you wish to achieve. Goals are typically in direct contrast to the problem your program will address, and in alignment with the overarching aim and any smaller objectives you have for your program. Use this information to complete Activity 7 in the *Workbook* on page 12. The aim, as well as the goals and objectives should be SMART. Although the characteristics that make up the SMART acronym are sometimes different,¹ we are using the following characteristics to define SMART goals:

Specific: Goals should be straightforward and emphasize what you want to happen. Specifics help to focus efforts and clearly define what we will do. Ensure the goals you set are very specific and clear.

Measurable: **If you cannot measure it, you cannot manage it.** Establishing goals that are measurable allows you to gauge progress toward the attainment of each goal. When you measure your progress, you stay on track.

Action-Oriented: The goals you set should relate to activities or tasks that you and your team can make progress toward, rather than rely only on the action of outside stakeholders. Sometimes you will see the “A” stand for attainable or achievable.

Realistic: Realistic here means “do-able.” It means that the learning curve is not extremely steep and that the skills needed to do the work are available. The goal should fit with the overall strategy of the organization. A realistic goal may push the skills and knowledge of the people working on it but it should not break them. Sometimes you will see the “R” stand for relevant.

Time-Bound: Set a timeframe for the goal: for next month, by December 31, in one year. Putting an end point on your goal gives you a clear target to work towards. If you do not set a time, the commitment is too vague. It tends not to happen because you feel you can start at any time. Without a time limit, there is no urgency to start taking action now.

Goal Examples:

- Provide patient navigation services to all patients. → *Not SMART*
- Provide patient navigation services to overcome barriers to timely, quality care for at least 100 breast cancer patients that were referred by the nurse practitioners at ABC Cancer Center by December 31, 2013. → *Better*
- Provide survivorship care plans in one month. → *Not SMART*
- Provide comprehensive survivorship care plans to 100 cancer patients transitioning out of active treatment within one year. → *Better*
- Decrease patient no-show rates from 30% to 0% in 3 months. → *Not SMART*
- Decrease patient no-show rates in radiation oncology from 30% to 10% within two years. → *Better*

Part I - Survivorship

Survivorship programs currently look different in different institutions, but there are some common components to consider. This section outlines program components, services, questions to consider, models of care, survivorship care plans, developing a protocol and developing an algorithm.

Defining Survivorship Programs and Components

Survivorship programs can vary widely, and the term “survivorship program” is used in different ways. To create clarity around the term, the National Cancer Survivorship Resource Center convened a workgroup of experts who created the following consensus-based definition:²

The goal of a cancer survivorship program is to maximize the quality of life of survivors and their caregivers. The program should include a comprehensive set of services provided by multidisciplinary groups working together to ensure effective medical care, education and emotional support. Communication between and among survivors, their caregivers and providers is essential for the seamless referral, navigation and coordination of these services.

Although an evidence-based standard of care has not been established, several key reports have outlined critical components of survivorship care. In its 2006 landmark report, [From Cancer Patient to Cancer Survivor: Lost in Transition](#),³ the Institute of Medicine (IOM) outlined the range of medical and psychosocial issues faced by cancer survivors and made recommendations to improve survivors' health care and quality of life. Based on expert consensus, limited research and experience from other areas of chronic disease, the IOM recommended essential components of survivorship care:

| FIGURE 1: IOM RECOMMENDED COMPONENTS OF SURVIVORSHIP CARE | | | |
|--|---|---|--|
| Coordination | Prevention | Intervention | Surveillance |
| Between specialists and primary care providers | Of recurrent and new cancers and late effects | For impacts of cancer and its treatment | For metastasis, recurrence or secondary cancers; assessment of medical and psychosocial late effects |

In 2011, LIVESTRONG brought together a group of 150 community leaders, stakeholders, experts, cancer survivors and cancer survivor advocates to achieve consensus around the [Essential Elements of Survivorship Care](#).⁴ Through the process, stakeholders identified 3 tiers of 20 critical components: five consensus elements that must be provided by institutions, ten high-need elements that institutions should provide and five elements that institutions should strive to provide when delivering survivorship care. Descriptions of each element are available from the LIVESTRONG website, and the process of refining the Essential Elements is ongoing. The full report is available at www.livestrong.org, and the Essential Elements are summarized in Table 1.

TABLE 1: LIVESTRONG Essential Elements**Tier 1**

All medical settings MUST provide direct access or referral to the following elements of care.

- Survivorship care plan, psychosocial care plan and treatment summary
- Screening for new cancers and surveillance for recurrence
- Care coordination strategy which addresses care coordination with primary care physicians and primary oncologists
- Health promotion education
- Symptom management and palliative care

Tier 2

All medical settings SHOULD provide direct access or referral to these elements of care for high-need patients and to all patients when possible.

- Late effects education
- Psychosocial assessment
- Comprehensive medical assessment
- Nutrition services, physical activity services and weight management
- Transition visit and cancer-specific transition visit
- Psychosocial care
- Rehabilitation for late effects
- Family and caregiver support
- Patient navigation
- Educational information about survivorship and program offerings

Tier 3

All medical settings should STRIVE to provide direct access or referral to these elements of care.

- Self-advocacy skills training
- Counseling for practical issues
- Ongoing quality-improvement activities
- Referral to specialty care
- Continuing medical education

In 2012 the Commission on Cancer released its new care standards, including standard 3.3 on survivorship care plans:⁵

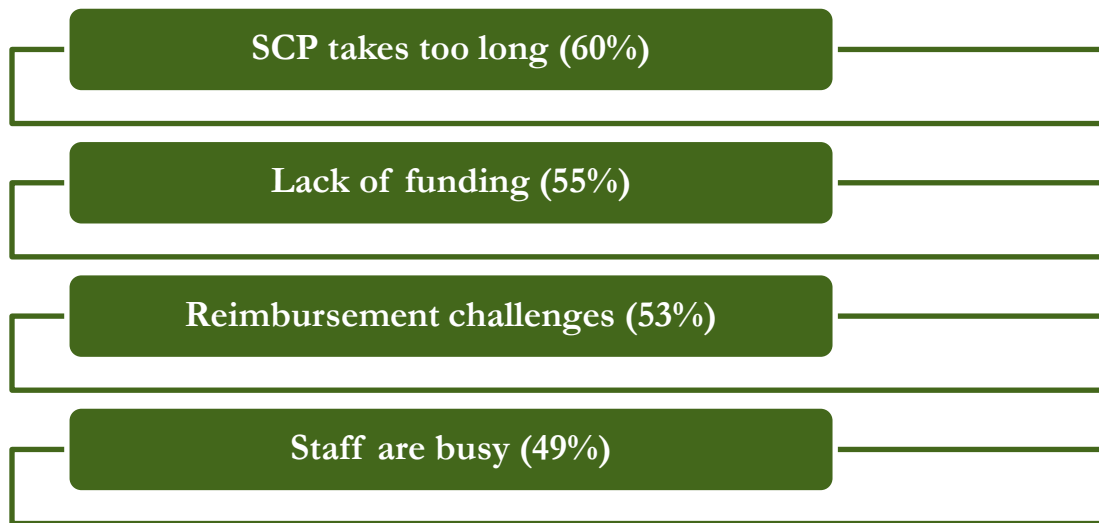
“The cancer committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. The process is monitored, evaluated and presented at least annually to the cancer committee and documented in minutes.”

In 2014 the Commission on Cancer revised this standard to include clarity around the timeframe and scope of implementation for the standard:⁶

“**January 1, 2015** – Implement a pilot survivorship care plan process involving 10% of eligible patients.
January 1, 2016 – Provide survivorship care plans to 25% of eligible patients.
January 1, 2017 – Provide survivorship care plans to 50% of eligible patients.
January 1, 2018 – Provide survivorship care plans to 75% of eligible patients.
January 1, 2019 – Provide survivorship care plans to all eligible patients.”

Despite the growing recognition of the need to focus on survivorship, some institutions have experienced barriers to setting up survivorship programs. A survey of Oncology Nursing Society members found the biggest barriers they experienced were related to funding and designated time.⁷ Another barrier identified is lack of survivorship knowledge and training.⁸ As the field of survivorship continues to grow, however, these barriers may be becoming less significant. In 2013 the GW Cancer Institute launched the Best Practices in Navigation and Survivorship Survey. Respondents, who all had survivorship programs already, were asked to identify their top challenges.⁹ Figure 2 summarizes their responses.

FIGURE 2: MOST COMMON SURVIVORSHIP CHALLENGES (n=47)



Questions to Consider When Designing Your Survivorship Program

These questions were designed to walk you through Activity 6 in your *Workbook* on pages 11-12.

Who are your champions?

Champions have been critical for helping to establish many survivorship programs. A champion could be an administrator, oncology or non-oncology physician, nurse, social worker or other clinician. Champions may not be in the most obvious place, but they can help with attaining buy-in or may be willing to help pilot the program.

Who needs to be ‘at the table’ for program development?

It is important to think about a variety of people who can assist with program development. Clinicians (those providing post-treatment care and those referring) and administrators may be the first people you think of, but it may also be important to include others, such as people involved with marketing, community outreach, billing, IT and/or the registry. Survivors can also provide valuable insight in the planning process.

Who is your patient population?

This could be low- or medium-risk patients, survivors of a certain cancer type or survivors treated by a certain oncologist or oncologists. You may need to start with a smaller, more manageable population and expand once the program has been established. Oftentimes the population is dictated by who the program champions are.

When will patients be eligible for the clinic?

Some programs transition survivors at 3 or 5 years after treatment, and some do it immediately. The new Commission on Cancer standards require that survivors be given a treatment summary and Survivorship Care Plan as they transition off of treatment; this time also represents a teachable moment when survivors may be highly motivated to change health behaviors. Oncologists, however, may be reluctant to “give up” patients at this time. You may need to start where you have support and adjust the eligibility requirements after the clinic is up and running. Also, you need to determine how often survivors will return to the clinic (if at all).

Which model may be appropriate?

You may want to start with a model and adapt it based on your capacity and needs.

What services will be provided?

You may already offer services that can be used in the program, some of which might be revenue-generating, such as rehabilitation, psychiatry, integrative medicine, etc. The services may be included in a multidisciplinary clinic visit or provided to survivors after they have been seen in the clinic.

Where will the clinic be located?

Clinics are often located where the champions are. This could be in hematology/oncology, internal medicine, radiation oncology, supportive care, palliative care or somewhere else that seems appropriate given your circumstances.

How will survivorship care be delivered?

What is the flow of your clinic? Who is responsible for which activities, such as completing the Survivorship Care Plan, delivering the Survivorship Care Plan to the patient, referring the patient to resources or specialists, coordinating with the primary care provider and following up with the survivor?

Survivorship Models at a Glance

In 2014 the Agency for Healthcare Research and Quality published a [technical brief on cancer survivorship models](#).¹⁰ The brief concludes that the “optimal nature, timing, intensity, format and outcome of survivorship care models continue to be uncertain,” therefore the best type of survivorship care model is unknown.¹¹ The GW Cancer Institute is helping to [identify models and their impacts on patient-centered outcomes](#) currently through a study funded by the Patient-Centered Outcomes Research Institute. Although the ideal model has not been established, model components have been described in several ways. To help you narrow down which model may work best in your institution, complete Activity 6 in the *Workbook* on pages 13-14.

Provider Type

Howell et al. conducted a systematic review to explore services delivery structures and models of care.¹² The researchers explored models there were:

- **Nurse-led**
- **Family-physician-led**
- **Specialist- or oncologist-led**
- **Shared care**

Although the evidence was weak, the study found that nurse- and primary care physician-led models were as effective as oncologist-led models when detecting recurrence. Moreover, patients were satisfied with non-oncologist-led models.

The shared-care model between generalists and specialists has been applied to many chronic conditions,

including cancer during and after treatment, to better coordinate appropriate care.¹³ Table 2 illustrates different roles in the shared-care model.

TABLE 2: SHARED CASE ROLES¹⁴

| Oncology Provider | Primary Care Provider (PCP) |
|--|---|
| Provide guidance and specialized treatment, as indicated. Conduct periodic evaluations at recommended intervals, provide guidance as questions or concerns arise and see patients for circumstances that exceed the PCP's capabilities. | Attend to patients' physical and mental health issues. Ensure that the survivor receives care for all health conditions and for preventive care. |
| Keep the PCP informed of the treatment plan. Provide written guidance to include in the chart as a reference for next steps, both when the cancer survivorship care plan is first developed and as treatment needs evolve. | Manage chronic care needs that are feasible in the primary care setting. Take responsibility for conducting examinations and ordering recommended tests that can be performed or arranged in the primary care setting. |
| Return the patient to primary care for ongoing needs. Both during and after treatment ongoing primary care is important to maintain treatment of other comorbid conditions and to follow up on implementation of the care plan. | Refer patient to cancer specialist(s) for periodic evaluations and issues requiring focused expertise. Identify circumstances that require survivors to be seen by specialists, and refer patients for periodic evaluations. |
| | Consult with specialists in areas of uncertainty. Contact specialty colleagues to discuss questions or concerns and to determine which follow-up steps should be taken. |

In addition, McCabe and Jacobs outlined a multi-disciplinary model:¹⁵

- Multiple providers see a survivor in a single clinical visit
- Providers can include: oncologist, psychiatrist, internist, dietitian, social worker, patient navigator, endocrinologist, neurologist, physical therapists, integrative medicine providers, genetic counselors, etc.
- Challenging and costly; NP often plays coordinating role

Program Structure

McCabe and Jacobs identified three structures for survivorship programs:¹⁶

- **Consultative Clinic Model**
 - One-time comprehensive visit while original oncology team continues ongoing care
 - Simple and needs few resources
- **Integrated Care Model**
 - Survivor is seen in oncology clinic where oncology care was delivered
 - Care often provided by NP who is part of the oncology team
 - Visit occurs when treatment ends
 - Continue to see oncology team and primary care provider
- **Transition to Primary Care**
 - Survivors may transition back to primary care immediately after treatment ends or at a pre-determined period, often risk-based
 - PCPs must be given information and have ongoing communication with the oncology team

Patient Population

McCabe and Jacobs also identified three ways to provide services based on patient population:¹⁷

- **Pediatric Long-Term Follow-Up Models**
 - Often in adult medical settings
 - Not disease-specific
 - Can be multi-disciplinary or NP-led in collaboration with oncologist or primary care provider
- **Disease-Specific Clinic**
 - Survivor receives individualized follow-up care and detailed disease-specific follow-up recommendations
 - Can be costly and require large enough patient population
- **General Survivorship Clinic Model**
 - Often NP-led
 - SCP should be developed by oncology team to guide clinicians
 - Makes referrals for additional services

Other Strategies Implemented in Various Community Settings

McCabe, Baker, Huffman and Miller identified additional strategies that have been implemented in community settings:¹⁸

- Internists specialize in survivorship
 - Get referrals from oncologists, within and beyond the practice
 - Request Survivorship Care Plan from oncologist
 - Survivor is incorporated into their practice with access to practice's multi-specialty resources
 - Focus on management of multiple comorbidities at the same time
- Patient navigators identify patients in community health center and case managers facilitate care based on Survivorship Care Plan created by internists who staff the program
- Patient education is emphasized related to maintaining health in survivorship
- Rural hospital developed patient navigator-driven education/resource center focused on both survivors and community providers that educates through providing resources, hosting workshops and giving presentations
- Separate survivorship-specific rehabilitation program with physical/occupational therapists
- Partnerships with community groups; community groups provide services at institution, or partnerships are formed where institution refers to community groups for survivorship services and programs
- Providing services in the evening hours

Survivorship Care Plans

In its 2005 *Lost in Transition* report, the Institute of Medicine recommended that survivors be given a Survivorship Care Plan (SCP) at the end of treatment. The SCP is an important tool for improving communication and coordination both between the patient and provider and among providers. There are two components of the SCP: a treatment summary and a follow-up plan.

The treatment summary should include:¹⁹

- Diagnostic tests and results
- Tumor characteristics
- Dates of treatment initiation and completion
- All treatment, including agents used, regimen, total dosage, response, toxicities
- Psychosocial and other supportive services provided

- Full contact information for treating institutions
- Key point of contact for coordinating care

The follow-up plan should include:²⁰

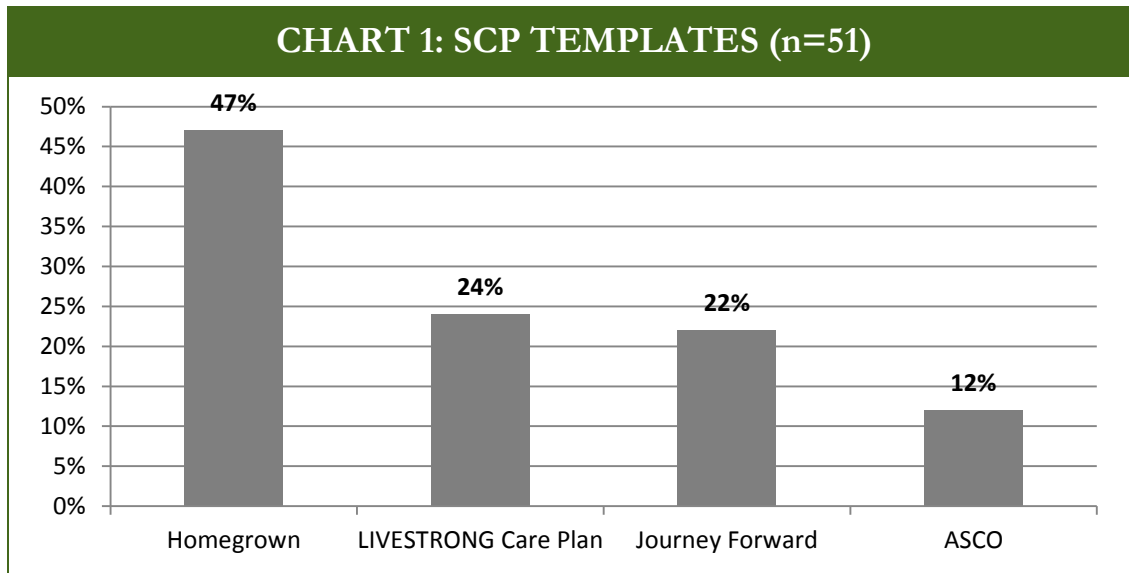
- Likely course of recovery/ongoing maintenance needs
- Recommended cancer screening and tests, including schedule and who should perform it
- Information on
 - Long term and late effects and their symptoms
 - Signs of recurrence and second cancers
 - Possible effects on relationships, sexual functioning, work, parenting and future needs for psychosocial support
 - Potential insurance, employment and financial consequences and referrals when needed
- Recommendations for healthy behaviors
- As appropriate, information on genetic counseling and testing
- As appropriate, information on known effective chemoprevention strategies for secondary prevention
- Referrals to specific follow-up care providers
- Listing of cancer-related resources and information

Despite consensus on the need to provide SCPs to survivors, they still have not become part of the standard of care. Several studies have found the SCPs are not standard, with 14-52% of providers using SCPs.^{21,22,23,24,25} Moreover, only 17-31% of patients report receiving an SCP.^{26,27} Other studies indicate that 32-40% of survivors receive a treatment summary and 44-74% receive follow-up care instructions.^{28,29}

The delayed adoption may be related to a lack of organizational resources (e.g., time, training, staff, funding), a lack of requirement from some professional societies and a lack of systems in place (e.g., electronic medical records).³⁰ The lack of evidence base on the effectiveness of SCPs may also be a barrier.³¹ A 2013 systematic review found only two quality studies on the effectiveness of SCPs.³² Additionally, completing the SCP may be time consuming, with it taking 45-90 minutes just to complete.^{33,34} While there are challenges, many institutions have found ways to address these challenges and have successfully implemented SCPs into the standard of care.

Survivorship Care Plan Templates

In 2013 the GW Cancer Institute conducted a survey of health care professionals to identify best practices in navigation and survivorship. Respondents were asked to identify the SCP template they use. Chart 1 summarizes their responses. Nearly half reported using a “homegrown” template that they created at their institution, while about a quarter each cited using LIVESTRONG Care Plan and/or Journey Forward. Fewer respondents use ASCO’s templates.



 **AN IN-DEPTH LOOK**

ASCO Templates

| ASCO Treatment Summary and Survivorship Care Plan | | |
|---|-------------------|--------------------------|
| General Information | | |
| Patient Name: | | Patient DOB: |
| Patient phone: | | Email: |
| Health Care Providers (including Names, Institution) | | |
| Primary Care Provider: | | |
| Surgeon: | | |
| Radiation Oncologist: | | |
| Medical Oncologist: | | |
| Other Providers: | | |
| Treatment Summary | | |
| Diagnosis | | |
| Cancer Type/Location/Histology Subtype: | | Diagnosis Date (year): |
| Stage: <input type="checkbox"/> I <input type="checkbox"/> II <input type="checkbox"/> III <input type="checkbox"/> Not applicable | | |
| Treatment | | |
| Surgery <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| Surgical procedure/location/findings: | | Surgery Date(s) (year): |
| Radiation <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| Body area treated: | | End Date (year): |
| Systemic Therapy (chemotherapy, hormonal therapy, other) <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| Names of Agents Used: | | End Dates (year): |
| Persistent symptoms or side effects at completion of treatment: <input type="checkbox"/> No <input type="checkbox"/> Yes (enter type(s)): | | |
| Familial Cancer Risk Assessment | | |
| Genetic/hereditary risk factor(s) or predisposing conditions: | | |
| Genetic counseling: <input type="checkbox"/> Yes <input type="checkbox"/> No | | Genetic testing results: |
| Follow-up Care Plan | | |
| Need for ongoing (adjuvant) treatment for cancer <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| Additional treatment name: | Planned duration: | Possible Side effects: |
| | | |
| Schedule of clinical visits | | |
| Coordinating Provider: | When/How often: | |
| | | |
| | | |

ASCO recently redesigned its 2-page SCP templates, which are available in Word format for general cancers as well as breast, colon, non small cell lung and small cell lung cancers and lymphoma.

The templates include prompts to discuss lifestyle modification as well as information on late and long term effects of cancer and cancer treatments with the patient’s doctor or nurse.

Journey Forward Cancer Survivorship Care Plan

Cancer Survivorship Care Plan

This Survivorship Care Plan will facilitate cancer care following active treatment. It may include important contact information, a treatment summary, recommendations for follow-up care testing, a directory of support services and resources, and other information. [1]

Survivorship Care Plan for Breast Cancer

Prepared by: on

General Information

Care team

| Name | Title | Phone |
|-----------------------------|-------|-------|
| General/breast surgeon | | |
| Radiation oncologist | | |
| Plastic surgeon | | |
| Primary care physician | | |
| OB-GYN | | |
| Nurse/nurse practitioner | | |
| Mental health/social worker | | |
| Other | | |

v1.0.2014
Printed: 2/11/2014
www.journeyforward.org

This multiple-page SCP includes contact information for the care team, a treatment summary, follow-up recommendations and patient resources. The site-specific templates include information regarding ASCO surveillance guidelines, symptoms of recurrence and general potential late effects of treatment. The SCP includes a place to recommend preventive care and lifestyle modifications.

The free software to create the SCP must be downloaded from the organization's website by the health care provider. Site-specific plans are available for colon cancer, lymphoma, non-small cell lung cancer and breast cancer. Patients can download a medical history builder, resource directory and tips on talking with their doctor.

LIVESTRONG CARE PLAN
POWERED BY
Penn Medicine's **OncoLink**

Care Plan Results for Breast Cancer

YOUR SUMMARY

Welcome to your personalized LIVESTRONG Care Plan. This tool is designed for survivors of adult cancers and your survivorship plan is developed based on the information you entered on the questionnaire. Childhood cancer survivors are encouraged to visit the Children's Oncology Group website for more information specific to them. The information in this plan is based on the available research and literature concerning cancer survivors. This area is continually growing and as new information becomes available, it will be added to the program. For this reason, you may want to redo your plan periodically. The LIVESTRONG Care Plan provides you with information regarding the health risks you may face as a result of cancer therapies. The level of risk can vary based on the duration, doses and combinations of therapy, therefore this plan should be discussed with your oncology team to better understand your personal risks. These results can be concerning, but remember, not every survivor experiences every side effect, and some do not experience any long-term effects. This plan is to make you aware of possible long-term effects that you and your healthcare team should keep in mind. If you would like to talk to someone about your concerns, LIVESTRONG can help you to understand how cancer may impact your life, answer questions you might have and provide support throughout your cancer experience. Please call 1-855-221-7777 or visit LIVESTRONG online at LIVESTRONG.org/Livestrong.

The information in the plan is broken down by the cancer therapies you received, future screening, healthy living tips and psychosocial issues you may face. Sometimes more than one therapy can cause the same long-term effect, so you may see a particular side effect in more than one section. If there are specific things you can do to reduce the risk for or evaluate for the presence of an effect, these will be summarized at the end of the section.

You were treated for Breast Cancer:

- Lymph nodes taken from above the waist
- Lymph Node Removal (Dissection)
- Mastectomy

This multiple-page SCP includes a brief treatment summary, risks related to medications (e.g., chemo), radiation side effects, surgery side effects, healthy living information and follow-up care needs.

The free online tool to create the SCP is completed by the survivor or the health care provider. Users fill out demographic information and select the treatment type, including chemotherapy agents and location of surgery and radiation field. The care plan provides general information about possible side effects based on the treatment types.

specify what constitutes low-, medium- and high-risk patients and it would establish the protocol for each risk level. Follow-up care recommendations may be based on ASCO or NCCN guidelines or based on clinical expertise within the institution.

MD Anderson has created numerous algorithms for different cancer types. In the *Journal of the Advanced Practitioner* in Oncology, Patterson from MD Anderson outlines the following process for developing guidelines for survivorship care:³⁶

- Identify the team
- Create or adopt a framework
- Identify the patient population
- Identify the end-users
- Conduct a literature review
- Summarize each article
- Draft the guidelines
- Finalize the guidelines
- Track outcomes

MD Anderson's extensive survivorship algorithms are available at no cost on the MD Anderson website and may be helpful for creating your institution's protocol.³⁷ The algorithm can be developed in several ways:

- One clinician is tasked with developing the final protocol. The clinician will gather information from other clinicians and assess existing evidence base to determine the algorithm.
- One clinician is tasked with developing a protocol to be reviewed and refined by a committee. This may involve several rounds of review to finalize. The clinician will be responsible for pulling together a draft based on the latest evidence, and other clinicians will review the draft and suggest modifications. The committee will need to reach consensus on modifications, and the lead clinician may need to do additional research to inform the process.
- A committee is established to create the algorithm. The committee members work together to establish and finalize the protocol.

Survivorship Guidelines

Limited guidelines for survivorship care exist and are summarized in Figure 3. The National Comprehensive Cancer Network (NCCN) includes surveillance guidelines as well as survivorship principles as part of existing care guidelines for limited cancers. NCCN also provides survivorship guidelines by topic. The American Society of Clinical Oncology also has limited survivorship guidelines by cancer type as well as guidelines by topic. Finally, the American Cancer Society has developed survivorship care guidelines by cancer type specifically for primary care providers. Although they are for primary care providers, they provide information that may be useful for oncology providers as well.

| FIGURE 3: Summary of Survivorship Guidelines | | |
|--|---|--|
| National Comprehensive Cancer Network | American Society of Clinical Oncology | American Cancer Society Survivorship Care Guidelines for Primary Care Providers |
| <ul style="list-style-type: none"> • By cancer type (limited) • By topic: anxiety and depression, cognitive function, exercise, fatigue, immunizations and | <ul style="list-style-type: none"> • By cancer type (limited) • By topic: neuropathy, fatigue, anxiety and depression, fertility preservation | <ul style="list-style-type: none"> • By cancer type: prostate, breast, colorectal |

| | | |
|--|--|--|
| infections, pain, sexual function (female/male), sleep disorders | | |
|--|--|--|

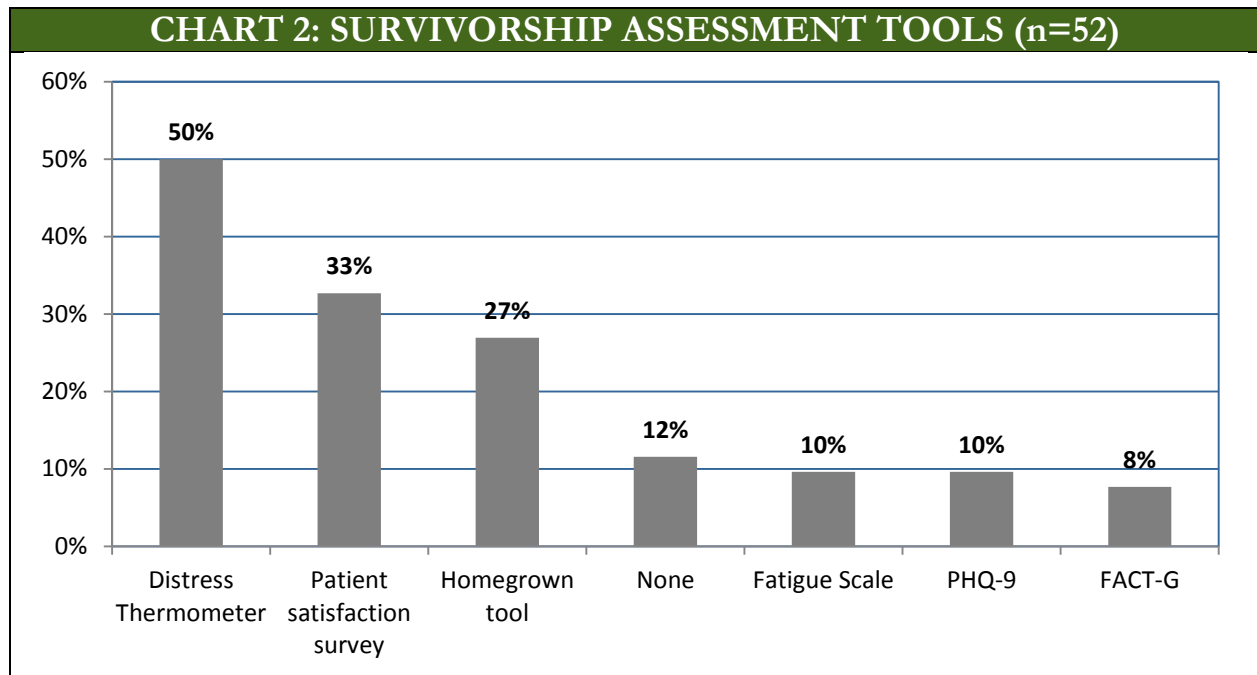
Patient Assessment Tools

The National Cancer Institute launched the Care Planning workspace as part of the Grid-Enabled Measures Database (GEM). The goal of the database is to catalog different measures that are being used for a variety of research projects so that eventually health care professionals can use the same measures to draw comparisons across different studies. The [GEM-Care Planning initiative](#) includes a list of constructs and measures related to care planning. Although it was created for survivorship, many of the constructs are applicable to patient navigation as well.

By clicking on a construct, such as care coordination or quality of life, in GEM you can see a list of tools to measure that construct. For example, if you click on quality of life you will find a list of about 20 tools for measuring quality of life. If you click on a particular tool you can see how other survivorship professionals have rated it, rate the tool yourself, read a summary of the tool components and, when possible, download a copy of the tool to use. In the screenshot below you can see what the FACT-G tool looks like in GEM.

The screenshot displays the GEM website interface. At the top, it shows the National Cancer Institute logo and the URL www.cancer.gov. The main navigation bar includes links for Home, Constructs, Measures, Datasets, Workspaces, About, and My GEM. The current page is titled 'Functional Assessment of Cancer Therapy-General (FACT-G)'. The page layout includes a sidebar with navigation options like 'Contact Information', 'Workspaces', 'History', 'Measure Characteristics', 'Language/Translations', 'References', 'Upload', 'Datasets', and 'Comments/Ratings'. The main content area is divided into sections: 'General Information' (Measure Name: Functional Assessment of Cancer Therapy-General (FACT-G), Measure Type: Quality of Life, Construct: Quality of Life, Primary Content Area: Cancer, Secondary Content Area: Cancer), 'Brief Description' (The FACT-G forms the core component in a set of instruments originally developed for assessing QoL outcomes for patients with cancer...), 'Keywords', 'Target Population' (Cancer Survivors), and 'Mode of Administration' (Self-Administered, Other/Unscale/Not-to-be-decided). On the right side, there is a 'Avg Rating' section showing 5 stars from 2 users, a 'Download' count of 385, and a 'Status' of 'Rate This!'. A 'Questions or feedback?' button is located at the bottom right.

In the 2013 Best Practices in Navigation and Survivorship Survey, the GW Cancer Institute asked respondents with survivorship programs which assessment tools they use. Chart 2 summarizes the most popular tools used.



ONLINE RESOURCES

Care Standards

[The Essential Elements of Survivorship Care: A LIVESTRONG Brief](#)

[Institute of Medicine From Cancer Patient to Cancer Survivor: Lost in Transition](#)

[Institute of Medicine Fact Sheet: Cancer Survivorship Recommendations](#)

[Institute of Medicine Fact Sheet: Survivorship Care Planning](#)

[Commission on Cancer Standard 3.3 Clarification](#)

[ASCO Cancer Treatment Summaries](#)

[Journey Forward: Survivorship Care Plan Builder](#)

[LIVESTRONG Care Plan](#)

[Memorial Sloan-Kettering SCP](#)

Survivorship Guidelines

[NCCN Guidelines](#)

[ASCO Guidelines](#)

[American Cancer Society Survivorship Care Guidelines](#)

[NCI Grid Enabled Measures- Survivorship Care Planning Initiative](#)

Additional Case Studies of Survivorship Programs

[Defining Survivorship Care: Lessons Learned from the LIVESTRONG Survivorship Center of Excellence Network](#)



AN IN-DEPTH LOOK

CASE STUDY 1 ON SURVIVORSHIP PROGRAMS

Organization Name:

Anne Arundel Medical Center

Program Type:

Survivorship Program

Organization Description:

- Anne Arundel Medical Center is a growing community hospital, located in Annapolis, Maryland.
- The cancer institute provides comprehensive care for oncology patients from preventive care through treatment. The survivorship program was needed based upon patient and provider feedback as well as industry recommendations.
- The survivorship program is currently operational, serving breast cancer patients following acute treatment. The program was championed by the executive director, allowing for program success and expansion by disease line.

Programmatic Approach:

- Planning phase activities: patient needs surveys; multi-disciplinary planning meetings which included primary care physicians; monitoring guidelines, consensus meeting using literature, NCCN and ASCO guidelines; creation of SCP template that provided appropriate content and form; program communication by lunch and learns, tumor boards and PCP site visits.
- Program details: consultative model with a 60 minute NP visit and 30 minute oncology social worker visit, typically scheduled 4-6 weeks following their last active treatment; **LIVESTRONG** Cancer Transitions 6 week program; activities including grocery store tours and cooking classes.
- Short-term goals include 80% of breast cancer patients schedule and attend survivorship appointments. The program is expanding to head and neck, GI and prostate cancers. This expansion is scheduled to begin operations in October of 2012.

Challenges and Solutions:

- Challenges include making sure providers and patients are aware that this is part of their treatment plan, not simply an add-on. Clinic staff are confronted with ongoing challenge of time-consuming process of developing the survivorship care plan. Challenges also include establishing the survivorship clinic in regulatory space.

Lessons Learned:

- The clinic should have formalized the program assessment criteria better during the planning phases of the program.

Program Successes:

- The clinic had overwhelmingly positive verbal feedback from our patients.
- Clinic staff presented 2 posters at national conferences, outlining our program design.

Results to Date:

- The clinic has seen 80+ patients and received local fundraising donation support for program expansion, including expanded nutritional offerings for survivors.

CASE STUDY 2 ON SURVIVORSHIP PROGRAMS

Organization Name:

Providence Cancer Center

Program Type: Survivorship

Organization Description:

- Providence Health and Services is a health care organization with locations in several western states. The region includes hospitals, clinics and other services providing health care to the greater Portland, Oregon area. The Cancer Center has a group of employed oncologists, and patients are also served by affiliated community based practices including: oncology, surgery and radiation oncology groups.
- The problem addressed was lack of a formal program for survivor care.
- A business case was developed, and a grant proposal submitted. Program champions included cancer center administration and a physician champion. There was uncertainty about the program amongst the oncology service providers as to how the program would interface with their practice. There was some concern that the program would take over care for patients completing therapy rather than add service.

Programmatic Approach:

- Initial activities included a needs assessment and meetings with key stakeholders. A business plan was developed shortly thereafter. As noted above, a grant proposal was drafted, but no funding was awarded.
- 2 individuals within the cancer center were chosen to attend the GW Executive Training—the Director of Clinical Programs and the Survivor Program Manager.
- Providence Cancer Center was selected as a NCI Community Cancer Center and received a financial award to further our efforts in program development.
- Additionally, staff met with employed oncologists to determine the model that fit best—a NP-led consultative clinic model was chosen. This was in an effort to provide quality, cost effective care. Medical oversight is provided by a medical oncologist.
- A full time NP was then hired. Responsibilities initially included 3 days per week of clinic and 2 days program development. The survivorship program works within existing clinical spaces and shares an office/medical assistant staff in order to reduce costs.
- Clinic staff obtained records, scheduled patients and performed insurance authorization if needed.
- The NP developed forms for clinic use. NP then completed all treatment summaries and care plans as well as conducted the clinic visit.
- Patients who had high levels of distress met with a social worker during the clinic visit—this has sometimes been difficult to maintain depending on availability of staff since the social worker has other responsibilities.
- Additionally, a multidisciplinary Advisory Board was developed to provide guidance as the program developed. This includes a community member/cancer survivor.
- Marketing included the development of brochures and mailers to internal physicians (including primary care). 2 television spots and a radio ad were done as well. These were aired around survivor day and Race for the Cure events.
- Quality initiatives include patient satisfaction, time to complete treatment summaries, insurance payment of services and whether our documents meet criteria outlined by the IOM. So far, patient satisfaction is high, and the program met pre-determined targets in terms of time spent on treatment summaries. The program has not encountered problems with payment by insurance, although co-pays or deductibles sometimes are challenging for patients to meet. IOM information to be included in the summary and care plan documents are met, although this makes a very lengthy document that is not quickly readable. The staff rearranged the form a bit so PCPs and other providers can easily determine the follow up schedule.
- Provider satisfaction has been challenging to ascertain.

Challenges and Solutions:

- The initial challenge was to identify where to start in terms of patient population, development of treatment summary and care plan documents vs. utilizing existing resources such as ASCO or Journey Forward.
- Based on the cancer registry citing the most commonly diagnosed cancers, the clinic focused on breast cancer patients initially, with expansion in a stepwise fashion—colon and rectal cancers next, then to re-evaluate. The program staff also agreed to see additional diagnoses given advance notice so there was enough time to prepare for the visit.
- Credentialing providers was a more lengthy process than anticipated, which delayed the clinic opening by a couple of months.
- Problem encountered included messaging for patients who were calling in to schedule appointments that were not able to be seen in clinic. The clinic currently sees patients who have completed active cancer treatment and are in remission. Patients that did not meet those criteria felt insulted they were not considered “survivors” by clinic staff if they were not granted an appointment. This was an unexpected issue. A script was subsequently developed to assist with these sometimes difficult encounters.
- Additional problems included the length of time required to prepare for a clinic visit along with the timing for the visit itself. Initially it was 6-8 hours per patient. The clinic staff did not meet our anticipated patient volumes due to this. Through discussion with other similar programs we discovered we were not alone in how much time was required in preparation for these visits. After some experience filling out the forms and with conducting patient visits the total time is now approximately 1.5-3 hours, depending on the complexity of the patient.
- Another more recent setback was our transition to an EMR that does not pre-populate any of the forms used by the clinic—this is a work in progress.

Lessons Learned:

- A single provider was not feasible to sustain the program. There was much time spent in reviewing records for the treatment summary, not actually seeing patients. The clinic opted for a nurse navigator to both add to the program with expansion of classes offered as well as assisting the NP in preparation for clinic visits.
- Despite adequate billing and payment, the program is still relatively new and in early stages of financial evaluation. It still requires significant Cancer Center commitment and support.
- Patients have blogs and are active in social media—this can be a great thing, but sometimes not. We learned a valuable lesson in interacting with our survivors.
- Issues of survivorship are a more important focus of care as opposed to experience or knowledge of a specific tumor type. The clinic received a referral for a cancer diagnosis we do not encounter frequently. There was concern the clinic would not meet this patient’s needs because of that. In reviewing the intake forms the staff opted to focus more on quality of life issues to determine what was causing them to seek out an appointment and considering referral to other programs if the clinic was unable to meet the need.
- More frequent meetings of the Advisory Board made for a more cohesive group.

Program Successes:

- The clinic successfully opened and began seeing patients in October 2010.
- Patient satisfaction is rated high.
- The addition of a nurse navigator in May 2012 has already had a positive impact on the patient volume and overall awareness of the program.

Results to Date:

- Improved clinic volumes to 4 patients per day.
- Expansion is planned for early 2013 to offer additional sessions of “New Norm” series of three classes. This is a series free to cancer survivors. Of note, a significant number of patients call to schedule appointments with our survivor clinic after attending this class.
- Discovered resources internal to our organization as well as in the community for referral of patients to appropriate services.
- Clinic staff have had a presence at community Survivor events.

- Clinic staff have been asked to speak on survivorship to a patient group through The Leukemia & Lymphoma Society.
- The program has begun to receive regular referrals from both internal and affiliated practices, as well as patient self-referral.

Part II - Navigation

The following Principles of Patient Navigation were proposed in 2011 by Dr. Harold Freeman, who coined the term patient navigation in oncology:³⁸

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

After identifying the need for a patient navigation program, it is helpful to consider the following questions when deciding how the program will be structured. Often these questions will be informed by your needs assessment, institutional priorities and available staff and resources. It is important to involve the relevant stakeholders when making these decisions. Support from clinicians, staff and administration is critical when choosing a model. To help you narrow down which model may work best in your institution, complete Activity 8 in the *Workbook* on pages 15-16.

Questions to Consider When Designing a Navigation Program

Who are your champions?

When embarking on any new program, it is important to have at least one person who will advocate for and on behalf of the program whether to clinicians, administrators, patients, caregivers or the community in general. An example of a program champion could be an oncologist, nurse, social worker or other clinician.

Who needs to be ‘at the table’ for program development?

Internal and external buy-in is a critical aspect of program development. It is important to include all stakeholders (clinicians, nurses, social workers, administrators, patients, etc.) from the beginning to secure support for your program. Additional stakeholders may include caregivers, community leaders and internal staff from marketing and communications, billing and IT.

Who is your patient population?

Defining your patient population is an important determining factor when developing your navigation program. If your institution sees a large number of uninsured or underinsured patients you may want to consider a lay navigator to handle insurance and financial issues. Alternatively if you have a population mostly made up of patients undergoing treatment for breast cancer you may want to have a nurse navigator focus solely on breast cancer patients.

What type of navigation services will be offered?

The type of navigation services will depend upon your patient population and results of your needs assessment. Services will also depend on the type of navigator you employ and resources available. For

example, if you have an oncology social worker on staff you may be able to offer psychosocial support services as part of the program through distress screening and referral.

Who will be eligible to receive navigation services?

In addition to establishing who your patient population is, determining who is eligible to receive navigation services is also important. You may open up your services to everyone who has received a cancer diagnosis or limit it to referral only or to a specific cancer type. We recommend to start small and grow the program as you refine your process. Again, this will be informed by your institutional analysis and capacity from your needs assessment.

Which type of navigator will deliver navigation services?

There are several types of navigators that can be utilized depending on the services provided. Types of navigators include: nurse, social worker and non-clinically licensed patient navigators (sometimes called “lay” navigator). If it is determined that there is a need to provide clarity around understanding a cancer diagnosis, treatment options and side effects then a nurse navigator would be the best option. If the navigator will be focusing more on removing practical barriers to care, then it might be best to have a non-clinically licensed navigator.

Which navigation model is most appropriate?

In navigation, one size does not fit all. Deciding which type of model is the right fit for your institution largely depends on the services being provided as well as who is providing those services, to whom and at what point(s) during the continuum. In short, the model you choose should reflect the needs of your patient population and the resources available at your institution or in the community.

Models of Navigation

Patient navigation programs can look different in different settings. Some components of navigation models include:

- Single navigator that follows each patient across the continuum vs. navigators stationed and specific points in the continuum
- Disease-specific navigator vs. a navigator that sees all patients
- Mix of types of navigators based on cancer program needs

Navigation Assessment Tool

The National Cancer Institute Community Cancer Centers Programs (NCCCP) developed the [NCCCP Navigation Assessment Tool](#) to demonstrate how patient navigation programs can vary across a variety of factors:

- Key Stakeholders
- Community Partnerships
- Acuity System (Ability to determine appropriate level of care/intervention based on patient need and disease process)
- Risk Factors
- Metrics/Reporting Measures
- Percentage of Patients Navigated
- Continuum of navigation (Outreach/Screening, Abnormal Finding to Diagnosis, Treatment, Outpatient &/or Inpatient, Survivorship and End-of-Life Care)
- Disparity
- Tools for Reporting Navigator Statistics
- Multi-Disciplinary Team Involvement

For example, a Level 1 program may have only administrative support (stakeholders), focus on one functional area of the continuum and is not focused on disparities. A Level 5 program, on the other hand, may receive referrals from employed and non-employed MDs/PCPs or community partners; include navigation across all functional levels of the continuum; and conduct a cultural sensitivity assessment with cultural objectives created on at least an annual basis.

Navigation Software Information

The information below is intended to be a brief overview of potential navigation tracking software systems. This list is not exhaustive and does not indicate an endorsement of any one product or system. Pricing and product information is subject to change. Please contact the company directly to discuss whether one system or another would be a good fit for your organization and the pricing information for your program.

| NAME | PRICING STRUCTURE | PRODUCT INFORMATION |
|------------------------|--|---|
| Nursenav | Yearly fee for site, based on number of patients | <ul style="list-style-type: none"> • Reports are easy to run, user friendly (according to past ET participant) • Nurse/treatment focused • Can create Treatment Summary • Will add Survivorship Care Plans for major tumor sites |
| MagView | One fee for first year, smaller fee for additional years | <ul style="list-style-type: none"> • Use for any tumor site • Nurse/treatment focused • User defines data collected to tailor application • User can design forms for intake, summary, barrier assessment • Can scan documents into file |
| Priority Consult | One fee for site and first navigator; additional navigators can be added for smaller fee/navigator | <ul style="list-style-type: none"> • Developed for breast cancer; can be used for others • Treatment focused, work flow management tool • Can create Treatment Summary & SCP |
| OncoNav (from Oncolog) | Flat fee per site with additional fee for multiple users | <ul style="list-style-type: none"> • Recent launch • Similar capabilities of other products- scheduling, tracking, organizing and reporting patient data • Built for navigation |
| Social Solutions (ETO) | Set-up cost and monthly fee based on operating budget | <ul style="list-style-type: none"> • Customizable • Patient can fill out intake via email • Can define access based on roles • Task management functions • Not built for nurse navigation; more case management focused |



CASE STUDY ON BEST PRACTICES IN NAVIGATION

Organization Name:

The George Washington University (GW) Cancer Institute

Program Type:

Patient Navigation

Organization Description:

- GW Cancer Institute's mission is to ensure access to quality, patient-centered care across the cancer continuum through community engagement, patient and family empowerment, health care professional education, policy advocacy and collaborative multi-disciplinary research. GW Cancer Institute accomplishes its mission by providing evidence-based interventions for patients, caregivers and survivors to remove barriers to care, reduce distress, promote self-efficacy and improve holistic support and post-treatment care, and by catalyzing patient-centered care through training, policy white papers, roundtables and research.
- The D.C. Cancer Consortium (a local cancer coalition) published the D.C. Cancer Control Plan, which detailed the high rates of cancer incidence and mortality in D.C. as well as access to care barriers in vulnerable groups and the medically underserved.
- Initially, the navigation program at GW Cancer Institute was a one-navigator partnership with the American Cancer Society targeting prostate cancer patients. After this successful start, GW Cancer Institute expanded patient navigation to other clinical areas.

Programmatic Approach:

- GW Cancer Institute used the DCCC Cancer Control Plan as a starting point for its needs assessment as it yielded community-wide data on the need for patient navigation. GW Cancer Institute also initiated a citywide research program funded by the National Cancer Institute to evaluate the impact of patient navigation on those at risk for breast cancer in metropolitan Washington, D.C.
- The GW Cancer Institute navigation program was piloted in urology with the support of a prostate cancer surgeon. Simultaneously, GW Cancer Institute led the DC Citywide Patient Navigation Research Program to assess impact of patient navigation on time to diagnostic resolution for women at risk for breast cancer. Building on the results of the pilot program and the research study, in 2010, GW Cancer Institute collaborated with primary care, tertiary care and community-based organizations to launch the Citywide Patient Navigator Network (CPNN) safety net for uninsured and vulnerable individuals to access appropriate screening, treatment and supportive care. Through this program, GW Cancer Institute expanded the number of navigators at GW Cancer Institute and placed navigators across the city to provide seamless support to patients accessing multiple health systems in DC for care.
- At GW Cancer Institute, non-clinically licensed navigators work as a team with a nurse navigator, and a survivorship navigator to assist patients across the cancer continuum. Their primary activities consist of breaking down barriers to accessing care.
- GW Cancer Institute navigators currently document their interactions through an Excel tracking log that captures demographics and barriers to care as part of the larger CPNN. The GW Cancer Institute Patient Navigation Program has focused on leveraging the navigators to improve quality in patient care. GW Cancer Institute navigators mapped the breast cancer patient experience across the continuum to document gaps in the system and make improvements to optimize patient support.

Challenges and Solutions:

- The issue of sustainability is a significant financial challenge to patient navigation. GW Cancer Institute recently finalized core competencies for non-clinically licensed navigators working with the Association of Oncology Nurse Navigators, the National Association of Social Workers, the Association of Community Cancer Centers and patient navigators across the country to identify the appropriate competencies and activities of the patient navigator versus the community health worker or nurse navigator. These findings may inform policy

recommendations for sustainability of the profession.

- GW Cancer Institute also has plans to work on access to care issues with local policy officials in the year ahead.
- Given that different clinical settings use different electronic medical records, data collection remains a challenge. GW Cancer Institute is now taking a systematic approach to its data tracking, determining what metrics to track to move from outputs to outcomes to illustrate the value of navigation. A standard navigation note has been created and implemented in the electronic medical record.
- Regular clinician referral for navigation services can be a challenge for some navigators. The process maps improved this by targeting key points in the continuum to ensure patients are aware of the navigation and survivorship resources available to them.

Lessons Learned:

- A clinical champion (or more than one!) is critical to success of a navigation program.
- Embedding the navigator in a particular clinic has yielded optimal results in working with the clinical team.
- Ongoing training of navigators for quality checks on data is a best practice.
- Communication is critical for a successful program. A weekly team navigator meeting to share cases is a best practice.
- Mapping the breast patient's process along the continuum helps prioritize quality improvement projects (QI), defines how navigators can contribute to QI and helps ensure navigators are focused on true navigation.

Program Successes:

- A GW Cancer Institute -led study showed that diagnostic time was reduced by 17 days (from 42.1 days to 25.1 days on average) for women who received breast cancer navigation.³⁹
- Flexibility, teamwork and communication between navigators have led to program success.
- The experience of the GW Cancer Institute navigators indicates that some patients would have never received their diagnosis or treatment if it were not for the CPNN safety net. The persistence and knowledge of the navigators has enabled patients to get follow-up and follow through from their medical team.
- GW's National Accreditation Program for Breast Center's (NAPBC) surveyor noted that the GW navigation program goes above and beyond other cancer centers. The surveyor stated he is recommending the GW navigation program as a clinical best practice and that the size and diversity of the team is commendable.

Results to Date:

- CPNN has navigated 8,000 individuals at various points along the cancer continuum and removed 26,000+ barriers to care. Of patients served, 86% were minority populations and nearly 30% were uninsured. Top patient barriers were social/practical support (16.7%), financial barriers (14.0%), system problems with scheduling care (14.0%) and language barriers (10.6%).



ONLINE RESOURCES

Commission on Cancer [best practices on Standard 3.1 Patient Navigation Process](#)

[NCI Community Cancer Centers Program Navigation Assessment Tool](#)

[ACCC Patient Navigator Responsibilities and Job Functions](#)

[ACCC Patient Navigation Tools](#)

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Building Blocks of Program Design

Section Overview

In this section, you will learn how to develop a structure for your program to achieve your identified goals. After completing this section you will be able to:

1. Complete a logic model.

Related Workbook Activity:

Activity 9: Creating a Logic Model

Guide to Logic Models

RESOURCES/INPUTS→ACTIVITIES→OUTPUTS→OUTCOMES

Use this logic model summary to understand the basics about logic models, why you would create one for your program and when and how to create one. This information will help you complete Activity 9 on pages 17-20 of your *Workbook*.

What is a logic model?

At the beginning of your program planning process, a logic model is:

- A tool to get you and your team thinking about all the possibilities for achieving your program goal.¹
- A helpful and practical tool for capturing and documenting useful program planning information.
- A picture of your program, what you are trying to achieve, how you are going about it and the resources you are putting into it.²

When your program is ongoing, a logic model is:

- A tool to keep you and your team focused on your program's progress and goal(s).
- A tool to help evaluate the program and enable process improvements, if progress is off-track.

Why would I need a logic model for my program?

- To build common understanding about how the program works and what you want to accomplish.
- To provide a structure for documenting necessary resources/inputs and activities to achieve your program goals.
- As a tool for organizing your team's planning efforts and easily communicating your plan and progress over time to colleagues, possible funders and your organization's leaders.
- As a tool for forecasting program outcomes and impact to demonstrate why your organization should invest in your program or sustain funding. It may also be beneficial for external sources of funding.

When do I create and use a logic model?

- Create your logic model during your program planning phase.
- Refer back to your logic model as often as needed to ensure that you have all the necessary resources/inputs, are engaging in the right activities and generating sufficient outputs to achieve your outcomes and goals.
- Refer to your logic model when designing and carrying out program evaluation.

How do I create and use a logic model?

- Keep in mind the long-term goal(s) that you have for your program. You may also have a problem statement and stated assumptions to keep in mind.
- Brainstorm collaboratively with your team and other stakeholders to generate content for each logic model section.³
- List the agreed upon content in a logic model.
- Revisit your logic model periodically as you implement and evaluate your program.⁴



Logic Model for Cancer Survivorship Program– SAMPLE⁵

| Resources/ Inputs | Activities | Outputs | Short-Term Outcomes (Year 1)* | Intermediate Outcomes (Years 2-4)* | Health Impact: Long- Term Outcome (Year 5+)* |
|---|---|---|---|---|---|
| <ul style="list-style-type: none"> • Funding from grants, reimbursement, departmental • BrCa, CRC cancer survivors • Program champion(s) • Clinical, Admin staff • Knowledge, skills, time of core team and support referral services staff • Clinical, office space/supplies • Distress thermometer • Educational class materials • Marketing materials • Organizational partnerships • Follow-up surveys | <ul style="list-style-type: none"> • Conduct consultative visits • Conduct psychosocial assessments • Refer patients for other services • Select/use survivorship care plan template • Educate survivors on survivorship care • Provide care plans to survivors • Provide care plans to PCPs • Conduct follow-up patient surveys • Track and collect process and outcomes data | <ul style="list-style-type: none"> • # of consultative visits • # of psychosocial assessments • Established referral process • # of patients referred to which services • Survivorship care plan template • # of survivors educated • # of care plans provided to survivors • # of care plans provided to PCPs • # of survivors with change in knowledge • # of survivors with change in satisfaction • Established evaluation process and tools | <ul style="list-style-type: none"> • Increased patient knowledge about survivorship care • Increased patient satisfaction with care | <ul style="list-style-type: none"> • Increased patient adherence with follow-up care plan • Increased delivery of survivorship care • Improved care coordination between providers (Oncology and PCPs) | <ul style="list-style-type: none"> • Improved quality of life for cancer survivors in patient population |

Logic Model for Cancer Navigation Program– SAMPLE

| Resources/Inputs | Activities | Outputs | Short-Term Outcomes (Year 1)* | Intermediate Outcomes (Years 2-4)* | Health Impact: Long-Term Outcome (Year 5+)* |
|--|--|--|---|--|--|
| <ul style="list-style-type: none"> • Funding from grants, org core budget • BrCa patients • Program champion(s) • Non-clinically licensed navigator staff (1.5 FTE) • Admin staff • Knowledge, skills, time • Organizational partnerships for referrals • Office space/ supplies • Promotional materials • Patient assessment – modified Distress Thermometer • Patient tracking tool | <ul style="list-style-type: none"> • Promote PN services in the community • Hold skills-based support group meetings • Refer patients for assistance • Track needs/barriers and status of patients • Conduct ongoing patient assessments/ surveys | <ul style="list-style-type: none"> • # of monthly support groups • # patients attended support groups • # patients referred for assistance • Established referral process • # and type of referrals | <ul style="list-style-type: none"> • Increased patient knowledge of community-based resources for practical issues • Increased patient self-efficacy to access resources for practical issues | <ul style="list-style-type: none"> • Increased patient ability/ behavior to access resources for practical issues | <ul style="list-style-type: none"> • Improved access to care through reduced patient barriers |



ONLINE RESOURCES

[CDC Developing and Using a Logic Model Guide](#)

[Community Tool Box: Developing a Logic Model](#)

[The Pell Institute: How to Create A Logic Model](#)

[University of Wisconsin: Logic Model Templates](#)

[W.K. Kellogg Foundation Evaluation Handbook and Logic Model Development Guide](#)

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³ The Pell Institute. How to Create a Logic Model. Accessed November 21, 2014 from: <http://toolkit.pellinstitute.org/evaluation-guide/plan-budget/use-a-logic-model-in-evaluation/>

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⁵ University of Wisconsin: Logic Model Templates. Accessed November 21, 2014 from: <http://www.uwex.edu/ces/pdande/evaluation/evallogicmodelworksheets.html>

Funding and Sustainability

Section Overview

This section focuses on the financial aspects of a program such as developing a budget that includes your anticipated costs as well as developing a long-term plan for sustainability. At the end of this section, you should be able to:

1. Identify components of a program budget.
2. Identify possible funding streams.
3. Learn strategies and techniques for demonstrating program value through return on investment.

Related Workbook Activities:

Activity 11: Making a Budget

*Activity 12: Identifying Stakeholders and
Demonstrating Value*

Financial Considerations for Patient Navigation and Survivorship Programs

Many health care professionals cite financial constraints as a significant barrier to program implementation. It is important to think upfront not only about how the program will be initially funded but also how it can be built to be sustainable. Before you can begin to think about funding, you need to identify the anticipated costs involved. Developing a realistic budget will help you determine what resources you need. Program needs will vary by institution and existing resources. The sample budget below offers some examples of budget line items that you may include. You may need to revisit your budget after your program is launched to make adjustments. Complete Activity 11 in the *Workbook* on page 22.

Core Program Costs

Whitley et al. have identified core costs of patient navigation programs that may be helpful to think about as you design your program.¹ The core costs of survivorship programs are similar and likely include the same items. The costs include:

- Human Capital Costs (Personnel)
 - Wages and benefits
 - Training (tuition, travel, time)
 - Supervision
 - Administrative support
- Program Costs
 - Office space, equipment and furnishings
 - Phones, pagers and computers
 - Patient materials
 - Time works
 - Travel
 - Office supplies
 - Patient assistance
- Direct Medicare Costs
 - Visits, screening, tests

In many navigation and survivorship programs, personnel costs are the largest costs. Oftentimes for navigation programs navigator salaries are the primary cost and can vary from \$0 to \$60,000 based on skill, background and responsibility of the navigator. Other personnel costs that may need to be factored in include supervision or administrative support costs.

The following are examples of published patient navigation costs for different programs. Because these examples are from research studies, some of the personnel costs were broken down to include only the time a person spent on patient navigation, rather than other activities.

1. The MGH Chelsea HealthCare Center in Chelsea, MA implemented a patient navigation program that included navigator training. The program included 5 part-time CRC screening navigators, and the total cost of training and patient navigation was \$70,000 for first 9 months. The ongoing costs were \$75k/year thereafter.²
2. In New York City, 3 CRC screening patient navigation programs were studied at public hospitals. The annual costs for each program were: \$104,868, \$116,221 and \$373,606. The latter costs were higher due to the costs of personnel other than the navigators, including a study coordinator and physicians.³
3. Another study looked at 3 breast and CRC patient navigation programs at community hospitals in Washington, DC, Kentucky and Louisiana. The programs were focused on the time between

abnormal screening and diagnostic resolution. Table 1 illustrates the average costs across categories for the 3 programs:⁴

| TABLE 1: AVERAGE COST CATEGORIES ACROSS THREE NAVIGATION PROGRAMS | |
|--|-----------------|
| Personnel | \$72,292 |
| Patient navigators | \$55,969 |
| Other personnel | \$16,323 |
| Materials | \$13,397 |
| Staff/personnel travel costs | \$2438 |
| General supplies (eg, printed supplies, mobile phone, postage) | \$6508 |
| Training | \$4452 |
| Total Average Cost | \$85,689 |

Much less has been published on costs of survivorship programs. One study in thoracic cancer survivors found that an NP-led model allowed the providers to bill and cover the program salary costs.⁵ Rosales et al. also looked at cost related to delivering SCPs and found that the average staff cost per patient was \$141.73 and that the cost was reimbursable at a 6% profit margin, with Blue Cross Blue Shield having the lowest reimbursement amount.⁶

Sample Budget Line Items

Many navigation and survivorship programs are funded by a combination of sources, including grants, reimbursement, internal funds and leveraging existing resources. The budget below demonstrates some of the costs that may be necessary to launch and maintain a program. For each line item a possible funding source is listed.

| | COST | FUNDING SOURCE |
|---|-------------|-----------------------|
| Personnel | | |
| Director of Survivorship/Nurse Practitioner (50% FTE) | \$ | Internal |
| Patient Navigator, RN (50% FTE) | \$ | Internal |
| Clinical Dietitian (25% FTE) | \$ | Grant |
| Clerical staff | \$ | Existing Resources |
| Program Costs | | Funding Source |
| Facility rental | \$ | Existing Resources |
| Facility utilities | \$ | Existing Resources |
| Printing & copying charges | \$ | Internal |
| Patient intake and follow-up tools | \$ | No Cost/Open Source |
| Marketing materials | \$ | Internal |
| Patient health education seminar costs | \$ | Grant |
| Conference attendance | \$ | Internal |
| Food for events | \$ | Grant |
| Direct Medical Care | | Funding Source |
| Referrals - non subspecialists | \$ | Billable |
| Lab and other tests | \$ | Billable |

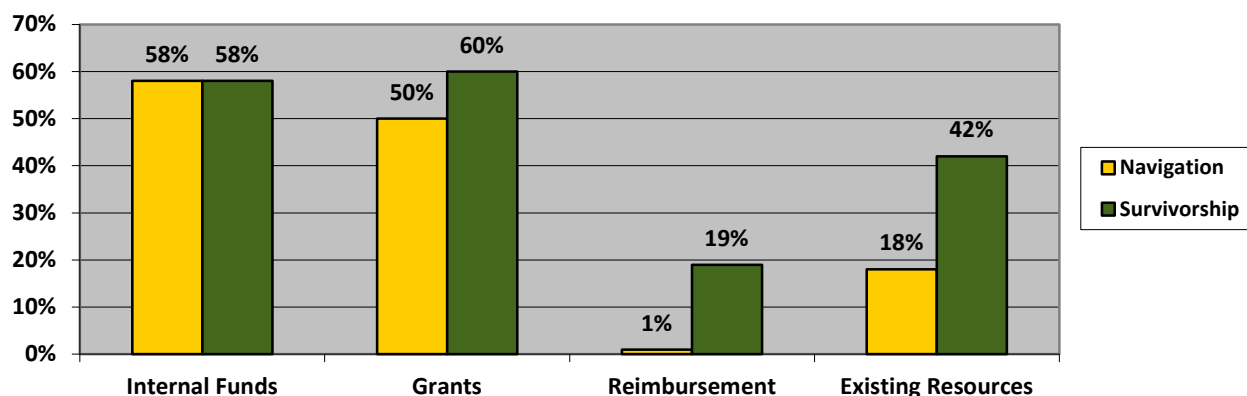
Current Potential Funding Sources

Once you have determined your budget you can begin looking at options to fund your program. You may identify different funding sources for different programmatic components. In general, the following are options for program funding:

- Internal sources (e.g., hospital foundation, research institute, philanthropy department, endowments)
- Grants/donations
 - Private or public donations from community, organizational or corporate sources (e.g., state health department)
 - Foundation grants (e.g., American Cancer Society, Avon Foundation, Susan G. Komen for the Cure)
 - Government research grants (National Cancer Institute, Centers for Medicaid and Medicare Services)
- Reimbursement (more likely for survivorship than navigation)
- Off-set post-treatment clinic using revenue from in-treatment services and specialty referrals
- Restructuring some staff functions and employees into new positions

In 2013 the GW Cancer Institute conducted a survey of health care professionals with navigation and/or survivorship programs.⁷ When asked about how their programs were funded, many respondents indicated a mix of sources, with internal resources and grant funding being most often cited. Chart 1 depicts the responses.

CHART 1: FUNDING SOURCES BY PROGRAM TYPE



Reimbursement is often not available for navigation programs, especially those that use non-clinically licensed patient navigators, but reimbursement may be an effective funding source for survivorship programs. Based on our experience, some programs have been successful using level 3-5 consultation codes or team codes. Additionally, group visits have been used in some institutions for survivorship visits. Trotter et al. piloted a group visit model for breast cancer survivors.^{8,9} Patients and clinicians liked the group visits, which were facilitated by a nurse practitioner who dedicated 15% of her time each week to the program. Each group of 6 survivors included a self-assessment sheet, 45 minutes of facilitated group discussion and individual activities such as optional one-on-one consultations with a physical therapist, dietitian and social worker or other prescheduled appointments. They used the 99078 code; however, during the pilot they were not successful in achieving reimbursement.

Demonstrating Value for Navigation and Survivorship Programs

You may have to demonstrate the value of your program for different stakeholders. It is important to think about how you will demonstrate value from the outset so you can collect information along the way. You may need to meet with different stakeholders to identify what measures of value are most important to them.

Cost Savings and Indirect Revenue Captured

One indicator of value is cost savings. Another is indirect revenue captured. Your administration, for example, may be interested in seeing that your program brings in additional revenue, and your program manager may be interested in seeing the impact of the program on patients.

Measuring value may not be something you have done before but it may be necessary. You will need two pieces of information: program costs and revenue generated. Once you have created a budget you can track your total program costs. Then you can compare that to the “return” from your program, or the revenue generated by your program. Indirect revenue can be generated through: ^{10,11,12,13,14,15,16,17}

- Increased number of appointments from avoiding no-shows or reducing outmigration (patients who were seen at your institution but continued care elsewhere)
 - How many additional appointments were made and what is the revenue generated from those appointments?
- Procedures, tests or consultations
 - How many procedures, tests or consultations occurred that would not have otherwise occurred and what is the revenue generated from these?
- Downstream revenue (revenue generated after the initial visit)
 - What additional services did patients use after the initial visit and what revenue is generated from those services?

For example, the Henricos Doctor’s Hospital conducted a “downstream analysis” to determine the impact of reducing outmigration through patient navigation by: ¹⁸

- Calculating the number of patients lost to outmigration cases before patient navigation and the number of patients lost to outmigration after patient navigation (240 vs. 28, for a net reduction of 212),
- Tracking procedures/services for those with and without diagnosis to establish baseline (e.g., 63% of patients without a diagnosis had a mammogram, 7% had emergency services; 19% of patients with a diagnosis had an MRI, 9% had lumpectomy),
- Determining cost/revenue for each procedure/service and
- Applying the % of use to the patients kept and multiplying that by the revenue for each procedure/service.

Just retaining the 212 patients led to 315 imaging procedures for \$125k in revenue. Additional non-imaging services would have brought in \$350k in revenue for *just one year*.

Cost Benefit Analysis

The financial benefit may be important to demonstrate, but you may also want to articulate the benefits of your patient navigation or survivorship program, such as:

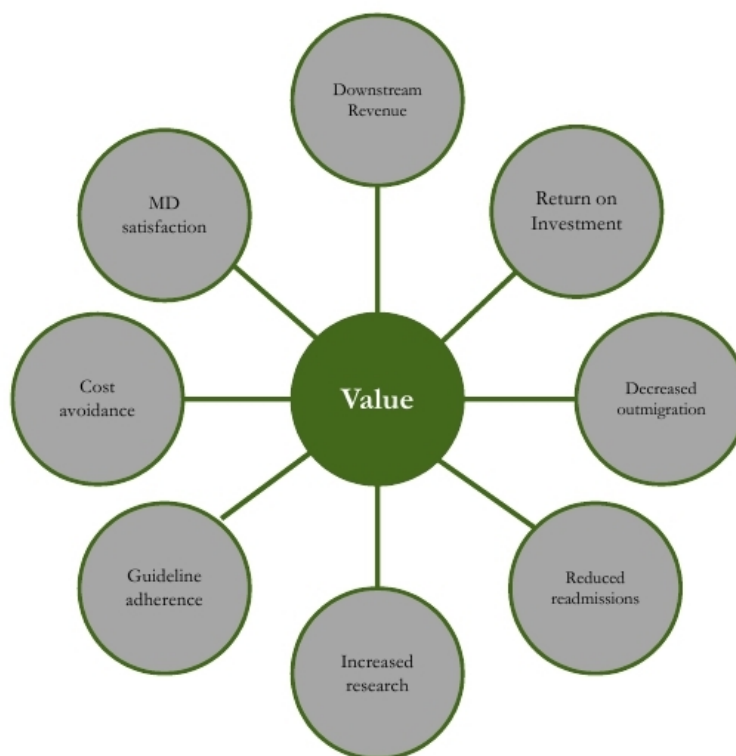
- Did referrals from other patients & navigators increase?
- How many patients benefited from the program?
- Are you reaching a particular demographic (e.g., uninsured, underserved)?

- Has patient navigation improved the stage at diagnosis over time?
 - Has the number or percentage of appointments missed decreased? Why did that happen? The latter may be helpful to demonstrate quality or process improvement.
- Patients accepting navigation: reasons why/why not
 - Did patient navigation improve timeliness of care? How does this compare to national standards or benchmarks?
- How many patients were educated and in what ways?
- What are the main barriers for your population and how were they resolved?
- Did patient navigation help increase clinical trial accrual?
- Did patient satisfaction improve?
- Do any patient testimonials demonstrate why the program is so important?
- Can you show improved adherence to treatment and recommendations?
- Did patients have better outcomes as a result of the program?
- Did the program improve quality?

Other Value Measures

In the 2013 Best Practices in Navigation and Survivorship Survey, the GW Cancer Institute asked respondents for suggestions for sustainability of navigation programs. Many respondents indicated demonstrating value is important. Figure 1 illustrates those responses.

FIGURE 1: SUGGESTIONS FOR DEMONSTRATING VALUE FOR PATIENT NAVIGATION (n=37)





ONLINE RESOURCES

[Best Practices in Navigation and Survivorship Survey Summary Report](#)

[Community Cancer Center Administration and Support for Navigation Services \(article\)](#)

[Return on Investment Estimation – AHRQ Quality Indicators Toolkit](#)

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Program Evaluation: Process and Outcomes Measures

Section Overview

In this section you will focus on the components of an evaluation plan. At the end of this section you will be able to:

1. Identify components of an evaluation plan.
2. Determine evaluation priorities and methods.
3. Identify survivorship and navigation measures.

Related Workbook Activity:

Activity 12: Developing an Evaluation Plan

Creating an Evaluation Plan

Creating an evaluation plan is important for being able to assess whether your program is meeting its goals. This section outlines components of an evaluation plan, which are adapted from the CDC's [Using Indicators for Program Planning and Evaluation](#) guide.¹ This information will help you complete Activity 12 in the *Workbook* on page 23. Below you will find evaluation terms defined.

Goals: A broad statement of intended outcomes for a program or organization. Goals typically guide the formation of more specific objectives that can be linked to goals.

Objectives: A statement of intended outcomes that is focused and are the steps leading to goals, and the changes required to achieve those goals.

Activities: The action steps that are needed to achieve the objective and goal. They should be stated specifically, not vaguely.

Evaluation Questions: The questions you devise to determine whether or not the goals/objectives have been achieved. Examples include: How many navigators completed navigation training? Were navigators satisfied with the training they received?

Indicators: The end you wish to measure. This may also be referred to as a performance measure. Examples include patients navigated, survivorship care plans provided.

Data Sources: The origin of information that relates to the indicator and informs the evaluation question(s). Examples include administrative data, meeting summaries, tracking logs.

Data Collection: The process of collecting data. Examples include interviews, surveys, review of administrative data.

Data Analysis: The methods for reviewing and assessing the evaluation data to address the evaluation questions.

Tips:

- There is no specified number of goals, objectives, activities, etc. that your program should have. It will vary depending on your program. Add more rows to the table as needed.
- You can add or delete columns as needed. For example, you may want to include an evaluation timeframe column to document when the evaluation for each goal should be complete.
- Review your logic model content and consider how the content relates to and shapes your evaluation plan.

| SAMPLE EVALUATION PLANS | | | | | | |
|---|---|---|--|--|-----------------------------------|---------------|
| Program Goals | Objectives | Evaluation Questions | Indicators | Data Sources | Data Collection | Data Analysis |
| Within 12 months, 50% of breast and colorectal cancer survivors will receive a Survivorship Care Plan | <ul style="list-style-type: none"> Deliver Survivorship Care Plans to 50% of breast and colorectal cancer survivors Assess impact on quality of life | <ul style="list-style-type: none"> What % of patients received a Survivorship Care Plan? What impact did the Survivorship Care Plan have on patient quality of life? | <ul style="list-style-type: none"> % patients who received the Survivorship Care Plan Change in quality of life scores | <ul style="list-style-type: none"> Tracking log or medical record Tracking log or medical record | Review logs or record abstraction | Quantitative |
| Within 6 months the patient navigator will increase the number of patients navigated by 10% | <ul style="list-style-type: none"> Conduct an internal education campaign on patient navigator role and capabilities Increase patient load by increasing referrals to patient navigator | <ul style="list-style-type: none"> Were clinicians and staff educated on the patient navigator? Did the patient navigator see an increase in the number of patients referred for navigation services? | <ul style="list-style-type: none"> # of educational meetings # of clinicians and staff educated # of patients navigated | <ul style="list-style-type: none"> Tracking log Tracking log Tracking log or medical record | Review logs or record abstraction | Quantitative |

PART I – Survivorship

Cancer Survivorship Measures

There is currently not a set of validated measures specific to cancer survivorship; however, some measures have been proposed. Malin et al. compiled a list of existing measures related to survivorship, which have been compiled in Table 1.² Table 2 shows survivorship measures, which have not been validated, or are in the process of being validated, which have been proposed by Rowland and Ganz³ and Pratt-Chapman et al.⁴

TABLE 1: EXISTING CANCER SURVIVORSHIP QUALITY INDICATORS

| Cancer Type | Quality Indicator ⁵ | Source |
|-------------|--|---------------|
| All | Chemo treatment summary completed, provided to the patient and communicated or provided to other practitioner(s) within 3 months of chemo end. | QOPI |
| | Smoking cessation counseling recommended to cigarette smokers by the second office visit. | QOPI |
| | Percentage of patients with a diagnosis of cancer who have undergone brachytherapy or external beam radiation therapy who have a treatment summary report in the chart that was communicated to the physician(s) providing continuing care within one month of completing treatment. | NQF |
| Breast | If a patient with stage I-III breast cancer who initiates treatment with tamoxifen does not meet the following criteria for discontinuing tamoxifen: there is evidence of disease progression, then the patient should receive 5 years of tamoxifen 20mg/day. | NICCQ |
| | If a patient has been diagnosed with stage I-III breast cancer and has not had bilateral mastectomies, then the patient should have had a mammogram in the last 12 months. | NICCQ |
| | Women with a history of breast cancer should have yearly mammography. | QATOOL (RAND) |
| | Women diagnosed with breast cancer in the last 5 years should have a clinical breast exam in the last 6 months. | QATOOL (RAND) |
| | Women diagnosed with breast cancer more than 5 years ago should have a clinical breast exam in the last year. | QATOOL (RAND) |
| | Referral for or genetic testing for patients with invasive breast cancer. | QOPI |
| | Patient with invasive breast cancer counseled, or referred for counseling, to discuss results following genetic testing. | QOPI |
| Colorectal | If the patient has a resection of a stage II or III colon rectal cancer, then the patient should be counseled about the need to have first degree relatives undergo colorectal cancer screening. | NICCQ |
| | Referral for or genetic testing for patients with invasive colorectal cancer with positive family history of colorectal cancer. | QOPI |
| | Patients with stage I-III colorectal cancer should receive colonoscopy or double contrast barium enema within 1 year of curative surgery if it did not occur within 12 months preoperatively. | QATOOL (RAND) |

| | | |
|-----------------|---|---------------|
| | Patients with stage I-III colorectal cancer should receive colonoscopy or double contrast barium enema within 3 years of curative surgery and every 5 years thereafter. | QATOOL (RAND) |
| | To ensure that all eligible members who have been newly diagnosed and resected with colorectal cancer receive a follow-up colonoscopy within 15 months of resection. | NQF |
| Prostate | Documentation/evidence of communication with patient's primary care physician or provision of continuing care. | RAND prostate |
| | At least two visits for follow-up by treating physician during the first post-treatment year. | RAND prostate |
| Melanoma | Patients with a personal history of cutaneous melanoma should receive a referral to a dermatologist for surveillance screening. | QATOOL (RAND) |

QOPI, Quality Oncology Practice Initiative (American Society of Clinical Oncology); NQF, National Quality Forum; Surv. Nav. Measures, Survivorship Navigation Measures; NICCQ, National Initiative on Cancer Care Quality; QATOOL, Quality Assessment Tool, RAND Corporation; ONS BCS, Oncology Nursing Society Breast Cancer Survivorship Measures.

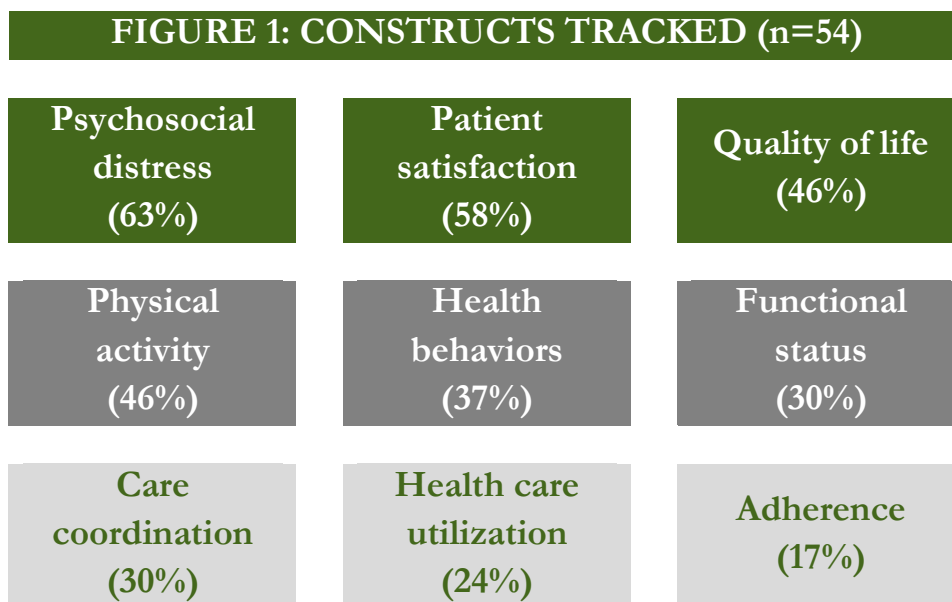
TABLE 2: PROPOSED CANCER SURVIVORSHIP-SPECIFIC MEASURES

| Level | Measures for Care Planning ⁶ |
|------------------|--|
| Survivor | Improved (perceived) patient/doctor communication |
| | Improved understanding of needed follow-up tests, their purpose and periodicity and who will conduct these |
| | Better understanding of potential late effects of illness and what symptoms might be important to report |
| | Better adherence to recommended follow-up activities |
| | Improved ability to identify providers and resources to address persistent effects of cancer and its treatment |
| | Decreased cancer-related morbidity |
| | Improved health-related quality of life and function |
| | Improved healthy lifestyle choices |
| Clinician | Potentially, improved overall survival |
| | Improved (perceived) doctor/patient communication |
| | Improved doctor/doctor communication |
| | Better ability to coordinate care |
| | Improved knowledge about and ultimately standardization of follow-up care behaviors |
| System | Improved ability to monitor survivor's health and implement changes in care in response to new information about treatment exposures and follow-up needs |
| | Reduced duplication of services |
| | Improved access to information necessary to guide follow-up care; less time spent searching for this |

| Outcome | Survivorship Navigation Measures ⁷ |
|---|---|
| Health care utilization: access to clinical care | Remove concrete barriers to care |
| | Track adherence to clinical follow-up measures |
| | Connect patient to usual source of care/medical home |
| | Connect patients to specialized survivorship care when possible |
| | Coordinate care amongst various providers to reduce duplication of services Ensure patients do not get lost to follow-up |
| Health care utilization: awareness of late and long-term effects | Provide survivors general information about long-term and late effects, customized to cancer type and treatment modality when possible |
| | Empower patients to request a survivorship care plan or adhere to their plan if they have one |
| Health care utilization: access to supportive care | Assess for distress |
| | Refer to social work, psychology or psychiatry as indicated |
| | Refer and coordinate appointments with subspecialists to address long-term or late effects (e.g., functional ability, fertility concerns, pain) |
| PRO: quality of life | Assess QOL; provide emotional support |
| | Link patients to appropriate community resources |
| | Provide information on support groups and peer support programs |
| | Assess social, financial and practical facilitators and barriers to QOL |
| | Assist with paperwork needed to access insurance, public safety net programs and health care system Provide information to address employment, financial or other practical concerns |
| PRO: self-efficacy and activation | Empower survivors through education about long-term and late effects |
| | Coach on interaction with medical team to help survivors negotiate care |
| | Empower patients to navigate the health system on their own through education and support |
| PRO: satisfaction with care and navigation | Provide emotional support, resource referral, and care coordination |
| | Consider language and culture when making referral recommendations |
| | Provide emotional support and information on spiritual support communities and programs |
| PRO: health knowledge and literacy | Educate survivors about their cancer and treatment history, as well as long-term and late effects |
| | Coach on interaction with medical team to help survivors understand their medical history and plan of care |
| PRO: healthy behaviors | Educate survivors on preventive behaviors and ways to optimize wellness |

PRO, Patient-Reported Outcome

In the GW Cancer Institute's 2013 Best Practices in Navigation and Survivorship Survey, participants were asked to identify which survivorship constructs they track. The results are summarized in Figure 1 below.⁸⁹



ONLINE RESOURCES

[NCI Grid Enabled Measures- Survivorship Care Planning Initiative](#)

[GW Cancer Institute Summary of Best Practices in Navigation and Survivorship Survey](#)

Part II - Navigation

Navigation Measures

Similar to survivorship, no set standard measures exist; however, several have been proposed. In 2010, the American Cancer Society hosted a National Patient Navigation Leadership Summit to develop a consensus on outcomes of patient navigation.¹⁰ The results were published in a supplement of *Cancer*, which is the source of these measures, referenced below. The supplement, *National Patient Navigation Leadership Summit (NPNLS): Measuring the Impact and Potential of Patient Navigation, Supplement to Cancer*, is a valuable resource for patient navigation constructs, outcomes and measurement tools across the cancer continuum. Table 3 outlines recommended common data elements for patient navigation from the supplement.¹¹

TABLE 3: RECOMMENDED COMMON DATA ELEMENTS FOR PROCESS METRICS

| Area | Measure | Indicator |
|-----------------------------|--|--|
| Patient Encounters | Navigator caseload: | <ul style="list-style-type: none"> • # of patients navigated per navigator • Time spent per patient (minutes, hours) • # days in navigation |
| | Communication between navigator and patient: | <ul style="list-style-type: none"> • Encounter type: in-person, phone, letter • Interpreter used (yes/no) • Date of first encounter • Date of last encounter |
| | Adherence to scheduled clinical visit: | Did they adhere? (yes/no) Track: Date of appointment Type of appointment Status of appointment: <input type="checkbox"/> Arrive <input type="checkbox"/> No show <input type="checkbox"/> Cancel <input type="checkbox"/> Reschedule |
| | Barriers/Actions: | <ul style="list-style-type: none"> • # and type of barrier per patient • # and type of action taken per barrier/patient • # of referrals to specialists or other services |
| Patient Satisfaction | Patient satisfaction: | <ul style="list-style-type: none"> • Patient satisfaction score before and after implementation of navigation services |
| | Outmigration: | <ul style="list-style-type: none"> • Number of patients leaving cancer center to receive services elsewhere (outmigration) before and after implementation of navigation services |
| Programmatic | Phases of cancer care treated by navigation program: | Outreach / Screening Diagnostic clinical visit / Follow-up Treatment Survivorship |
| | Marketing of program | <ul style="list-style-type: none"> • # of physician referrals before and after program • Development of patient/caregiver materials |
| | Navigation policy and process | <ul style="list-style-type: none"> • Eligibility of services (e.g., cancer type, need) • Description of navigation services |
| | Evaluation | <ul style="list-style-type: none"> • Development of patient satisfaction survey |
| | Patient Education | <ul style="list-style-type: none"> • Support group or other program • Patient materials |

TABLE 4: POTENTIAL OUTCOMES, ACTIVITIES AND MEASURES FOR PATIENT NAVIGATION

| Outcome | | Navigator Activity | Measurement Tools |
|---|---|--|--|
| Prevention/early detection of cancer ¹² | Timely cancer screening | Educate patients regarding screening guidelines; facilitate screening appointments | Tracking log (education yes/no; completion of screening test yes/no) |
| | Early-stage disease detection | Educate patients regarding early signs/symptoms of cancer; facilitate diagnostic appointments | Tracking log (completion of diagnostic resolution yes/no); medical records for referrals and stage at diagnosis |
| Health care access and coordination ¹³ | Perceived & actual ability to obtain timely care; Access to evidence based care | Assist with facilitating appointments; Assist with facilitating ancillary care; Assist with transportation as needed | Tracking logs; medical records; patient satisfaction surveys |
| Health care utilization ¹⁴ | Access to clinical care | Remove barriers to care | Barriers checklist with patient plan to address barriers |
| | | Track adherence to clinical recommendations (treatment initiation, post-treatment follow-up) | Medical records; baseline and post-navigation no-show rates; tracking log |
| | | Connect patient to medical home | Tracking logs |
| | | Coordinate care between providers | Medical record; tracking log; documentation of care plan |
| | | Ensure patients are not lost to follow-up | Tracking log; survivorship clinic record |
| Health care utilization ¹⁵ | Awareness of late and long term effects (specific to survivorship navigation) | Provide survivors with information regarding late and long term effects specific to their treatment history | Tracking log (information provided) |
| | | Empower patients to request a survivorship care plan & promote adherence | Tracking log |
| | Access to advance care planning, palliative care and hospice ¹⁶ | Educate patients regarding advance care planning, palliative care, hospice | Tracking log; medical record for documentation of advance care plan; number and timing of referrals to palliative care and hospice |
| Health care utilization ¹⁷ | Access to supportive care | Assess for distress; referral to social work, psychology or psychiatry as indicated | Distress Thermometer; medical records for referral |

| | | | |
|--|---------------------------------------|---|--|
| Patient Reported Outcomes ¹⁸ | Quality of life | Assess quality of life, provide support | Examples of quality of life measures: Impact of Cancer Scale, Functional Assessment of Chronic Illness Therapy (FACT), Patient-Reported Outcomes Measurement Information System (PROMIS) |
| | | Connect to appropriate community resources | Barriers checklist and referral records |
| | | Provide information on support groups | Tracking log |
| | | Assess social, financial, practical barriers and facilitators to quality of life | Patient Navigation Research Program Barriers Checklist |
| | | Assist with paperwork to access insurance and other programs | Tracking log |
| | | Provide information regarding employment, financial, practical concerns | Tracking log |
| Patient Reported Outcomes ¹⁹ | Self-efficacy | Empower patients through education | Communication and Attitudinal Self-Efficacy-Cancer (CASE-C) |
| | | Empower patients to navigate the health care system | Impact of Cancer Scale, Patient Activation Measure (PAM) |
| Patient Reported Outcomes ²⁰ | Satisfaction with care and navigation | Provide emotional support, resource referral, care coordination; consider language and culture in recommendations; provide information on spiritual support | Patient satisfaction surveys and scales; Consumer Assessment of Healthcare Providers and Systems (CAHPS-Cancer), Patient Satisfaction with Cancer-related Care (PSCC) |
| Patient Reported Outcomes ²¹ | Health knowledge and literacy | Educate patients on cancer, treatments, late and long term effects | CAHPS-Health literacy module; Tracking log |
| Patient Reported Outcomes ²² | Healthy behaviors | Educate patients on ways to optimize wellness | Patient interview: compare patient behaviors at baseline and post navigation; adherence to referral to dietician; tracking log |

Table 4 outlines of potential outcomes, activities and measures for navigation.^{23,24}

In the GW Cancer Institute's 2013 Best Practices in Navigation and Survivorship Survey, participants were asked to identify which navigation constructs they track and how they track each construct.²⁵ The results are summarized in Figure 2 below.

FIGURE 2: NAVIGATION CONSTRUCTS AND TRACKING (n=72)

| | |
|-------------------------------|--|
| Care coordination (79%) | <ul style="list-style-type: none"> • Tracking log • Medical record |
| Barriers (75%) | <ul style="list-style-type: none"> • Tracking log |
| Communication (69%) | <ul style="list-style-type: none"> • Medical record • Tracking log |
| Time to treatment (68%) | <ul style="list-style-type: none"> • Tracking log • Medical record |
| Psychosocial distress (68%) | <ul style="list-style-type: none"> • Validated tool |
| Adherence to visits (65%) | <ul style="list-style-type: none"> • Tracking log • Medical record |
| Patient satisfaction (57%) | <ul style="list-style-type: none"> • Homegrown tools |
| Treatment adherence (54%) | <ul style="list-style-type: none"> • Medical record • Tracking log |
| Time to screening (50%) | <ul style="list-style-type: none"> • Tracking log • Medical record |
| Health care utilization (47%) | <ul style="list-style-type: none"> • Medical record • Tracking log |
| Healthy behaviors (44%) | <ul style="list-style-type: none"> • Medical record • Tracking log |
| Quality of life (39%) | <ul style="list-style-type: none"> • Medical record • Validated tool |



ONLINE RESOURCES

[Association of Community Cancer Centers Patient Navigation Tools \(Sample Patient Navigation Satisfaction Surveys\)](#)

[NCI Grid Enabled Measures- Survivorship Care Planning Initiative](#)

[GW Cancer Institute Summary of Best Practices in Navigation and Survivorship Survey](#)

[Supplement: National Patient Navigation Leadership Summit \(NP-NLS\): Measuring the Impact and Potential of Patient Navigation, Supplement to Cancer](#)

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Making the Business Case

Section Overview

In this section you will learn how to make the business case for your program. After completing this section you will be able to:

1. Understand the importance of a business plan.
2. Identify the components of a business plan.
3. Compose a business plan for your program.

Related Workbook Activity:

Activity 13: Writing a Business Plan

Creating a Business Plan

A business plan is a tool for creating a roadmap for your program. By clearly articulating what you hope to achieve and how you will achieve it, writing a business plan is a critical part of developing your program. Not only is it helpful for you, but it can also be shared with other staff and clinicians, administrators and funders to demonstrate your program plan. This *Guide* and corresponding *Workbook* were developed to walk you through these components. By completing the activities you will have a solid starting place for completing your business plan. Please refer to Activity 13 in the *Workbook* on pages 23-25.

Business Plan Components

Below are the components of a traditional business plan along with a description of content to go in each section.

Executive Summary

- Enthusiastic snapshot of your program, explaining who you are, what you do and why
- Less than 2 pages in length
- Written last

Description and Vision

- Mission statement (program purpose that addresses who, what and how)
- Vision statement (big picture)
- SMART goals and objectives
- Brief history of organization/program
- Key principals of organization/program

Definition of the Market

- Describe your industry (survivorship, navigation, cancer) and outlook
- Define critical needs of your perceived or existing patient population
- Identify your patient population
- Provide a general profile of your targeted patients
- Describe what share of the targeted patient population you currently have and/or anticipate

Description of Services

- Specifically describe all of your services
- Explain how your services are competitive
- If applicable, reference a picture or brochure of your program and include in appendix

Organization and Management

- Provide a description of how your program is organized and an organization chart, if available
- Provide a brief bio description of key program managers and staff

Marketing Strategy

- Identify and describe your market – who are your patients and what is the demand for your services?
- Describe your channels of distribution (web, mail, personal referral)
- Explain your marketing strategy, specific to pricing, promotion, products and place (4Ps)

Financial Management

- Budget (with start-up costs)
- Sustainability plan – funding sources, long-term planning
- Return on Investment – cost savings, increased revenue to institution

Appendices

- Brochures, flyers
- Resumes of personnel
- Equipment/space
- Organization Chart
- Staff descriptions



AN IN-DEPTH LOOK

Cherry Blossom Cancer Center Sample Business Plan

The following business plan was drafted based on a fictitious institution, the Cherry Blossom Cancer Center. Rather than providing you with a full business plan, we have outlined potential content that goes in each section. The previous activities you completed were designed to help you easily pull this information together, so you may want to reference them as you go through the business plan activity.

Executive Summary

The Cherry Blossom Cancer Center is located in metropolitan Washington, DC. In this urban setting, CBCC serves approximately 800 patients a year. CBCC is a Commission on Cancer-accredited non-profit medical center primarily serving wards 1-8 in the District as well as nearby Maryland and Northern Virginia counties.

Be sure to complete the Executive Summary after you have completed the other sections of your business plan.

Our patient population consists of a high percentage of African American and Hispanic patients, with most over the age of 65. Females make up the majority of our population (60%). CBCC sees patients that tend to have private insurance followed by Medicare, Medicaid and those without insurance.

In response to the high incidence and death rate due to cancer in the Washington, DC area, CBCC is developing navigation and survivorship programs to reduce health disparities and improve health outcomes and quality of life for those affected by cancer.

Though there are several other cancer centers in the area, currently no institution provides survivorship care, making CBCC a unique provider of comprehensive cancer care in Washington, DC.

Description and Vision

Organizational Mission and Vision

Mission: To provide high-quality health care to our patients along the entire cancer continuum.

Vision: To be the top-ranked cancer center in our region.

Use the information you compiled from Activities 6 and 7 to complete this section.

Navigation Program Mission and Vision

Program mission: To provide high-quality health care through patient navigators who reduce barriers to care for cancer patients along the entire cancer continuum.

Program vision: To be the first choice for cancer care in our region.

Navigation Program Year 1 SMART Goals

- By January 1, 2016, navigate 350 high-risk patients through treatment.
- By January 1, 2016, remove 1,000 barriers for high-risk patients undergoing treatment.

- By January 1, 2016, conduct psychosocial assessment using the Distress Thermometer with 100% of patients.
- By January 1, 2016, review Community Needs Assessment for Commission on Cancer accreditation and identify top barrier to focus on in 2017.

Survivorship Program Mission and Vision:

Program mission: To provide high-quality health care to cancer survivors after they have completed active treatment.

Program vision: To be the first choice for cancer survivorship care in our region.

Survivorship Program Year 1 SMART Goals (assume program launch of January 1, 2014):

- By January 1, 2015, 25% of eligible cancer survivors receive a SCP at first follow-up visit after active treatment ends.
- By January 1, 2015, 100% of eligible cancer survivors who received a SCP assessed for psychosocial distress and referred for services according to the assessment.
- By January 1, 2015, 50% of cancer survivors have their SCP sent to their Primary Care Physician.
- By January 1, 2015, 50% of cancer survivors have an increase in their knowledge of their individual survivorship care.

Definition of the Market

Competitors and Description

- There are 3 other cancer centers within 20 miles.
- There are several community-based patient navigation programs at hospitals and clinics in the area.
- No cancer centers in the area have a survivorship program.

Use the information you compiled from Activities 1-5 to complete this section.

Target Market/Patient Population

- Breast cancer patients diagnosed and/or in treatment (navigation)
- Cancer survivors
- Underserved populations (Wards 7 and 8)

Description

More than 1.6 million Americans are diagnosed with cancer each year, and it is estimated that almost 600,000 people will die of cancer in 2012 (NCI 2012). Sadly, the District of Columbia is ranked highest in overall cancer mortality in the nation. Breast, colorectal and prostate mortality rates are higher in Washington, DC as compared with the national average (DCCC 2012). While there are many types of cancer, the CBCC focuses on the leading cancers with which we can most effectively conduct education and outreach and that affects our area residents at an increased rate. These are colorectal, prostate and breast cancers.

The CBCC primarily serves wards 1-8 in Washington, DC as well as Maryland and Northern Virginia surrounding areas. There are three other cancer centers in the area that serve the metropolitan Washington, DC area, and cancer patients often receive different components of their care at different institutions. There

is also a significant survivor population that is lacking adequate follow-up care. CBCC will be the only cancer center in the region to provide survivorship care.

Description of Services

Navigation Program

Our program will provide the following services:

- Support groups
- Referrals to housing assistance and other assistance with practical concerns (food, employment)
- Language assistance for patients for whom English is a second language
- Nutrition education
- Care coordination
- Financial assistance
- Transportation assistance
- Scheduling assistance
- Psychosocial assessment using the Distress Thermometer

Use the information you compiled from Activity 8 to complete this section.

Survivorship Programs

Our program will provide the following services:

- The NP will provide the treatment summary and survivorship care plan to breast and colorectal cancer patients transitioning off treatment.
- Clinical services will include medical and psychosocial assessment as well as specialty referrals. This is a one-time consultative visit.
- Additional support programs, such as support groups and educational seminars, will be provided for cancer survivors and their caregivers.

Organization and Management

Key Personnel

Navigation

Non-Clinically Licensed Navigator

- *Professional qualifications/ background:* The non-clinically licensed navigator has attended several intensive patient navigation trainings and will complete the GW Cancer Institute's competency-based training for non-clinically licensed navigators.

Use the information you compiled from Activities 2 and 8 to complete this section.

- *Responsibilities:* The non-clinically licensed navigator will be responsible for connecting cancer patients to financial and insurance resources and helping to acquire transportation assistance to reduce the rate of no-shows. S/he will focus on newly diagnosed patients and those still in treatment.

Nurse Navigator

- *Professional qualifications/ background:* The nurse navigator has 28 years of experience in oncology, the last 2 of which have been in our breast clinic.
- *Responsibilities:* The nurse navigator will focus on navigating women who have been screened and have a positive finding to treatment. S/he will follow-up with women by phone to explain the results, answer questions and assist in setting an appointment with the oncologist, conducting a psychosocial assessment and providing referrals when needed. S/he will participate in the initial appointment and review the diagnosis and treatment options with the patient.

Survivorship

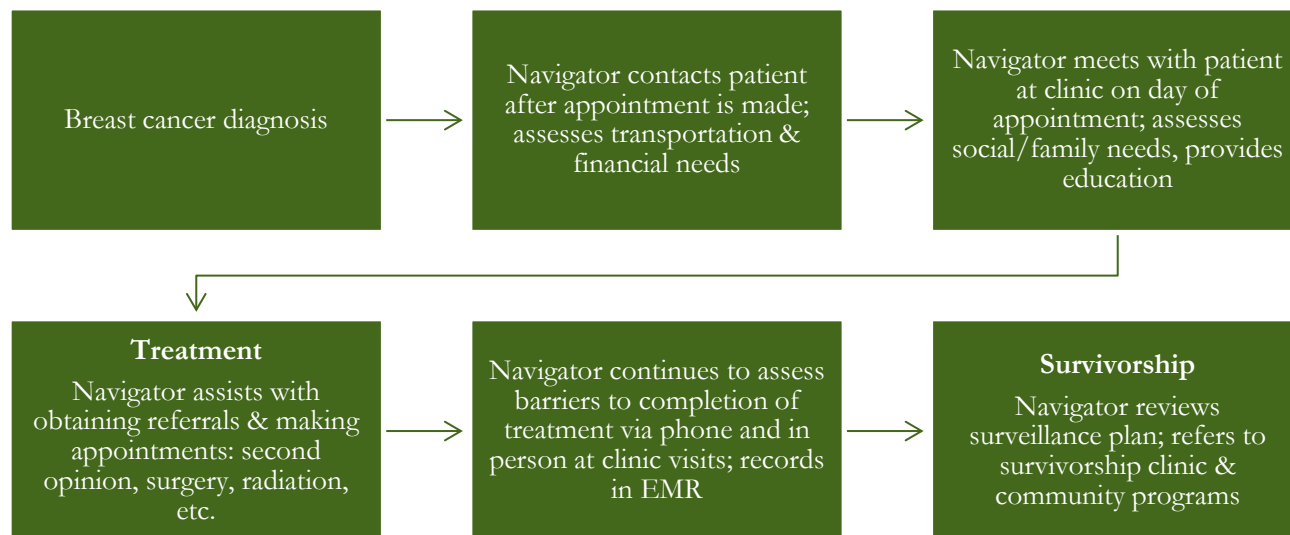
Nurse Practitioner

- *Professional qualifications/ background:* The nurse practitioner is an oncology certified nurse with over 11 years of oncology experience.
- *Responsibilities:* As the survivorship director, the nurse practitioner will be responsible for gathering treatment information and creating the survivorship care plan and coordinating communication between the oncology team and the primary care providers.

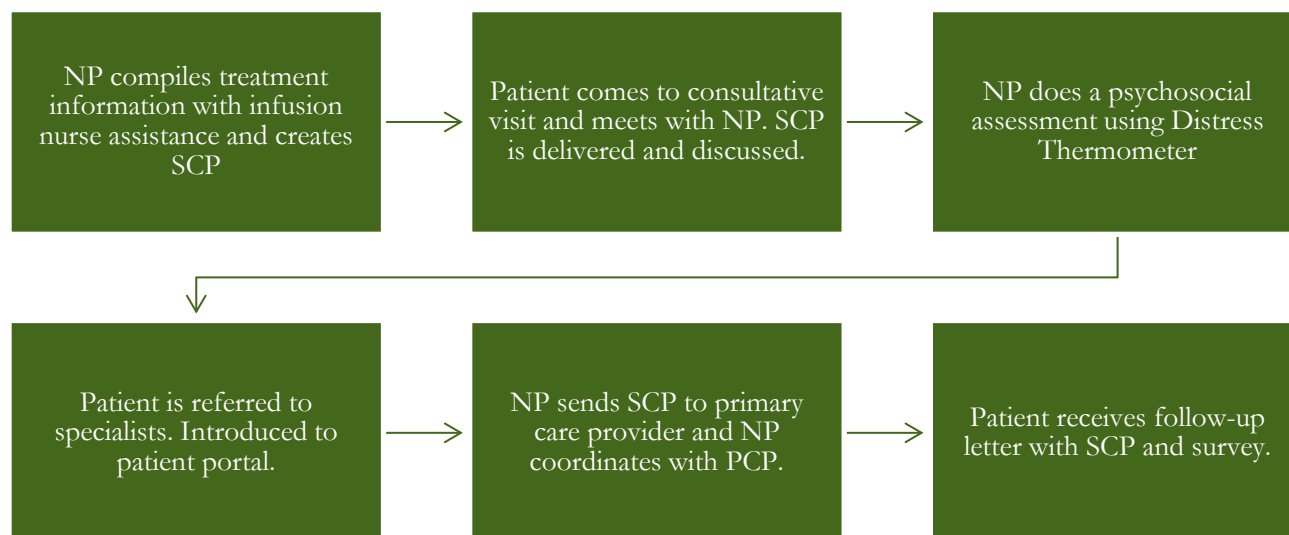
Registered Nurse

- *Professional qualifications/ background:* The registered nurse has 5 + years of experience in oncology.
- *Responsibilities:* The registered nurse will assist with providing the SCP to the PCP and with financial aspects of the clinic.

Work Flow and Responsibilities – Navigation



Work Flow and Responsibilities – Survivorship



Management – Navigation

The nurse navigator will be responsible for oversight of the patient navigation program and report to the Director of Oncology. The non-clinically licensed navigator will report directly to the nurse navigator. They will submit monthly reports and present every 6 months at Cancer Committee meetings.

Management - Survivorship

The clinic is led by the nurse practitioner. Patient initiatives are developed at monthly survivorship task force meetings where operations and outcomes are also reviewed. Members include receptionist, administrative and clinical staff, cancer survivor, community partners, marketing, IT and development.

Marketing Strategy

Target Audiences

- Cancer patients and survivors
- Medically underserved individuals/communities
- Family and friends of those facing cancer
- Cancer center clinicians and staff
- Volunteers/potential volunteers
- Community organizations
- Media

Refer to pages 83-87 for tips on developing a marketing strategy for your program.

Marketing Goals

- Raise awareness about our program
- Strengthen our unique identity within the community
- Form new relationships and strengthen existing relationships with other community agencies
- Understand who we are serving and who is not being served
- Garner physician buy-in
- Increase patient referrals both from clinic physicians and self-referrals

Marketing Activities

- Hire an intern or volunteer to assist with outreach efforts
- Provide a monthly program calendar of events and services that is sent to clients, community organizations and medical providers
- Send e-newsletter alerts that include announcement of new program
- Write a press release to announce the survivorship clinic

- Develop a general brochure used to inform the community (including clients, donors and volunteers) about our services
- Create a flyer to post at cancer center
- Post information on institution's website
- Presentations at meetings in institution (regular in-services, grand rounds, etc.)
- Give out information in new patient/survivor packets

Financial Management

Budget for Navigation Program

In the first year we expect the navigation infrastructure costs to be about \$100,000. Infrastructure funding will be sought from a local foundation grant and some internal funds. After the initial year, the cancer center will absorb the program costs. By the third year we anticipate the program will break even based on the revenue generated by reducing no-show rates and increasing referral appointments within the facility.

Use the information you compiled from Activities 10 and 11 to complete this section.

| Item | Amount | Funding Source |
|---|------------------|----------------|
| Personnel Costs | \$100,000 | |
| Nurse Navigator (1 FTE) | \$60,000 | Internal |
| Non-clinically licensed (1 FTE) | \$40,000 | Grant |
| Program Costs | | |
| Printing | \$50 | |
| Patient materials | \$50 | Grant |
| | | |
| Marketing and Outreach | \$250 | |
| Brochure printing | \$250 | Grant |
| | | |
| Supplies | \$150 | |
| Patient informational binders | \$150 | Grant |
| | | |
| Travel | \$1,850 | |
| Annual professional society meeting presentation (hotel, airfare, ground transportation, meals) | \$1,600 | Grant |
| Local outreach (miles reimbursement) | \$250 | Grant |
| | | |
| Total | \$102,300 | |

Budget for Survivorship Program

In the first year we expect the survivorship program infrastructure costs to be about \$90,000. Infrastructure funding will be provided through our internal budget and a small grant. By the second year we anticipate the program will break even through reimbursement for services provided.

| Item | Amount | Funding Source |
|---|-----------------|----------------|
| Personnel Costs | \$57,500 | |
| NP/Survivorship Project Coordinator (.50 FTE) | \$35,000 | Internal |
| Dietitian (.25) | \$12,500 | Grant |
| Medical Director (.05 FTE) | \$10,000 | Internal |
| Program Costs | \$4,100 | |
| Print and Promotional Materials | \$2,250 | |
| Print newsletters | \$2,000 | Internal |
| Flyers to post at cancer center | \$250 | Internal |
| | | |
| Marketing and Outreach | \$0 | |
| Press release | \$0 | Internal |
| | | |
| Supplies | \$250 | |
| Survivorship binders | \$250 | Internal |
| | | |
| Travel | \$1,600 | |
| Annual professional society meeting presentation (hotel, airfare, ground transportation, meals) | \$1,600 | Internal |
| | | |
| Total | \$61,600 | |

Appendices

This section should include as attachments:

- Brochures/flyers
- Resumes of key employees
- Other relevant materials



ONLINE RESOURCES

[U.S. Small Business Administration's Business Plan Writing Tool](#)

Creating Excitement and Enhancing Success for Your Program

Section Overview

This section focuses on internal marketing of your program to create buy-in and support from within your organization. At the end of this section you will be able to:

1. Identify marketing tips and strategies for getting buy-in from administration, health care providers and staff.
2. Identify ways to educate providers, survivors and the community about the benefits of your program.
3. Understand components and value of crafting an elevator pitch for multiple stakeholders.

Tip:

An elevator pitch is a short, 30 second to two minute summary of the services you provide and value added.

Internal Marketing to Garner Buy-In and Support

A successful marketing approach can help educate patients and survivors about the services your program offers. It can also help educate providers and staff and give them an opportunity to be involved in the process. The tips below are broken down by target audience to guide you in creating a comprehensive approach that includes multiple stakeholders.

Institution

- Create a multi-disciplinary committee/task force to address cancer survivorship and/or navigation
- Align program goals and objectives with organizational mission, vision and values
- Set a bold vision and clear goals for your program
- Articulate key messages and keep them simple so everyone can remember and repeat them
- See the value of data and “use it to improve it”
- If patient satisfaction scores are a driver for the organization, think about how you can utilize satisfaction scores for your program and demonstrate that early and often
- Show outputs and outcomes of your program/services
- Brainstorm and “trystorm”

Providers

- Raise awareness about what benefits your program offers or will offer for health care providers, patients/ survivors; it is not a one-time activity, but continuous
- Tap existing relationships and build new ones as needed
- Be multi-lingual, know your audience and speak in their language
- Send mail to all referring physicians
- Create a brochure for providers with a letter signed by Medical Director
- Host Lunch and Learn sessions
- Promote at existing meetings (cancer committee, tumor board, grand rounds, etc.)
- Create flyer
- Talk with providers individually
- Follow up with providers to give them feedback (e.g., their patient did not make an appointment)
- Talk with patient navigators
- Post information on intranet
- Have champions discuss the program with others
- Develop brief informational handout on survivorship needs
- Host a reception for physicians
- Provide continued professional training through webinars and teleconferences

Survivors

- Create brochure/flyer – ask for survivor feedback in the development
- Promote survivorship at last oncology visit
- Tie-in to other existing programs (support groups, educational seminars, etc.)
- Post information on website
- Write a newsletter article (electronic or hard copy)
- Provide a monthly program calendar on events and services that is sent to clients, community organizations and medical providers
- Promote via social media (Facebook, Twitter, etc.)
- Give out information in new patient/survivor packets
- Create information with a literacy level appropriate to your population
- Create information for the range of preferred languages of your patient population/community

External Marketing to Promote Awareness

Community

- Notify local community organizations, such as Cancer Support Community, American Cancer Society or Leukemia & Lymphoma Society
- Hold an open house
- Write a newsletter article that organizations can put in their own publications
- Write a press release to announce the clinic
- Serve as an expert to be interviewed for local radio, newspapers and cancer-related websites
- Promote your services at a health fair
- Identify community leaders and levers (spiritual leaders, libraries, recreation centers) that can carry the messages

Tips for Crafting an Elevator Pitch

An elevator pitch is a short, 30 second to two minute summary of the services you provide and value added. The purpose of the elevator pitch is to grab a person's attention and interest to want to know about your services and program to continue the conversation. It should be tailored to different audiences based upon what they value to maximize effectiveness. The tips below are broken down by target audience to guide you in creating a tailored elevator pitch.

- Keep it short and simple
- Should generate excitement and be compelling
- Include the value added to stakeholder
- Know your audience
- Have an action item at the end

Providers

- Your added value to them
- Reduction in no-shows/missed appointments
- Adherence to treatment/follow-up recommendations
- Assisting with nonclinical issues (administrative, financial and practical)
- Free up their time to address clinical issues
- Reduces burden on oncologist so they can see patients in active treatment
- Address provider specific patient issues/challenges
- "Gap filler"

Patients

- Your added value to them- alleviating burden of...
- Acting as "guide" through the health care system
- Helps address unmet needs
- Services you provide- assisting with...
- Connection to community/culture
- Liaison between patient and provider
- Help you to "get care at the right place, right time"
- Reduces anxiety/stress
- Minimize long-term health impacts

Institution

- Align your role with organizational mission, vision and values
- Include a short patient story or testimonial
- Outputs and outcomes of your services
- Return on investment/cost-effectiveness
- Reduction in readmission or emergency room visits
- Single point of contact between patient and provider
- Help to meet Commission on Cancer standards

Funders

- # of patients served
- # of barriers eliminated
- # of uninsured/underserved patients
- Outputs and outcomes of your services
- “Reach”
- Public health impact
- Cancer patients living longer through and beyond treatment

Benefits of Survivorship Programs

Being able to clearly articulate the benefits of survivorship programs can help in attaining buy-in from providers and staff. Some potential benefits for different audiences are detailed in Table 1.

| Table 1: Benefits of Survivorship Programs | |
|--|--|
| Benefits for Providers | Benefits for Survivors |
| <ul style="list-style-type: none"> ▪ Reduce the burden on oncologists so they can continue seeing new patients ▪ Serve as a communications hub to help coordinate care across providers and with survivors ▪ Provide additional resources to address many of the issues that oncologists do not have time to address or that primary care providers do not know need to be addressed ▪ Help to better keep track of patients ▪ Can serve as an opportunity to train residents | <ul style="list-style-type: none"> ▪ Opportunity to leverage a “teachable moment” and promote healthy behaviors ▪ Help address needs that are currently going unmet ▪ Reduce anxiety/provide peace of mind ▪ Better coordination can reduce stress on the survivor and reduce unnecessary tests ▪ Increase adherence to recommended follow-up to prevent or minimize long-term health impacts |

Benefits of Navigation Programs

In addition to the Principles of Patient Navigation outlined by Freeman and Rodriguez, there are many patient and organizational benefits of patient navigation. The following benefits come from C-Change's Cancer Patient Navigation Toolkit, which is available at www.cancerpatientnavigation.org.

Patient Benefits¹

- Improved access to cancer screening and diagnostics
- Improved access to timely medical treatment
- Improved prognosis with early identification and treatment of cancer
- Improved coordination of care
- Improved comfort level with health care providers and the health care system

- Improved access to financial resources
- Improved access to support resources

Organizational Benefits²

- Earlier identification of patients with cancer, and better prognosis
- Improved coordination of care with cancer providers in the health care system and in the community
- Identification and removal of systemic barriers in access to care
- Improved efficiency in use of resources
- Improved patient satisfaction with cancer treatment experience
- Improved integration of the community's cancer support resources
- Enhanced connection to the cultural and geographic community

¹ C-Change Patient Navigation Brochure <http://www.cancerpatientnavigation.org/docs/Brochure.pdf>

² C-Change Patient Navigation Brochure <http://www.cancerpatientnavigation.org/docs/Brochure.pdf>

IMPLEMENT

Putting Your Plan Into Action

Section Overview

In this section you will learn about the steps needed to achieve your program plan. After completing this section you will be able to:

1. Identify short-term and intermediate activities prior to launching your program.
2. Develop an action plan with concrete next steps.
3. Implement your next steps.

Related Workbook Activity:

Activity 14: My Next Action Steps

Potential Next Steps

Once you have developed a plan for how to implement and sustain your patient navigation and/or survivorship program, you can identify the next steps that need to be taken to launch your program. Activity 14 in the *Workbook* on page 27 helps you identify concrete next steps for the short- and intermediate-term. The following tips are suggestions for actions that can be taken and are meant to help guide you through the activity.

Needs Assessment

- Create a patient/physician needs survey
- Conduct informal/formal interviews or focus groups

Building a Program

- Refine mission, vision, goals and objectives
- Write a business plan
- Create job descriptions for staff
- Hire new staff
- Identify training opportunities for existing staff
- Determine appropriate clinical tools needed
- Determine referral process
- Identify potential services to include
- Follow-up with Executive Training participants
- Select or create Survivorship Care Plan template

Garnering Support

- Identify key stakeholders
- Convene a meeting with champion(s)
- Meet individually with key people
- Establish a multi-disciplinary Survivorship Task Force

Marketing

- Create a survivor brochure or flyer
- Create a flyer to educate providers
- Meet with Marketing/Communication staff
- Post information about the program on the institution's website
- Contact community organizations
- Create or implement a survivorship transition education program

Funding/Sustainability

- Create a budget
- Identify funding opportunities
- Meet with registrar or billing

Evaluation

- Establish key metrics and determine measures
- Develop a logic model
- Develop an evaluation plan
- Create or buy a tracking system

EVALUATE

Evaluating Outcomes and Refining your Program Plan

Section Overview

The final section highlights steps you can take to refine your program plan using the information from your continuous evaluation that may reveal program challenges or weaknesses. You should refer back to your needs assessment to help guide you through process improvement. At the end of this section, you should be able to:

- Identify program implementation barriers and possible solutions.

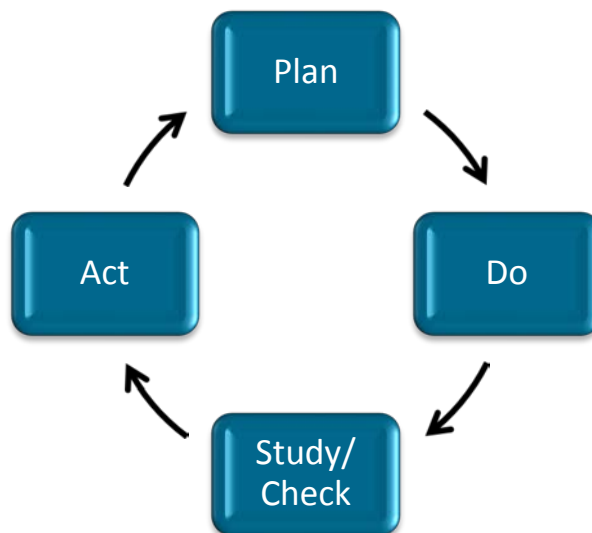
Tip:

Many programs look different after they get up and running. The best programs result from continual process improvement.

Evaluating Outcomes

Evaluating outcomes is an important part of the program development process and success of your program. What you do with your results is as equally important. Use the information gathered through your needs assessment, process evaluation and outcomes evaluation to improve your program so that it is achieving the intended results.

One method often used for quality improvement is the PDSA cycle.¹ It may help you frame your evaluation efforts. PDSA stands for: Plan (P), Do (D), Study (S) and Act (A). Sometimes PDCA is used, where the C stands for Check.



According to the PDSA cycle, you start by planning (Plan) your program and then you implement (Do) the program. Once it has been implemented you assess whether/how it is working (Study/Check) and then you decide whether you want to keep the program as-is, make changes to the program or not move forward with the program. You would then continue to repeat the cycle to make sure your program best meets your needs.

Brief tips 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 the information you provide to them (e.g., cost savings, revenue generated, increased patient satisfaction)

Use of evaluation outcomes may include:

- Inclusion in your organization's annual report, website or other publication
- Justification to administration for program funding and program value
- Inclusion in proposals to funders
- Inclusion in marketing and outreach to patients, caregivers and providers on program effectiveness
- Improvement in quality of life for those affected by cancer – knowing that what you do makes a difference

Refining your Program Plan - Overcoming Barriers and Identifying Solutions

As you launch your program, you may run into barriers. The chart below summarizes some commonly identified barriers and offers some solutions that may be helpful. You may want to consider these challenges while you are in the program planning phase so you can design a program that is realistic given your constraints.

| BARRIER | SOLUTIONS |
|---|---|
| Lack of time for current staff to incorporate these aspects of care into work and/or Lack of staff to provide a program | <ul style="list-style-type: none"> • Start with a small/manageable population • Identify priority services to start with • Consider a consultative model • Identify allies or other providers who may be able to assist • Think beyond physicians for creating the SCP • Consider community organizations that can provide resources and services on- or off-site • Explore ways to streamline SCP development, such as working with IT to automate parts of the process |
| Lack of funding to support such a program | <ul style="list-style-type: none"> • Clearly define goals, activities and resources needed • Build program evaluation to gather information to demonstrate its value • Consider community funders to build infrastructure • See Potential Funding Sources in the Funding, Sustainability and Resources section • Talk with the billing department to identify and track revenue-generating services |
| Lack of knowledge regarding survivorship issues and needs | <ul style="list-style-type: none"> • Professional societies, like ASCO and ONS, and community organizations, like the American Cancer Society, provide survivorship information • Create a CE program at your institution to share survivorship knowledge • Provide survivorship information at existing meetings, or convene a meeting to raise awareness about post-treatment issues |
| Lack of consensus-based guidelines | <ul style="list-style-type: none"> • Either create a committee or designate a person to draft institutional guidelines • ASCO and NCCN have symptom based guidelines • Some guidelines by tumor type for primary care providers are available through the National Cancer Survivorship Resource Center • MD Anderson has clinical practice algorithms for use at various stages of cancer treatment. |
| Lack of resources to offer in program | <ul style="list-style-type: none"> • Conduct a needs assessment and look at internal and external resources that are available |
| Lack of interest in such a program by leadership in the work setting | <ul style="list-style-type: none"> • Bring leadership into the discussion early on • Educate leadership on the need for a survivorship program • Start a survivorship task force • Use Commission on Cancer standards to incentivize • Demonstrate clear vision and program plan |
| Travel time or distance for patients to attend relevant program activities | <ul style="list-style-type: none"> • Consider alternative models, such as using internists with survivorship expertise who can manage multiple comorbidities at |

| BARRIER | SOLUTIONS |
|---------|-----------------------------|
| | once or telemedicine models |

| | |
|---|---|
| <p>Physician support but not referrals and/or</p> <p>Lack of interest in such a program by patients or families</p> | <ul style="list-style-type: none"> • Clearly articulate benefits for patients, providers and the institution • Educate all clinicians and staff about the program, including patient navigators, schedulers, etc. • Follow up with clinicians to let them know whether their referred survivors make appointments • Create informational resources (e.g., flyers or brochures) for both survivors and providers • Integrate the program into the standard of care so it does not seem optional • Educate survivors at final treatment visit about the survivorship program • Implement educational programs or workshops for survivors who are transitioning off treatment • Target services to what is most needed by patients and providers |
|---|---|

¹ Institute for Healthcare Improvement. Plan-Do-Study-Act (PDSA). Accessed August 29, 2014 from: <http://www.ihl.org/resources/Pages/Tools/PlanDoStudyActWorksheet.aspx>.

RESOURCES

Online Resources for Health Care Professionals

Academy of Oncology Nurse Navigators

www.aonnonline.org

A professional organization dedicated to improving patient care and quality of life by defining, enhancing and promoting the role of oncology nurse and patient navigators.

American Cancer Society

www.cancer.org

The American Cancer Society is a nationwide, community-based voluntary health organization dedicated to eliminating cancer as a major health problem. Headquartered in Atlanta, Georgia, the ACS has 11 geographic Divisions, more than 900 local offices nationwide and a presence in more than 5,100 communities.

Association of Community Cancer Centers

<http://www.accc-cancer.org/resources/patientnavigation-PNT2009-toc.asp>

ACCC provides health care professionals with tools and tips on patient navigation program development.

Association of Oncology Social Work

www.aosw.org

An organization for psychosocial oncology professionals dedicated to the enhancement of psychosocial services to people with cancer and their families.

C-Change

<http://www.cancerpatientnavigation.org/>

C-Change provides a Patient Navigation Promotional Tool Kit for marketing your program.

Cancer.net

www.cancer.net/patient/survivorship

The Survivorship section of Cancer.net is geared towards patients. It offers information about survivorship, rehabilitation and being an advocate.

Cancer Care

www.cancercare.org/professionals

The 'Healthcare Professionals' section of the Cancer Care web site offers educational materials for clinical practice, distance learning programs and professional consultations.

Commission on Cancer

<http://www.facs.org/cancer/coc/bestpractices.html>

CoC Best Practices Repository houses tools and best practice resources to help institutions meet the CoC Cancer Program standards.

LIVESTRONG

www.livestrong.org

The 'Survivorship Centers' section offers information about the LIVESTRONG Survivorship Center of Excellence Network. The 'Cancer Support' section provides helpful resources for cancer survivors and their families.

National Association of Social Workers

www.naswdc.org

With the largest membership organization of professional social workers in the world, NASW works to enhance the professional growth and development of its members, to create and maintain professional standards and to advance sound social practices.

National Cancer Institute Office of Cancer Survivorship

<http://dcccps.nci.nih.gov/OCS>

The NCI Office of Cancer Survivorship site provides information about funding priorities in survivorship research.

National Cancer Survivorship Resource Center

www.cancer.org/survivorshipcenter

A collaboration between the American Cancer Society and the GW Cancer Institute through a 5-year cooperative agreement from the Centers for Disease Control and Prevention, the Survivorship Center's goal is to shape the future of cancer survivorship care and improve quality of life of cancer survivors as they transition from treatment to recovery.

National Coalition for Cancer Survivorship

www.canceradvocacy.org

The NCCS is a cancer survivorship advocacy organization. The web site provides legislative updates concerning cancer survivorship issues. The 'Cancer Survivorship Toolbox' is a useful resource to provide your patients.

National Comprehensive Cancer Network

<http://www.nccn.org/> (search Clinical Practice Guidelines in Oncology)

NCCN provides disease-specific treatment follow-up guidelines. Registration is required, but access to these guidelines is free.

Oncology Nursing Society

www.ons.org

A professional organization of registered nurses and other healthcare providers dedicated to excellence in patient care, education, research and administration in oncology nursing.

APPENDIX

List of Abbreviations

ACS: American Cancer Society

APRN: Advance Practice Registered Nurse

ASCO: American Society of Clinical Oncology

BrCa: Breast Cancer

CDC: Centers for Disease Control and Prevention

CE: Continuing Education

CEU: Continuing Education Units

CLL: Chronic Lymphocytic Leukemia

CML: Chronic Myelogenous Leukemia

CMO: Chief Medical Officer

CoC: Commission on Cancer

CRC: Colorectal Cancer

DO: Doctor of Osteopathic Medicine

FT: Full-time

FTE: Full-time equivalent

IOM: Institute of Medicine

IRB: Institutional Review Board

IT: Information Technology

MD: Medical Doctor

NCCN: National Comprehensive Cancer Network

NCI: National Cancer Institute

NICCQ: National Initiative on Cancer Care Quality

NP: Nurse Practitioner

NQF: National Quality Forum

ONS: Oncology Nursing Society

PA: Physician Assistant

PCP: Primary Care Provider

PDSA/PDCA: Plan-Do-Study-Act/ Plan-Do-Check-Act

PN: Patient Navigator

PRO: Patient-Reported Outcome

QATool: Quality Assessment Tool

QOPI: Quality Oncology Practice Initiative (American Society of Clinical Oncology)

RN: Registered Nurse

ROI: Return on Investment

SCP: Survivorship Care Plan

SES: Socioeconomic status

SMART goals: Specific Measurable Action-Oriented, Realistic, Time-Bound

SW: Social Worker

SWOT: Strengths, Weaknesses, Opportunities, Threats

TS: Treatment Summary