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

Program Development Workbook

GW | Cancer Institute

THE GEORGE
WASHINGTON
UNIVERSITY
WASHINGTON, DC

TABLE OF CONTENTS

ASSESS

Activity 1: Defining Your Patient Population

Instructions: The goal of this activity is to help you describe the patient population for which you will be establishing a navigation and/or survivorship program. Think about your different stakeholders (e.g., patients, providers, administrators, board of directors, funders) and what information would be most important to share with them. If you do not know the answers to some of the questions, try to answer them to the best of your ability if they are important to your stakeholders. Your institution may have compiled some of this information, or you may need to look at available city or state data.

Race/Ethnicity:

1. Please indicate the % or # of your patient population that is:

_____ American Indian and Alaska Native   _____ Native Hawaiian & Other Pacific Islander

_____ Asian   _____ White/Caucasian

_____ Black or African American   _____ Other

_____ Hispanic/Latino

Age:

2. Please indicate the % or # of your patient population that is:

_____ 0 to 17 years   _____ 50 to 64 years

_____ 18 to 34 years   _____ Over 65

_____ 35 to 49 years

Gender:

3. Please indicate the % or # of your patient population that is:

_____ Male   _____ Female   _____ Transgender

Socio-economic status (income, occupation, education, wealth and environmental factors):

4. Please indicate the % or # of your patient population that is:

_____ Low SES   _____ High SES

_____ Middle SES   _____ Unsure

Insurance:

5. Please indicate the % or # of your patient population with the following insurance:

_____ Private insurance   _____ Other

_____ Medicaid   _____ Uninsured

_____ Medicare

Disease Specification:

6. Please indicate the % or # of your patient population with the following cancer type within the last year:

_____ Bladder Cancer   _____ Lung Cancer

_____ Blood Cancer   _____ Melanoma

_____ Breast Cancer   _____ Pancreatic

_____ Cervical Cancer   _____ Pediatric Cancer

_____ Colorectal Cancer   _____ Prostate Cancer

_____ Endometrial Cancer   _____ Thyroid

_____ Kidney (Renal Cell) Cancer   _____ Other specific cancer type(s):

7. Please indicate the % or # of abnormal screening findings in the last year: _____

8. Please indicate the % or # of cases lost to follow-up that required medical treatment:_____

9. Please indicate the no-show rate for your patient population: _____

Health Barriers and Needs:

10. What are the barriers to quality cancer care for your primary patient population that make it difficult to access care or manage their health care needs? (Check all that apply)

_____Availability of health services   _____Fear/anxiety (mistrust of health system)

_____Communicating between care providers   _____Fragmented care
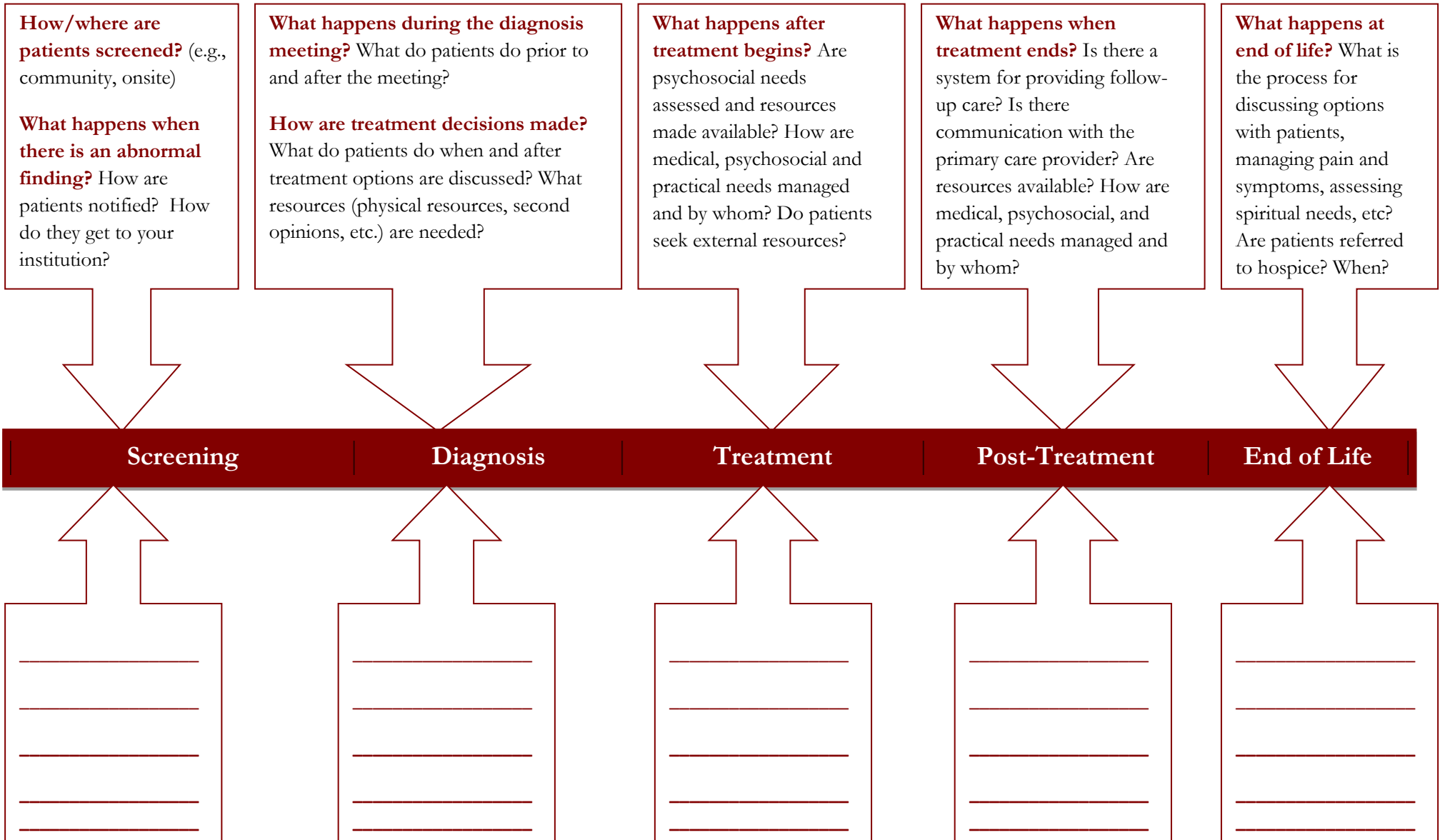
_____Cultural/Language   _____Gaps in financial/health Insurance coverage

_____Employment/School concerns   _____Lack of knowledge of late and long-term effects

---

_____Lack of long-term follow-up   _____Literacy barriers

_____Lack of PCP   _____Patient and caregiver education needs

_____Lack of support groups   _____Physical (location of facility)/Transportation

_____Lack of survivorship care plan

           _____Transition from oncologist to PCP

11. What percentage of your patient population does not speak English? _____

12. What are the most common primary languages spoken by your patient population?

     1. _____

     2. _____

     3. _____

     4. _____

     5. _____

13. Where along the cancer continuum are the greatest needs of your patient population? (Check all that apply)

_____Outreach/health promotion   _____Treatment

_____Screening   _____Post-treatment/survivorship

_____Diagnosis   _____End of Life

14. Is there additional information that would be helpful to gather, such as:

Obesity rates: _____

Smoking Rates: _____

Other: _____

Other: _____

Other: _____

Activity 2: Determining Patient Flow

Instructions: The goal of this activity is to clarify how your patients move through your institution to identify where barriers may exist. Understanding these touch points and the flow can help you identify problems and propose solutions. You may also consider when patients are screened for distress or when/which resources are provided. Fill in what currently applies to your institution. Once you have determined the current patient flow and areas of improvement, you can repeat this activity to create the ideal patient flow.

How/where are patients screened? (e.g., community, onsite)

What happens when there is an abnormal finding? How are patients notified? How do they get to your institution?

What happens during the diagnosis meeting? What do patients do prior to and after the meeting?

How are treatment decisions made? What do patients do when and after treatment options are discussed? What resources (physical resources, second opinions, etc.) are needed?

What happens after treatment begins? Are psychosocial needs assessed and resources made available? How are medical, psychosocial and practical needs managed and by whom? Do patients seek external resources?

What happens when treatment ends? Is there a system for providing follow-up care? Is there communication with the primary care provider? Are resources available? How are medical, psychosocial, and practical needs managed and by whom?

What happens at end of life? What is the process for discussing options with patients, managing pain and symptoms, assessing spiritual needs, etc? Are patients referred to hospice? When?

Screening	Diagnosis	Treatment	Post-Treatment	End of Life

## Activity 3: Conducting an Institutional Analysis

Instructions: The goal of this activity is to determine the circumstances of your institution so you can identify program development strategies that align with your institutional situation. A SWOT analysis identifies your institutional strengths, weaknesses, opportunities and threats to help set direction and chart the future course for your program. Strengths and weaknesses are often internal to the organization, and opportunities and threats are often external to the organization. Complete the activity below by filling in the boxes with your institution's strengths, weaknesses, opportunities and threats.

Strengths	Weakness
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.

Opportunities	Threats
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.

Activity 4: Internal Resource Mapping

Instructions: The goal of this activity is to help you think about *internal* resources that can be leveraged for your program. Internal resources can include people, services or physical items or other resources. Identify resources below using your knowledge and outside research. Feel free to add additional information or categories.

☐ Billing Specialist:

☐ Clinical Staff:

☐ Financial:

☐ Marketing Rep.:

☐ Patient Advocate:

☐ Physical Space:

☐ Program Champion(s):

☐ Scheduler:

☐ Other: _____
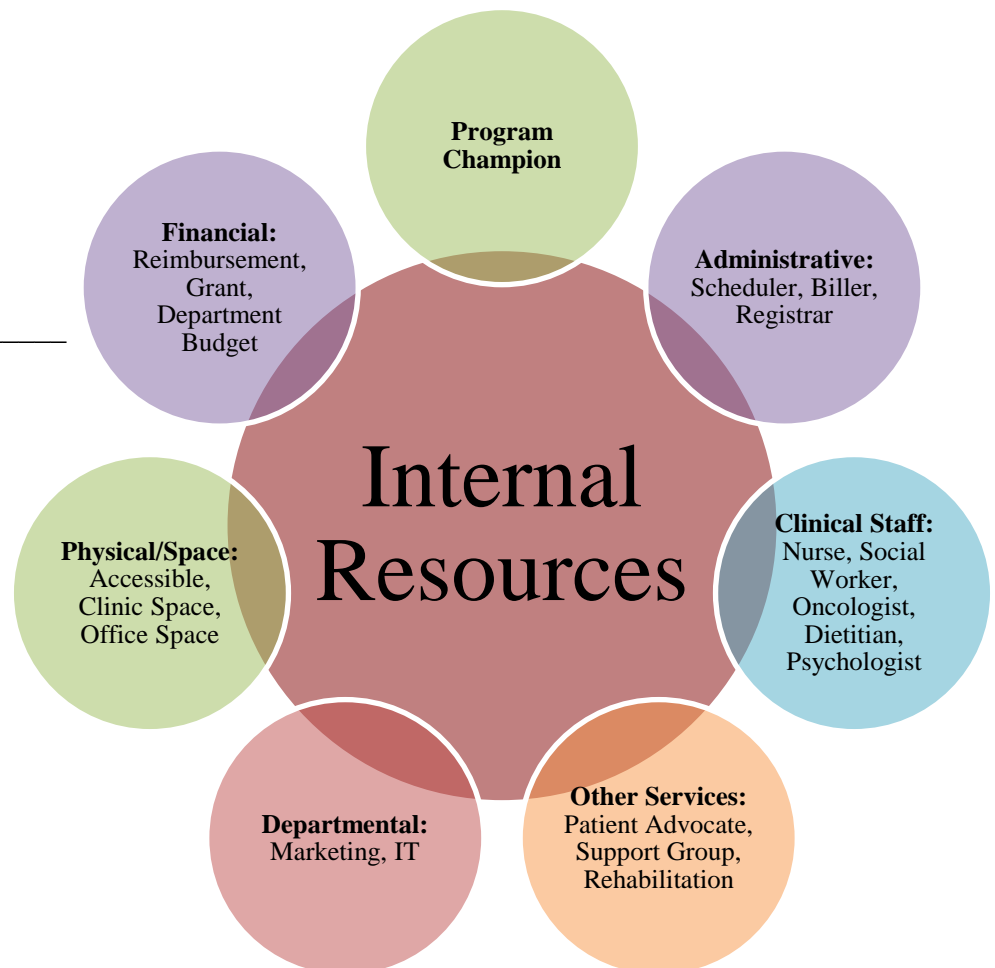
Activity 4: External Resource Mapping

Instructions: The goal of this activity is to help you think about *external* resources that can be leveraged for your program. External resources can include people, services or physical items or other resources. Identify resources below using your knowledge and outside research. Feel free to add additional information or categories.

☐ Financial Resources:

☐ Individuals:

☐ Local Orgs:

☐ National Orgs:

☐ Physical Resources:

☐ Other: _____
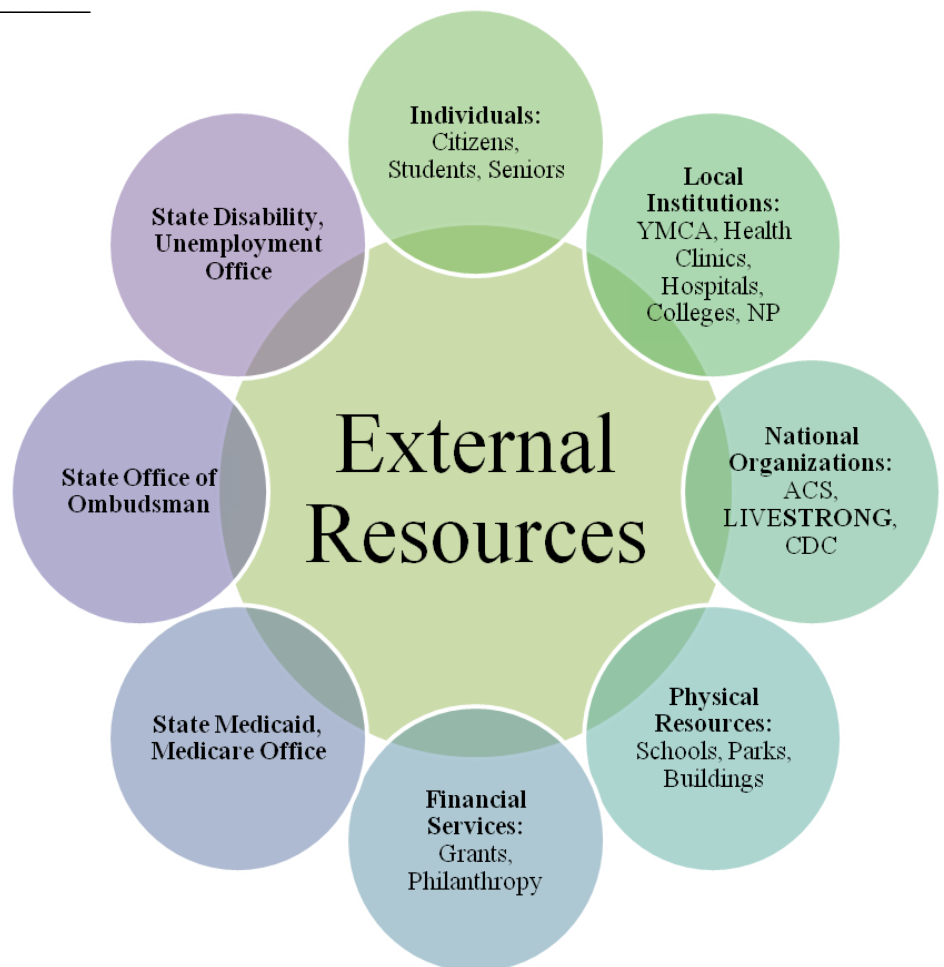
Activity 5: Assessing Stakeholder Needs

Instructions: This activity is made up of three parts focused on different stakeholders: patients/survivors/caregivers; providers and staff; and community organizations. This activity will help you plan your stakeholder needs assessments, and sample surveys are included in the *Guide* on pages 17-23.

<div style="background-color:#8B0000; color:white; text-align:center; font-weight:bold;">

Patient/ Survivor/ Caregiver Needs Assessment

</div>

The goal of this worksheet is to guide you through creating a patient/survivor/caregiver needs assessment.

1. What are the goals of the assessment? What information do you need to know?

   _____

2. How will you conduct your patient/survivor/caregiver needs assessment?

   ☐ Electronic survey   ☐ Interviews

   ☐ Hard copy survey   ☐ Other: _____

   ☐ Focus group(s)

3. What is the timeframe for your patient/survivor/caregiver needs assessment?

   _____

4. Who will be responsible for gathering data, analyzing it and reporting on it? Do you need to get approval (IRB or other) to implement the assessment?

   _____

5. Who is your target audience? In other words, whose needs are you assessing (particular demographics or cancer type)?

   _____

6. How will you reach your target audience? Are there other people or organizations that can help?

   _____

7. What questions will you ask in your patient/survivor/caregiver needs assessment?
   Make sure the questions you use match the goals you identified. Remember to keep these assessments short, avoid asking complex questions and only ask one question at a time.

   _____

   _____

   _____

8. Who will you share the results with and how (e.g., board of directors, CMO, marketing department, cancer committee)?

   _____

Provider Needs Assessment

The goal of this worksheet is to guide you through creating a health care provider/staff needs assessment.

1. What are the goals of the assessment? What information do you need to know?

   _____

   _____

2. How will you conduct your provider needs assessment?

   ☐ Electronic survey   ☐ Interviews

   ☐ Hard copy survey   ☐ Other: _____

   ☐ Focus group(s)

3. What is the timeframe for your provider needs assessment?

   _____

4. Who will be responsible for gathering data, analyzing it and reporting on it? Do you need to get approval (IRB or other) to implement the assessment?

   _____

5. Who is the audience for your provider needs assessment? Whose needs are you assessing?

   ☐ MDs/ DOs   ☐ Administrators

   ☐ RNs   ☐ Program staff

   ☐ SWs   ☐ Other: _____

6. Who will you share the results with and how (e.g., board of directors, CMO, marketing department, cancer committee)?

   _____

   _____

   _____

Community Needs Assessment

The goal of this worksheet is to identify information from community groups and members that may be useful in designing your program. This assessment may be more informal than the other assessments and can help you establish relationships in the community to enhance your program.

1. What are the goals of the assessment? What information do you need to know? *(i.e., what services they offer, what they see is the greatest need, how they might partner with you)*

   _____

   _____

2. How will you conduct your community group needs assessment?

   ☐ Electronic survey ☐ Interviews

   ☐ Hard copy survey ☐ Other: _____

   ☐ Focus group(s)

3. What is the timeframe for your community group needs assessment?

   _____

4. Who will be responsible for gathering data, analyzing it and reporting on it? Do you need to get approval (IRB or other) to implement the assessment?

   _____

5. Who will be included in your community group needs assessment (see Activity 4)?

   _____

6. What questions will you ask in your community needs assessment?

   Based on your assessment goals listed in this activity, identify which questions can help you gather the necessary information. The questions could be: What services/resources do you offer? What is the greatest community need you see? Are there opportunities to partner to leverage resources? Have you already conducted an evaluation that you can share? What are other organizations doing?

   _____

   _____

7. Who will you share the results with and how (e.g., board of directors, CMO, marketing department, cancer committee)?

   _____

PLAN

Activity 6: Writing Your Mission and Vision Statements

Instructions: The goal of this worksheet is to provide you with an opportunity to construct your program's mission and vision statements. Your mission statement should broadly define your program's purpose and your vision should include guiding principles for your program. Both statements should be in alignment with your organization's priorities.

Mission:

Vision:

Activity 7: Developing SMART Program Goals

Instructions: Draft your own program goal(s). Jot down your ideas; then discuss them with your team to see if they are SMART. Revise as needed. Consider the following questions:

	Goal #1	**Goal #2**	**Goal #3**
Specific: What specifically do you want to achieve?			
Measurable: How are you going to measure it?			
Action-Oriented: What is it that you and your staff can do?			
Realistic: What is "do-able" given your circumstances?			
Time-Bound: When will your goal be achieved?			
State your final goal:			

Activity 8: Designing Your Survivorship Program

Instructions: The purpose of this worksheet is to guide you through designing your survivorship program. As you complete the prompts below, think about who will be your program stakeholders and what services you can feasibly provide to your patient population.

Who are your champions _and_ how might they be helpful?

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

Who needs to be at the table for program planning?

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

Who in your patient population will your program initially serve?

- ☐ Cancer type: _____
- ☐ Treatment type: _____
- ☐ Risk level: _____
- ☐ Treated by: _____
- ☐ Other: _____

When will patients be eligible for the program?

- ☐ Immediately after treatment ends
- ☐ __ months after treatment ends
- ☐ __ years after treatment ends
- ☐ Depends on risk level
- ☐ Depends on patient population
- ☐ Other:_____

What services will be provided?
You may want to note which services are internal and which services are provided externally.

Clinical Services

☐ Endocrinology

☐ Fertility

☐ Genetic Counseling

☐ Gynecology

☐ Integrative Medicine

☐ Neurology

☐ Nutrition Consultation

☐ Patient Navigation

☐ Psychiatry

☐ Rehabilitation

☐ Other: _____

☐ Art Therapy

☐ Educational Workshops

☐ Exercise Program

☐ Financial Assistance

☐ Support Groups

☐ Transition Class

☐ Transportation Assistance

☐ Vocational/Career Counseling

☐ Other: _____

☐ Other: _____

☐ Other: _____

Additional Services

Which model might work best in your institution?
_____

Which provider "might lead your program?"

☐ Nurse   ☐ Nurse Practitioner   ☐ Family Physician
☐ Oncologist   ☐ Shared care   ☐ Other

Where will the program be located?
_____

How will survivorship care be delivered?

Where will the TS/SCP info come from?
_____

Who will create the SCP?
_____

Who will deliver the SCP?
_____

Who will do a psychosocial assessment?
_____

What assessment tools will be used?
_____

Who will follow up with the survivors?
_____

Who will track metrics?
_____

Who will coordinate care with the PCP?
_____

Activity 8: Designing Your Patient Navigation Program

Instructions: The purpose of this worksheet is to guide you through designing your patient navigation program. As you complete the prompts below, think about who will be your program stakeholders and what services you can feasibly provide to your patient population.

Who are your champions and how might they be helpful?

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

Who needs to be at the table for program planning?

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

Who in your patient population will your program initially serve?

- ☐ Cancer type: _____
- ☐ Treatment type: _____
- ☐ Risk level: _____
- ☐ Treated by: _____
- ☐ Other: _____

When will patients be eligible for navigation services?

- ☐ Outreach/screening
- ☐ Diagnosis
- ☐ Initiation of treatment
- ☐ Depends on risk level
- ☐ Depends on patient population
- ☐ Other:_____

What services will be provided?
You may want to note which services are internal and which services are provided externally.

- ☐ Accompany patients to appointments
- ☐ Address health literacy challenges
- ☐ Appointment scheduling
- ☐ Assess family/caregiver needs
- ☐ Care coordination (internal)
- ☐ Care coordination with referring physicians
- ☐ Clinical trial recruitment
- ☐ Conducting informational classes
- ☐ Coordinate clinic or multidisciplinary conference
- ☐ Distress screening
- ☐ Employment assistance & referral
- ☐ External/community resource referral

- ☐ Financial assessment and referral
- ☐ Genetic counseling referral
- ☐ Improve timeliness of care
- ☐ Insurance coverage assistance
- ☐ Language assistance
- ☐ Logistical barrier assistance (e.g., housing, utilities, dependent care)
- ☐ Nutrition referral
- ☐ Patient education
- ☐ Psychosocial support
- ☐ Transportation assistance
- ☐ Treatment planning
- ☐ Vocational/career/career counseling
- ☐ Other: _____

What type(s) of navigator will your program utilize?
- ☐ Community health worker
- ☐ Layperson
- ☐ Nurse navigator
- ☐ Peer
- ☐ Social worker

Where will the navigator(s) be located? Who will be the direct supervisor?

_____

How will navigation services be unique (not duplicative of services already offered)?

_____

Activity 9: Creating a Logic Model

Instructions: Brainstorm collaboratively with your team and other stakeholders to generate content for each of the following logic model sections.

Resources/ Inputs
What your organization has and/or what will need to be acquired

What resources will be needed to implement the project/ program? Include personnel, financial, etc.

1.

2.

3.

4.

5.

6.

7.

8.

9.

10.

Activities
The actual tasks and what the program needs to do to produce the outputs

What are the main functions that the project/ program will do or provide?

1.

2.

3.

4.

5.

Outputs
The actual services or products your program will create and deliver

How many and what tangible results will be achieved as a result of the activities?

1.

2.

3.

4.

5.

6.

7.

8.

9.

10.

Outcomes
The changes that your program will bring about

Short-term Outcomes
Typically changes in knowledge, skills and attitudes

What changes do you want to bring about as a direct result of the activities and outputs?

1.

2.

3.

4.

5.

Intermediate Outcomes (optional)
Typically changes in behavior, policies and practice

What changes and results will follow the initial outcomes?

1.

2.

3.

4.

5.

Long-term Outcomes
Typically changes in broader/ significant conditions or the consequences

What changes and results will follow the intermediate outcomes?

1.

2.

3.

4.

5.

Optional

Problem Statement:

Assumptions:

20

Logic Model Template

Assumptions:

Goal(s):

INPUTS	ACTIVITIES	OUTPUTS	SHORT-TERM OUTCOMES	MEDIUM-TERM OUTCOMES	LONG-TERM OUTCOMES
In order to accomplish our goals will need the following resources:	Accomplishing the following activities will result in the following measurable deliverables:	Accomplishing these activities will result in the following evidence of progress:	We expect the following measurable changes within the next _____:	We expect the following measurable changes within the next _____:	We expect the following impacts/trends within the next _____ or more:

Activity 10: Identifying Stakeholders & Demonstrating Value

Instructions: During this activity think about who the stakeholders are relevant to your program. In the first part of the activity, list your program's relevant stakeholders. Then, match ways of demonstrating value to the stakeholders they would most appeal to using the bank provided. Again, the benefits you choose to measure should align with what key stakeholders value. An administrator may focus on financial benefits or indicators of financial benefits, such as reduced no-shows, but a funder might care about patients served or improved outcomes. Take a moment to think about and identify the key stakeholders in your program. What do they value?

Potential Program Benefits		
• #, types of referrals from other patients & navigators	• # patients benefited	• Patient demographics (e.g., uninsured, underserved)
• Changes in stage at diagnosis	• Patients accepting navigation: reasons why/why not	• # patients were educated and in what ways
• Identification of the main barriers/resolutions	• Increase in clinical trial accrual	• Improved patient satisfaction
• Patient testimonials	• Improved adherence to treatment and recommendations	• Better outcomes
• Quality Improvement	• Total program costs (personnel, program and direct medical care)	

Stakeholder	Program Benefits they may value

Activity 11: Making a Budget

Instructions: To the best of your ability fill in the budget template below according to your program needs. If there are items that are not applicable indicate "n/a." Feel free to add additional items as needed.

Item: Indicate the time each staff member will devote to the program to calculate salary.

Amount: You do not need to fill in the exact amount at this time but can enter that information at a later time.

Funding Sources: Internal department budget, grant, in-kind, donation, reimbursement, etc.

Item	Amount	Funding Source
Personnel Costs		
Salaries and Benefits for Program Staff		
Survivorship Director (___FTE)	$	
Nurse Navigator (___ FTE)	$	
Scheduler (___FTE)	$	
Medical Director (___FTE)	$	
Program Costs		
Print and Promotional Materials		
Print newsletters	$	
Flyers to post at hospital	$	
Marketing and Outreach	$	
Press release	$	
Health fair booth	$	
Supplies	$	
Patient informational binders	$	
Travel		
Annual professional society meeting presentation (hotel, airfare, ground transportation, meals)	$	
Local outreach (miles reimbursement)	$	
Other		
Overhead cost annual cost (space, utilities, etc)	$	
Technology and data management	$	
Direct Medical Care		
	$	
	$	
Total	$	

Activity 12: Developing an Evaluation Plan

Instructions: This worksheet serves as a template for your program's evaluation plan. Draft your evaluation plan using the chart below and discuss your ideas with your team.

Program Goals	Objectives	Evaluation Related Activities	Evaluation Questions	Evaluation Indicators	Data Sources	Data Collection	Data Analysis

Activity 13: Writing a Business Plan

Instructions: To the best of your ability begin to fill out sections of a business plan. Focus on one section at a time, and start where you are most comfortable.

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 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

IMPLEMENT

Activity 14: My Next Action Steps

Instructions: Now that you have gone through the Executive Training, think about some small incremental steps that you can take within 3 months of returning to your institution and list them below.

Name: **Organization:**

Program Type:

1. My first action step will be…

2. Once, I've completed my first step, I will then…

3. A third action step I will complete is…

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