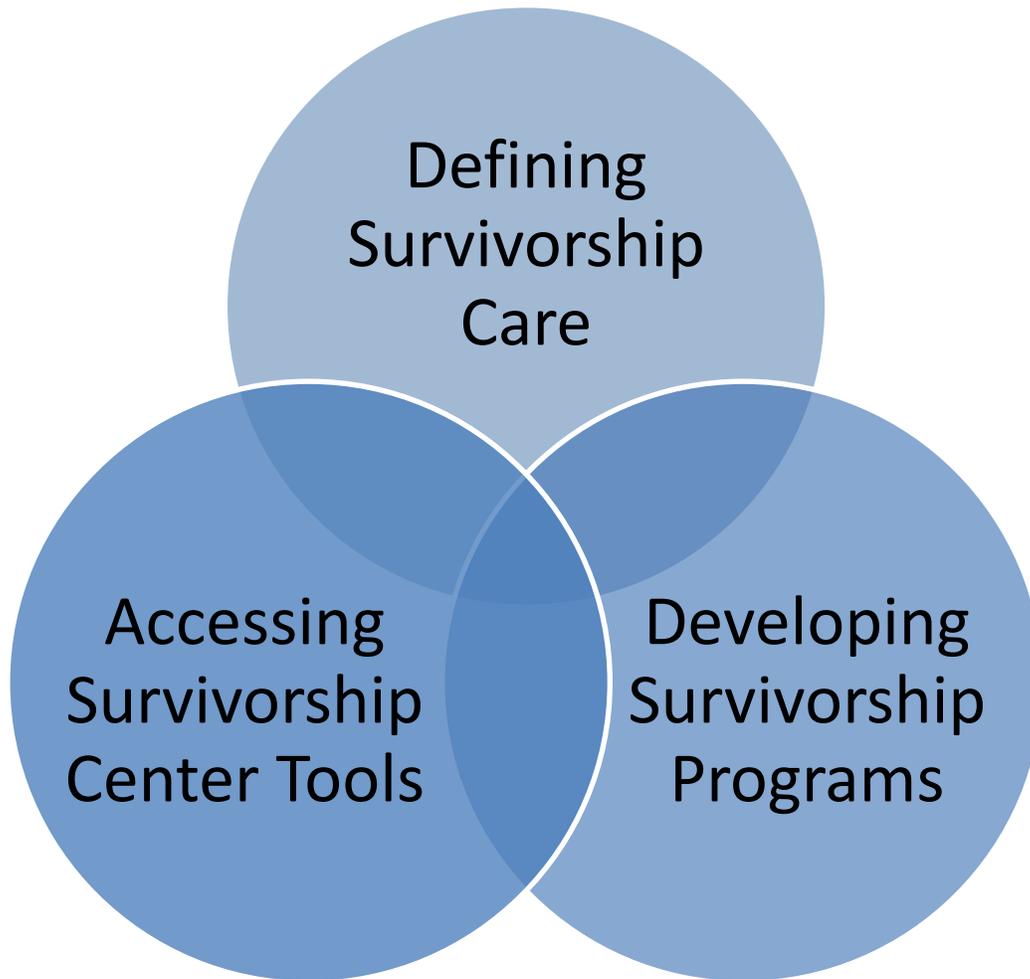


Guide for Delivering Quality Survivorship Care



GW Cancer Institute

THE GEORGE WASHINGTON UNIVERSITY

INTRODUCTION

The Guide for Delivering Quality Survivorship Care is a resource developed by the George Washington University Cancer Institute (GW Cancer Institute) as part of the National Cancer Survivorship Resource Center (The Survivorship Center). Funded by a five-year cooperative agreement from the Centers for Disease Control and Prevention, The Survivorship Center is a collaboration between the American Cancer Society and the GW Cancer Institute. The Survivorship Center is committed to improving the quality of life of cancer survivors and caregivers and the overall health and well-being of survivors by improving the survivorship knowledge and skills of health care professionals, community-based organizations and government organizations.

Survivorship is now recognized as a distinct phase of the cancer care continuum. Health care providers (HCPs) and survivors are increasingly identifying the need for comprehensive, coordinated, follow-up care to address the long-term and late effects of cancer and its treatment. It is critical as the field grows to share successes and promising practices.

The purpose of this Guide is to provide health care professionals with the knowledge, tools and resources to deliver high-quality follow-up care to cancer survivors. The Guide is divided into three sections: Defining Survivorship Care, Developing Survivorship Programs and Accessing Survivorship Center Tools. Each section of the Guide distills best practices, evidence-based interventions and lessons learned in delivering survivorship care and developing survivorship programs. We hope that this Guide will aid health care providers in delivering care to cancer survivors to improve quality of life and health outcomes. The Guide will continue to be updated with the latest information, research and evidence-based interventions. Please visit the Survivorship Center website for updates at: cancer.org/survivorshipcenter.

Sincerely,



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Associate Director, The GW Cancer Institute



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About Us

The George Washington University Cancer Institute (GW Cancer Institute)

Created in 2003, the vision of the [GW Cancer Institute](#) is to set the standard for patient-centered care and eliminate cancer health disparities. The 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 multidisciplinary research.

Part of the GW Cancer Institute, 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 health care professional training, research, policy analysis, outreach and education.

Acknowledgements

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The National Cancer Survivorship Resource Center

The [National Cancer Survivorship Resource Center](#) (The Survivorship Center) is a collaboration between the [American Cancer Society](#) and the [George Washington University Cancer Institute](#) funded through a 5-year cooperative agreement with the [U.S. Centers for Disease Control and Prevention](#). The Survivorship Center's mission is to improve the quality of life of cancer

survivors and caregivers and reduce death and disability due to cancer by focusing on the importance of improving functioning and helping survivors achieve optimal health and well-being. The Survivorship Center achieves its mission by:

- Providing evidence-based information, resources and support to cancer survivors, caregivers, friends and family;
- Improving the survivorship knowledge and skills of health care professionals, community-based organizations and government organizations; and
- Recommending action to policy- and decision-makers.

Currently, The Survivorship Center is focused on:

- Creating cancer survivorship clinical guidelines for primary care providers;
- Implementing health care provider education and training, such as the [Cancer Survivorship E-Learning Series for Primary Care Providers](#); and
- Developing resources, including the [Prescription for Cancer Information](#) for health care providers and Life [After Treatment Guide](#) for cancer survivors.

Learn more about [The Survivorship Center](#) at www.cancer.org/survivorshipcenter.

Acknowledgements and Disclaimers



Development of this Guide was made possible by cooperative agreement #1U55DP003054 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not represent the official views of the Centers for Disease Control and Prevention. The views expressed in the Guide and by authors do not necessarily reflect the official policies of the U.S. Department of Health and Human Services; nor does mention of trade names, commercial practices or organizations imply endorsement by the U.S. government.

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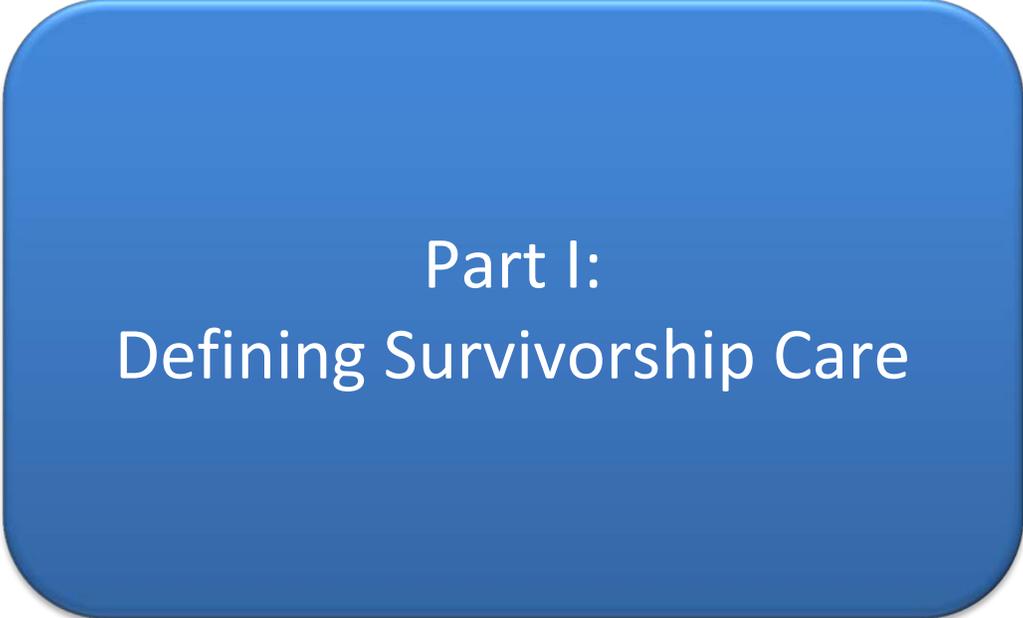
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Part I: Defining Survivorship Care

The State of Cancer Survivorship

FACT »»»»»»

There are currently nearly 14 million cancer survivors in the United States and that number is expected to rise to 18 million by 2022.¹

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 cancers 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, approximately 13.7 million Americans are alive with a history of a cancer diagnosis, and this number is expected to grow to 18 million by 2022.¹ Several national reports on survivorship have identified the need to improve post-treatment care, and new care standards are being developed to include the survivorship phase by organizations such as the American College of Surgeon’s Commission on Cancer and the Association of Community Cancer Centers.

Studies by the American Cancer Society, **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. For example, the American Cancer Society’s 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.² Table 1 illustrates the severity of some of the top concerns experienced by cancer survivors in the SCS.³

¹ Siegel R, DeSantis C, Virgo K, et al. Cancer treatment and survivorship statistics, 2012. *CA: A Cancer Journal for Clinicians*. 2012;62(4):220–241. doi: 10.3322/caac.21149

² Stein K, Smith T, Kim Y, et al. The American Cancer Society’s Studies of Cancer Survivors: the largest, most diverse investigation of long-term cancer survivors so far. *Am J Nurs*. 2006;106(3):83-85.

³ Zhao L, Portier K, Stein K, et al. Exploratory factor analysis of the cancer problems in living scale: a report from the American Cancer Society’s Studies of Cancer Survivors. *Journal of Pain and Symptom Management*. 2009;37(4):676-86.

Table 1: Survivor Concerns From the American Cancer Society’s Studies of Cancer Survivors⁴

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

Recently, 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. 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. 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. Efforts are also underway to

⁴ Stein K, Smith T, Kim Y, et al. The American Cancer Society's Studies of Cancer Survivors: the largest, most diverse investigation of long-term cancer survivors so far. *Am J Nurs*. 2006;106(3):83-85.

identify standards of survivorship care. In September 2011, The Survivorship Center contributed to the **LIVESTRONG** Essential Elements of Survivorship Care Meeting in Washington, DC, to develop expert consensus around the essential elements of survivorship care. 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. Finally, the GW Cancer Institute and the GW School of Public Health and Health Services (SPHHS) have partnered to conduct a comprehensive effectiveness study on survivorship models of care. The 3-year study is funded by the Patient-Centered Outcomes Research Institute (PCORI) and includes representatives from ACS, **LIVESTRONG** and the CoC. The project will result in a patient prioritized framework for quality care, an environmental scan of existing survivorship care delivery practices and a comparison of how different care models impact patient-centered outcomes. Through these concerted national efforts, the field of cancer survivorship is gaining momentum.



Online Resources for Further Reading:

[American Cancer Society Cancer Treatment & Survivorship Facts & Figures](#)

[LIVESTRONG Essential Elements of Survivorship Care](#)

[Evaluating Cancer Survivorship Care Models](#)

Survivorship Standards of Care

FACT »»»»»»

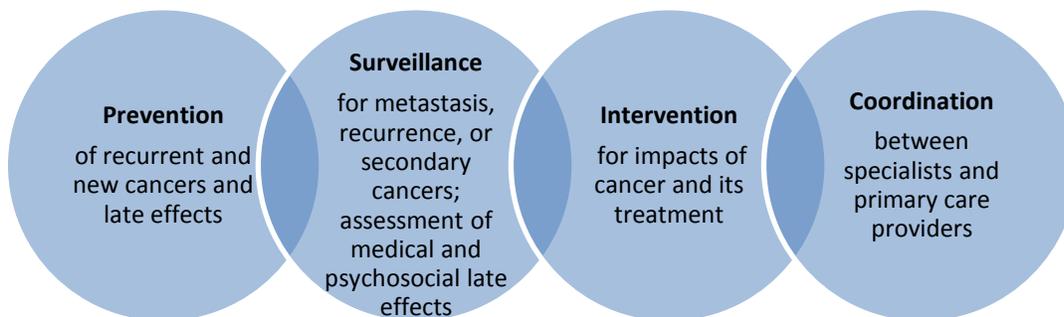
By 2015, all Commission on Cancer-accredited institutions will need to have a process in place for the development and delivery of survivorship care plans.

With the advances in the field of survivorship, the need to define quality cancer care and standards has grown. Organizations such as the Institute of Medicine, Commission on Cancer, National Comprehensive Cancer Network, American Cancer Society and The Survivorship Center are involved in efforts to define the standards and delivery of care for cancer survivors.

Institute of Medicine

In its 2006 landmark report, [*From Cancer Patient to Cancer Survivor: Lost in Transition*](#),⁵ 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 include:

Figure 1: IOM Recommended Components of Survivorship Care



⁵ Hewitt M, Greenfield S, Stovall E. From Cancer Patient to Cancer Survivor: Lost in Transition. 2005. Washington, D.C.: The National Academies Press.

Commission on Cancer Survivorship Care Plan Standard

In 2012, the American College of Surgeon's Commission on Cancer (CoC) released the [Cancer Program Standards 2012, Version 1.2.: Ensuring Patient-Centered Care](#). The manual outlines the standards that address patient-centered needs and brings an additional focus on the quality of care and outcomes. Included is a new patient-centered standard on the survivorship care plan (3.3) to be phased in for CoC accredited institutions by 2015.

The standard states, "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."⁶

LIVESTRONG Essential Elements of Survivorship Care

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](#).⁷ Through the process it became clear that there are 3 tiers of 20 critical components; some are necessary for all programs, and some are important but not necessarily appropriate for all programs. Descriptions of each element are available from the LIVESTRONG website, and the process of refining the Essential Elements is ongoing.

National Comprehensive Cancer Network Guidelines for Survivorship

The [National Comprehensive Cancer Network](#) (NCCN) released its first version of 'Guidelines for Survivorship' in March 2013. The guideline topics include: anxiety and depression, cognitive function, exercise, fatigue, immunizations and infections, pain, sexual function and sleep disorders. Most of the content may apply to survivors of a variety of cancer types. As applicable, the guidelines also include content specific to select cancer types (e.g., colorectal cancer survivors with ostomies should empty their ostomy bag before exercise).

Because accurate assessment of survivors' needs and concerns is important for proper care, the NCCN Guidelines for Survivorship include a sample assessment tool with two to three questions for each of the eight topics addressed in the guidelines. Some of the assessment tools for clinicians have been tested and validated, while other tools have not but are included for guidance. This reflects the relative early stage of cancer survivorship research. NCCN created these guidelines for both oncology and primary care providers and the guidelines promote care coordination.

⁶ American College of Surgeons Commission on Cancer. *Cancer Program Standards 2012: Ensuring Patient-Centered Care V1.2*. 2012. Chicago, IL; American Colleges of Surgeons.

⁷ Rechis R, Beckjord EB, Arvey SR, et al. *The Essential Elements of Survivorship Care: A LIVESTRONG Brief*. 2011. Washington, DC; LIVESTRONG Foundation.

National Cancer Survivorship Resource Center Survivorship Guidelines for Primary Care Providers

The Survivorship Center is committed to educating primary care providers about how to best care for survivors. The Survivorship Center's Systems, Policy and Practice Workgroup identified the gaps in clinical survivorship care including: lack of clinical survivorship care guidelines, lack of clarity on which health care professionals should be responsible for clinical survivorship care, variation in the availability of and services provided for post-treatment care and gaps in clinical information on survivorship, education and training of health care professionals.⁸ The Survivorship Center began to address these gaps through the development of cancer survivorship clinical practice guidelines for primary care providers (PCPs).⁹ Ten (10) primary cancer sites were prioritized for the development of follow-up guidelines and three (3) sites, breast, prostate and colorectal, are currently undergoing final review for publication and dissemination. Development of clinical practice guidelines for head & neck cancers are also underway. The guidelines encourage PCPs to:

- Request a treatment summary and survivorship care plan from patients' oncology team
- Routinely counsel patients on health promotion issues & follow American Cancer Society's Nutrition & Physical Activity Guidelines for Cancer Survivors
- Follow American Cancer Society cancer screening guidelines to screen for second primary cancers
- Know and recognize the signs/symptoms of cancer recurrence and refer patients to appropriate follow-up test or to oncology provider for follow-up
- Routinely assess psychosocial status of patients and refer to psychosocial services or prescribe medication as needed
- Routinely assess for and manage physical long-term and late effects that may arise from cancer and its treatment

American Cancer Society Nutrition and Physical Activity Guidelines for Cancer Survivors

The American Cancer Society recommends that people living with cancer maintain a healthy weight, get enough exercise and eat a healthy diet.¹⁰ More than ever before, scientific evidence shows that healthy nutrition and physical activity behavior after a cancer diagnosis can lower the chances of the cancer returning and can improve the chances of disease-free survival. The

⁸ National Cancer Survivorship Resource Center. Systems, policy and practice: clinical survivorship care: expert panel summit workgroup overview. 2012. Available at: <http://www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/NationalCancerSurvivorshipResourceCenter/ncsrc-clinical-care-narrative>

⁹ Cowens-Alvarado R, Sharpe K, Pratt-Chapman M, et al. Advancing survivorship care through the National cancer Survivorship Resource Center: developing American Cancer Society Guidelines for Primary Care Providers. *CA: A Cancer Journal for Clinicians*. 2013; March 63(3):147-150

¹⁰ Rock CL, Doyle C, Demark-Wahnefried W, et al. Nutrition and physical activity guidelines for cancer survivors. *CA: A Cancer Journal for Clinicians*. 2012;62(4):242-274.

updated [‘Nutrition and Physical Activity Guidelines for Cancer Survivors’](#) was published in the July/August 2012 issue of *CA: A Cancer Journal for Clinicians*. The report presents health care providers with a summary of findings and provides information to help cancer survivors and their families make informed choices related to nutrition and physical activity. The guidelines address the continuum of cancer care, but largely focus on the needs of cancer survivors who are disease-free or who have stable disease following their recovery from treatment.

Survivorship Measures

There is currently not a set of validated measures specific to cancer survivorship, but several efforts to identify or establish measures have been underway. Malin et al. compiled a list of existing quality indicators related to survivorship that have been established by the American Society of Clinical Oncology’s Quality Oncology Practice Initiative (QOPI), National Quality Forum, National Initiative on Cancer Care Quality and RAND Corporation.¹¹ Three indicators were identified that apply to all cancers, 7 apply to breast cancer, 5 apply to colorectal cancer, 2 apply to prostate cancer and 1 applies to melanoma. The authors also note that most of the indicators are based on Level II or III evidence (Level I is the strongest).

Rowland and Ganz proposed metrics for success at the survivor (e.g., decreased cancer morbidity), clinician (e.g., better ability to coordinate care) and system levels (e.g., reduced duplication of services) that can be used to evaluate the impact of survivorship care planning and different care models.¹² The Oncology Nursing Society developed and piloted breast cancer-specific survivorship measures related to symptom assessment, symptom intervention, post-treatment education, goal setting, goal attainment, follow-up care, fatigue improvement and distress improvement.¹³ Pratt-Chapman et al. proposed measures for survivorship patient navigation related to health care utilization (access to clinical care, awareness of late and long-term effects and access to supportive care) and patient reported outcomes (quality of life, self-efficacy and activation, satisfaction with care and navigation, health knowledge and literacy and healthy behaviors).¹⁴ Also, care transitions measures that have been validated and used in other disease areas may be applicable to cancer survivorship transitions.¹⁵

To build consensus in the survivorship community around high-priority process and outcome measures for use in studies of survivorship care planning, the National Cancer Institute launched its [GEM-Care Planning Initiative](#) through its Grid Enabled Measures System. The

¹¹ Malin J, Sayers E, Jefford M. What is quality health care for cancer survivors? *Health Services for Cancer Survivors*. Feuerstein M and Ganz PA (Eds). 2011:27-49.

¹² Rowland JH, Ganz PA. Cancer survivorship plans: a paradigm shift in the delivery of quality cancer care. *Health Services for Cancer Survivors*. Feuerstein M and Ganz PA (Eds). 2011:169-185.

¹³ Oncology Nursing Society. Development and testing of breast cancer survivorship measures 2012. Available at http://www.ons.org/research/media/ons/docs/research/bcs_01-08_mifs.pdf.

¹⁴ Pratt-Chapman M, Simon MA, Patterson AK, et al. Survivorship navigation outcome measures. *Cancer*. 2011;117(15):3573–3582.

¹⁵ Coleman EA, Parry C, Chalmers S, et al. The care transitions intervention: results of a randomized controlled trial. *Arch Intern Med*. 2006;166(17):1822-1828.

initiative allows health care professionals and researchers to identify measures across a variety of constructs related to survivorship care planning. These measures can then be discussed and rated by others as well as downloaded when the measure is available.

Strategies for Improving Survivorship Care

FACT »»»»»»

Nearly 70% of cancer patients are living five or more years beyond diagnosis.¹

Many advances have been made in elevating survivorship as a public health priority and defining the elements to deliver high-quality follow-up care to cancer survivors; however there is still a lack of research and evidence on how best to care for cancer survivors and the most effective and efficient strategies for delivering survivorship care.

The Survivorship Center convened Expert Panel Workgroups to explore four key topic areas and provide recommendations for improving survivorship care. The workgroups focused on: 1) Quality of Life: Information Delivery, 2) Quality of Life: Programs and Navigation, 3) Systems Policy and Practice: Clinical Survivorship Care and 4) Policy Advocacy. Each workgroup identified gaps/barriers, recommendations and performance indicators at the individual/survivor level, organization/health care system level and at the society/policy level.¹⁶ Some of the recommendations from the workgroups are provided on the following page. The items in red are activities that are currently being addressed by The Survivorship Center.

¹⁶ National Cancer Survivorship Resource Center. Executive summary: year one overview. 2012. Available at: <http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-031407.pdf>.

Figure 2: The Survivorship Center's Workgroup Recommendations^{17,18,19}

Survivor/Individual

- Develop culturally appropriate adaptation of existing evidence-based interventions
- Raise awareness of communication tools, self-management resources and Survivorship Care Plans (SCPs)
- **Develop resources for recurrence, post-treatment effects and long-term healthy behavior maintenance**
- **Programs on managing health and wellness from the chronic disease perspective**
- Create online peer support programs
- Develop information appropriate for all literacy levels
- Create tools for assessing quality of information
- Develop resources for information-poor areas (e.g., employment, caregiver issues)

Organization/Health Care System

- **Health care provider education**
- Deliver SCPs
- Empower survivors
- Develop survivor-specific healthy behavior guidelines
- Implement culturally appropriate programs
- Proactively address survivorship concerns
- Increase surveillance guideline adherence
- SCP quality measures
- **Develop "survivorship program" definition**
- Assess psychosocial distress
- **Develop post-treatment guidelines**

¹⁷ National Cancer Survivorship Resource Center. Quality of life: information delivery recommendations. 2012. Available at:

<http://www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/NationalCancerSurvivorshipResourceCenter/ncsrc-information-delivery-narrative>

¹⁸ National Cancer Survivorship Resource Center. Quality of life: programs and navigation recommendations. 2012. Available at:

<http://www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/NationalCancerSurvivorshipResourceCenter/ncsrc-quality-of-life-programs-and-navigation-workgroup>

¹⁹ National Cancer Survivorship Resource Center. Policy and advocacy recommendations. 2012. Available at: <http://www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/NationalCancerSurvivorshipResourceCenter/ncsrc-policy-advocacy-narrative>

Policy/Advocacy System

- Educate policymakers through the dissemination of white papers and legislative briefings
- Advocate for reimbursement for SCP creation and delivery
- Create data linkages to monitor effects
- Establish SCP efficacy
- Advocate for professional societies to adopt best practices in survivorship care
- Promote data collection standards

Cancer Survivorship: A Policy Landscape Analysis

Understanding the policy landscape is also important. The Survivorship Center staff wrote a white paper titled *A Policy Landscape Analysis* to highlight some key policy issues impacting survivorship care. A summary of the paper and recommendations is provided below, and you can access the full white paper and references at www.cancer.org/survivorshipcenter.

Summary

With a growing number of U.S. cancer survivors facing life-altering effects after treatment, a comprehensive, coordinated approach to meeting post-treatment care is critical. The biggest challenges in the delivery of survivorship care are the lack of health care providers to care for survivors, variation in care elements and models, limited evidence base for how to best care for survivors, and lack of adequate reimbursement for clinical services.

Background

Cancer patients are now increasingly likely to survive, with nearly 70 percent of patients living five years or more following their diagnoses. Well over one million new cancer patients are added each year to the 13.7 million alive today.

Issue

Cancer has become more of a chronic than an acute disease. Appropriate post-treatment survivorship care can increase independent living, positively affect quality of life, and ease the economic burden on the country from a depleted workforce. While the number of survivors is growing, workforce shortages in oncology and primary care are worsening. A challenge to delivering equitable, quality survivorship care is lack of training for the many practitioners needed to appropriately address the physical and psychosocial needs of the cancer survivor. Cancer patients require health promotion education to prevent occurrence of new or second cancers as well as late effects that may arise as a result of treatment for their primary cancer. Survivors also need ongoing surveillance for recurrence, cancer spread, and second cancers. Survivors have often received multiple modes of treatment from several providers at separate locations, with limited coordination of care between providers. Despite an already strained health care delivery system, quality survivorship care demands improved communication and coordination of care.

Recommendations

- Implement the Affordable Care Act to ensure access to health insurance, coverage and quality care for cancer survivors and expand training and residency programs for health care professionals.
- Support the Comprehensive Cancer Care Improvement Act (CCCCIA, H.R. 3705) introduced by Rep. Lois Capps (D-CA) and Rep. Charles Boustany (R-LA) to advance the Institute of Medicine's recommendation for written treatment summaries and survivorship follow-up care plans
- Support the American Cancer Society Cancer Action Network Patient Centered Quality of Life Act to amend the Public Health Services Act to address the symptoms and needs of patients with chronic disease.
- Appropriate research funds to the National Cancer Institute's Office of Cancer Survivorship to expand the evidence base for effective and cost-efficient survivorship care models.

Survivorship Care Delivery

FACT »»»»»»

Less than 50% of breast and colorectal cancer survivors report receiving a treatment summary upon completion of active treatment at National Cancer Institute-Designated Cancer Centers.¹⁸

Cancer care delivery could be significantly improved for cancer survivors through the implementation of clinical survivorship programs. A core component of survivorship programs is the survivorship care plan. The survivorship care plan and other survivorship services can be delivered through different models of care that best fit an institution's needs and resources. Institutions should also develop a protocol to determine which patients receive which services. Self-management interventions may help to improve the survivor's ability to manage their post-treatment care and could be incorporated into post-treatment care.²⁰ Despite some concerns about payment for survivorship care several options exist for reimbursement of the clinical visit.

Defining Survivorship Programs

Survivorship programs can vary widely, and the term "survivorship program" is used in different ways. To create clarity around the term, The Survivorship Center convened a workgroup of experts who created the following consensus-based definition:²¹

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.

Survivorship Care Plans

In its 2006 *Lost in Transition* report, the Institute of Medicine (IOM) recommended that survivors be given a survivorship care plan (SCP) at the end of treatment. The SCP is an

²⁰ McCorkle R, et al. Self-management: enabling and empowering patients living with cancer as a chronic illness. *CA: A Journal for Cancer Clinicians*. 2011 Jan-Feb;61(1):50-62.

²¹ National Cancer Survivorship Resource Center. Quality of life: programs and navigation overview. 2012. Available at: <http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-031410.pdf>

important tool for improving communication and coordination both between the patient and provider and among providers and is recognized as a core component of survivorship programs. According to the IOM, there are two components of the SCP: a treatment summary and a follow-up plan.²² The IOM provided recommendations for fields to include in each part of the SCP, which have been the basis for several free care planning templates.

In addition to these templates, commercial SCP software and electronic medical records might help to complete the SCP. Many institutions, however, develop their own homegrown tool. A survey by The GW Cancer Institute found that nearly half of respondents created their own template while almost a quarter used each the [LIVESTRONG Care Plan](#) or the [Journey Forward Care Plan](#). About ¼ used the [American Society of Clinical Oncology Care Plan and Summaries templates](#). Although the IOM report provides specific details about the components to include in an SCP, these fields may be refined as research on SCPs and survivorship care planning grows.

Despite consensus on the need to provide SCPs to survivors, they still have not become part of the standard of care. In a study of National Cancer Institute-Designated Cancer Centers, only 43% of the institutions provided SCPs for breast and colorectal cancer survivors.²³ Moreover, a study of 2010 Behavioral Risk Factor Surveillance System data indicates that only 31% of survivors received a treatment summary and 66% received written follow-up instructions.²⁴ Other studies indicate that 32-40% of survivors receive a treatment summary and 44-74% receive follow-up care instructions.^{25,26} With the Commission on Cancer survivorship standard, however, a significant increase in provision of SCPs is expected.

Survivorship Models At a Glance

Due to variation in patient populations, institutional resources and staff capacity, there is no one-size-fits-all approach for survivorship programs. Several models have emerged with variations of these models in practice.

²² Hewitt M, Greenfield S, Stovall E. From Cancer Patient to Cancer Survivor: Lost in Transition. 2005. Washington, D.C.: The National Academies Press.

²³ Salz T, Oeffinger KT, McCabe MS, et al. Survivorship care plans in research and practice. *CA: A Cancer Journal for Clinicians*. 2012;62(2): 101–117.

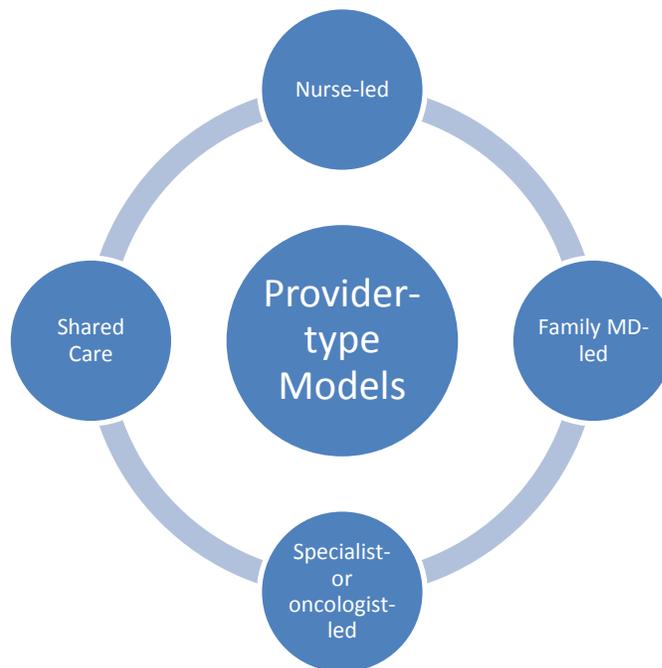
²⁴ Jabson JM, Bowen DJ. Cancer treatment summaries and follow-up care instructions: which cancer survivors receive them? *Cancer Causes & Control*. 2013 May;24(5):861-71.

²⁵ Underwood JM, Townsend JS, Stewart SL, et al. Surveillance of demographic characteristics and health behaviors among adult cancer survivors—Behavioral risk factor surveillance system, United States, 2009. *MMWR*. 2012; 61(1): 1–23.

²⁶ Sabatino S, Thompson T, et al. Receipt of cancer treatment summaries and follow-up instructions among adult cancer survivors: results from a national survey. *Journal of Cancer Survivorship*. 2012; 7(1):32-43.

Howell et al. conducted a systematic review to explore services delivery structures and models of care.²⁷ The models were defined by the provider delivering care, as shown in figure 3. 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.

Figure 3: Survivorship Care Models by Provider Type



In 2012, McCabe and Jacobs published an article with an overview of current survivorship care models.²⁸ These models provide more detail on how the survivorship program is structured and include:

- Pediatric Long-Term Follow-Up Models
- Disease-Specific Clinics
- General Survivorship Clinics
- Consultative Clinics
- Multi-Disciplinary Clinics
- Integrated Care Model (survivorship visit is part of ongoing cancer care)
- Transition to Primary Care Model

²⁷ Howell D, Hack TF, Oliver TK, et al. Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence. *Journal of Cancer Survivorship*, 2012;6(4): 359-371.

²⁸ McCabe MS, Jacobs, LA. Clinical update: survivorship care - models and programs. *Seminars in Oncology Nursing*. 2012; 28(3): e1–e8.

In 2013, the GW Cancer Institute and the GW SPHHS received an award from the Patient-Centered Outcomes Research Institute to study the comparative effectiveness of different survivorship care models. In partnership with LIVESTRONG, CoC, American Cancer Society and Cancer Support Community, the project will result in:

- A patient-prioritized framework for quality survivorship care
- A tool for measuring survivorship care alignment with patient preferences
- A more detailed description of models of care with a focus on what care is provided, how and by whom
- An environmental scan of current survivorship practices
- An evaluation of how different models of care impact patient-centered outcomes

Project updates are available at: <http://smhs.gwu.edu/gwci/research/gwci>.

Developing a Protocol for Caring for Cancer Survivors

Institutions must decide how to best implement survivorship care for their patient populations. Determining the responsibilities of each member of the survivorship team and how the patient's other health care providers fit in is essential. Questions to consider when determining cancer survivorship service line include:

- Who will be providing clinical services for the survivorship program?
- Are oncologists supportive of surveillance and symptom management being entirely overseen by the survivorship clinic? At what point post-treatment are they comfortable with this?
- Is there an established follow-up schedule?
- Will the survivorship program only be responsible for compiling treatment summaries and care plans or will it provide other services?
- Will there be a social worker available to assist survivors with accessing services and providing psychosocial support?
- Are other departments interested in a multi-disciplinary clinic?
- How will the clinic services be billed?

Cancer Survivors and Self-Management

Self-management, which Davies, Bateup and Thomas have been defined as “the tasks individuals undertake to deal with the medical, role, and emotional management of their health condition(s),”²⁹ has emerged as a way for survivors to be more involved in managing the impact of cancer and its treatment. According to Davies et al., survivorship self-management programs can focus on addressing the *emotional* transition to survivorship and/or enhancing

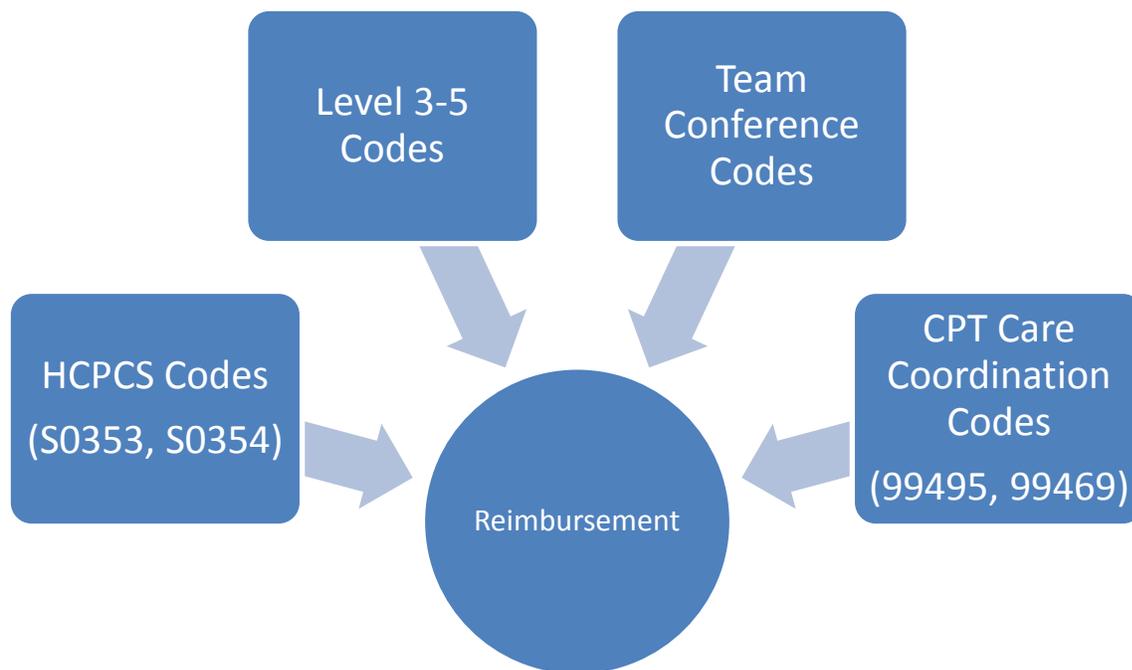
²⁹ Davies NJ, Bateup L, Thomas R. The role of diet and physical activity in breast, colorectal, and prostate cancer survivorship: a review of the literature. *British Journal of Cancer*. 2011;105(1):S52-73.

copied skills for *specific problems or symptoms* (e.g., nutrition, physical activity, fatigue). The Survivorship Center is piloting the Cancer: Thriving and Surviving online workshop developed at Stanford University to increase cancer survivor self-management. The six-week program covers a variety of topics, such as setting goals, exercise, healthy eating, communication, depression and others. Key health outcomes will be evaluated in order to determine the impact the workshop has on common survivorship issues.

Survivorship Reimbursement

Although reimbursement is currently not available for creating the SCP, many providers have had success with reimbursement for delivering survivorship care. The following options may be appropriate for your survivorship program, but it is recommended that you meet with your billing specialist to confirm the best billing options:

Figure 4: Survivorship Reimbursement Codes



Level 3-5 codes can be used for single or multiple providers, such as a nurse practitioner and/or physician. The providers would see the patient in the context of the same visit but not at the same time. Team conference codes can be used for a multi-disciplinary visit in which the providers meet with the patient together. HCPCS codes (Health care Common Procedure Coding System) are not accepted by Medicare but may be accepted by private payers. Finally,

new CPT Care Coordination codes are covered by Medicare and may be appropriate options for billing for a survivorship visit.³⁰



Online Resources for Further Reading:

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

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

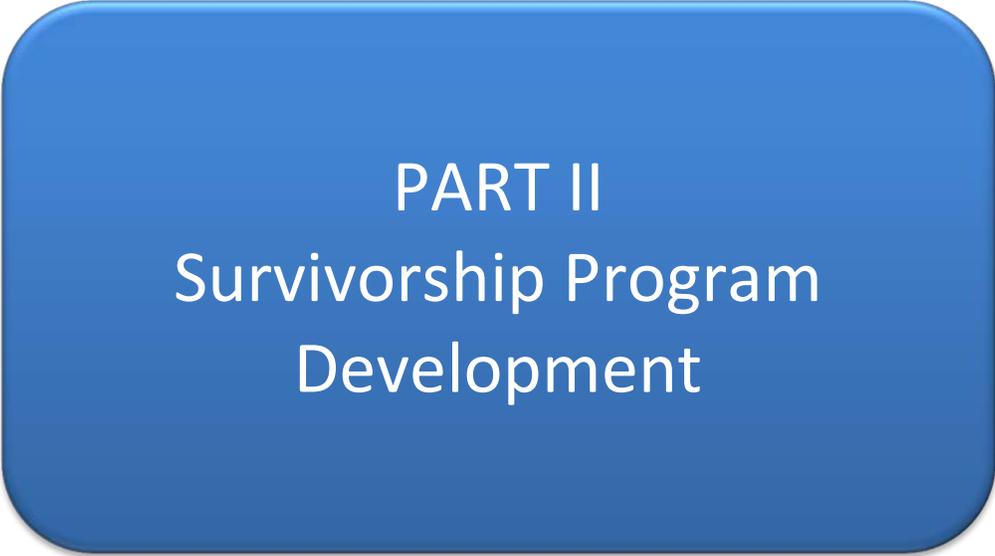
[Institute of Medicine Fact Sheet: Cancer Survivorship Recommendations](#)

[Institute of Medicine Fact Sheet: Survivorship Care Planning NCI Grid Enabled Measures- Survivorship Care Planning Initiative](#)

[Commission on Cancer Patient-Centered Standards 2012](#)

[Billing Challenges for Survivorship Services](#)

³⁰ Comprehensive Cancer Settings. How to get paid for care coordination. Available at http://www.ccsettings.com/blog-posts/how-to-get-paid-for-care-coordination/?goback=.gde_1776891_member_213814434



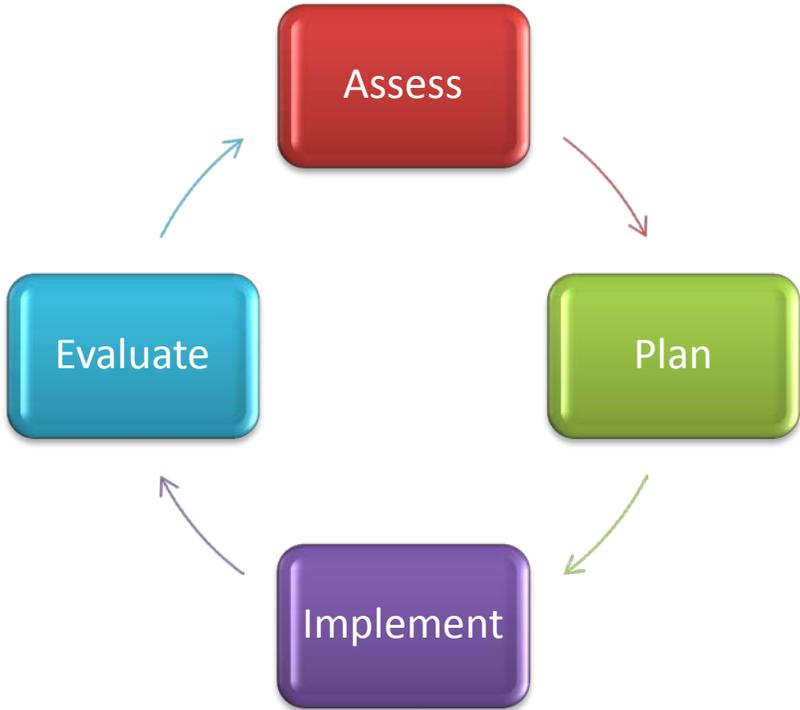
PART II
Survivorship Program
Development

Program Planning Cycle Overview

Since 2010, the GW Cancer Institute’s Center for the Advancement of Cancer Survivorship, Navigation and Policy has trained over 250 health care professionals through the Executive Training on Navigation and Survivorship: Finding your Patient Focus. The purpose of the program is to provide individuals with strategic planning techniques for developing, implementing, evaluating and sustaining patient-centered programs. Based on feedback from participants, a *Guide for Program Development* was developed to provide health care professionals with a step-by-step approach to program development, provide key resources and tools and enable health care professionals to develop a cohesive, institution-specific program plan.

The *Guide for Program Development* is based on a cycle, adapted from the CDC’s *Framework For Program Evaluation*, that features four (4) elements of program planning: assessment, planning, implementation and outcomes evaluation. Each of these components is highlighted below and explored in detail in the separate *Guide for Program Development*.

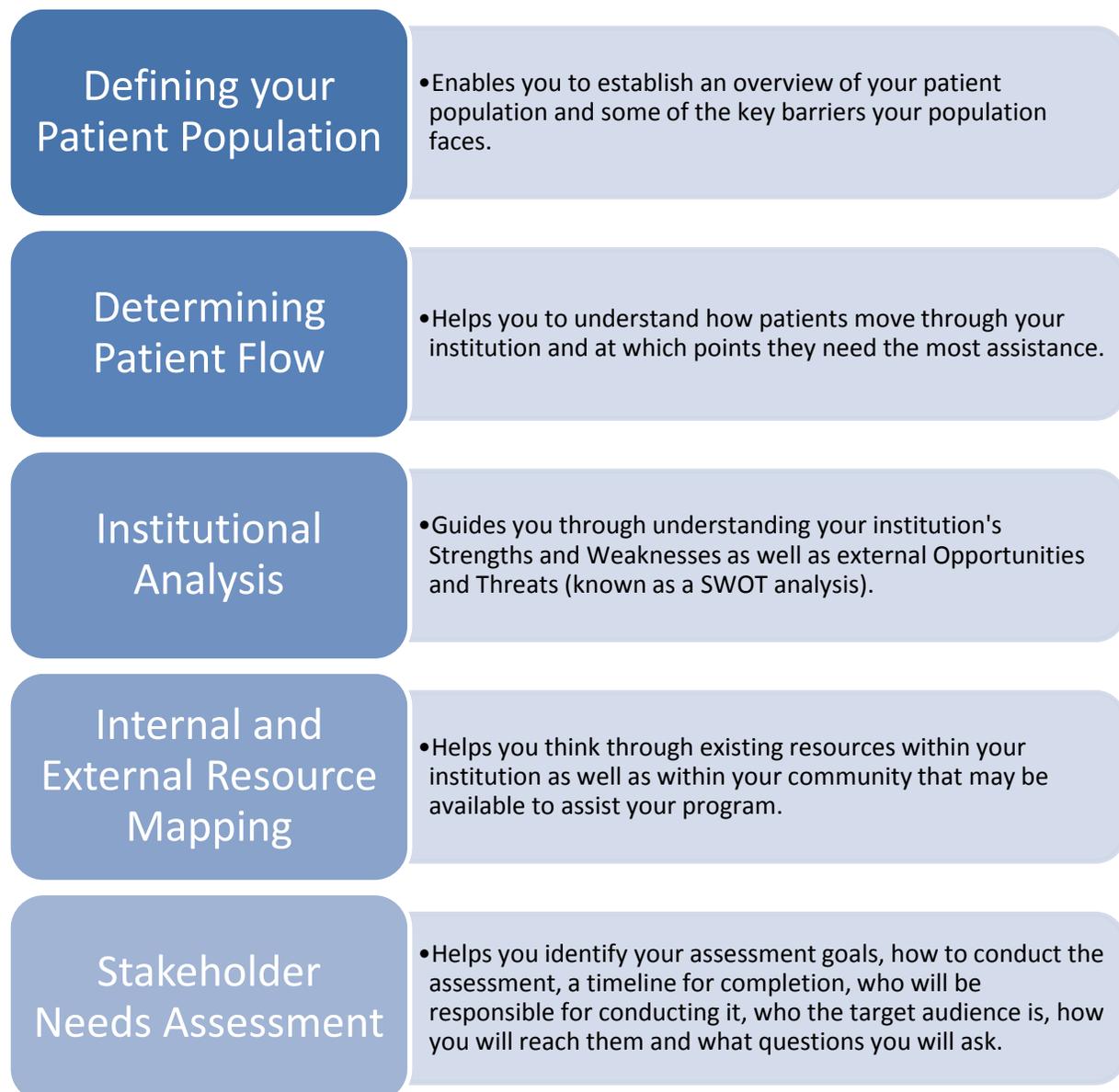
Figure 5: Program Development Cycle³¹



³¹ Centers for Disease Control and Prevention. Framework for program evaluation in public health. *MMWR*. 1999;48(11).

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. When conducting a needs assessment, consider:

Figure 6: Needs Assessment Components





Determine program components

Select which model might work best at your institution.

Figure 7: Survivorship Program Models



Select which services which services will be provided and if internal or external.

Figure 8: Survivorship Program Services



Select the Survivorship Care Plan template you will use.

ASCO Breast Cancer Survivorship Care Plan

The form is titled "Breast Cancer Survivorship Care Plan" and includes sections for patient name, oncologist name, and provider to contact. It contains detailed instructions for follow-up care, including frequency of visits and monitoring. A table lists monitoring frequencies for breast exams, mammography, and physical exams. A "Years Breast Cancer Follow-Up & Monitoring Schedule" table shows visit frequencies for the first 5 years and thereafter. A "Visit Frequency" table lists visits at 0, 6, 12, and 18 months. A "Notes" section includes instructions on how to use the plan and a list of symptoms of recurrence.

This single-page SCP provides columns for providers to indicate appropriate referrals and whom to contact for these services. Oncologists can indicate how often patients should be seen for a physical exam or mammography. A brief description of symptoms of recurrence to be watchful for is included.

This SCP should be accompanied by a treatment summary. It does not include recommendations regarding lifestyle modification or information on late and long term effects of cancer and cancer treatments.

Journey Forward Cancer Survivorship Care Plan

The form is titled "Cancer Survivorship Care Plan" and includes a description of the plan's purpose. It contains a section for "Survivorship Care Plan for Breast Cancer" prepared by a provider. A "General Information" section is highlighted in yellow. A "Care team" table lists various roles such as General/breast surgeon, Radiation oncologist, Plastic surgeon, Primary care physician, OB-GYN, Nurse/nurse practitioner, Mental health/social worker, and Other. The footer includes the version number (v2.0.204) and the date (Revised 2/11/2011).

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.

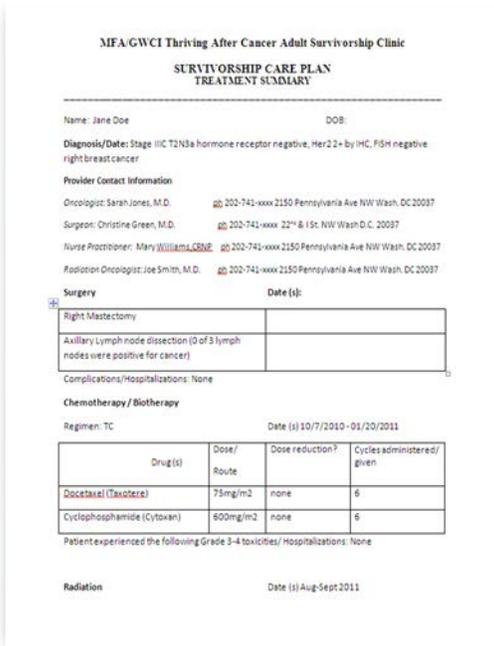
[LIVESTRONG Care Plan](#)



This multiple-page SCP includes a brief treatment summary, risks related to medications (e.g., chemotherapy), 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.

[GWCI Thriving After Cancer Adult Survivorship Clinic Care Plan](#)



This three-page SCP includes contact information for the care team, a treatment summary, follow-up recommendations, health maintenance and healthy lifestyle recommendations, symptoms of recurrence and general potential late effects and risks of treatment.

The SCP is developed by the oncology nurse practitioner to be delivered in the survivorship clinic. Recommendations are adapted for each survivor.

Note: the GWCI SCP was adapted from the [Memorial Sloan-Kettering SCP](#).

Identify assessment tools to identify survivor needs.

Several validated assessment tools exist, many of which are available at no cost with permission. The National Cancer Institute's GEM-Care Planning Initiative includes a list of possible tools, reviews of assessment tools by construct (e.g., quality of life, fatigue, body image) and access to the freely available tools. The initiative can be accessed online for free at www.gem-beta.org in the Workspace tab.

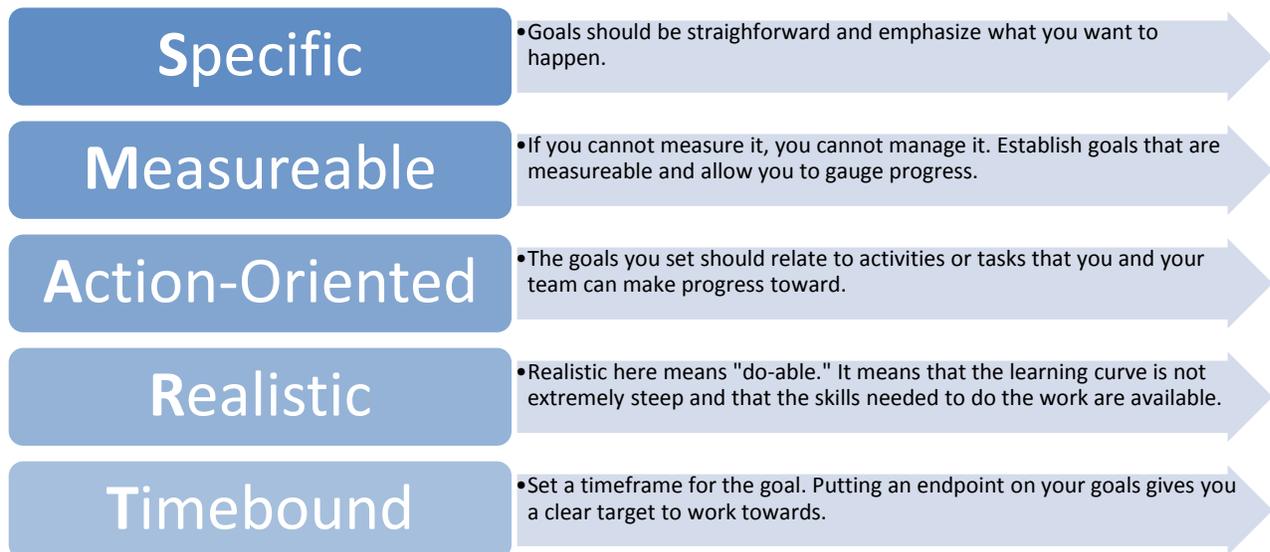
Develop an algorithm to determine service eligibility.

To ensure consistency across providers, you may need to establish an algorithm to guide follow-up care. The algorithm defines which survivors will be eligible for which services and determines the guidelines for follow-up recommendations. For example, if you are providing risk-based survivorship care, the algorithm would 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.

Identify program goals and objectives

Goals represent the quantifiable target that you wish to achieve. The aim, as well as the goals and objectives, should be SMART:

Figure 9: SMART Goals³²

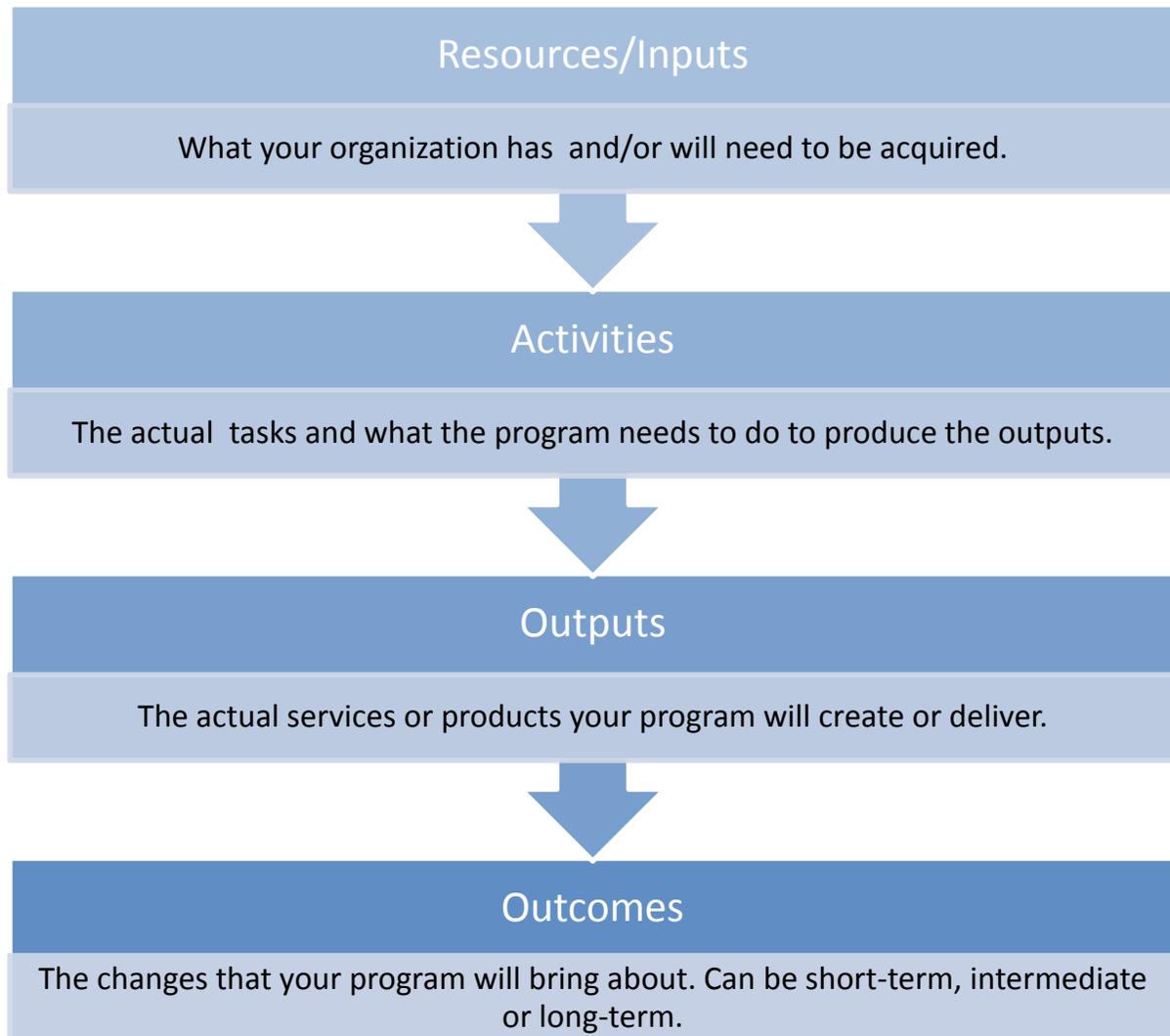


³² Centers for Disease Control and Prevention. Develop smart objectives. 2012. Available at http://www.cdc.gov/phcommunities/resourcekit/evaluate/smart_objectives.html

Create a logic model

A logic model is the “road map” or “blue print” to document your program plan. The logic model links goals, objectives, activities and inputs, outputs and outcomes. It clarifies what you plan to do, why, how and by when to keep you focused on program goals, track progress and evaluate the program. A logic model has the following components:

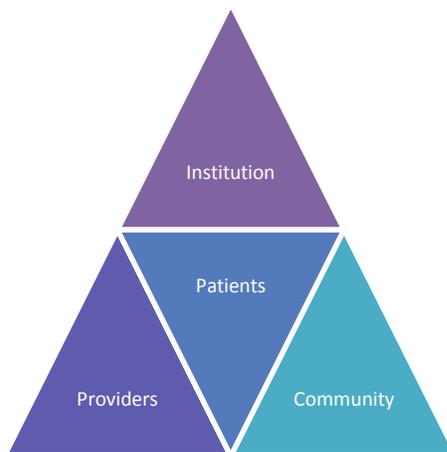
Figure 10: Logic Model Components



Develop a communication plan

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. When developing a communications plan think about creating a comprehensive approach that includes multiple stakeholders such as:

Figure 11: Multiple Stakeholder Communication



Create a budget and identify program funding options

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.

Many survivorship programs are funded by a combination of sources, including grants, reimbursement, internal funds and leveraging existing resources.³³ The budget below demonstrates some of the costs that may be necessary to launch and maintain a program. For each line item a funding source is listed.

³³ The George Washington University Cancer Institute Center for the Advancement of Cancer Survivorship, Navigation and Policy. Best practices in cancer survivorship and navigation survey summary report. 2013. Washington, DC. Available at: <http://smhs.gwu.edu/gwci/survivorship/reports>

Table 2: Sample Budget

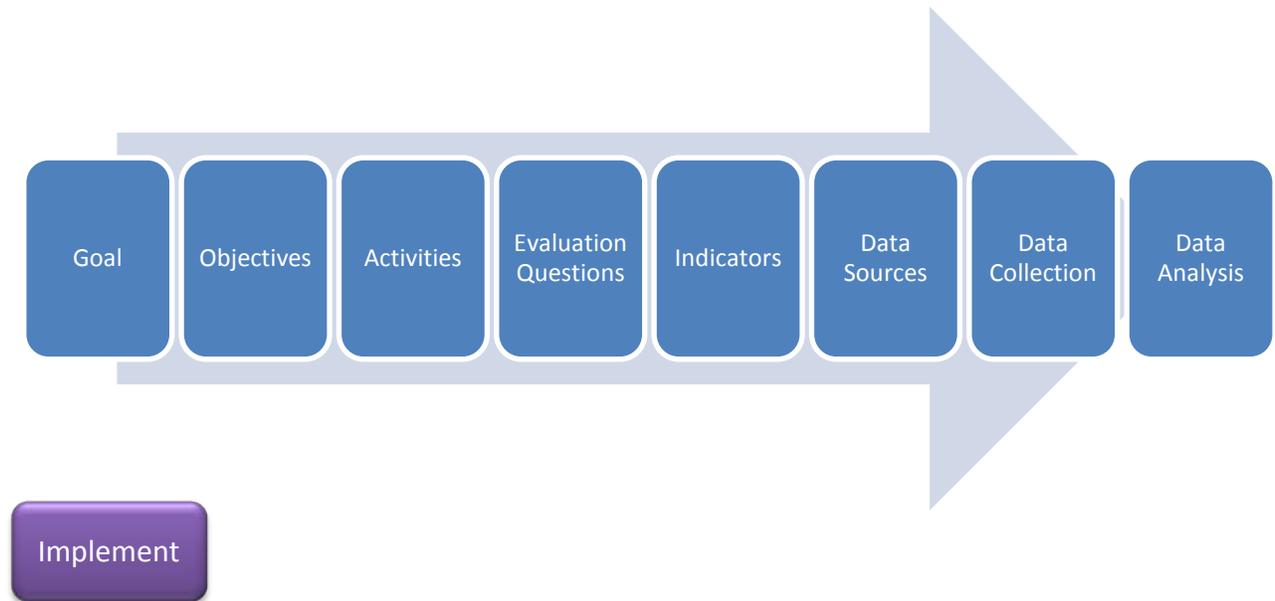
	Cost	Funding Source
<i>Personnel</i>		
Director of Survivorship/Nurse Practitioner (50% FTE)	\$	Internal
Patient Navigator, RN (50% FTE)	\$	Internal
Clinical Dietitian (25% FTE)	\$	Grant
Clerical staff	\$	Existing Resources
<i>Program Costs</i>		
		Funding Source
Facility rental	\$	Existing Resources
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
<i>Direct Medical Care</i>		
		Funding Source
Referrals - non subspecialists	\$	Billable
Lab and other tests	\$	Billable

Identify evaluation measures and procedures

Evaluation is the systematic collection of information about some or all aspects of a program to guide judgments or decisions. Evaluation can be formative, such as needs assessment or process evaluation, or summative, such as outcomes evaluation.³⁴ Formative evaluations help determine need and problems to address. Process evaluations focus on program fidelity by assessing activities that were implemented and the quality, strengths and weaknesses of the implementation. Outcomes evaluation measures that change that your program will bring about in your target population or social condition. The evaluation plan should build off of your logic model. When choosing measures, select measures that relate to your program and have a purpose in mind. An evaluation plan should include:

³⁴ Centers for Disease Control and Prevention. Framework for program evaluation in public health. *MMWR*. 1999;48 (RR-11).

Figure 12: Evaluation Plan Components



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.

Table 3: Survivorship Program Barriers and Solutions

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 • Talk with the billing department to identify and track revenue-generating services
Lack of knowledge regarding	<ul style="list-style-type: none"> • Collaborate with professional societies, like ASCO and

Barrier	Solutions
survivorship issues and needs	<p>ONS, and community organizations, like the American Cancer Society</p> <ul style="list-style-type: none"> • Create a continuing education program at your institution to share survivorship knowledge • Convene a meeting to raise awareness about post-treatment issues • Access the Cancer Survivorship E- Learning Series for Primary Care Providers available at www.cancersurvivorshipeducation.org
Lack of consensus-based guidelines	<ul style="list-style-type: none"> • Either create a committee or designate a person to draft institutional guidelines • Refer to existing guidelines documents for primary care providers will be available soon through the National Cancer Survivorship Resource Center
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 once or telemedicine models
<p>Physician support but not referrals</p> <p>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

Evaluate

Evaluating outcomes is an important part of the program development cycle and success of your program. What you do with your results is 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.

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

For more on program evaluation, see The Survivorship Center's publication, [Moving Beyond Patient Satisfaction: Tips to Measure Program Impact Guide](#).

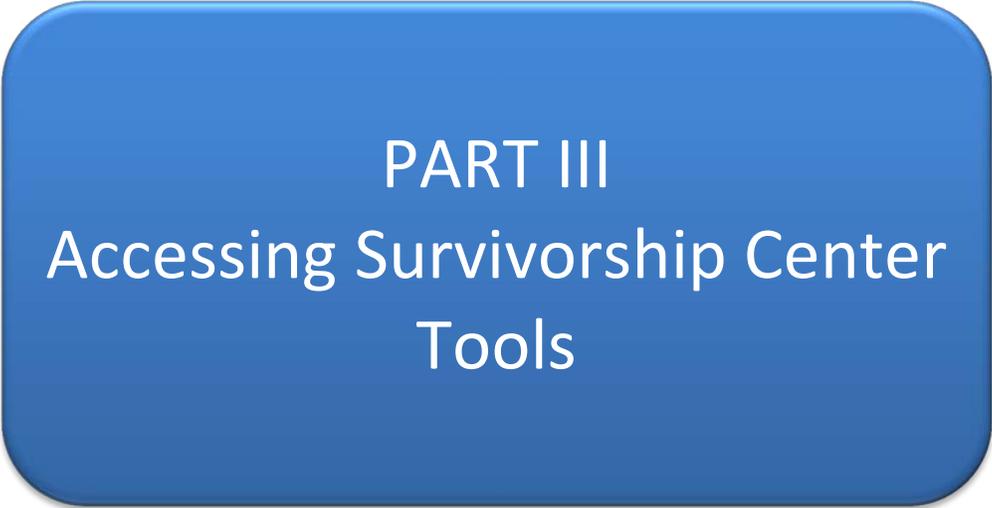


Online Resources For Further Reading:

[Strategic Management: Overview of SWOT Analysis.](#)

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

[Developing and Using A Logic Model](#)



PART III
Accessing Survivorship Center
Tools

Survivorship Center Tools

Tools for Cancer Survivors and Caregivers

Life after Treatment Guide

A concise booklet for post-treatment survivors that provides information about common survivorship late effects, defines a treatment summary and a survivorship care plan, lists online resources for information and provides tips for how survivors can use the information they find online to communicate with their health care team. The booklet is available for free download at: www.cancer.org/survivorshipguide. (Free copies available in the distribution center #.004598).

Tools for Health Care Professionals

Prescription for Cancer Information

A communication resource for health care professionals to easily refer survivors to resources available in their office or clinic, in their community, via the telephone and online. This is a perforated sheet, similar to a prescription for medication. The prescription pad is available for free download at www.cancer.org/survivorshipprescription. (Free copies available in the distribution center # .004599).

Moving Beyond Patient Satisfaction: Tips to Measure Program Impact Guide

This Guide provides tips to measure program impact. Suggested measures include program satisfaction, program attrition and past participant referrals. The Guide also provides a list of validated tools to help programs evaluate impact on key quality of life outcomes. The Guide is available for free download at: www.cancer.org/survivorshipprogramevaluation.

Cancer Survivorship E-Learning Series for Primary Care Providers

The GW Cancer Institute, in collaboration with the American Cancer Society as part of The Survivorship Center's work, developed the *Cancer Survivorship E-Learning Series for Primary Care Providers*. This online resource features content on the role of clinical generalists and specialists in providing follow-up care to cancer survivors, how to manage late and long-term medical and psychosocial effects of cancer and its treatments, and the importance of survivorship care planning. Free continuing education credits for physicians, physician assistants, nurse practitioners and nurses are available. The e-learning series supports the dissemination of post-treatment survivorship education and the clinical follow-up care guidelines to primary care providers. To learn more, please visit: <https://cancersurvivorshipcentereducation.org>.

Resources

Select Survivorship Publications

Adler NE, Page AE. (Eds). *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. 2008. Washington, DC: Institute of Medicine (IOM), National Academies Press.

Campbell MK, Tessaro I, Gellin M, et. al. Adult cancer survivorship care: experiences from the LIVESTRONG centers of excellence network. *Journal of Cancer Survivorship*. 2011;5(3):271-282.

Franco R, Stanton MP, Kindall SS. Cancer survivorship programs. *Oncology Issues*. 2012 January/February:36-41.

Ganz PA (Ed). *Cancer Survivorship Today and Tomorrow*. 2007. New York, NY: Springer.

Hahn EE, Ganz PA. Survivorship programs and care plans in practice: variations on a theme. *Journal of Oncology Practice*. 2011 Mar;7(2):70-5.

Hewitt M, Greenfield S, Stovall E (Eds.). *From Cancer Patient to Cancer Survivor: Lost in Transition*. 2005. Washington, DC: Institute of Medicine (IOM), National Academies Press.

Jacobs LA, Vaughn DJ. Care of the adult cancer survivor. *Annals of Internal Medicine*. 2013;158(11):ITC6-1.

Lance Armstrong Foundation, Centers for Disease Control & Prevention. *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*. 2004. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Available at <http://www.cdc.gov/cancer/survivorship/pdf/plan.pdf>.

Office of Cancer Survivorship (OCS) at the National Cancer Institute. *Facing Forward Series: Life After Cancer Treatment*. 2012. Available at <http://www.cancer.gov/cancertopics/life-after-treatment>

President's Cancer Panel. *Living Beyond Cancer: Finding a New Balance*. 2004. Bethesda, MD: U.S. Department of Health and Human Services, National Cancer Institute.

Rechis R, Beckjord EB, Arvey SR, et al. *The Essential Elements of Survivorship Care: A LIVESTRONG Brief*. 2011. Washington, DC: LIVESTRONG Foundation. Available at: <http://www.livestrong.org/pdfs/3-0/EssentialElementsBrief>

Spinks TE, Walters R, Feeley, TW, et. al. Improving cancer care through public reporting of meaningful quality measures. *Health Affairs*. 2011;30(4): 664-672.

Listing of Organizations with Survivorship Resources

American Society of Clinical Oncology

www.asco.org

The American Society of Clinical Oncology is a professional organization representing physicians of all oncology subspecialty who care for people with cancer.

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

LIVESTRONG provides resources for cancer survivors, caregivers and families such as the **LIVESTRONG** Guide and Care Plan as well as resources for health care professionals such as the Essential Elements of Survivorship Care.

National Cancer Institute Office of Cancer Survivorship

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

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

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 Survival Toolbox' is a useful resource to provide to patients and survivors.

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.

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.

Oncology Nursing Society

www.ons.org

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