

Moving Beyond Patient Satisfaction: Tips to Measure Program Impact

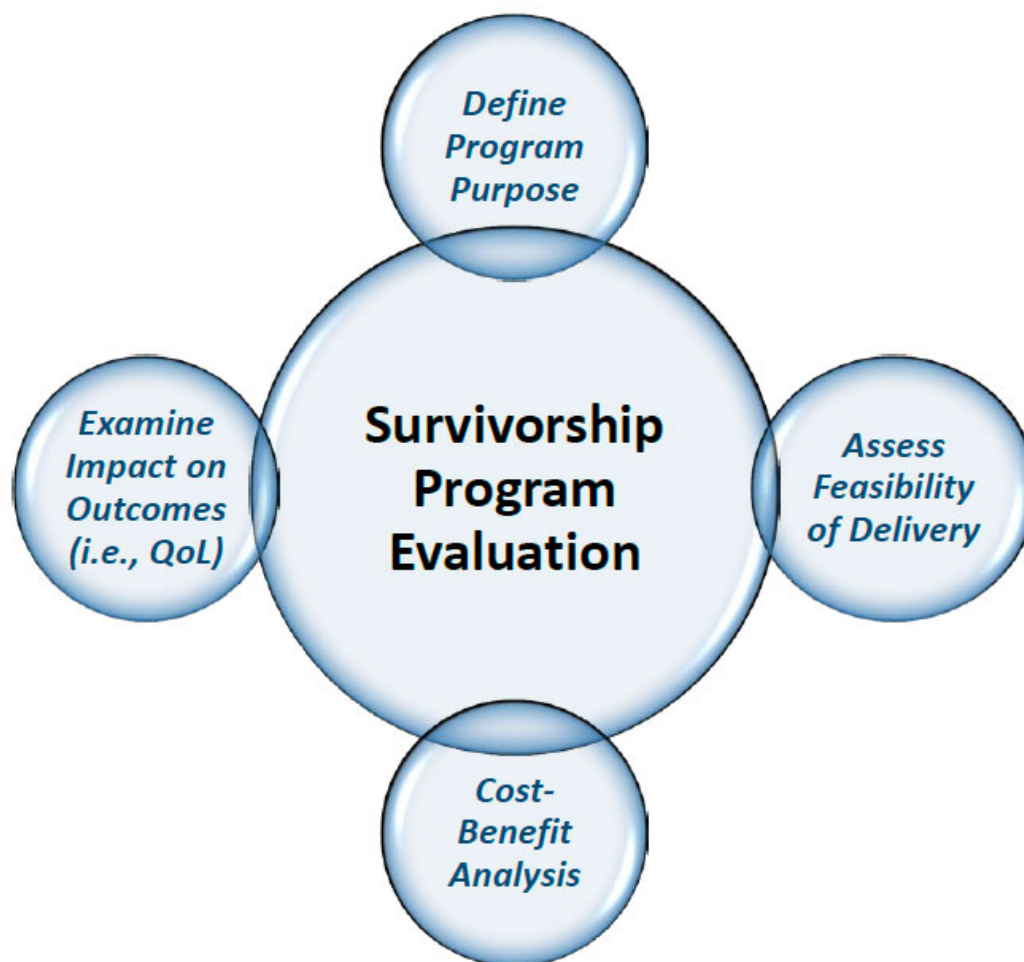


Figure 1 - Survivorship Program Evaluation Image

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Purpose

This guide is intended to help organizations and communities gain a better understanding of how to evaluate survivorship programs designed to improve the quality of life of cancer survivors. This guide will:

1. Identify the phases of cancer survivorship and provide a definition of a survivorship program
2. Establish the importance of program evaluation
3. Illustrate the quality of life domains and provide examples of program interventions, possible intended outcomes and suggestions for measurement.

What is Cancer Survivorship?

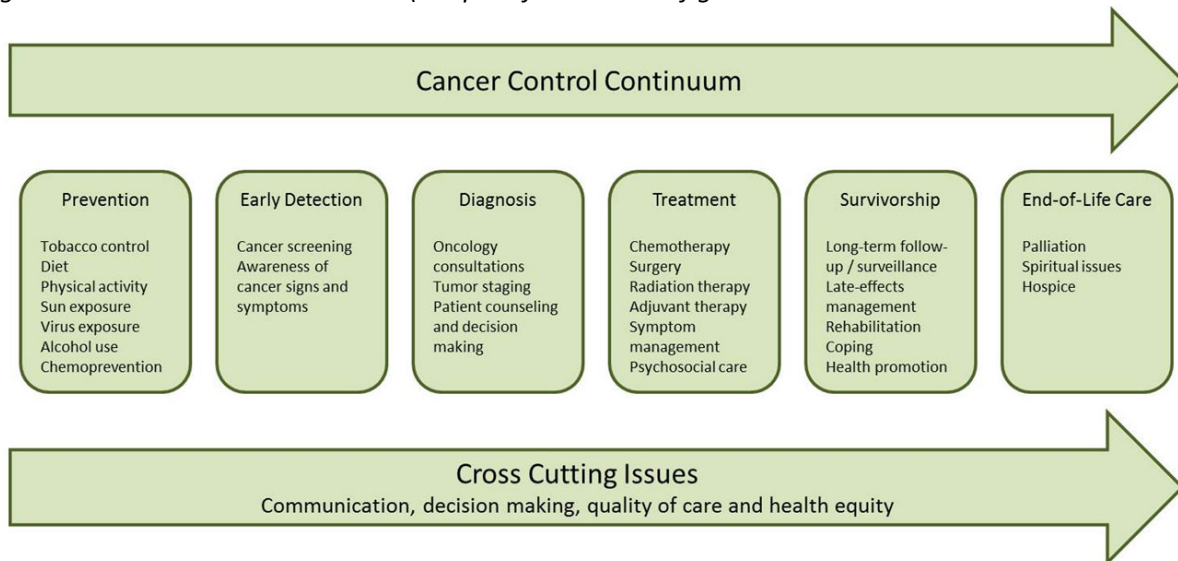
The National Cancer Institute (NCI) defines a **cancer survivor** as *“one who remains alive and continues to function from the time of diagnosis until the end of life”*. The NCI also establishes **cancer survivorship** as covering *“the physical, psychosocial and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers and quality of life. Family members, friends and caregivers are also part of the survivorship experience.”* The NCI’s definition of cancer survivor and survivorship are commonly accepted by cancer-focused organizations, providers and cancer centers. In addition to the psychosocial issues recognized by NCI, spirituality is also an integral part of a survivor’s life. Many survivorship programs often address one or more of these issues and encourage survivors to work with their health care providers to develop a survivor care plan that includes spiritual as well as physical, emotional and social needs.

For the purpose of this guide, the term survivor refers to anyone who has **completed** active treatment for cancer and survivorship refers to the **post-treatment** phase of the cancer continuum. Cancer survivors may experience a variety of physical, psychosocial and spiritual long-term or late effects as a result of the cancer type, stage of diagnosis and treatment regimen. Furthermore, these effects may vary by the time since treatment ended. Post-treatment survivorship has historically been a neglected phase in the cancer care trajectory, but more programs have been developed over the last decade to address post-treatment needs. However, there is limited published information available to guide the development of interventions aimed at addressing those specific needs identified by post-treatment survivors. To begin addressing this gap, it is important to build a foundation of evidence-based programs focused solely on the post-treatment period of survivorship.

To better understand cancer survivorship, one must first have a basic understanding of the cancer continuum. The cancer control continuum, shown in Figure 1, has been used since the mid-1970’s to describe the basic phases of prevention, early detection, treatment, survivorship and end-of-life. Advances in cancer biology, treatment, psychosocial and spiritual care have led to an increased understanding of the complexities and interdependencies of the basic categories of the cancer control continuum. Several issues, such as quality of care, health equity, provider communication and decision making are relevant across the continuum and ultimately impact the long-term health and psychosocial outcomes of cancer survivors.¹

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Figure 1: Cancer Control Continuum (adapted from the NCI figure on the “Cancer Control Continuum”²)



For example, survivors just transitioning out of treatment may face issues returning to work or may feel anxious about returning to normal social activities. Survivors may experience distress that may extend along the continuum of care from common, normal feelings of vulnerability, sadness and fear, to problems that become disabling such as depression, anxiety, panic, social isolation and existential spiritual crises. Survivors that are two to five years post-treatment may begin to experience late-term effects due to treatment or have concerns over cancer recurrence. Survivors that are five to 10 years post-treatment may begin to experience additional health concerns, such as heart disease or diabetes, which can interfere with ongoing adjuvant therapies or impact one’s ability to manage the follow-up care required for their specific cancer type. Ten years or more post-treatment, cancer survivors may experience a cancer recurrence or new primary cancers, as well as additional psychosocial and spiritual late-effects stemming from the original cancer diagnosis and treatment.¹

Survivors must be proactive in managing post-treatment issues. Adopting healthy behaviors, such as eating fruits and vegetables and cutting back on fatty and sugary foods, getting regular physical activity, avoiding tobacco products and maintaining a relationship with a primary health care provider can help survivors achieve optimal health and improve quality of life during the post-treatment phase. To better achieve positive health outcomes, survivorship programs should be developed and implemented to address the essential components of survivorship care and improve care coordination.

What are the Essential Components of Survivorship Care?

According to the Institute of Medicine’s (IOM) 2006 report *From Cancer Patient to Cancer Survivor: Lost in Transition*¹, there are four essential components of survivorship care:

1. Prevention of recurrent and new cancers, and of other late effects;
2. Surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects;
3. Intervention for consequences of cancer and its treatment, for example: medical problems such as lymphedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; and concerns related to employment, insurance, and disability; and
4. Coordination between specialists and primary care providers to ensure that all of the survivor’s health needs are met. (p. 3)

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The IOM report also recommended that care delivery systems facilitate this care in a comprehensive and coordinated way. By better understanding the impact on the intended outcomes of survivorship programs, health care providers and survivors can work together to ensure that the multitude of needs faced during survivorship are adequately addressed.

What is a Survivorship Program?

For the purpose of this guide, a survivorship program is defined as having a *goal 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 assure 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.* This consensus-based definition was developed by the National Cancer Survivorship Resource Center's Quality of Life: Programs and Navigation Workgroup (membership listed on page 10 of this guide).

Survivorship programs should be developed and implemented using evidence-based approaches that are tailored to meet the needs of specific populations. As you develop your program, conducting a needs assessment can help define program components that best meet the needs of the survivor population being served. A needs assessment includes questions such as:

- What are the issues faced by cancer survivors during the post-treatment phases?
- In what ways do cancer survivors want to receive information about long-term and late effects of treatment?
- What are the primary barriers cancer survivors face to receiving survivorship follow-up care?
- What are the gaps in existing programs and services offered to cancer survivors and how can these gaps be addressed?

As the number of clinical survivorship programs implemented since the IOM report has grown, it is increasingly important to evaluate the different programs and services to assess the impact on the physical, psychosocial and spiritual issues faced post-treatment. Better understanding the impact of a program can help develop a standard of care for survivorship programs to ensure that cancer survivors receive quality follow-up care that appropriately addresses the issues often faced during survivorship.

Why Should You Evaluate Your Survivorship Program?

Effectively addressing the post-treatment survivorship needs of the nearly 14 million cancer survivors in the United States is a priority issue for health promotion and cancer control programs across the nation. In order to assure the effective development and implementation of post-treatment survivorship programs, organizations and communities need to emphasize the value of program evaluation and ongoing program improvement.

Program evaluation is an essential component necessary to increase the availability of high-quality, effective programs to improve the quality of life of cancer survivors. Furthermore, evaluation demonstrates the program's ability to reach the intended audience and to achieve the intended outcomes. Program evaluation also helps to build practice-based evidence for interventions, which can (1) inform both public health practice and research agendas and (2) complement rigorously tested evidence-based practices.³

What is a Logic Model?

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When you begin developing or implementing your survivorship program, you may find it helpful to create a logic model. A logic model details the types of programmatic activities necessary for program delivery and links these activities to necessary resources to ensure successful implementation. The logic model will map program to outputs, such as the number of participants and how long a participant may have stayed in the program. Outputs help provide initial measurement of program success. For longer term measures of program success, the logic model details the expected short-, intermediate and long-term outcomes of the program. Appendix A provides an example of a logic model for an online self-management workshop for post-treatment cancer survivors. The logic model can be used to guide the development of key questions to evaluate various aspects of the program.

What are Some Evaluation Questions to Measure Program Implementation?

Evaluation questions will be developed to examine program delivery. Evaluating program delivery will help to identify areas of success and potential opportunities for improvement. Here are a few questions you could ask to better understand success of program delivery:

- Which program activities were effective in reaching the intended audience?
- Which elements of program promotion were most successful and why?
- Which program materials and activities were most effective at reaching the program participants?
- What, if any, were the barriers to participants remaining in the program for the full duration?
- What suggestions do participants have for improving the program?
- Would participants recommend the program to others?

What are Some Evaluation Questions to Measure Program Impact?

To ensure a comprehensive evaluation of program impact, one should ask questions that explore the expected short-, intermediate and long-term outcomes. To explore the impact of short-term outcomes, the evaluation should pose questions to determine participant satisfaction and knowledge improvement specific to program objectives. Intermediate outcome evaluation will explore behavior changes related to program intent and may include questions related to functional status, adherence to clinical recommendations or coping and self-management skills. Evaluation of long-term outcomes often includes assessment of morbidity and mortality.

Improving quality of life for cancer survivors is often a key goal of survivorship programs. It is important that program evaluations use reliable and valid tools to measure outcomes; doing so will enable researchers and program directors to develop program standards that leverage successful elements from existing programs and ensure that survivors' needs are being met. The examples in Table 1 illustrate the basic quality of life domains, potential intervention types and suggested outcome measurement tools for non-navigator programs. These examples are not meant to be a comprehensive list of all potential measures and intervention types, but rather are provided to help guide programs to move beyond simply measuring participant satisfaction and begin to evaluate program impact on quality of life and other aspects of survivorship.

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Table 1: *Examples of Survivorship Program/Intervention Types and Outcome Measurement Tools*

Domain	Program/Intervention Type	Indicator	Measurement Tool (Acronyms defined in next section)
Physical			
<i>Fatigue</i>	Physical Activity	Decreased fatigue; improved sleep; increased number of survivors using fatigue self-management strategies; increased education on preventive behaviors and ways to optimize health	BFI ⁴ ; EORTC-QOL-30 Fatigue Module ⁵ ; FACIT-Fatigue ^{6,7} ; FSI ⁸ ; POMS-SF Fatigue subscale ⁹
<i>Pain</i>	Relaxation Training (Cognitive-Behavioral Therapy)	Decreased pain; better pain management; increased mobility; decreased psychological distress; increased productivity	BPI ¹⁰ ; McGill Pain Questionnaire ¹¹
<i>Sexual Functioning</i>	Sex Therapy and/or Pharmacologic	Increased physiological arousal; increased interest in sex; increased sexual attractiveness for self and partner; increased ability to achieve orgasm	MOS SPSI ¹² ; CARES-SF Sexual subscale ¹³ ; FSFI ¹⁴
Psychological			
<i>Fear of Recurrence</i>	Mindfulness (Cognitive-Behavioral Therapy)	Less frequent intrusive thoughts of cancer returning, perceived control over the future; decreased cancer-related psychological distress	CARS ¹⁵ ; FCRI ¹⁶ ; IES-R ¹⁷
<i>Anxiety</i>	Stress Management (Cognitive-Behavioral Therapy)	Decreased sense of general worry or fear; decreased isolation; improved coping skills	HADS ¹⁸ ; POMS-SF Anxiety subscale ⁹ ; STAI ¹⁹
<i>Depression</i>	Coping Skills Training (Cognitive-Behavioral Therapy) + Psychoeducation	Increased interest in activities; increased feelings of worthiness; decreased feelings of guilt; increased level of energy; improved level of concentration; decreased sadness	BDI ²⁰ ; CES-D ²¹ ; HADS ¹⁸ ; PHQ-9 ²² ; POMS-SF Depression subscale ⁹
Social			
<i>Family Distress</i>	Family Therapy	Increased communication; increased family cohesion; improved relationship quality; improved decision making	CCAT-PF ²³ ; FACES-II ²⁴ ; F-COPES ²⁵ ; FES ²⁶ ; FRI ²⁷ ; FSS ²⁸ ; MSPSS ²⁹ ; MOS SSS ³⁰
<i>Marital Distress</i>	Couples Therapy	Increased relationship satisfaction; increased intimacy; improved sexual function and satisfaction; increased partner appreciation	DAS ³¹ ; DCI ³² ; ENRICH ³³ ; PRCI ³⁴
<i>Appearance/Body Image</i>	Support Group	Increased self-confidence; decreased isolation	BIAQ ³⁵ ; BIQ ³⁶ ; BIS ³⁷

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Table 1 con't: *Examples of Survivorship Program/Intervention Types and Outcome Measurement Tools*

Domain	Program/Intervention Type	Indicator	Measurement Tool (Acronyms defined in next section)		
Medical					
<i>Continuity of Care</i>	Survivorship Care Plan	Utilization of a Survivorship Care Plan; improved tracking of service referrals; survivor's identification of a medical home; improved tracking of referrals to other HCPs/programs; compliance with follow-up recommendations; increased self-efficacy	Receipt of a Survivorship Care Plan; PCDCS ³⁸ ; PHCS ³⁹ ; SCE ⁴⁰ ; SEMCDS ⁴¹		
<i>Patient-Physician Communication</i>	Communication Skills Training	Initiates discussions with HCP regarding long-term and late effects; increased discussion with HCP regarding spirituality; increased survivor spiritual well-being; increased survivor satisfaction with care; increased number of conversations about self-managed care strategies	CASE-C ⁴² ; PSCC ⁴³		
Spiritual					
<i>Existential Concerns</i>	Training clinicians on appropriate physician-patient communication	Increased discussion between patient and physician regarding spirituality	FACIT-SP ⁴⁴ ; SBI-15R ⁴⁵ ; QOL-CS (Spiritual Well-being subscale) ⁴⁶ ; DUREL ⁴⁷ ; PTGI ⁴⁸		
<i>Abandonment</i>					
<i>Anger</i>					
<i>Concerns about relationship with deity</i>				Mindfulness training	Increased survivor satisfaction
<i>Conflicted or challenged belief systems</i>				Spiritual Counseling	Increased survivor spiritual well-being and QOL
<i>Despair/Hopelessness</i>				Referral to board certified or board eligible chaplains	Increased Meaning/Purpose
<i>Grief/Loss</i>					
<i>Guilt/Shame</i>				Meaning-centered therapy	Sense of Hope
<i>Reconciliation</i>					
<i>Isolation</i>				Dignity Therapy	Ability to forgive
<i>Religious-specific</i>					
<i>Religious/spiritual struggle</i>				Art Therapy	Decreased guilt/shame
<i>Personal Growth</i>					
	Spiritual Support Groups	Improved connection with higher power/god, nature, the significant or sacred			

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Scale Abbreviations

BDI – Beck Depression Inventory
BIAQ – Body Image Avoidant Questionnaire
BIQ – Body Image Questionnaire
BIS – Body Image Scale
BFI – Brief Fatigue Inventory
BPI – Brief Pain Inventory
CCAT-PF – Cancer Communication Assessment Tool for Patients and Families
CARES-SF Sexual subscale – Cancer Rehabilitation Evaluation System-Short Form
CES-D – Center for Epidemiologic Studies-Depression 10
CASE-C – Communication and Attitudinal Self-Efficacy Scale-Cancer
CARS – Concerns About Recurrence Scale
DAS – Dyadic Adjustment Scale
DCI – Dyadic Coping Inventory
DUREL – Duke University Religion Index
ENRICH – Enriching & Nurturing Relationship Issues, Communication and Happiness
EORTC-QOL-30 Fatigue Module – European Organization for the Research and Treatment of Cancer, Quality of Life
FACES II – Family Adaptability and Cohesion Evaluation Scales
F-COPES – Family Crisis Oriented Personal Evaluation Scales
FES – Family Environment Scale
FSS – Family Satisfaction Scale
FRI – Family Relationship Index
FSI – Fatigue Symptom Inventory
FCRI – Fear of Cancer Recurrence Inventory
FSFI – Female Sexual Function Index
FACIT-Fatigue – Functional Assessment of Chronic Illness Therapy-Fatigue
FACIT-Sp – Functional Assessment of Chronic Illness Therapy-Spirituality
HADS – Hospital Anxiety and Depression Scale
IES-R – Impact of Events Scale - Revised
MPQ – McGill Pain Questionnaire
MOS SPSI – Medical Outcomes Study Sexual Problems Survey Instrument
MOS SSS – Medical Outcomes Study Social Support Survey
MSPSS – Multidimensional Scale of Perceived Social Support
PRCI – Partner Response to Cancer Inventory
PHQ-9 – Patient Health Questionnaire
PSCC – Patient Satisfaction with Cancer-Related Care
PHCS – Perceived Health Competence Scale
PTGI – Post-traumatic Growth Inventory
PCDSCS – Primary Care Delivery of Survivorship Care Scale
POMS-SF Anxiety, Depression and Fatigue subscales – Profile of Mood State-Short Form
QOL-CS (Spiritual Well-being subscale) – Quality of Life-Cancer Survivors
SEMCDs – Self-Efficacy for Managing Chronic Disease Scale
STAI – State-Trait Anxiety Inventory
SCE – Survivorship Care Expectations
SBI-15R – Systems of Belief Inventory

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What are Some Ways to Measure the Cost-Benefit of a Program?

In addition to conducting process and outcomes evaluations, programs may also want to measure the cost-benefit of the program. Cost-benefit may be difficult to calculate and will depend on the needs of different stakeholders, but will provide invaluable information to ensure adequate resources necessary to sustain the program. The following are examples of questions that may be useful for various stakeholders:

- How much does this program cost the patient and what are the benefits they receive from participating?
- Are the resources allocated appropriate for implementing the program activities? Did the cost of the program exceed the estimated budget?
- How much does the program cost to run compared with how much revenue the program generates? What indirect revenue can you attribute to your program (e.g. referrals to specialists within your institution)? You may need to work with your billing department to estimate program revenue.
- How did the program impact healthcare utilization rates?

What are Additional Resources to Help Develop a Program Evaluation?

There are many evaluation books and resources available to help develop program evaluations. It is important to develop an evaluation plan as the program is developed. The following list of resources is not a comprehensive list, but should provide some basic tools and tips to build and conduct a high quality program evaluation.

- The George Washington Cancer Institute's Center for the Advancement of Cancer Survivorship, Navigation and Policy offers training opportunities and resources to assist health care professionals with implementing and evaluating patient navigation and survivorship programs. A comprehensive guidebook for implementing programs is available at no cost at <http://gwcancerinstitute.org>.
- Additional social and behavioral science measures and examples of quality of life measures can be found at the National Cancer Institute's Grid Enabled Measures Database website in the Care Planning Initiative workspace; <https://www.gem-beta.org>
- Comprehensive Cancer Control Branch Program Evaluation Toolkit, CDC DCPC, June 2010; http://www.cdc.gov/cancer/ncccp/pdf/CCC_Program_Evaluation_Toolkit.pdf
- The Community Toolbox, University of Kansas; <http://ctb.ku.edu/en/default.aspx>
- Western Michigan University – The Evaluation Center; <http://www.wmich.edu/evalctr/home/>
- American Evaluation Association – provides educational resources and conference opportunities and links to identify evaluation consultants; <http://www.eval.org/>
- Improving Care at the End of Life: How Robert Wood Johnson Foundation and Its Grantees Built the Field; <http://www.rwjf.org/pr/product.jsp?id=71944>

In addition to measuring programs aimed at improving the quality of life of cancer survivors, many cancer centers offer patient navigation programs to facilitate high quality cancer diagnosis, treatment and survivorship services. For specific guidance on evaluating the impact of patient navigation programs on quality of life, please refer to *Cancer* (2011) Supplement: National Patient Navigation Leadership Summit (NPNLS): Measuring the Impact and Potential of Patient Navigation (Volume 117, Issue S15, page i-ii, 3535-3623).

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Appendix A. Logic Model for Online Self-Management Workshop for Post-treatment Cancer Survivors

