

National Cancer Survivorship Resource Center

# Policy/Advocacy

Expert Panel Summit Workgroup Overview

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### Creating Survivorship Policies: Current models and barriers

From a policy perspective, one of the most challenging aspects of cancer survivorship is limited agreement regarding a definition of “survivorship care” among clinicians, researchers, administrators and policy-makers. Multiple models of care exist and within each model there are often differences in the methods by which care is delivered. Further, these models, shown in Table 1, are not mutually exclusive and can be used in a variety of combinations within the organization providing survivorship care. As a result, it is difficult to articulate professional training support needs for delivering optimal survivorship care and to devise meaningful payment options to reimburse delivery of the various components of survivorship care. While survivorship care is increasingly recognized as an important aspect of quality cancer care it is also often identified as a “non-revenue generating” service (The Advisory Board Co., 2008).

**Table 1: The most common models of Survivorship Care**

Model	Model Definition	Primary Professionals utilized
Academic/Oncology-Based Models	Introduced originally by pediatric cancer care institutions. Commonly organized by cancer or treatment type, and often “resource-intense”	Providers within the academic cancer center
Shared Care	Care shared between two or more providers of different specialties	Primary Care Provider (PCP) and Oncologists
Community-Based Models	Care provided by PCP and patient is referred to various specialists as needed.	PCP and various specialists
Nurse Practitioner Managed Care	Nurse Practitioner follows survivors for a period of time and acts as a bridge between primary care and oncology. Often utilized in underserved areas and where patient volume requires oncologists to focus on new patient care needs.	Nurse Practitioners

Varying models of survivorship care provide an opportunity for information technology to play an increasingly important role in survivorship. These varied and ever-changing models of health care delivery and management of health information combined with the shortage of health care professionals and the exponentially growing numbers of survivors increase the opportunity for survivors (and caregivers) to play a primary role in self-directing survivorship care (Wagner & McCorkle, 1998 and Cockle-Hearne & Faithful, 2010). Electronic tools such as toolkits and electronic medical records systems could facilitate these provider-survivor communication efforts. (The Advisory Board Co., 2009 and Rechis, 2010)



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Other models of chronic disease care (e.g., HIV, diabetes, kidney dialysis approaches) may help to inform the development of survivorship care models. In addition, providing palliative care alongside disease-directed treatment throughout the cancer continuum can provide better quality care and insight into what steps are necessary – and what pitfalls to avoid – when creating health care professional training mechanisms as well as reimbursement and billing structures to support survivorship care models.

Finally, variations in models of care do not tell the whole story. There is a wide range of service provided within the various models by individuals with varied levels of education and credentialing- from “bare bones” development of a survivorship plan by trained but non-credentialed individuals (such as other survivors or peers) to delivery of a full range of physical and psychosocial services by licensed health care professionals.

### Barriers Identified in Current Literature

- **Financial Barriers:** One of the most significant barriers to survivorship care is the lack of reimbursement for delivering important components of care. Third party reimbursement of survivorship services is inconsistent and many survivorship programs are entirely dependent upon philanthropic sources including private donations or grant support. For example, **LIVESTRONG** sponsors a Survivorship Centers of Excellence Network and other nonprofit organizations (National Coalition of Cancer Survivorship, Cancer Support Community, American Cancer Society, Patient Advocate Foundation and others) have also directly assisted survivors by providing or finding financial support for care.
- **Clinical Barriers:** Research also suggests there are two factors that differentiate cancer care from other chronic disease models that must be resolved prior to successful implementation of the shared care model. First, the therapeutic treatments, toxicities of those treatments, side effects and long-term implications of treatment (e.g., late effects) are largely unfamiliar to primary care providers; thus, inhibiting the PCPs ability to actively participate in care. Much of the science in toxicities and late effects of treatment in long-term survivorship is still emerging, so it is also unknown territory for the cancer specialty community. Second, because oncologists typically manage all the care of patients undergoing active treatment, these patients, if otherwise healthy, often disconnect from their primary care provider for a 2-3 year period. This makes it challenging for patients to transition across care settings or back to the primary care provider and often creates tension between oncologists, PCPs, and other health care professionals (Oeffinger and McCabe, 2006).
- **Research Barriers:** Cancer survivorship research also plays an important role in delivering better quality care and overcoming obstacles to comprehensive cancer care. Research may focus on toxicities and late effects/symptoms in survivorship, the type or components of care delivered, the manner in which that care is delivered, including who is delivering the care and the efficacy of the various models and iterations. Unfortunately, there are two significant barriers impacting research in this area. First, the Health Insurance Portability and Accountability Act (HIPAA) privacy regulations pose challenges for researchers trying to access information related to survivors and their care. Second, limited resources available to fund the breadth of needed



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cancer survivorship research while existing research has not focused deliberately on post-treatment survivorship issues, with the important exception of studies funded by the National Cancer Institute’s Office of Cancer Survivorship.

- **Operational/Organizational Barriers:** Finally, the variation of types of survivorship services and delivery models makes survivorship care a challenging topic to discuss with policy and decision-makers not familiar with the topic. It is difficult to provide clear and succinct information to policy-makers at the state and federal level and this hampers their ability to propose and implement policy change.

### Workgroup Progress: Prioritizing barriers and opportunities for action

The Policy Advocacy workgroup began by prioritizing the four common barriers to delivering comprehensive survivorship care, described above, listing existing or possible policy solutions and steps to implementing those policies. The results of the prioritization are shown below:

**Table 2: Prioritization of Barriers**

Barrier	Average Priority Rank 1-4 (1= highest priority)	Range of responses (from 1-4)
Financial Barriers	1.5	Range: 1-2
Clinical Barriers	2	Range: 1-4
Research Barriers	2.5	Range: 1-4
Operational/Organizational Barriers	2.6	Range: 2-3

Overwhelmingly, financial barriers were ranked the number one priority with an average priority ranking of 1.5 and all respondents ranking it either a 1 or 2. Another striking result from the group’s initial response was the continued call for training/education as a step to achieving policy adoption and implementation. Education of health care professionals, survivors/family caregivers and policy makers was listed as a “step to achieving effective policies” to address each of the barriers. Other cross cutting needs included increased funding for research and increased surveillance of cancer survivors.

The workgroup decided that to affect any of the barriers listed above, policy makers must become aware of the needs of cancer survivors and the impact cancer survivorship has on public health and the health care system. To increase this awareness the workgroup agreed a series of white papers addressing priority areas of concern would be the most useful contribution. Over the remaining meetings, white paper outlines were debated, developed and resulted in the following four topics:

- **A Landscape Analysis:** This paper will serve as an introduction to cancer survivorship, as well as to the remaining three papers. The paper will strive to highlight the importance of cancer survivorship to the public’s health and the stability of the health care system as the population of cancer survivors continues to increase and the workforce shortages in oncology and primary care grow. The paper will also convey how cancer has, in many cases, become a chronic disease and appropriate survivorship care can assist the national movement toward independent living. The target audience for this paper is broad and includes policy makers as well as employers, providers and payers.



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- **Survivorship Services:** This paper will utilize data from workgroup member's organizations to highlight services currently being used or requested by cancer survivors. The goal of this paper is to show the importance of these services to the recovery and quality of life of cancer survivors as well as highlight the importance of training health care professionals on survivors' needs and in the administration of these services. The target audience for this paper includes providers, provider training organizations, "think tanks" and employer groups.
- **Reimbursement for Survivorship Services:** This paper will highlight, in detail, current models that are already in use to pay for survivorship services mentioned in the previous papers. The paper will demonstrate how these models can be adapted to become sustainable in the larger health care system and cite other similar chronic disease models that have successful reimbursement models. The target audience for this paper includes payers, health care writers, the Centers for Medicare and Medicaid Services (CMS), the Department of Labor, National Business Groups, Employee Assistance Program contractors and organizations such as The Leapfrog Group (a voluntary program aimed at mobilizing employers' purchasing power to impact health care quality and affordability).
- **Funding for Research related to Survivorship Service:** This paper will highlight the importance of leveraging and expanding the evidence base to influence the implementation of survivorship policies. An evidence base for survivor needs now exists, but translational research showing the efficacy of programs and treatment is still needed. The target audience for this paper will include policy makers as well as agency partners such as the National Institutes of Health (NIH), Health Resources and Services Administration (HRSA), Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC) and cancer community partners such as the American Society of Clinical Oncology (ASCO), Oncology Nursing Society (ONS), as well as state and federal departments of health and health care financing.

### Recommendations for the Future

The workgroup developed a recommendations matrix that included recommendations, performance indicators and identified gaps. The matrix is structured using the socio-ecologic framework, focusing on individual/survivor, organization/health care system and society/policy levels of intervention in the four essential areas of survivorship care: healthy habits, early detection disease surveillance, psychosocial and physical post-treatment side effects and provider communication. These recommendations are described in the following section.

**Survivors:** The Policy Advocacy workgroup focused on opportunities for organizational and societal policy change. The workgroup recognizes the importance of individual/survivor and organization/health care system level recommendations as essential components of a multi-level strategy to improve survivorship care. The workgroups recommendations support recommendations put forth by the quality of life workgroups.

**Health Care System:** Recommendations for health care system policy change centered on health care professional education, communication and care coordination. The workgroup emphasized the



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importance of continuing education, hands-on training and the incorporation of education into formal health care professional curricula on the elements and delivery of survivorship care. To facilitate improved information sharing and communication among health care professionals and survivors, the workgroup recommends the utilization of a survivorship care plan and electronic medical records triggers when screenings or follow-up are needed. These efforts combined with health care professional –health care professional communication and defined reimbursement models will lead to greater care coordination.

**Society/Policy:** Society/policy recommendations focused on the barriers and needed steps for achieving policy adoption and implementation to address the barriers of training/education, funding, reimbursement and surveillance. The workgroup recommends the education of policy makers through white papers, meetings and public briefings, the identification and prioritization of funding available for survivorship translational research and identification of the most utilized and needed survivorship services. The group also recommends the reimbursement of the most utilized and needed survivorship services as well as an analysis of the current surveillance system, identification of data points available in surveillance and the creation of data linkages to monitor survivors with co-morbid conditions.

### Indicators to Help Measure Progress

In order to evaluate and monitor progress on the group’s recommendations, the following performance indicators were developed based on the workgroup discussions and strategic matrix. The Policy and Advocacy workgroup performance indicators largely focus on the dissemination and adoption of the four white papers. Additional work is needed to determine the specific measures, establish baseline value and set specific outcome goals for each of the performance indicators. An assessment of the current capacity of nationwide surveillance systems to support the measurement of these indicators is underway; once capacity is determined, recommendations for measures or proxy measures corresponding to each performance indicator will be developed.

**Table 3: Policy and Advocacy Performance Indicators**

Outcome Domain	Outcome Goal
Healthy Habits	Increase policy maker awareness of cancer survivorship as a public health issue and the importance of healthy habits among cancer survivors
	Increase collaboration among cancer organizations to educate policy makers on the key issues identified in the white papers.
	Increase in opportunities for research and applications for current RFPs related to cancer survivorship and healthy behaviors
Early Detection / Disease Surveillance	Increase in policy maker awareness of the importance of early detection and surveillance in cancer survivors
	Increase collaboration among cancer organizations to educate policy makers on the key issues identified in the white papers.
	Increase in opportunities for research and applications for current RFPs for early detection / disease surveillance for cancer survivors
Post-Treatment Side Effects (Psychosocial and Physical)	Increase in policy maker awareness of survivorship late effects and the need for treatment and self-management



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Outcome Domain	Outcome Goal
	Increase collaboration among cancer organizations to educate policy makers on the key issues identified in the white papers.
	Increase in opportunities for research and applications for current RFPs related to post-acute cancer care effects
Health Care Professional Communication	Increase policy maker awareness of the need for provider communication in quality survivorship care
	Increase collaboration among cancer organizations to educate policy makers on the key issues identified in the white papers.
	Increase in opportunities for research and applications for current RFPs to optimize health care professional communication for cancer survivors

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