

# A Framework for Cancer Survivorship Research and Translation to Policy

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## Abstract

Awareness has grown over the past few years that needs specific to cancer survivors have long been neglected. Clinicians and policy makers continue to struggle, however, with exactly how to address these needs. We present a comprehensive framework for survivorship research and couple it with a model for translating research into policy, using two examples for illustration. *Cancer Epidemiol Biomarkers Prev*; 20(10); 2099–104. ©2011 AACR.

## Introduction

Since publication of the seminal Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition* (1), the concept that cancer survivorship is a unique phase of the cancer control continuum has been widely accepted. Among the benefits and responsibilities that follow from this is the need to develop a research agenda that is specific to cancer survivorship and, in order for the research to have relevance and impact, to implement policies that stem from the research findings. However, to date, a comprehensive framework for survivorship research that is evidence based and encompasses translation of research into policy and practice has yet to be articulated.

The overall objective of this article is to discuss the strategies for research and policy that need to be in place for effective and sustained advancement of a cancer survivorship agenda. Some examples of the breadth of issues relevant to a cancer survivorship agenda are health care issues, such as cancer-specific surveillance strategies, preventive care, and general health care, and psychosocial issues such as quality of life, employment, and insurance concerns. The specific objectives of this article are twofold: (i) To propose a framework for a comprehensive cancer survivorship research agenda and (ii) To describe a framework that links the research agenda to policy. In this context, we will consider policies only at the macro level (e.g., state, provincial, or national levels). While we acknowledge that policies related to the meso level (e.g., regional or institutional) and micro levels

(e.g., patient or health care provider) are of equal importance, the factors influencing them have their own complexity and warrant separate discussions that are addressed by other articles in this series [e.g., Pollack and colleagues (ref. 2) and Hudson and colleagues (ref. 3)].

Two examples of relevance to cancer survivorship will be used to illustrate the application of these proposed frameworks.

### Example 1: Organization of health services for providing long-term follow-up care for cancer survivors

For many types of cancer, it has been a standard practice to provide long-term follow-up after completing cancer treatment. Long-term follow-up consists of periodic visits and tests, which usually take place in specialist cancer settings for sometimes prolonged periods after the treatment ends. However, there has been growing awareness in recent years that optimal cancer survivorship care involves more than surveillance tests. From the patient perspective, the exclusive reliance on cancer treatment specialists without involvement of primary care or other providers may leave unaddressed other and often complex medical (including other chronic conditions) and psychosocial needs of patients. From a health services perspective, it draws on scarce oncology resources without clear evidence of clinical benefit (4). Studies have shown that nonspecialist providers are able to deliver surveillance care with similar clinical outcomes and usually greater patient satisfaction (5–10). From both perspectives, there is the potential risk of specifically focusing on cancer care at the expense of that which is necessary to achieve optimal overall health (11), or lack of clarity about the roles of patients' various providers (12). There are substantial research questions about both the type of survivorship care and the providers that should be involved, considering a risk- and needs-based approach, that must be addressed to determine how best to organize health services for long-term follow-up care of cancer patients (3). As research leads to a better understanding of these aspects of survivorship care, supportive social service and health care policies can facilitate the delivery of evidence-based care.

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## Example 2: Long-term and late effects of cancer treatments

The success of cancer treatment regimens (whether surgery, radiation, or chemotherapy) has traditionally been determined by cancer recurrence and survival. However, now that the majority of cancer patients will survive their cancer (13), there is greater concern about the potential long-term and late effects of these treatments, in addition to endpoints that are narrowly focused on cancer progression and mortality (14, 15). Cancer treatments may result in higher incidence of second cancers, substantial reduction in health-related quality of life, impairment of functional status, or development of other medical conditions (16, 17). With growing awareness of these potential consequences, the benefits of the treatment for cancer must be balanced against the potential harms. To do this in a rigorous way requires a deeper understanding of what those effects are and their underlying mechanisms, their prevalence, factors that may predispose an individual to developing them, and experimental studies to test interventions to prevent or ameliorate them. While these are clinical questions, they also have an impact on broader psychosocial, educational, and occupational functioning (18) that may impair the survivors' overall rehabilitation and quality of life. Furthermore, awareness of these issues is essential for informed decision making about cancer treatment.

## A Framework for Cancer Survivorship Research

In addition to synthesizing what is known about cancer survivorship and establishing it as an important new focus for cancer care, the IOM report describes potential directions for future survivorship research (1). The report provides examples of current survivorship research (both topics and methodologies used), areas for future focus, potential challenges conducting survivorship research, and the relative contributions of

research granting agencies. Following this, Ayanian and Jacobsen (19), Earle (20), and Aziz (21) each further explicated the research domains, settings, and potential research questions relevant to cancer survivorship. What becomes apparent from these reviews is that despite the growth in survivorship research, there remains a paucity of studies looking at issues important to cancer survivorship such as supportive care, late effects, and optimal surveillance care. We propose a framework for cancer survivorship research (Fig. 1). This is intended as a guiding framework to be of use for both researchers and organizations responsible for planning research agendas, which can assist their efforts by identifying important areas of research that may not be adequately studied. Some examples of funding agencies that have launched strategic initiatives on cancer survivorship are the NIH Office of Cancer Survivorship (22), the Canadian Institutes of Health Research, Institute of Cancer Research (23), and the U.K. NHS (24).

In Fig. 1, the multidimensional nature of the research is represented by a cube. The most prominent surface of the cube explicitly states that not all topics are relevant to all survivors. Rather, there are unique elements that are determined by the type of cancer and its anatomic site, specific type of surgery and treatment regimens, and patient-specific risk factors and age. The framework also explicitly recognizes that adult survivors of childhood and young adult cancer are different from survivors of adult-onset cancer. On the top surface of the cube are those elements that are common to all cancer survivors: aspects related to their overall wellbeing (i.e., cancer follow-up care, general health care for prevention and management of other medical conditions, as well as rehabilitation, occupational, and broader psychosocial issues). The left side of the cube defines the following 4 research domains: basic biomedical, clinical, health systems, and population research. The multidimensionality is intended to convey

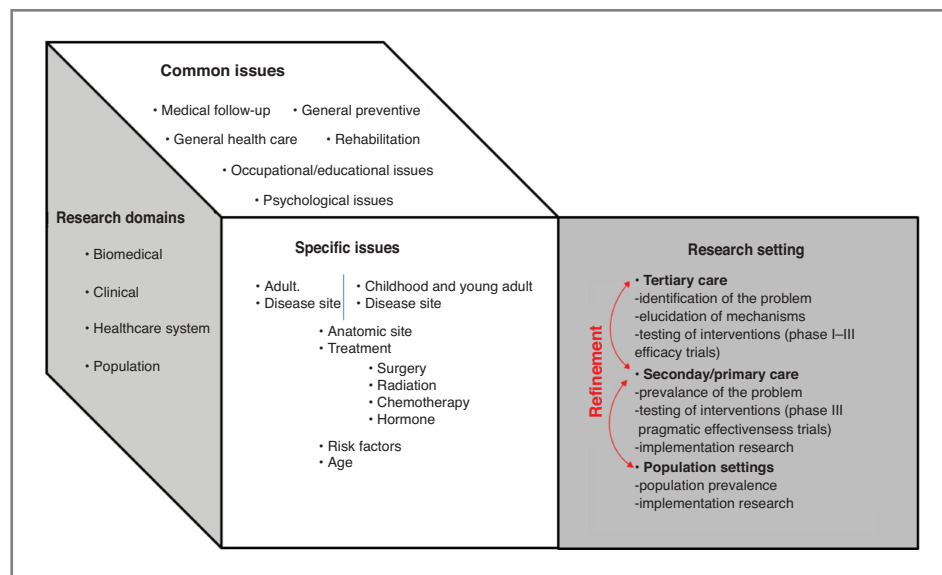


Figure 1. Framework for cancer survivorship research.

the fact that all 4 research domains are relevant to the specific and common issues, recognizing that some domains will be more important than others for some questions. Moreover, the multidimensionality emphasizes that the elements are interdependent. For example, general health status, such as comorbidities or other medical conditions, will have an impact on cancer-specific follow-up or the severity of late effects of cancer treatment.

The fourth surface of the cube shows the settings in which the research is to take place and the relevant range of research methodologies. This will vary according to the question. For example, initial identification of the problem and understanding of the basic underlying mechanisms would occur in specialist tertiary cancer clinics, as would phase I and II trials and phase III trials of the efficacy of interventions. However, measuring the population prevalence of the problem, phase III pragmatic effectiveness trials, or phase IV implementation studies would take place in primary care or population settings. There is a feedback loop where further questions about basic mechanisms or refinement of interventions would loop back to the tertiary setting.

In Table 1, we show the application of this framework using our 2 examples. For each domain, we describe specific research topics and the appropriate clinical setting for studying those topics.

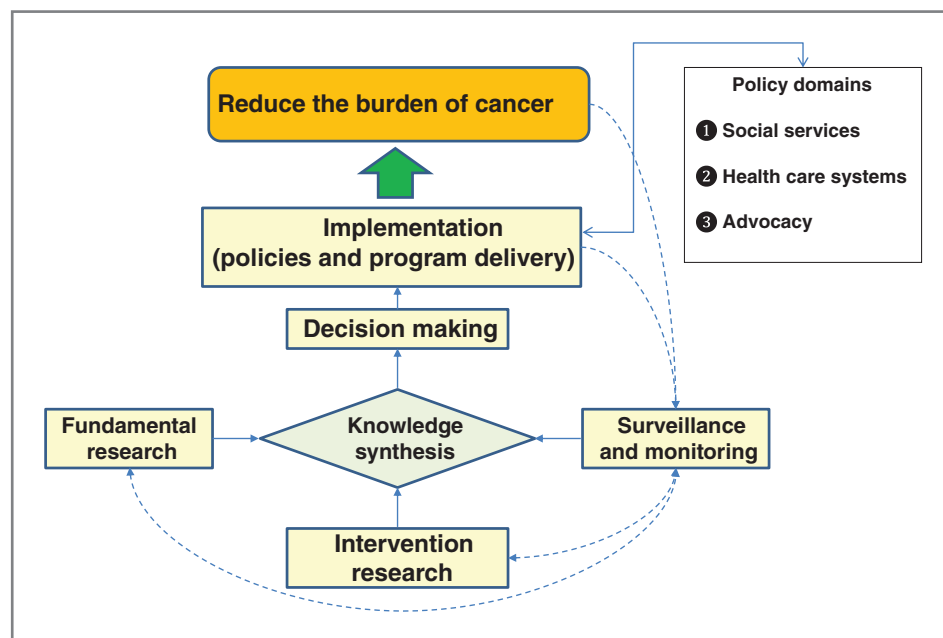
## Translation of Cancer Survivorship Research to Policy

### The missing link

The research and policy arenas run the risk of being akin to 2 parallel lines that never meet, unless there are specific

mechanisms to link the two. The American Cancer Society (ACS) and Canadian Cancer Society (CCS) recognized the importance of integrating the research and policy arenas so that each benefits from the other's knowledge, expertise, and ability to effect change, ultimately through clinical implementation of results. These societies jointly developed an *Analytic Framework for Cancer Control* (Fig. 2) which was first described in 1999 by Hiatt and Rimer (25) further developed by the ACS and CCS and adopted later by the Canadian Strategy for Cancer Control (26). This framework, as a generic template for cancer research and policy, is equally relevant to cancer survivorship as it is to other aspects of cancer research. In Fig. 2, we have adapted the framework by identifying the potential policy domains that are relevant to the application of cancer survivorship research results: social services, health care systems, and advocacy. We also show in Table 1 the application of these policy domains to our 2 examples. As research results lead to the development of more precise understanding of the optimum elements of long-term follow-up programs for cancer survivors, health care and social service policies must align with that understanding to encourage access to needed services and discourage unnecessary services. For example, is screening for particular subclinical late effects useful to add to follow up programs? ... or should some of the blood tests and imaging studies currently in use be discontinued? Similarly, research will enable better characterization of the extent to which long-term and late effects occur: that is, what are they, who experiences them, with what frequency and severity, how can they be identified, can they be prevented, and can they be treated? Once research has informed what should be done for patients, the various policy instruments described in Table 1 can be used to

Figure 2. Analytic framework for cancer control. Adapted from Advisory Committee on Cancer Control, National Cancer Institute of Canada (26).



**Table 1.** Application of a framework for cancer survivorship research and translation to policy: two examples of research topics

Domains	Example 1: organization of health care services for cancer follow-up	Example 2: long-term or late effects of cancer treatment
Research domains		
Basic biomedical	<p>Identification and testing of tumor markers as potential predictive tests for surveillance for cancer recurrence.</p> <p>Setting: academic health sciences laboratory studies for identification of candidate biomarkers. Tertiary care survivorship clinics for preliminary testing of sensitivity and specificity.</p>	<p>Elucidation of mechanisms by which chemotherapy or hormonal therapy cause long-term or late effects such as cognitive impairment or fatigue. Identification of potential mechanisms by which those effects can be prevented.</p> <p>Setting: academic health science laboratory studies. Tertiary cancer survivorship clinics for identification and characterization of the problem.</p>
Clinical	<p>Clinical trials to evaluate the benefits of surveillance tests (including identified biomarkers) and visits on clinical and patient-reported outcomes.</p> <p>Setting: tertiary care survivorship clinics for phase III efficacy trials.</p>	<p>Identification of individuals at higher risk of long-term or late effects because of genetic predisposition or comorbidities.</p> <p>Clinical trials to test interventions to prevent or treat long-term or late effects; development of tools that are sensitive and specific for measuring specific late effects.</p> <p>Setting: tertiary care survivorship clinics for phase I and II trials and phase III efficacy trials.</p>
Health care system	<p>On the basis of findings from basic biomedical research and phase III efficacy trials, evaluation of the effectiveness and cost-effectiveness of surveillance tests and visits using pragmatic trial methodologies.</p> <p>Setting: community cancer clinics and primary care settings.</p>	<p>Replicability and generalizability of tested interventions to community-based health settings, assessment of effectiveness, and cost-effectiveness in those settings.</p> <p>Setting: primary care or community and social service agencies.</p>
Population	<p>Adherence to guidelines on surveillance tests and visits for long-term cancer follow-up care.</p> <p>Setting: population-based studies using administrative health databases.</p>	<p>Prevalence of long-term or late effects at the population level.</p> <p>Setting: population-based survey studies drawn from cancer registries or based on administrative health databases.</p>
Policy domains		
Social services	<p>Municipal or state/provincial social service policies are introduced so that health insurance, child care services, and other community services (e.g., for transportation) are available to assist cancer survivors receive evidence-based surveillance visits and tests.</p>	<p>Recognizing the effect of cancer treatment on cognitive functioning, occupational health policies are established to support neurocognitive testing that is sufficiently sensitive to detect impairment of higher level executive cognitive function. Employment insurance policies are adopted that recognize that cancer survivors' may not be able to return to their previous occupation because of long-term effects such as fatigue or impaired cognitive functioning.</p>
Health care system	<p>Health care professional remuneration contracts are contingent on providing surveillance visits and tests recommended by evidence-based guidelines; surveillance visits, and tests that are not recommended are not reimbursed.</p>	<p>Health insurance companies are required to provide coverage for services for rehabilitation of individuals with fatigue or cognitive impairment due to cancer treatment.</p>

*(Continued on the following page)*

**Table 1.** Application of a framework for cancer survivorship research and translation to policy: two examples of research topics (Cont'd)

Domains	Example 1: organization of health care services for cancer follow-up	Example 2: long-term or late effects of cancer treatment
Advocacy	Local and national cancer organizations advocate for cancer care planning and tools and services to help coordinate posttreatment follow-up. These tools are tested in multiple settings to determine their effectiveness for using patient-centered, evidence-based decision methods to improve the quality of care survivors receive. The face validity of the need for these services alone should allow for advocacy of payment and delivery reforms to occur concurrently while studies are underway.	Advocacy for delivery and payment reforms for established surveillance interventions may reduce the risk of morbidity for already-known long-term and late effects of treatment and for care planning which incorporates patient preferences into treatment decisions. Advocacy for these reforms should be determined to be reasonable and necessary in all settings to reduce the posttreatment burdens associated with cancer survivorship. Advocacy groups will advocate for the establishment and payment for evidence-based long-term surveillance.

establish the health care and social services needed to enable cancer survivors to benefit from that research.

Advocacy, that is to say persuasive communication with policy makers, can play an important role in translating research findings into effective policy. It is through advocacy that the research-informed voice of cancer survivors is heard in policy-making venues. This can give momentum for successful adoption of evidence-based policies that address the health care needs of cancer survivors. An example is advocacy for reimbursement for cancer care planning services that can facilitate incorporation of patient preferences into treatment decision making.

### National policy initiatives

The need to prioritize cancer survivorship received an enormous boost through the publication of the IOM report (1). While the IOM report stood as a very influential overarching document, there had to be concurrent endorsement that the issue is important (both for clinical and health care system reasons) for the organizations responsible for cancer policies. Over the last few years, there have been notable examples of that endorsement.

In Canada, Cancer Care Ontario, the agency responsible for cancer services in the province of Ontario, is undertaking a major initiative to align policies (including physician remuneration policies) with evidence-guided recommendations on organization of services for cancer survivors within Ontario's tertiary care cancer centers (27). It is developing tools, such as evidence-based guidelines on follow-up care (28), to support the implementation of those policies. This provincial initiative is further supported at the national level through the Canadian Partnership Against Cancer's initiative on survivorship, which has funded demonstration projects of alternative models of survivorship care across the country (29). Denmark offers another example of how a national orga-

nization is driving forward a cancer survivorship policy agenda. The Danish Cancer Society was determined to set cancer survivorship on the political agenda. To do so, their document "*Strategic Presentation on Cancer Rehabilitation*" (30) specifically states that the Danish Cancer Society will request a change to health legislation to include "rehabilitation." Underpinning this request for new health legislation is recognition of the needs of cancer survivors for rehabilitation services and the expectation that the health care system should provide those services. The Danish Cancer Society will support this request for policy change with evidence-based pathways and guidelines to define what the rehabilitation services should be, as well as earmarking research funds to fill in the evidence gaps. The United Kingdom is also developing a national cancer survivorship agenda, as described in *The National Cancer Survivorship Initiative Vision* (24). Thus, working models exist that effectively align cancer survivorship research with resulting policy—models which are dynamic and which iteratively and reciprocally inform each other.

### Conclusions

These frameworks and the examples given to illustrate their application make the point that research strategies and policy strategies are iterative, continuously informing, and refining each other. As national funding organizations start to prioritize survivorship research (24, 29, 30), a coherent framework for survivorship research could help define the range of research domains and, within them, the topics that are common and unique to different types of cancers. A research framework could also enable different organizations with an investment in survivorship research to work collaborative and select the domain that aligns best with the specific mandate of their organization, without losing sight of the broader



survivorship research agenda. The framework for cancer survivorship research we propose here is intended to stimulate discussion, with the goal that it will be further refined, and its utility for facilitating the cancer survivorship research agenda tested.

The *Analytic Framework for Cancer Control*, which directly links research results to policies, reminds us that in isolation, it is more difficult to translate cancer survivorship research into benefits for cancer survivors. While decisions must be made on a strong evidentiary base derived from research, unless that research evidence is implemented in the health care system and social service domains, it will have no impact on the health and well-being of cancer survivors. Health care and social service

policy instruments are essential to provide the means by which the research findings can be implemented. Related advocacy activities can raise awareness about the issues and can be a strong catalyst for research-funding allocation decisions, dissemination of research results, and introduction of new policies for health service provision.

### Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

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