



# A call for action in survivorship research and care

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The term “cancer survivor” has been used to convey various meanings over time. When cancer was considered incurable, “survivor” described family members who had lost a loved one to cancer<sup>1</sup>. With time, as treatments improved, “survivor” referred to individuals who remained cancer-free for a minimum of 5 years<sup>2,3</sup>. The U.S. National Cancer Institute’s Office of Cancer Survivorship definition states that an “individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life”<sup>4</sup>. Most commonly, survivorship is described as a distinct phase in the cancer trajectory that occurs between the end of primary treatment and recurrence or end of life<sup>5,6</sup>.

The number of cancer survivors has risen considerably in recent decades as a result of advances in prevention, screening, and treatment. Currently in Canada, close to 1 million people are living as cancer survivors<sup>7</sup>. Today, approximately 65% of adults and 80% of children diagnosed with cancer are expected to live at least 5 years post diagnosis. Approximately 1 in 46 Canadians (2.2%) who were diagnosed with one or more primary invasive cancers in 1995 were alive 10 years later on January 1, 2005<sup>7</sup>. As survival rates improve and the length of survival time increases, developing a national research agenda in Canada to inform health care service delivery to survivors and to foster collaboration between stakeholders is essential<sup>8</sup>.

Canada, the United States, the United Kingdom, and more recently, Australia have been active in establishing cancer survivorship as an area of priority in cancer control. Although realized somewhat differently in each country, some shared priorities have been identified, including the development of effective care models and interventions; the investigation of long-term effects of cancer diagnosis and treatment on patients, their families, and caregivers; and the needs and characteristics of unique or disadvantaged populations<sup>9,10</sup>. Translating those priorities into an active research agenda that will inform best practice and lead to improved care for survivors is

the logical next step. And yet achieving this goal poses many challenges given the relatively small Canadian research capacity in this area. El Ansari *et al.*<sup>11</sup> suggested that, to accelerate research activity, research consortiums deserve attention by funding bodies. We agree, and we propose the establishment of a consortium to advance needed work in cancer survivorship in Canada.

A research consortium has been described as a group of individuals or organizations that works collaboratively with respect to a particular theme or funding strategy<sup>11</sup>. At both the national and international levels, consortia have been reported in cancer prevention<sup>12</sup>, quality of life<sup>13</sup>, and epidemiology<sup>14</sup>, among other applications. The Lance Armstrong Foundation created a network of eight comprehensive cancer centers, the LiveStrong Survivorship Centers of Excellence Network<sup>15</sup>, but we know of no efforts to create a research consortium in the field of survivorship. Consortia would seem to be an ideal approach where research capacity is limited and where broad interest in a particular research theme area has been apparent. That statement would appear to describe the situation of the psychosocial aspects of cancer survivorship in Canada.

## THE MERITS AND CHALLENGES OF A CONSORTIUM APPROACH

The merits of a research consortium are frequently cited when the aim is to achieve efficiencies in creating generalizability of findings<sup>11,16</sup>, reducing duplication of efforts<sup>16</sup>, and reaching greater statistical power, thereby increasing the validity and reliability of findings<sup>17</sup>. A significant potential advantage of this approach is the opportunity to access large and diverse sample populations that can facilitate early research results and the potential to translate findings into clinical practice at a much faster rate.

The consortium approach is even more germane to the Canadian system because the issue of equitable access to quality cancer care is a fundamental Canadian

value. Experiments with various levels of access in clinical trials cannot be pursued, but provincial differences in service delivery would constitute an important natural experiment, permitting study and the recommendation of best practices. Benefits of collaboration between researchers and health care organizations include the opportunity for clinicians to shape the research agenda and for researchers to access and to become aware of current care and delivery issues. Cancer centres and hospitals delivering cancer care provide comprehensive services to a defined population over a long period of time; information on the characteristics and care of those patients is therefore documented. The inclusion of geographically dispersed health care centres to increase the size and diversity of potential study populations and approaches to care<sup>18</sup> is highly pertinent to Canada. This relationship fosters national team-building among researchers working in the same field and focusing on collaboration and innovation<sup>19</sup>.

Despite the numerous advantages of the approach, a few significant challenges remain. El Ansari and colleagues summarized the complexities in a model for international collaborations<sup>11</sup>. A number of the characteristics in that model are applicable to the national consortium envisioned in Canada. They include preparatory work germane to the planning of the consortium and methodology challenges such as management of the various approaches for conceptual model building, capacity for sampling, and reconciliation of ethics board approvals. Funding and other operational issues such as leadership and ownership present considerable barriers as well.

Early steps in our national work are documented elsewhere<sup>a</sup>. A strong commitment to further explore strategies that will maximize collaborative efforts in the survivorship field emerged from that work, most notably the value of developing a research consortium specifically for cancer survivor research. The benefits and challenges of developing a research consortium in survivorship care were therefore recently explored at two meetings in 2010. The first was a workshop held in Vancouver, British Columbia, titled *Fostering Cancer Survivorship Research in Canada: Building Capacity through a Research Consortium*. A second workshop followed, being held just before the annual meeting of the Multinational Association of Supportive Care in Cancer (MASCC). Here, we outline the context and outcomes of those two meetings, and we highlight the potential benefits and challenges of a collaborative pan-Canadian approach to establishing programs of research in cancer survivorship.

<sup>a</sup> An environmental scan<sup>20</sup>, a workshop funded by the Canadian Partnership Against Cancer (Toronto, Ontario; March 2008); and a second workshop funded by the Canadian Institutes of Health Research, the Canadian Partnership Against Cancer, the Canadian Cancer Society, and the University of British Columbia (Identifying Priorities for Cancer Survivorship Research; Vancouver, British Columbia; November 2008).

## PRIORITIZING SUPPORTIVE CANCER CARE IN SURVIVORSHIP

### **Fostering Cancer Survivorship Research in Canada: Building Capacity through a Research Consortium; Vancouver, British Columbia; May 6–7, 2010**

The Fostering Cancer Survivorship Research workshop brought together researchers from key cancer survivorship programs operating in Canada to discuss and develop terms of reference for a Canadian consortium in survivorship research. The development of partnerships is essential for advancing a Canadian research agenda. The workshop served as an appropriate next step in maintaining the momentum of priority setting for cancer survivorship research in Canada and in creating a research agenda that will inform service delivery.

The workshop embraced an interdisciplinary approach that incorporated a range of cancer survivorship research domains, including psychology, epidemiology, social work, nutrition, nursing, physiotherapy, occupational therapy, and oncology. Invited participants included cancer survivors and other representatives from community treatment agencies and community-based organizations, researchers from academic institutions across Canada, and funding and policy-oriented organizations. Speakers presented on their unique perspectives and expertise in the field of survivorship and offered lessons learned from their own experience with consortium planning and development. Those with a research background highlighted the potential collaborations between their established research programs and the proposed consortium, and special-interest groups contributed their thoughts on the current state of survivorship care. Representatives from national funding organizations presented on current and upcoming funding priorities.

The workshop garnered support for continuing the momentum of developing a research consortium. A vision, purpose, and objective and some preliminary thoughts concerning an organizational structure were developed. Since the workshop, a number of partnerships and collaborations have been formed as investigators work together on programs of research that unite their expertise.

#### **Vision**

Our vision is to create new knowledge and to build national capacity in cancer survivorship research that will influence health policy and practice to enhance the Canadian health care system and to improve the health of Canadian cancer survivors.

#### **Purpose**

Our purpose is to incorporate cancer survivorship research priorities into the Canadian context and

to integrate various ongoing initiatives at both the national and international levels.

## Objectives

1. Develop pan-Canadian strategies for implementing key research priorities.
2. Establish linkages between researchers, practitioners, policymakers, and cancer survivors to align research priorities with existing and emerging needs in cancer survivorship.

## Multinational Association of Supportive Care in Cancer; Vancouver, British Columbia; June 23, 2010

### PROPOSED ORGANIZATIONAL STRUCTURE

Building on the experience of developing a Canadian consortium, efforts to promote the development of an international consortium in survivorship (Figure 1) were expanded. The expanded approach differs somewhat from the Canadian Consortium approach: the international strategy adopts a broader philosophy in scope and discipline representation in keeping with the MASCC mandate. Because MASCC already had a well-developed study group in rehabilitation and survivorship with a mandate similar to that of the fledging Canadian consortium approach, it was an ideal group to emulate.

The annual meeting of MASCC convened in Vancouver in June 2010. An international, multi-disciplinary, multi-professional organization encompassing all aspects of cancer care (<http://www.mascc.org/mc/page.do?sitePageId=86914&orgId=mascc>), MASCC has members representing more than 60 countries on 5 continents. Its membership profile includes medical, surgical, and radiologic oncology physicians, nurses, dentists, dental hygienists, pharmacists, social workers, dieticians, outcomes

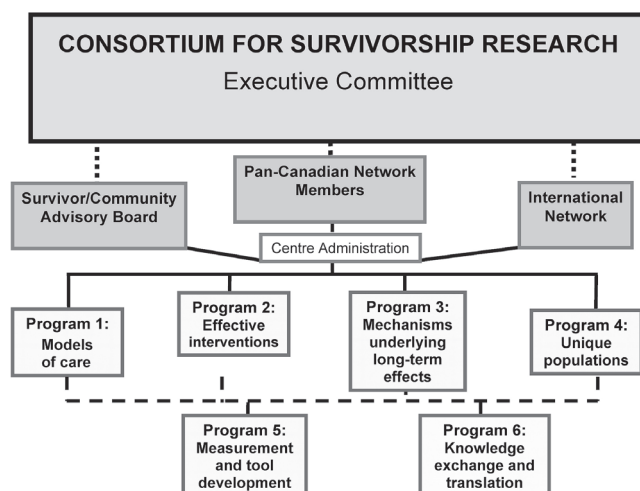


FIGURE 1 Proposed governance structure for the consortium.

specialists, psychologists, physiotherapists, occupational therapists, statisticians, infectious disease specialists, educators, and representatives from industry and non-profit sectors. Cancer survivorship has been present on the international agenda for the past few years, and Canadian researchers have been directly involved in participating and shaping that agenda.

To take advantage of the international and multidisciplinary expertise converging in Vancouver, an invitational collaborative workshop was organized for the day before the start of the symposium. The goals of the workshop were to share information and to form international alliances to further survivorship priorities under the umbrella of a consortium. The objectives were to highlight existing cancer survivorship initiatives at the national and international levels; to discuss the benefits and challenges of establishing an international survivorship consortium; to identify potential collaborations between researchers, clinicians, and funders; to identify a process for knowledge dissemination, exchange, and translation; and to commit to develop partnerships under the umbrella of a cancer survivorship research consortium.

The single-day workshop was attended by 55 MASCC members. The morning was dedicated to presentations, and the afternoon fostered discussion through breakout groups. During the breakout sessions, three short-term projects and project leads were identified:

- Survey of survivors and support people
- Survey of health care providers
- Catalogue of current guidelines for cancer survivorship

The workshop was successful in bringing together researchers interested in collaborating across national borders to improve supportive cancer care. The workshop continued the momentum of discussion that had started at the consortium workshop held a few weeks earlier by widening the scope to include an international focus.

### NEXT STEPS

During the meetings described, stakeholders were given the opportunity to align their individual expertise and programs of research with research priorities already identified at the earlier meeting in Vancouver 2008. The resulting discussion served to further translate priorities into concrete research agendas informed by the experiences of survivors, the expertise of clinicians, and the mandates of decision-makers and national funding agencies.

Identifying and assessing current models of care in Canada and internationally was understood to be key in determining the feasibility, acceptability, and sustainability of existing ad hoc interventions. Ensuring a smooth transition from active treatment

to follow-up care and recognizing the importance of the relationship between cancer and community centres was deemed to be fundamental in establishing effective models of care. Meeting the needs of unique populations and identifying and developing effective interventions—particularly psychosocial interventions—were the other top priorities identified. Effective knowledge exchange and translation strategies were themes that bridged all discussions.

Steps have been taken to recognize the importance of survivorship research and care, but those efforts have often been disconnected and scattered. Efforts in survivorship would benefit from a collaborative and holistic approach. Within Canada, collaboration and the building of partnerships have challenges—such as the geographic distance separating investigators, and differences in provincial health care and systems delivery—to surmount, but the benefits of collaboration are such that efforts to overcome those challenges have been deemed worthwhile and necessary. The proposed consortium will pursue a cohesive research strategy through collaborations that are transdisciplinary and inter-professional, with a commitment to national and international collaborations on existing and emerging challenges in survivorship research. It will bring together researchers, policymakers, and clinicians from Canada's prominent cancer research organizations to form a collaborative environment with an unprecedented level of expertise in cancer survivorship.

A research consortium has the potential to facilitate interaction between diverse stakeholders. It is not limited to researchers, but includes survivors, clinicians, and policymakers, and is not bound by their geographic locations. This multidisciplinary and multi-sector interaction will promote early alignment of research questions both to survivor experiences and to clinical and health care policy questions. Furthermore, a consortium will facilitate transdisciplinary collaboration among a broad group of academic and research institutions that may not otherwise communicate.

To continue the momentum generated by these face-to-face meetings and thus to move the vision of a pan-Canadian research consortium into reality, continued dedication and directives are fundamental. Many of the consortium researchers and clinicians already engage in collaborative work, and so strengthening the newly formed consortium relationships will be a priority, so as to develop a sound and substantive body of survivorship research that can be translated into clinical practice and improved patient care. As existing relationships are strengthened, other stakeholders and funding agencies will recognize the value of being part of this collaborative approach to building capacity in research. A strong and effective Cancer Survivorship Research Consortium will define Canada as an international leader in the field. The consortium will achieve its vision through strategic leadership, cutting-edge research, and integrated

partnership with the health care system, to deliver the best and most effective survivorship care.

## CONFLICT OF INTEREST DISCLOSURES

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