

FOSTERING CANCER SURVIVORSHIP
RESEARCH IN CANADA:
BUILDING CAPACITY
THROUGH A RESEARCH CONSORTIUM



May 6-7, 2010, Vancouver BC

Proceedings of Pan-Canadian Invitational Workshop

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Executive Summary

The number of cancer survivors is growing annually in Canada and worldwide. It is therefore critical to understand the unique needs of this population and develop a Canadian research agenda that will inform policy and service delivery. Recent initiatives led by the British Columbia Sociobehavioural Research Centre (SRC) housed at the BC Cancer Agency have paved the groundwork for survivorship research, including an environmental scan, two 2-day national invitational survivorship workshops, and a national invitational 1-day meeting. This work has been part of the long-term strategy of the SRC to facilitate a pan-Canadian approach for research priority setting and team building for research in cancer survivorship.

The purpose of this 2-day invitational workshop was to bring together researchers working in key areas of cancer survivorship to brainstorm and plan the development of a Canadian consortium of survivorship research. The aim of the research consortium will be to maintain the momentum of priority setting for cancer survivorship research in Canada and create a research agenda that will inform service delivery to advance these priorities.

The workshop consisted of several presentations and two breakout sessions. Each speaker brought forth their unique perspective and expertise. Topics included the field of survivorship, the value of a consortium, and lessons learned from personal experiences with consortium planning and development. Each speaker highlighted potential collaborations and research connections that the existence of a consortium would foster. Representatives from national funding organizations and special interest groups across Canada also presented on funding priorities and current research activities in cancer survivorship. Guest attendees also shared their unique survivorship perspective.

The presentations were followed by two break-out sessions. In Breakout Session 1, participants discussed (a) what a Canadian research consortium in cancer survivorship would look like in terms of the model and funding/infrastructure and (b) what some of the challenges, barriers, and opportunities a Canadian research consortium in cancer survivorship might face and how and these would be realized and overcome.

In Breakout Session 2, participants self-selected one of the previously identified research priorities arising from a meeting funded by the Canadian Institutes of Health Research (CIHR) and University of British Columbia (UBC). The meeting objective was to reach a consensus for research priority areas. In this regard, five research priority areas were agreed upon: (1) preventing and ameliorating (late)

effects of cancer and its treatment, (2) effective interventions, particularly psychosocial interventions, (3) determining optimal models of follow-up care, (4) needs of unique (high risk or needs) populations, and (5) risk assessment for adverse survivorship outcomes.

The final outcome of the two day meeting was a commitment to continue working towards the development of a Pan-Canadian Survivorship Research Consortium through the leadership provided by the SRC that would excel in research, inform clinical practice, and develop research priorities in collaboration with those who have experienced cancer.

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Background

Due to advances in early detection and treatment, the number of cancer survivors has risen considerably in recent decades. According to recent estimates, cancer survivors represent 2.7% of the population in Canada (NCIC 2008). Today, approximately two thirds of adult and over three quarters of children diagnosed with cancer are expected to live at least five years after diagnosis (OCS 2007). As the number of cancer survivors increases in Canada and worldwide, it is becoming increasingly important to understand the unique needs of this population, and to develop a Canadian research agenda that will reflect these needs and also inform policy and service delivery.

'Cancer survivorship' is defined broadly as a distinct phase in the cancer trajectory between the end of primary treatment and recurrence, or end-of-life. Although many initiatives address the early detection, prevention and control of cancer, it is only recently that the survivorship phase has become the focus of attention for researchers, clinicians and policy-makers.

Cancer survivorship is becoming a priority at a national level. The Canadian Partnership Against Cancer (CPAC) is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. The Partnership is bringing together cancer survivors, patients and families, cancer experts and government representatives to implement the first pan-Canadian cancer control strategy. Its vision is to be a driving force to achieve a focused approach that will help prevent cancer, enhance the quality of life of those affected by cancer, lessen the likelihood of dying from cancer, and increase the efficiency of cancer control in Canada.

CPAC has established collaborative networks, or advisory groups, consisting of experts in six priority areas¹ to draw on cancer control expertise across the country and facilitate its accessibility to all stakeholders. Each Advisory Group is headed by a Chair and has membership from across Canada, including health practitioners and administrators, epidemiologists, researchers, patients and families. *The Cancer Journey Action Group* was created to provide leadership to "rebalance the focus" of cancer care. The current challenge faced by this group is to assist the system in moving from a predominantly tumour-centred focus to a patient-centred approach. This rebalanced system would take into account the needs of the whole person (i.e. psychological, social, spiritual, informational, practical, emotional and physical) during clinical care and treatment.

¹ These areas are: Primary prevention, screening, cancer guidelines, cancer journey, research and surveillance. <http://www.partnershipagainstcancer.ca/actiongroups>

The mandate of this action group is to provide leadership to change the system so that patients and families are better served through a coordinated and less fragmented approach. Ultimately, the goal is to increase the quality of life for those living with, and after, cancer and to decrease the burden of suffering throughout the cancer experience. The topic of cancer survivorship was identified as needing further attention and specific action.

In line with becoming an area of national priority, there have been a number of initiatives that have paved the groundwork for survivorship research in Canada. Most recently, these include two environmental scans, two 2-day national invitational survivorship workshops, and a national invitational 1-day meeting.

An environmental scan on existing survivorship services in Canada highlighted the importance of developing stronger collaborations across institutions and identifying research topics for a national research agenda as key priorities for next steps in cancer survivorship research (Ristovski-Slijepcevic, 2008). A second scan surveyed programs offered in major cancer centres in Australia and the United States (CJAG, March 2009). The report recommends the development of a pan-Canada agenda in survivorship be informed by a number of program models currently being trialed and evaluated at cancer centres across the United States.

At a 2-day invitational meeting organized by the BC Sociobehavioural Research Centre and funded by CPAC, research was identified as one of seven priorities for a pan-Canadian survivorship agenda (Toronto, March, 2008). Later that year, a second meeting identified five priority areas for cancer survivorship research and potential strategies for moving this research forward (Vancouver, November, 2008). The meeting was funded by the Canadian Institutes of Health Research, CPAC, the Canadian Cancer Society, and the University of British Columbia. The identified priorities include:

1. Preventing and ameliorating (late) effects of cancer and its treatment
2. Effective interventions, particularly psychosocial interventions
3. Determining optimal models of follow-up care
4. Needs of unique (high risk or needs) populations
5. Risk assessment for adverse survivorship outcomes

Most recently, at a 1-day invitational meeting, the Canadian Cancer Research Alliance translated the five research priorities into four research goals (Toronto, April, 2009). These goals mirror the priorities identified at the Vancouver meeting in November, 2008, and were identified as a possible underpinning for a national research agenda in cancer survivorship.

Why a Consortium?

Participants at the Vancouver 2008 meeting identified the establishment of a Canadian survivorship research consortium as a strategy to move the five priority areas forward and develop research partnerships. First and foremost, a consortium will facilitate interaction between a variety of stakeholders, including researchers, survivors, practitioners and policy makers, regardless of their geographic location in Canada. Furthermore, a consortium will facilitate trans-disciplinary collaboration amongst a broad group of academic and research institutions across the country that may not otherwise communicate. This multi-sector interaction will promote early alignment of research questions to survivor experiences, and practice and policy questions. As the emphasis of a consortium is collaboration not competition, members will work together to identify knowledge gaps and areas for future research.

The mission of the consortium is to facilitate four-pillar research (basic, clinical, health services, psychosocial), and to share information and knowledge that will assist in the development, application and utilization of research in survivorship care across Canada. As an information hub, the Consortium will also be a vehicle through which survivorship research results will be discussed, peer reviewed and disseminated electronically through a public portal and by way of scholarly publications and conferences.

During an invitational meeting in Vancouver 2010, participants came together to discuss the purpose, objectives and potential structure of a pan-Canadian research consortium in cancer survivorship.

Laying the Groundwork for a Research Consortium in Cancer Survivorship – Vancouver, 2010

Fostering cancer survivorship research in Canada: Building capacity through a research consortium brought together researchers from key cancer survivorship programs currently operating in Canada to discuss and develop terms of reference for a Canadian consortium. The workshop laid the foundation for facilitating research partnerships and collaborations under the umbrella of a consortium, and worked towards aligning programs of research with the five established research priority areas.

The **purpose** of the 2-day invitational workshop was to bring together trans-disciplinary researchers working in key areas of cancer survivorship to brainstorm and plan the development of a Canadian consortium of survivorship research. Such partnerships are essential for advancing a Canadian research agenda as they allow for the collection and sharing of evidence that will help health care providers and

patients make decisions about treatment options that will affect their future; tailor treatments and therapies so that they maximize cure and minimize adverse treatment-related effects; develop and disseminate evidence-based interventions that reduce cancer morbidity and mortality; and improve quality of care. The workshop thus served as an appropriate next step to maintain the momentum of priority setting for cancer survivorship research in Canada and create a research agenda that will inform service delivery to advance the identified research priorities.

The workshop utilized an interdisciplinary approach that incorporated a range of cancer survivorship research domains, including psychology, epidemiology, social work, nursing and oncology. This multi-sector approach included cancer survivors, community treatment agencies, community-based organizations, academic institutions, and policy oriented organizations.

The five workshop objectives were to:

- Formulate the terms of reference for the consortium.
- Identify potential challenges and barriers and how to overcome these.
- Highlight initial and ongoing funding and infrastructure opportunities.
- Identify research questions and facilitate research partnerships/collaboration.
- Integrate knowledge synthesis, dissemination, and exchange into the Canadian survivorship research consortium agenda.

Discussion during the two day meeting centered on identifying the purpose and objectives of a Pan-Canadian consortium, and discussion of potential administrative structures and decision making processes that the consortium might embrace. The groundwork for establishing a Canadian consortium was laid during this first meeting as participants expressed enthusiasm and dedication to moving the concept of a consortium into a reality.

Day 1 Key Messages

Day 1 featured several presentations that served to illustrate the research and practice value of establishing a pan-Canadian survivorship research consortium. Speakers offered their unique perspective and expertise in the field of survivorship, offered lessons learned from their own experience with consortium planning and development, and highlighted the potential collaborations and research connections between established programs and the consortium. Complete presentation slides are available upon request.

Invited Speakers

Surviving Cancer

Andrew Gregory, Cancer Survivor

Mr. Gregory shared his experience of cancer diagnosis, treatment and remission. His presentation outlined some of the many psychosocial, physical and existential issues faced by cancer survivors that future care and service delivery research should address. Mr. Gregory spoke of the support of his friends and family in helping him through his cancer experience, as well as the power of activism and exercise in generating support for research in survivorship care.

North American Quitline Consortium: A Case Study on Building a Research-to-Practice Consortium

Ms. Linda Bailey, President and CEO, North American Quitline Consortium

Ms. Linda Bailey described the history and development of the North American Quitline Consortium (NAQC).

Quitlines are telephone-based tobacco cessation services that help tobacco users quit. Today, residents in 10 provinces and three territories in Canada, Mexico, and all 50 U.S. states, Puerto Rico, Guam, and the District of Columbia have access to quitline services. The North American Quitline Consortium (NAQC) is comprised of Canadian and U.S. quitline professionals, including funders, service providers, researchers and national advocacy and policy professionals. The decision to create a consortium was related to the dramatic increase in adoptions of quitlines (from 4 in 1992-1996, to 35 in 1999-2002) and the resulting need for greater technical assistance and training. Furthermore, this increase in adoption presented an ideal opportunity to conduct research to improve outcomes that would move the field of telephone support forward. The NAQC identifies as a learning organization with a mission to maximize the access, use and effectiveness of quitlines, and provides

leadership and information to those interested in participating in the promotion of quitlines.

Ms. Bailey discussed pertinent lessons learned in establishing the NAQC, from organization and sustainability, to research and program agenda setting. While a consortium will produce better “results” by virtue of the combined intellectual and professional capacity, working together under the umbrella of a consortium requires time, process and the establishment of a shared vision and common agenda. As such, all workgroups must include representatives from each stakeholder group, and the headquarters must be regarded as a fair and balanced broker with no stake in the outcomes. Decision-making structures should reflect members’ areas of expertise. The establishment of a board and the hiring of talented staff for business and administration decision making have contributed to transparent and accountable operations at the NAQC. In working towards sustainability, creating a balanced funding portfolio of foundations, voluntary organizations, government agencies and national funders is necessary. Ensuring that members gain value through their association with the consortium will ensure that they are willing to pay dues to be a member. Finally, the mission of any consortium must continue to be dynamic and vital.

Healthy Lifestyles in Cancer Survivors: Connections to Cancer Prevention

Dr. Carolyn Gotay, Canadian Cancer Society Chair in Cancer Primary Prevention; Professor, School of Population and Public Health, University of British Columbia

Dr. Gotay presented on the risk for developing chronic health conditions, as well as additional primary cancers and/or recurrence of their disease, among cancer survivors and the importance of illness prevention and health promotion in cancer survivorship. The presentation also highlighted recent research in this area, as well as suggested potential interactions between the cancer survivorship consortium and ongoing cancer prevention initiatives.

Long life after cancer diagnosis and treatment may mean recurrence, second primary cancers, and susceptibility to other chronic diseases. Survivors may be at special risk based on the factors that led to the first cancer, such as lifestyle and genetics, and cancer therapies underwent. Some of these factors are potentially modifiable. There are three approaches to cancer prevention: primary prevention that focuses on additional new cancers and chronic disease; secondary prevention with a focus on monitoring and screening; and tertiary prevention, which is preventing recurrence.

Approaches to cancer prevention include a focus on healthy lifestyle behaviours such as monitoring tobacco use, physical activity and nutrition, screening and

adherence to cancer preventive agents. Research illustrates, however, that the majority of Canadian cancer survivors are inactive and 1/5 are obese, and that neither cancer survivors nor non-cancer controls are obtaining sufficient physical activity. Survivors in the U.S. show consistent trends. The research suggests that there appears to be a disconnect between perceptions (or perhaps intentions) and actual behaviour. This may be due to a lack of targeted interventions.

Dr. Gotay's research and others in the field have highlighted a number of important yet still unanswered questions related to cancer prevention:

- Do the same risk factors affect outcomes before and after a cancer diagnosis?
- What dosages of preventive behaviours are needed to affect outcomes in survivors?
- Should lifestyle recommendations be the same for survivors and the population?
- How does cancer treatment affect strategies for prevention of new cancers, recurrences, and other chronic diseases?
- How can behaviours that affect cancer risk be balanced with those that affect risks of other diseases?
- What about the relationship between multiple risk behaviours?
- How can compliance to medical regimens be enhanced?

The prevention of primary cancers has been identified as a priority for the Canadian Cancer Society. Major funding foci have been the establishment of a chair in prevention (2008), the development of infrastructure for a CCS/UBC Cancer Prevention Centre (current), and designated space to house this centre (future). The focus of the Cancer Prevention Centre will be research, education, collaboration with BC universities, NGOs and government, knowledge exchange and public education. The centre currently has two programs of research, one focusing on worksite research and the second risk assessment, communication and reduction for breast cancer for women. There is considerable overlap in research priorities and interests in the fields of prevention and survivorship and great potential for collaboration.

Collaborative Opportunities for Capacity Building with the Canadian Centre for Applied Research in Cancer Control (ARCC)

Dr. Stuart Peacock, Co-Director, Canadian Centre for Applied Research in Cancer Control (ARCC); Associate Professor, School of Population and Public Health, University of British Columbia; Senior Scientist, British Columbia Cancer Agency

Dr. Peacock provided an overview of the recently established ARCC and highlighted challenges of establishing a pan-Canadian centre of collaborative research. The

presentation also explored integrating knowledge synthesis, dissemination, and exchange activities into a Canadian cancer research agenda.

ARCC is an interdisciplinary, inter-provincial and inter-professional organization with a commitment to cross-national collaboration on existing and emerging challenges in cancer control. The Centre is an equal partnership of the British Columbia Cancer Agency, Cancer Care Ontario, the University of Toronto and the University of British Columbia. ARCC's mission is to be Canada's first national centre of excellence in *health economics, services, policy and ethics* dedicated to creating new knowledge and building national capacity in cancer control research, education, policy, and practice to enhance the Canadian health system and to improve the health of Canadians. The Centre aims to establish linkages between researchers, policy-makers, practitioners, trainees and the public. By building on the Centre's expertise in linkable administrative data, ARCC plans to design a best practice, multi-province data platform to address cancer control for all Canadians. The Centre will build capacity by providing health economics, services, policy and ethics training opportunities for researchers, decision-makers and practitioners.

Drawing on two case studies, Dr. Peacock reviewed some of the lessons learned in his experience engaging in various KT strategies. For example, priority setting is an activity that requires top down leadership and bottom up engagement. Effective KT, however, does not necessarily mean that decision-making will change – decision makers often do not have the time to fully understand core issues. It *is* possible to translate complex methods into policy; however the KT component and the 'climate' must be right. Conflicting objectives, a lack of engagement by stakeholders and weak evidence may all contribute to unsuccessful KT.

ARCC's KT strategy draws on its strength as a pan-Canadian Network involved in health economics, services, policy and ethics research related to cancer. Members of the ARRC Network have access to a database of ongoing research projects and profiles of researchers, and Canada-wide knowledge dissemination and translation tools and support, including the ARCC newsletter. Furthermore, ARCC facilitates the engagement of researchers and decision makers by organizing specialized conferences and workshops tailored to bring these groups together.

Breakout Session 1

Following a brief presentation by Dr. Arminee Kazanjian and Richard Doll outlining the proposed structure of the Canadian Consortium (as per a pre-circulated business plan), the attendees broke into four small discussion groups to brainstorm and discuss issues relating to the consortium structure itself, such as the vision, objectives, and governance model. Each group consisted of 7-8 people with a mix

of geographic and program representation. Each group was assigned a group leader to facilitate the discussion, and a scribe was self-selected to take notes of the key issues identified during the discussion.

Each of the groups discussed the following topics:

1. Using the pre-circulated draft business plan as a starting point, what would a Canadian research consortium in cancer survivorship look like in terms of (a) the model (vision, core values, organizational structure/leadership, decision making, and communication); and (b) initial and ongoing funding/infrastructure?
2. With consideration to the model (i.e., decision-making, communication) and funding opportunities, what are some challenges, barriers, and opportunities that a Canadian research consortium in cancer survivorship might face, and how would it overcome these?

Each group reported back to all of the meeting participants to encourage discussion about the terms of reference for a consortium.

Vision

A number of ideas emerged when discussing the *vision* for the proposed consortium. The importance of embracing a patient centred approach was unanimous, as was the ultimate aim of enhancing the health and wellbeing of people who have experienced cancer. As the term survivorship is very broad, clearly defining who is included, as well as what aspects of survivorship research the consortium will produce, broker or facilitate, is necessary.

Participants asserted that the consortium should work towards engaging all stakeholders (practitioners, public, funders, survivors, advocates, community survivor groups, information technology specialists, etc.), and facilitate a dialogue in which research evidence informs care, and the experiences of clinicians contributes to and shapes the research agenda (a holistic approach). Research activities should be focused on the present day and immediate action – cancer research is not limited to discovery only.

It was generally agreed that the consortium should serve as a vehicle to bring together researchers with a shared vision to collaborate and produce research that will influence policy and practice. Many participants also expressed the vision that the consortium be recognized as a body of experts and/or advisors in the field of cancer survivorship, and that developing critical mass through training and mentorship be a priority.

Core values

Participants highlighted the following core values:

- Patient focused
- Meaningful involvement of survivors in determining priorities
- Multiple stakeholder involvement
- Collaboration not competition
- Shared vision
- Trust
- Inclusiveness
- Team work
- Productive conflict resolution
- Sustainable and accountable
- Transparent
- Ethics/Policy/Application
- Influential

Objectives

The objectives of a research consortium need to be focused, manageable and set by a reference body of peers and a multitude of stakeholders (i.e. the public, clinicians, policy makers, funding agencies, etc.). The research objectives need to be realistic and measurable, and should be undertaken with a common agenda and a coordinated approach to avoid duplication. Primary objectives discussed included working to increase public awareness and involvement in issues related to survivorship and illustrating the value of this collaborative approach to research. Furthermore, the consortium should highlight the quality of the research conducted, how this evidence will enhance the Canadian health system, and the cost effectiveness of working together as a group rather than individually.

Organizational structure/leadership

Identifying the most effective organizational structure and style of leadership is best done by consulting the literature and individuals who have experience with developing a consortium structure. Many participants stated that until the function and objectives of the consortium are clear, determining a governance structure is premature. Some expressed that the organizational structure should not be hierarchal, and questioned whether having a CEO would be an effective leadership structure. Participants agreed that a headquarters for central administration is needed. Participants unanimously agreed that all members must contribute to identifying the research priorities, and some noted the option of having leaders for each identified priority.

Decision making, communication processes, funding and infrastructure

Participants reiterated the importance of modeling this consortium on the success of other groups. Establishing a communication process that will engage members across the country in order to make it truly “pan-Canadian” and “representative” is necessary. Some examples of communication strategies included establishing a list-serve, website, newsletter and face to face meetings. Identifying a mediator for conflict resolution was also discussed.

Participants discussed the importance of hiring talent to ensure that the consortium will be managed effectively. Shopping around a business plan in order to establish sustainable core infrastructure funding will be important, as will coordinating with provincial and federal funding agencies.

Challenges and opportunities

The challenges involved in establishing and sustaining a consortium are well documented in the literature. Many of these issues were highlighted by participants. First and foremost, participants discussed the challenge of finding sustainable funding, and determining the funding allocation process. Consortium members will need to illustrate that there is indeed value added in working under a consortium structure, and that this structure offers more than fostering collaborative partnerships. Furthermore, establishing protocol for engaging researchers and communicating expectations to members in terms of productivity will also be difficult. Another challenge includes the diversity of provincial health systems, and the fact that some provinces excel in particular areas and are less successful in others. Finally, participants discussed challenges related to engaging survivors, and how research will tackle the disparities, inequalities, socio economic and personal challenges that arise as the number of survivors increases.

Despite these challenges, participants agreed on a number of opportunities that will likely emerge if a consortium is realised. First and foremost, a consortium approach to research has strength in numbers – “the whole is greater than sum of its parts”. By drawing on available skills, pursuing existing opportunities and mitigating barriers, the consortium as an organization can overcome structural barriers and engage in effective collaboration.

Day 2 Key Messages

Day 2 featured presentations illustrating the benefits of collaboration, and the opportunities and challenges associated with a consortium structure. Representatives from national funding bodies participated in a panel discussion with workshop attendees. Complete presentation slides are available upon request.

Survivorship: Lost in Transition or Interpretation?

Simon Sutcliffe, Chair, Canadian Partnership Against Cancer

Dr. Simon Sutcliffe presented on the benefits and added value of integrated action and collaboration under the umbrella of a consortium. Dr. Sutcliffe discussed the magnitude and burden of survivorship; the meaning and consequence of interpreting survivorship; the system response to need and opportunity; and finally, priorities, actions and next steps.

A practical definition of survivorship is inclusive of cancer survivors and their caregivers. This phase of the cancer journey is not marked by a distinct start or end time. While defining this term remains important and continues to be the focus of academic and clinical discussions, we must also focus on the actions addressing survivorship. First, however, two issues must be addressed:

1. Is there equal opportunity to survive?
2. Is there equal opportunity to derive the benefits of survival?

Investigating determinants of health and access to services is central to understanding opportunity to survive. Comprehending whether there is equal opportunity to derive benefits of survival, however, is related to investigating well being and health, quality of life, the ability to fulfill aspirations, and the existence of opportunity, circumstance and choice.

To address these two questions, research and care priorities must be both focused and integrated. Priority areas should include the prevention of new cancers and other late effects; surveillance and interventions assessing the consequences of cancer and its treatment; coordination of services and communication between stakeholders. Whose responsibility is it to respond to these priorities, and what should the contribution of these stakeholders be? These stakeholders collectively comprise the health care system. Specific examples include the government and health authorities and their role in policy making and funding; foundations and charities and their participation in funding, advocacy and support; health professionals who administer care, treatment and participate in research; and finally, care givers offering care and support, and the voices of the patients themselves. Each component of the system must work collectively and collaboratively, whereby policy, funding, education, research care and service are integrated with the intent of enacting positive change.

Panel Presentation – National Organizations and Special Interest Groups: Research, Funding, and Organizational Priorities

Elizabeth Eisenhower, CCRA; **Richard Doll** on behalf of **Michael Wosnick**, CCSRI; **Margaret Fitch**, CIHR; **Jeff Sisler**, CAPCA; **Sheila Pritchard**, C17

The panel presentation moderated by Dr. Simon Sutcliffe involved representatives from national funding organizations and special interest groups across Canada. Each speaker provided a brief overview of funding priorities and current research activities in cancer survivorship. Their presentations were followed by a question and answer period with participants.

The LIVESTRONG Survivorship Center of Excellence Network: A Collaborative Approach to Addressing the Physical and Psychosocial Needs of Cancer Survivors in the US

Caroline Huffman, Director of Navigation Services for the Lance Armstrong Foundation

Ms. Huffman provided a brief overview of activities at the Survivorship Center of Excellence Network and the organization's approach to research and identifying funding priorities in cancer survivorship.

The **LIVESTRONG** Survivorship Centers of Excellence is a collaborative effort between **LIVESTRONG**, cancer centers and community affiliates. The Network aims to work collaboratively with leading centres to provide survivorship services and increase the effectiveness of care through research, the development of new interventions and sharing of best practices². The purpose of the network is to act as "a mechanism for accelerating progress in addressing the complex needs of the rapidly growing number of people living with, through, and beyond cancer".

Network Goals:

- Transform how survivors are perceived, treated, and served
- Help create body of knowledge, understanding, evidence
- Develop and deliver evidence-based treatment and care interventions
- Increase quality, integration of survivorship services
- Strengthen linkages between survivorship services and primary cancer treatment & care
- Increase accessibility to services among ethnically diverse & underserved survivors
- Create insurance/reimbursement mechanisms to cover survivor care, services
- Find sources of support to sustain survivorship centres over the long term

² <http://www.livestrong.org/What-We-Do/Our-Actions/Programs-Partnerships/LIVESTRONG-Survivorship-Centers-of-Excellence>

Ms. Huffman identified Centers of Excellence and community based centres as the central players, with LAF serving to provide oversight, leadership, evaluation and facilitate collaboration. Each Center of Excellence meets with their identified community-based center through semi-annual meetings, conference calls, emails and working groups. A steering committee consisting of a consultant and LAF staff design the closed RFPs and outline requirements, then review proposals and select recipients.

Moving into phase two (2009-2013), the overall goal of the network is to continue to prepare patients, caregivers, health care providers, third-party players, other funding agencies and policymakers to anticipate and deal with the growing reality and scope of cancer survivorship. Specifically, the aim is to assure the presence of strong and sustainable survivorship care in all cancer centres and to train and support non-network cancer centres that are committed to establishing survivorship programs. Furthermore, the network aims to increase knowledge of long-term cancers, and to ease the transition for patients and their caregivers from oncology centres to community hospitals, clinics and primary care physicians. While all Network members offer survivorship services, there exists no “one size fits all” formula for survivorship care. Currently there is a lack of evidence for best practices and there is no consensus on post-treatment follow-up care for survivors of adult cancer. While different models of care are currently in development, little attention has been granted to evaluation.

Breakout Discussion: Creating a Research Agenda

Facilitated by Kathy Scalzo

During a two day invitational workshop held in Vancouver in 2008, participants identified five priority areas for a Canadian cancer survivorship research agenda. These areas are:

1. Preventing and ameliorating (late) effects of cancer and its treatment
2. Effective interventions, particularly psychosocial
3. Determining optimal models of follow-up care
4. Needs of unique (high risk or needs) populations
5. Risk assessment for adverse survivorship outcomes

During Breakout Session 2, participants self selected their individual priority research interests. Models of care, effective interventions, and unique populations were the priorities chosen. Once in their self selected groups, participants explored the following discussion questions:

1. What are the research questions for this priority area?
2. What are the target groups (i.e. tumour, trajectory, populations)?
3. Where are the potential collaborations?

4. What would a knowledge translation plan for this research question look like?

At the end of the breakout session, a reporter presented an overview of the strategies discussed by participants for each priority. The following recommendations were made during the reporting back from each group.

Group 1: Effective interventions, particularly psychosocial

1. Research Questions and Topics

- Preference for an intervention that can yield multiple outcomes
- Interventions that include family and/or partners
- Interventions to increase adherence in populations
- Cost effectiveness of particular interventions
- Adherence to tamoxifen and other medication (possibly an RCT 3 Arm trial), and surveillance
- Adherence to healthy lifestyle changes (smoking, diet and exercise)
- The use of hand held devices and treatment adherence
- Fatigue, coping, healthy behaviours
- Family, sexuality, intimacy
- Communication
- Return to work
- Fear of reoccurrence
- Content for lifestyle

2. What are the target groups?

Narrowly defining populations was deemed unnecessary

3. Where are the potential collaborations?

- The survivorship program Cancer Transitions
- Canadian Cancer Society telephone information service
- Caring Voices and CancerChatCanada are options for moderation/support at a distance

Group 2: Models of Transition (*this was deemed more appropriate than "models of follow-up care"*)

1. Research Questions

Models of follow up care optimize:

- Feasibility
- Affordability
- Acceptability
- Outcomes
- Comprehensiveness sustainability/cancer centre community

- Smooth transition/continuity
- Mobilization of “natural” supportive care
- Personalized care

2. What are the target groups?

The focus should be on cancer trajectories according to type of cancer diagnosis

Group 3: Needs of Unique Populations

1. Research Questions

There are many cross cutting issues with these populations and other priority areas. Identifying what is unique about these specific populations will assist in identifying what to address.

- A needs assessment is needed to identify the current state of evidence/information
- Is the available research informing practice? If not, why not? What are the barriers? What are strategies to overcome these barriers?
- What are the gaps in knowledge? What research can be done to target these gaps?
- Access and ethno-cultural needs?

2. What are the target groups?

- Paediatric and post paediatric survivors
- Surveillance variable by province
- Ethno cultural, multicultural
- Young adult cancer survivor
- Rural/remote/frontier populations
- Hereditary, high risk survivors
- Underprivileged

3. Where are the potential collaborations?

- Researchers, policy makers, stakeholders, clinicians and community groups

4. What would a knowledge translation plan for this research question look like?

First and foremost, researchers must identify the current state of knowledge/evidence, and identify the gaps in knowledge in the Canadian context. Topics to consider for knowledge translation include:

- Strategies for addressing identified gaps and areas where knowledge is not being used
- Identifying the barriers to implementing evidence based guidelines
- Stakeholder engagement:
 - Public involvement

- Traditional and non-traditional strategies
 - Consortium needs a champion
- Bringing information to the public
 - Take risks
 - Do something, especially where unequal potential outcomes exist
 - Translate for public awareness
 - Identify and integrate end users
- What unique attributes of adverse outcomes should we focus on?
 - Costs – loss of income
 - Psychosocial
 - System (health care)

Concluding Remarks

Richard Doll and Arminee Kazanjian

The objective of this invitational workshop, to bring together trans-disciplinary researchers to communicate ideas and develop a vision for the development of a Pan-Canadian consortium in cancer survivorship research, was accomplished. A great deal of information and knowledge was shared during these two days, reflecting the diversity of stakeholders in attendance. Participants voiced their enthusiasm for a research consortium that would facilitate collaborative work. A number of topics emerged as being particularly important to this vision, such as actively engaging stakeholders in order to align research questions with clinical and policy questions and survivor experiences, and establishing the consortium as a respected reference body in the field of survivorship. Participants also further refined previously identified research priorities to reflect their own research interests and expertise.

The difficulties associated with establishing a research consortium are well documented, and participants identified those issues that were most pertinent to the Canadian context. The need to develop strategies that attend to barriers related to the geographic distance separating investigators and the differences in provincial health care and systems delivery requires further attention, as does identifying an effective and sustainable organizational structure and decision making process. However, the benefits of collaboration are such that efforts to overcome these challenges were deemed worthwhile and necessary.

Regularly engaging stakeholders through further face to face discussions, teleconference meetings, and correspondence is essential to maintaining the momentum generated at the workshop and to move the vision of a Pan-Canadian research consortium into a reality. As many researchers and clinicians already engage in collaborative work, strengthening these relationships must also be a priority so as to develop a strong body of survivorship research that is representative of the consortium's primary goal of improving patient care. Engaging in effective knowledge exchange and translation strategies will ensure that other stakeholders and funding agencies recognize the value in our collaborative approach. We look forward to engaging with others in successfully creating a Cancer Survivorship Research Consortium that will define Canada as an international leader in the field.

References

Cancer Journey Action Group. (2009). A Brief Review of Survivorship Programs in Australia and the United States. Report Prepared for Canadian Partnership Against Cancer.

NCIC – National Cancer Institute of Canada. (2008).

www.ncic.cancer.ca

OCS – Office of Cancer Survivorship. (2007).

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

Ristovski-Slijepcevic S. (2008). *Environmental scan of cancer survivorship in Canada: Conceptualization, practice and research*. Report prepared for ReBalance Focus Action Group, Canadian Partnership Against Cancer.

Appendix A: Local Organizing Committee

Co- Chairs

Dr. Arminee Kazanjian – School of Population and Public Health, University of British Columbia

Mr. Richard Doll - Sociobehavioural Research Centre, BC Cancer Agency

Committee Members

Dr. Tracey Brickell - Sociobehavioural Research Centre, BC Cancer Agency

Ms. Kimberly Burrus - Sociobehavioural Research Centre, BC Cancer Agency

Ms. Joanne Magtoto - Sociobehavioural Research Centre, BC Cancer Agency

Ms. Vickie Mattimoe – Sociobehavioural Research Centre, BC Cancer Agency

Dr. Svetlana Ristovski-Slijepcevic - Sociobehavioural Research Centre, BC Cancer Agency

Ms. Kirsten Smillie - School of Population and Public Health, University of British Columbia

Dr. Amanda Ward - Sociobehavioural Research Centre, BC Cancer Agency

Appendix B: Facilitator Information

Kathy Scalzo

Adjunct Research Associate, Sociobehavioural Research Centre, BC Cancer Agency
Core Faculty, Physician Management Institute, Canadian Medical Association
Clinical Instructor, School of Rehabilitation Sciences, University of British Columbia

Kathy Scalzo is President of K. Scalzo & Associates, a Vancouver based consulting group. For the past twenty years, Kathy has assisted individuals, groups and organizations initiate, plan for, and adapt to change. Her expertise in strategic planning, organization development, change and transition planning, and facilitation and training has been used by more than 200 health care organizations, professional associations, and non-profit agencies.

As an organization development consultant, Kathy has assisted large organizations as well as small work groups in planning and goal setting, issue identification, change and transition management, conflict resolution, establishing new workplace agreements, and team building. Her clients include such diverse organizations as: BC Paraplegic Society, Canadian Medical Association, Royal Inlands Hospital Foundation, Kamloops Hospice, Northern British Columbia Mental Health Services, Richmond Savings Credit Union, Girl Guides of Canada, Vancouver Coastal Health Society, and the YWCA.

Kathy is the co-author of the British Columbia Bestselling book - Picking Up the Pieces Moving Forward After Surviving Cancer (Raincoast Books, 2006). The book is based on four years of qualitative research that includes interviews with over 200 survivors of different types of cancer, as well as feedback from focus groups and conference workshop participants.

Kathy holds a Master's of Science in Organization Development from Pepperdine University (Los Angeles, California) and a B.Sc. in Occupational Therapy from the University of Washington (Seattle, Washington).

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Appendix C: Agenda

Time	Day 1: May 6 th 2010
8:00 am – 8:30 am	Registration and Breakfast
8:30 am – 9:00 am	Welcome / Priorities and Goals / Workshop Objectives (Richard Doll and Arminee Kazanjian)
9:00 am – 10:30 am	Individual Program Leads: “Why a Consortium?” How Will We Contribute to the Consortium? - Moderated by Richard Doll and Arminee Kazanjian
10:30 am – 10:45 am	Networking Break
10:45 am – 11:15 am	Surviving Cancer (Andrew Gregory)
11:15 am – 12:15 pm	North American Quitline Consortium: A Case Study on Building a Research-to-Practice Consortium (Linda Bailey)
12:15 pm – 1:00 pm	Networking Lunch
1:00 pm – 1:30 pm	Healthy Lifestyles in Cancer Survivors: Connections to Cancer Prevention (Carolyn Gotay)
1:30 pm – 2:00 pm	Collaborative Opportunities for Capacity Building with the Canadian Centre for Applied Research in Cancer Control (ARCC) (Stuart Peacock)
2:00 pm – 2:15 pm	Networking Break
2:15 pm – 2:30 pm	Breakout Session Instructions
2:30 pm – 3:30 pm	Breakout Discussion 1: Canadian Research Consortium in Cancer Survivorship: Considerations for Moving Forward - Facilitated by Kathy Scalzo
3:30 pm – 4:00 pm	Reporting Back and Discussion
4:00 pm – 4:30 pm	Wrap-up – Key Learnings (Richard Doll and Arminee Kazanjian)
4:30 pm	Adjournment

Time	Day 2: May 7th 2010
8:00 am – 8:30 am	Registration and Breakfast
8:30 am – 8:45 am	Welcome and Workshop Objectives for Day 2 (Richard Doll and Arminee Kazanjian)
8:45 am – 9:15 am	<i>Survivorship: Lost in Translation or Interpretation (Simon Sutcliffe)</i>
9:00 am – 9:40 am	Panel Presentation - <i>National Organizations and Special Interest Groups: Research, Funding, and Organizational Priorities</i> (Elizabeth Eisenhauer, CCRA; Michael Wosnick, CCSRI; Margaret Fitch, CIHR; Jeff Sisler, CAPCA; Sheila Pritchard, C17) - Moderated by Simon Sutcliffe
9:40 am – 10:00 am	Question and Answer Session with the Panel
10:00 am – 10:15 am	Networking Break
10:15 am – 10:45 am	<i>The LIVESTRONG™ Survivorship Center of Excellence Network: A Collaborative Approach to Addressing the Physical and Psychosocial Needs of Cancer Survivors in the U.S.</i> (Caroline Huffman)
10:45 am – 11:15 pm	Response Forum - Facilitated by Kathy Scalzo
11:15 pm – 11:45 pm	Open Group Discussion - Facilitated by Kathy Scalzo
11:45 pm – 12:30 pm	Lunch
12:30 pm - 2:00 pm	Breakout Discussion 2: <i>Creating a Research Agenda</i> - Facilitated by Kathy Scalzo
2:00 pm - 2:15 pm	Next Steps / Concluding Remarks (Richard Doll and Arminee Kazanjian)
2:15 pm	Adjournment

Appendix D: Participants

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Appendix E: Program Leads

Individual program leads expressed why a consortium is needed and how their program will contribute to its development and success.

Dr. Sharon Campbell, Senior Scientist, Propel Centre for Population Health Impact, University of Waterloo, Waterloo, Ontario

Propel's survivorship program focuses on the quality of life of cancer patients and survivors. Specifically, our purpose is: (i) to determine the prevalence and predictors of survivors' and their support persons' unmet needs and determine which unmet needs can be addressed by Canadian Cancer Society (CCS) programs and services; (ii) to demonstrate the impact of CCS cancer information and peer support on cancer patients' and family members' quality of life; (iii) to answer CCS organizational and operational questions about the type, dose, frequency, methods of delivering and cost-effectiveness of service options for information and peer support to improve quality of life; and, (iv) to identify resource implications of meeting information and peer support needs for non-profit sector and health care system.

Propel works in partnership CCS to jointly determine the agenda for its survivorship program of research, which allows CCS to address survivorship issues on a population level. As our key partner the CCS is able to move evidence into practice and policy more rapidly than researchers can alone which is an important for building research capacity.

Dr. Linda Carlson, Associate Professor, Department of Oncology, University of Calgary, Calgary, Alberta

With more 82,165 adult survivors currently in the Alberta Cancer Registry, there is high demand to address survivorship needs in Alberta. This team, led by psycho-oncology researcher Dr. Janine Giese-Davis, has built a multi-disciplinary provincially focused team (currently 30 active members) committed to researching and delivering evidence-based survivorship care. A well-attended 2-day survivorship workshop in June, 2007 launched the Alberta CancerBRIDGES Team (Building Research Innovation into the Development and Growth of Excellence in Survivorship Care).

The efforts of Alberta CancerBRIDGES Team and the current research group have widespread support throughout Alberta from medical, psychosocial, and community groups. The team meets regularly to brainstorm and develop survivorship programs and research projects, and operates by consensus. Our long-term goals include addressing survivors' needs and developing an evidence-based coordinated approach to cancer survivorship care in Alberta.

Dr. Martin Chasen, Department of Medicine, University of Ottawa, Ottawa, Ontario

The results of a Needs Assessment Survey administered by the Cancer Foundation in 2008 suggests that while local cancer patients have access to top medical care when dealing with the tumour, once treatment is complete, patients are often left on their own as they attempt to return to their day-to-day routine. After researching available support services, the Cancer Foundation identified Wellspring as the best option to address these gaps. Wellspring Ottawa is now under construction and will be the region's first centre for cancer survivorship. The facility will be built adjacent to the Richard and Annette Bloch Cancer Survivors Park. Wellspring Ottawa will be open to all cancer patients and their caregivers free of charge and without the need for referral. The centre will provide programming to meet the non medical needs of local cancer patients, their families and caregivers, and will cover a number of key issues including: assistance navigating your cancer journey; coping mechanisms; individual and group counselling; post treatment recovery; financial concerns; nutrition, health and fitness and cancer prevention.

Richard Doll, Director, Sociobehavioural Research Centre, BC Cancer Agency, and Adjunct Professor, School of Population and Public Health, University of British Columbia

Dr. Arminee Kazanjian, Professor, School of Population and Public Health, University of British Columbia, and Research Scientist, Sociobehavioural Research Centre, BC Cancer Agency

In the past five years, Mr. Doll and Dr. Kazanjian have been successful in securing research funding from CIHR and CPAC, and developing and leading national teams, including two CIHR funded collaborations: the *Cross-Cultural Palliative Care NET* (PCEOL 69768), and the *CIHR Team for Supportive Cancer Care* (AQC 83559).

Founded in 2003, the Sociobehavioural Research Centre (SRC) coordinates research under the BC Cancer Agency's Cancer Rehabilitation Network. Contributing to the development of programs and research priorities that are consistent with the Canadian Strategy for Cancer Control, SRC research focuses on psychosocial oncology, cross cultural health care, palliative and end-of-life care, oncology nutrition, lifestyle and population health. As director, Mr. Doll's responsibilities include implementing supportive care programs within BCCA and promoting the development of community based programs. His research expertise lies in the areas of psychosocial oncology, palliative care, cancer rehabilitation and cancer survivorship.

A sociologist by training, Dr. Kazanjian's most recent research interests are in cancer supportive care, psychosocial oncology and knowledge translation. She is a pioneer of population-based data linkage for surveillance purposes and her recent work focuses on immigrant health and service utilization, linking health program databases with immigration databases. Dr. Kazanjian is an internationally known health services researcher for her work delineating the social context of health seeking behaviour and the evaluation of health systems.

Dr. Lise Fillion, Senior Researcher in Psycho-oncology, Laval University, Quebec City, Quebec

The survivorship team from Quebec Province includes several researchers from Quebec City and Montreal, all whom are affiliated with either Laval University or McGill University, and are formal members of a cancer research centre (in Quebec City, the CRCHUQ (Centre de recherche du Centre Hospitalier universitaire de Quebec- axe cancer), and in Montreal, the Lady Davis Institute (LDI)). In Quebec City, survivorship researchers could also come from the Maison Michel Sarrazin research team (MMS-RT). The two research centres, CRCHUQ and the LDI are each linked to a comprehensive cancer centre, the Centre de recherche clinique et evaluative en oncologie (CRCEO) and the Segal Comprehensive Cancer Centre, respectively. The MMS PC research team is part of the MMS, a supraregional palliative care hospice for cancer patients.

The three health care organizations provide a wide range of survivorship services including cancer treatment, pain and symptom management, psychosocial and spiritual support, and palliative care. In Quebec Province, these 3 organizations are strong leaders in new treatments, interventions and models of care. The CRCEO and Segal directors have recently developed the Q-CROC aiming at increasing individualized interventions and quality of care for cancer survivors.

Dr. Margaret Fitch, Canadian Partnership Against Cancer, Toronto, Ontario

The Cancer Journey Advisory Group (CJAG) provides leadership for a survivorship agenda in Canada. CJAG strives to influence program development and implementation by drawing on research evidence and working with cancer agencies and community organizations. The national task group has a membership of 16 individuals – a cross section of health professionals and survivors.

A national workshop (March 2008) on survivorship invited 84 individuals to determine priorities for cancer survivorship in Canada. This priority list has been embraced by several groups across the country and led to the beginning of active consideration of this important topic area. CJAG's national task group on survivorship, co-chaired by a survivor and a community agency leader, has focused on understanding the barriers to implementing Survivorship Care Plans in the Canadian environment. Four pilot projects are underway and will report by January 2011. The guidelines committee is focusing efforts on the development of follow-up guidelines and standards. They have released a practice guideline on the screening and assessment of psychosocial distress in adult cancer patients.

Dr. Jennifer Jones Director of Research, Care Princess Margaret Hospital *on behalf of Dr. Pamela Catton*, Medical Director, Breast Cancer Survivorship Program, Princess Margaret Hospital, Toronto, Ontario

The Princess Margaret Hospital (PMH) Cancer Survivorship Program provides comprehensive on-going care across the age spectrum and is rolled out to all cancer sites. This clinical program is both consultative and risk based and, based on clinical practice guidelines, anticipatory guidance in self-management is initiated at the start of treatment (NCCN, 2008).

The goal of the PMH Survivorship Program is that all care taking place within the program be provided within the context of clinical research. Clinical program elements are evaluated for quality and feasibility. Efficacy will be assessed in several domains including physical and psychological outcomes, disability, QoL, and behaviour change. Standardized longitudinal data is being collected.

Goals of the program include:

- Empower and prepare survivors to manage their health with appropriate self-management support
- Recruit and train cancer survivors as a human resource
- Reallocate health care human resources through changing scopes of practice
- Apply e-health technologies to engage survivors by providing information and support at point of need
- Organize patient and population data to facilitate education, survivorship research and efficient and effective survivorship care