

Cancer Journey Portfolio

# Advances in Survivorship Care: Resources, Lessons Learned and Promising Practices

CANADIAN PARTNERSHIP  
AGAINST CANCER



PARTENARIAT CANADIEN  
CONTRE LE CANCER

May 2012

## Acknowledgements

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Many thanks to the members of the National Survivorship Working Group for their contributions to and oversight of the Cancer Journey Portfolio's initiative in survivorship:

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Barbara Cameron	Tom Hack
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Craig Earle	David Muise (Co-Chair, Working Group)
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Margaret Fitch (Chair, Cancer Journey)	Maureen Parkinson
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### Reference:

Cancer Journey Portfolio. 2012. *Advances in Survivorship Care: Resources, Lessons Learned and Promising Practices*.

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This report was prepared by Cardinal Consultants.

Production of this publication has been made possible through a financial contribution from Health Canada, through the Canadian Partnership Against Cancer and the Public Health Agency of Canada. The views expressed herein represent the views of the authors.

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## Background

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### Canadian Partnership Against Cancer

The **Canadian Partnership Against Cancer** (the Partnership) is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. Since 2007, the Partnership has brought 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.

### Cancer Journey Portfolio

The **Cancer Journey Portfolio** (formerly the ReBalance Focus Action Group) of the Partnership was created to provide leadership to “rebalance the focus” of cancer care. The challenge is to help move the system from a predominantly tumour-centred focus to a patient-centred approach.

Cancer Journey’s vision is a high-quality, person-centred cancer system that meets the full range of needs of all Canadians and their families through all stages of life with cancer. A “rebalanced” system would therefore take into account:

- The needs of the whole person (i.e., psychological, social, spiritual, informational, practical, emotional and physical)
- The range of Canadians requiring cancer care and their diverse needs (i.e., economic, cultural, regional, age-related)
- The needs of families, caregivers and other supporters
- The span of cancer care phases (i.e., screening, diagnosis, treatment, recovery, survivorship, palliative, end-of-life and bereavement)

Ultimately, the goal is to increase quality of life for those who have been diagnosed with cancer and their supporters and to decrease the burden of suffering throughout the cancer trajectory.

To further this vision, Cancer Journey designed its portfolio around four main program areas: Screening for Distress, Navigation, Survivorship, and Palliative and End-of-Life Care. While distinct programs have been developed in these areas, the programs are complementary in their efforts to address gaps in psychosocial and supportive care throughout the cancer experience. Screening for Distress has gained prominence as an approach to detecting and appropriately addressing patients’ support needs; it is often carried out once a patient is diagnosed but is also advisable throughout cancer care and beyond, particularly at transition points such as the end of treatment. Some programs are beginning to make use of Screening for Distress as a way to improve survivorship ser-

vices. Navigation programs are also concerned with helping patients through the various stages of cancer, including survivorship and palliative care. Overall, the last several years have seen a swell of interest in and awareness of the need for greater focus on the transition from active treatment to post-treatment follow-up.

As the population ages and cancer treatments become more advanced, an increasing number of Canadians are living as cancer survivors. When treatment ends, many survivors live with continuing challenges that receive insufficient attention in the health care system and are not well understood by society generally, such as:

- Ongoing physical side effects, some of which profoundly affect life decisions (e.g., infertility)
- The need for appropriate ongoing screening
- Living with the fear of recurrence
- Uncertainty about what is needed in terms of follow-up care and where to obtain it
- Returning to work
- Altered relationships with family and friends
- Financial hardship as a result of cancer treatment

## **The National Survivorship Working Group: Background Exploratory Work**

Early in its mandate, Cancer Journey began to look at the evidence related to factors that affect the quality of life of cancer survivors and learned a great deal about the need for systematic support during the survivorship phase of the cancer trajectory. Survivorship care planning was identified as a key priority and the National Survivorship Working Group was established.

The group began its work with several main goals, including:

- To compile knowledge about the existence and scope of survivorship programs and services in Canada
- To consult with international experts regarding applicable work from other countries
- To work with the provinces to create an agenda for cancer survivorship care and to disseminate strategies
- To convene a national consensus meeting on priorities for program development, education and research

To these ends, Cancer Journey carried out two environmental scans, which are summarized below. Cancer Journey also supported two workshops in 2008, one to establish a national agenda for survivorship care and one to identify research priorities. These are described following.

## **Environmental Scan of Cancer Survivorship in Canada: Conceptualization, Practice and Research**

This scan included a literature search and interviews with 47 key informants. Its purposes were to:

- Investigate the ways in which cancer survivorship treatment is conceptualized, researched and practiced in Canada
- Identify key Canadian contributors to cancer survivorship initiatives
- Identify resources from the literature that may prove useful in future cancer survivorship efforts

In conceptualizing the essential components of cancer survivorship care, respondents referred to the Institute of Medicine's four essential components: prevention, surveillance, intervention and coordination. Respondents also expressed concern that survivorship care be person-centred, holistic and economically feasible and include referral to appropriate resources and support. Gaps in current cancer care were described as:

- Lack of legitimacy of survivorship issues
- Lack of continuity in care
- Poor integration of services
- Disparities in access to resources
- Lack of community involvement

Key priorities for planning and implementing future cancer survivorship care were:

- To identify survivors' needs
- To develop and implement appropriate models for care, guidelines and follow-up care plans
- To increase collaboration between the health and cancer care systems and the community

Key priorities for survivorship research included:

- Raising awareness of cancer survivorship research
- Identifying and agreeing on research priorities
- Developing stronger collaborations across institutions
- Developing better funding mechanisms

## **A Brief Review of Survivorship Care Plans in Canada and the United States**

This environmental scan was designed to:

- Identify the current status of survivorship care plans in Canada
- Identify potential issues regarding care plan implementation
- Present a brief overview of current survivorship programs in Canada
- Develop a bibliography of evidence-based research on survivorship care plans

The research determined that Canadian survivorship care plans are much more developed in pediatric treatment than for adult cancer patients. Formal survivorship care planning for adults is inconsistent, and many survivors seek support from community organizations and support groups. Many community-based organizations offer health and wellness programs, including the development of a healing or wellness plan, and some are developing education programs to empower patients to take greater responsibility for their health care needs.

At the same time, the implementation and evaluation of care plans is underway in several cancer centres across Canada.

This research also describes several survivorship care plan models from the United States, noting that a key underlying difficulty in survivorship care is lack of clarity for both the patient and their care team as to the source and nature of the care that needs to be provided. Family doctors, oncologists and community support organizations, along with survivors, must therefore work together to develop policies and protocols for survivorship care.

### **The Canadian Invitational Cancer Survivorship Workshop: Creating an Agenda for Cancer Survivorship**

The aims of this workshop were:

- To bring together survivors, clinicians, researchers, decision-makers and other experts in the field to identify key needs for program implementation in Canada
- To analyze approaches underway in Canada through a literature review and environmental scan
- To create a national agenda for survivorship care and support
- To galvanize support for a pan-Canadian approach to survivorship through a consensus meeting

This workshop had 84 participants, including health providers, policy-makers, decision-makers, researchers and cancer survivors. Presentations and breakout discussions addressed a range of survivorship concerns and identified key priorities, including:

- Identifying appropriate models of care
- Promoting research and ensuring knowledge translation
- Developing and implementing survivorship care plans
- Establishing national standards and guidelines
- Facilitating communication plans
- Forming a national advocacy network

## **The Pan-Canadian Invitational Workshop: Identifying Priorities for Cancer Survivorship Research**

This two-day invitational workshop aimed to identify priorities for cancer survivorship research for the Canadian context and to integrate various initiatives and efforts at both the national and international levels. It was attended by 86 participants, about 40% of whom were cancer survivors.

Speakers from Canada, Australia and the United States presented on the following themes:

- Adult and young adult perspectives in Australia and Canada
- Pediatric perspectives
- Disparities and transitions
- Integrated care in the United States and Canada
- Biomedical perspectives
- Health services perspectives
- Follow-up care
- Knowledge translation in survivorship research

The presentations were followed by discussions in which participants identified 30 key components of a Canadian cancer survivorship research agenda. These components were later grouped into five priority areas by the local organizing committee. The top five priorities for cancer survivorship research investment were as follows:

- Evaluation of effective care models
- Development of effective interventions
- Development of measurements and tools
- Understanding and managing long-term side effects
- Determining needs and characteristics of unique populations

In another session, participants discussed coordinated approaches to advancing this agenda and agreed to form a consortium on cancer survivorship. The consortium will provide networking opportunities, facilitate trans-disciplinary cooperation, help align research directions with survivors' experiences, identify knowledge gaps and optimize the translation of knowledge into policy and practice.

The two workshops were foundational in providing a clearer picture of the landscape of survivorship care and in setting national priorities. What was learned from these meetings has been used by the National Survivorship Working Group to determine necessary directions for the future, including subsequent projects.

## This Report

This report on survivorship care represents the culmination of Cancer Journey's work in survivorship to date, including:

- Development of an evidence-based survivorship care guidance document
- Implementation and evaluation of four survivorship care plan demonstration projects
- Implementation of several support programs for survivors and families
- Investigations of workplace issues for cancer survivors

This report offers an overview of the various projects supported by the Cancer Journey Portfolio; strategies, successes, challenges and key knowledge that has been gained; and the tools and resources produced. It is intended to consolidate the most recent advances in the field of survivorship for those planning further implementation of survivorship care plans and related projects.

The following diagram illustrates the evolution of the survivorship initiative under the National Survivorship Working Group, its key projects and resulting resources, and upcoming priorities. Following the diagram, the projects are described in more detail.

### Cancer Journey Portfolio Survivorship Initiative



## Pan-Canadian Guidance on Survivorship Services

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The objective of the Guidelines and Standards working group of the Cancer Journey Portfolio is to develop and implement pan-Canadian practice guidelines and standards to enhance the quality of psychosocial cancer care and to improve the satisfaction of both patients and care providers. The guidelines address a broad range of issues within psychosocial, supportive and palliative care. Survivorship has been a central priority, resulting in the development of [\*Pan-Canadian Guidance on Organization and Structure of Survivorship Services and Psychosocial-Supportive Care Best Practices for Adult Cancer Survivors\*](#). This guidance document was developed through collaboration between the Partnership and the Canadian Association of Psychosocial Oncology (CAPO); CAPO is the steward of the document.

A literature scan was conducted to determine the best available evidence, using targeted searches of medical databases and cancer guidelines resources. A total of 14 practice guidelines, eight systematic reviews and 63 randomized controlled trials were included in the systematic review of the evidence.

Prior to completion, the guidance document was distributed to content experts and key stakeholders across Canada, who provided feedback on data interpretation and the final recommendations. Final approval of the document was obtained through consensus of the Cancer Journey Survivorship Expert Panel.

The aim of the guidance document is to inform Canadian health authorities, key decision-makers in administration and policy, and health practitioners about the optimum organization of survivorship services, best care practices and interventions to maximize the psychosocial health and wellbeing of adult cancer survivors. A guideline on this topic was needed to inform best practices, to provide a basis for identifying gaps in care, and to set priorities and directions for future research. The document pertains to individuals in the post-primary phase of cancer treatment (e.g., surgery, chemotherapy and radiotherapy), as well as those who receive adjuvant treatment or live with advanced disease.

The recommendations are based on the consensus of the Cancer Journey Survivorship Expert Panel. Each recommendation was developed considering the expected health benefits balanced with the potential harms, side effects or risks associated with the guidance offered. The full guidance document<sup>\*</sup> elaborates each recommendation and provides tactics for a course of action. For the purposes of this report, a brief list of the recommendations follows.

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<sup>\*</sup> Howell, D, Hack, TF, Oliver, TK, Chulak, T, Mayo, S, Aubin, M, et al. (2011). *Pan-Canadian Guidance on Organization and Structure of Survivorship Services and Psychosocial-Supportive Care Best Practices for Adult Cancer Survivors*. Toronto, Canada: Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology. Available at: <http://www.capo.ca/>

Recommendations for the organization and care delivery structure of survivorship services include:

- Access to survivorship services to meet a broad range of needs
- Support during the transition to extended survival
- A treatment summary and follow-up care plan
- Care models and coordination of survivorship services
- Screening for distress and evidence-based practice
- Support for active engagement of survivors in self-management
- Survivorship education for health care providers
- Promotion of awareness of survivorship issues
- Leadership in research
- Evaluation of services
- Inclusive health public policy

Recommendations for psychosocial and supportive care interventions include:

- Supporting healthy lifestyle behaviours
- Using theory-based approaches
- Managing psychosocial concerns and distress
- Monitoring symptoms and late and long-term effects
- Managing concerns regarding sexual health
- Managing post-treatment fatigue
- Managing vasomotor symptoms
- Managing disruptions in sleep-wake patterns

The working group recognized that there will be challenges in applying the policy and practice recommendations in a variety of settings across Canada because of variations and limitations in resources, among other factors. While the research found no evidence that provided insight regarding the potential resource implications of applying the recommendations, intuitively, the group believes that improving the health and wellbeing of cancer survivors is an investment worth making, possibly leading to cost reductions and improved efficiencies in care.

Cancer survivors need access to evidence-based, best care practices to optimize their psychosocial health and to facilitate decision-making regarding necessary services and resources. The guidance document aims to raise awareness of survivorship issues, to guide organizations in evaluating their programs and services, and ultimately to improve the quality of survivorship care across Canada.

## Supporting Sustainable Survivorship Care Plans

Beginning in January 2010, the National Survivorship Working Group of the Cancer Journey Portfolio supported the implementation and evaluation of survivorship care plans in four provinces in Canada. A national request for proposals was issued, articulating the common elements of the care plan, reporting and evaluation requirements (see Appendix A for evaluation framework), and the expectation that a minimum of 30 cancer survivors would participate in each of the 12-month projects.

The opportunity was described as a demonstration project. The aims were to learn about barriers encountered in creating and implementing survivorship care plans, to identify the strategies required to overcome those barriers, to record the implementation steps and to understand how to sustain the initiative.

Four provinces entered into agreements with the Cancer Journey Portfolio to deliver survivorship care plans. The projects were selected in part to represent a broad range of settings for delivery of care plans: a community-based organization, a cancer centre, a rural/urban provincial program and an online community-based organization. All of the projects addressed the transition from active treatment to survivorship for people whose primary cancer treatment had ended in the previous six months. The projects also shared key elements of the care plan, which included, but was not limited to:

- Basic diagnostic information and a treatment summary
- A follow-up plan
- Recommendations and guidelines for coping and adjustment
- Recommendations and guidelines for healthy living
- Resources and activities for survivors
- Contact information for the care team

### Project Descriptions

#### *Young Adult Cancer Canada*

This survivor care plan, in keeping with the organization's mandate, was geared to survivors aged 15 to 39 and used a web-based tool. [Goaltender](#), launched in 2010, set the standard for Internet-based survivorship care plans for young adults. The tool was developed to assist young adults with self-care and goal-setting, and to provide important information about long-term medical effects from treatment, an issue that this demographic is often unaware of. The tool included a place for users to enter their medical information and also included information about mental health, spirituality and social life. The platform had a social-media style, and users could provide feedback and recommendations for improvement.

The tool was promoted through the Young Adult Cancer Canada network and using advertisements on various Internet sites. A video tour was available for health care providers. Although it began as a tool for individuals, users requested a means of linking with peers, which was then developed. As of March 2011, there were 96 users.

The program is now offered permanently by Young Adults Cancer Canada.

### *Alberta CancerBRIDGES*

BRIDGES is an acronym for Building Research Innovation into the Development and Growth of Excellence in Survivorship Care. The project, which targeted survivors of breast and head and neck cancers and had 59 participants, was led by a large multi-disciplinary team of researchers and clinicians from across Alberta. Team members contributed their expertise to develop a comprehensive care plan that included the Edmonton Symptom Assessment System, since one goal of this initiative was to address anxiety and depression in survivors. Nurses delivered the care plan in rural and urban settings, cancer centres, clinics and community-based settings for a cross-sectional, provincial approach to program delivery.

The care plan was delivered by nurses in one sitting, individually and in small groups, both to good effect. The project's rigorous evaluation data indicated that care plans are a useful tool for navigating the survivorship phase in these tumour groups. Nurses, survivors and family physicians all reported high levels of satisfaction with usefulness, communication value and emotional reaction to the care plan.

The following resources from this program are available at <http://www.cancerbridges.ca/research/care-plan-demonstration-project/>

For survivors and professionals:

- Care Plan Template for Breast Cancer Survivors
- Care Plan Template for Head and Neck Cancer Survivors

For professionals:

- Care Plan Evaluation Form (Survivor Version)
- Care Plan Evaluation Form (Medical Professional Version)
- Nurse Training Manual

### *CancerCare Manitoba*

This project, entitled "Moving Forward after Rectal Cancer: A Demonstration Project in Survivorship Care Planning," was initially developed for rectal cancer patients but was later expanded to include those with colorectal cancer. The cancer agency's electronic system was configured to pull critical patient, disease and treatment summaries into new follow-up care plan packages for patients and their health care providers. Patients at a number of centres completed the Screening for Distress tool as part of a transition appointment. An oncologist or nurse met with each survivor to review the information, and a psychosocial clinician followed up two weeks later with a phone

call. The Project Advisory Team also created a three-hour education module, the care plan tool and resource documents that could be adapted and applied to different tumour groups across the province and country.

CancerCare Manitoba has continued survivorship care planning beyond the demonstration project. Survivorship care has been integrated into standard treatment for colorectal cancer survivors and is being piloted with breast cancer patients. As a result of an assessment of the plan, the follow-up phone call has been eliminated. Patients are now referred to an ongoing *Cancer Transitions* program for any type of cancer, rather than the disease-specific three-hour workshop. Further data analysis is underway.

### *Wellspring, Toronto*

Wellspring delivered a peer-led program, “Proposal for the Creation and Implementation of a Sustainable Survivorship Care Plan,” that was designed for cancer survivors of any diagnosis within six months following treatment. A comprehensive care plan document was created and compiled in a binder to address the main concerns of cancer survivors. The document is based on a model of self-management. The program was delivered by a trained and supervised team of volunteers. The volunteers went through a selection process and attended a two-day training program. Volunteers were supervised and there were regular opportunities for debriefing.

The care plan was delivered over four meetings set approximately two weeks apart. During the demonstration period, 20 cancer survivors attended the program and 26 were on the waiting list. Volunteers and attendees evaluated the project. The evaluation showed that the volunteer leadership model is sustainable. In addition, the role of volunteer was carefully expanded from “peer support” to highly skilled expertise in “guided conversation,” with a focus on each survivor’s self-management and self-determination. The program is continuing and is expected to expand.

## Findings

In addition to the findings from these four projects, researchers collected feedback from senior executives, project leads, coordinators and front-line staff using qualitative interviews. Valuable information was gathered regarding survivorship care planning and programs for a variety of tumour groups (see Appendix B: Program Logic Model for Survivorship). The following are preliminary findings regarding successful strategies and barriers.

### *Successful Strategies*

**Leadership:** Direct leadership and project support from executive leaders was critical for uptake and adoption at all sites. Access to funding allowed for direct leadership and project coordination in launching each program and fostering responsibility for the new practices and processes among different members of each organization.

**Teamwork and collaboration:** At all four sites, the project was overseen by a multidisciplinary team, and in two cases this team included patients. One program lead acknowledged that the diverse team “was key to implementing change in clinic and or-

ganizational practice [because it] increased the knowledge exchange and enhanced interprofessional communication.” Team involvement went beyond front-line staff and volunteers to include site managers, clerks, administrative support, project coordinators, survivors and IT personnel to ensure new tools and practices were integrated at all levels of the organization. The care plan can be a means of streamlining care processes and professional collaboration.

**Tailoring the care plan:** Considerable time and resources were spent tailoring the survivorship care plan to local needs and current processes to create a unique tool. This was necessary to ensure that the care plan served the site-specific gap(s) it aimed to address. The process of tailoring the care plan also ensured that stakeholders had a means of shaping the product and thereby becoming engaged in its implementation.

**Education and training:** At three of the four sites, education and training were primary areas of development and were successful. Training was mandatory and intensive to fulfill the needs of program users. Two sites developed comprehensive training modules, which were evaluated and revised accordingly. These training tools will be highly transferable as programs are expanded in the future.

**Dissemination:** Project teams actively communicated and disseminated plans to raise awareness of the program.

**Conceptualizing survivorship:** Three of the four project teams learned that participants, and patients and professionals generally, found the terms “survivorship” and “survivor” controversial. Further, the terms may be ambiguous because the care plan model could apply to people not in the survivorship phase of the cancer trajectory. These teams preferred to refer to their programs differently.

### *Barriers*

**Infrastructure:** Challenges and delays related to information technology were encountered at all sites (e.g., integration of electronic medical records, the interface or software development). At several sites human resources was a challenge because of staff changes and shortages. Information technology and human resources were more of a challenge than anticipated.

### **The care plan:**

1. Developing and refining the care plans took longer than anticipated. Each of the project teams felt that they were breaking new ground. The investment in resources for this part of the project was higher than anticipated.
2. Tailoring the survivorship care plans to tumour groups and populations (e.g., young adults) ensured a targeted program but also limited the transferability of the tool to other tumour groups or populations. More research is needed to understand the essential elements of a care plan and which elements should be tailored for specific groups.

3. There was little consensus about some of the key logistical issues of care planning because of the uniqueness of each of the four programs. For example, this research did not specifically clarify who should initiate access to care planning (i.e., screening tool, automatic prompt or self-selection), how to ensure that people do not miss the opportunity, when is the right time to initiate survivorship care plans or how the care plan can be fully integrated into standard practice.

**Access to services:** The project teams recognized that the delivery of care plans is affected by the availability and accessibility of psychosocial and supportive care. The teams were able to facilitate links to some services and resources, but recognized gaps in availability.

**Evaluation:** The teams measured staff and patient satisfaction, and more robust patient data is still emerging from CancerCare Manitoba and Alberta CancerBRIDGES. Young Adult Cancer Canada maintained an open forum on its website for feedback regarding content and functions. Further research and consultation with practitioners are required to determine the key metrics by which to evaluate survivorship care planning.

## Conclusion

The four projects demonstrate the variability in survivorship care planning, where all projects addressed a significant gap in care and designed a context-specific solution to ease the transition for cancer patients after treatment has ended. Two of the sites aimed to streamline information and communication between the patient, nurse and family physician at end of treatment. The other two sites worked from a self-management model, empowering survivors and preparing them for the next phase of the cancer journey. In all cases, the projects served to streamline this period of transition and to significantly increase the capacities of patients and health care providers to address this gap in care. It is possible that community, cancer centre and online modalities could all work as complementary systems to bridge the gap for cancer survivors, offering care plan services at a variety of times and places to suit the range of patients' needs along the survivorship trajectory.

## National Survivorship Programs

### *Cancer Transitions* and *EMPOWER*

The Cancer Journey Portfolio supported and the National Survivorship Working Group oversaw development and implementation of the *Cancer Transitions* and *EMPOWER* pilot programs. The objective of these programs is to support, educate and empower survivors and their families as they transition from active cancer treatment to survivorship.

In 2011, a project team developed two self-directed programs based on findings from the pilot programs: *Transitions for Cancer Survivors* and *EMPOWER for Families/Supporters of Cancer Survivors*.

### *Cancer Transitions: Moving Beyond Treatment – Pilot Study*

This program for cancer survivors was developed in 2006 through a partnership between the Cancer Support Community and LIVESTRONG. The program was adapted for the Canadian context by a survivorship research team at the BC Cancer Agency. This program includes written materials and interactive components to address the long-term effects of cancer treatment and survivors' psychosocial needs. The six-week series of classes addresses physical, psychosocial and quality-of-life issues through support groups, education, nutrition and exercise. It helps survivors formulate a personal action plan for their care. The evidence-based program was created with experts in cancer survivorship and incorporates information from peer-reviewed literature.

The *Cancer Transitions* pilot was delivered and evaluated at four Canadian sites:

- Northern Health Authority, Prince George
- Hope & Cope, Montreal
- Wellspring, Toronto
- BC Cancer Agency, Vancouver Island

**Phase I** of the pilot study aimed to:

- Examine the feasibility of delivering the *Cancer Transitions* program in various Canadian settings
- Provide a preliminary evaluation of the impact of the program on the participant's quality of life, including social, emotional and physical wellbeing
- Provide recommendations regarding the effectiveness and sustainability of the program

**Phase II** aimed to create a sustainable Canadian *Cancer Transitions* program, which would involve:

- Creating a Canadian *Cancer Transitions* participant workbook and facilitator guide
- Conducting facilitator training for 40 facilitators
- Continuing to monitor sustainability and delivery
- Continuing to evaluate the program and participant outcomes

*Cancer Transitions* was evaluated by participants at the four pilot sites. Participants completed five validated questionnaires at the beginning and end of the program, and three additional questionnaires at the end. They also completed questionnaires following each session (i.e., weekly).

Descriptive and inferential statistics were used to evaluate the program and changes that occurred during the course of participation in the program in relation to self-efficacy, physical and mental health status, and overall quality of life. After three

months, the participants were also mailed a follow-up questionnaire to measure any sustainable improvements from the program.

General findings from participant self-reported questionnaires were as follows:

- Statistically significant improvement in eating patterns in 4 of 8 subscales
- Trends toward and some statistically significant improvements in the negative impact of cancer (e.g., life outlook, body and health, feelings about cancer, meaning of cancer, activities and relationships)
- Slight improvement in general self-efficacy at the end of the program; significant improvement at the three-month follow-up
- Significant improvement in health-related quality of life
- No significant improvement in physical activity

The support, advice and information were rated very highly by participants. Overall, participants gave positive feedback about the program workbooks and resource materials.

Program feasibility was measured according to survivor recruitment, adherence and retention, as well as site capacity and the expertise of the personnel delivering the program. Recruitment was very successful; interest in the program was strong and some sites had wait lists. Adherence and retention were also strong. Site and personnel requirements were fairly minimal and minor problems (i.e., space and facilitator recruitment) were resolved.

Evaluation of *Cancer Transitions* provided the following information:

- Most questionnaires are not specifically intended for cancer survivors.
  - A review of relevant measures and questionnaires is required to clarify the desired primary and secondary outcomes and whether the questionnaires effectively measure for those outcomes.
- It may be beneficial to evaluate logs and journals.
- It would be beneficial to include six-month and one-year follow-ups to monitor the sustainability of improvements.
- Researchers should consider the influence of variations by site and other external factors, such as facilitator and delivery of the program.
- More detailed analysis of outliers might reveal subgroups of participants showing more or less change.

The Canadian edition of the [Cancer Transitions](#) materials is now available to all facilitators across Canada. The participant workbook and facilitator guide can be ordered from the BC Cancer Agency for a moderate fee. Online facilitator training is available through the [Cancer Support Community](#). This free online training provides access to the American version of the training slides, participant workbook and facilitator guide.

Facilitators continue to deliver *Cancer Transitions* and ongoing evaluation contributes to evidence-based knowledge that is used to guide clinical practice. Different methods of program delivery are being tested for feasibility (e.g., telehealth delivery in remote areas).

*Cancer Transitions* has been offered at more than 15 sites in Canada, serving approximately 245 individuals. Cancer Journey has supported facilitator training and awarded a number of bursaries for program materials.

### *EMPOWER: Education and Support for the Family of Cancer Survivors – Pilot Study*

*EMPOWER* was developed by the Survivorship Research Team of the BC Cancer Agency to provide a program similar to *Cancer Transitions* but for families and other supporters of cancer survivors in the post-treatment stage of the cancer journey. The three-session program addresses medical management, self-care, practical issues, exercise, nutrition and emotional wellbeing.

The primary goal of this project was to develop and pilot the *EMPOWER* program to determine the feasibility of launching it nationally. *EMPOWER* was implemented, along with the previously implemented *Cancer Transitions* program, at two sites.

The *EMPOWER* pilot study included an evaluation component similar to that of *Cancer Transitions*. Participants completed a series of pre- and post-program questionnaires, including a follow-up questionnaire at three months, and weekly questionnaires. Some of the surveys were the same as those used for *Cancer Transitions* and others were added specifically for families and supporters of cancer survivors. The surveys measured factors such as unmet needs, generalized self-efficacy, coping, anxiety and depression, intrusiveness of the illness experience, social support and quality of life. Descriptive and inferential statistics were used to evaluate the program and changes experienced by participants over the course of the program.

Data from the pilot study are still being analyzed and, since the sample size was very small, it is difficult to make conclusions at this point. However, the pilot did provide preliminary evidence that supports *EMPOWER* and suggests that, with small modifications identified by participants and facilitators, it is a useful program.

To date, evaluation of *EMPOWER* has provided the following information regarding recruitment and site selection:

- It is difficult to recruit family members; long lead times and a variety of strategies are required.
- It is important to make the program accessible and easy to attend to attract survivor family members.
- It is important to access a large pool of survivors and their families in the early post-treatment phase.

- It is helpful to engage champions at the site to promote the program.
- Beware of “Site Exhaustion” – some sites may have offered a survivorship program a number of times, leaving an insufficient pool of new participants.
- Beware of “Site Burden” – offering more than one program at a time can be challenging.
- It is important to maintain consistency in personnel resource management and communication.

Ten facilitators have been trained to lead *EMPOWER*.

### ***CancerChatCanada***

Cancer Journey supports professionally led online support groups for Canadian cancer patients and family caregivers through the online platform [CancerChatCanada](#). The primary objective of these groups has been to make professionally facilitated support available to all cancer patients and their caregivers, with particular emphasis on those who may have difficulty accessing support. The long-term goal is a pan-Canadian program of online cancer support.

In 2005, a group of Canadian researchers, clinicians and program leaders, known as the National Alliance of Psychosocial Oncology and Supportive Care Online (NAPSCO), began to investigate methods and models with which to implement and evaluate an online support program for cancer patients and their families. The rationale for this project was that most psychosocial oncology services are available only in urban centres, where many Canadians are unable to access them. The researchers believed that an online format might address access issues while also ensuring the confidentiality and anonymity that many patients prefer. *CancerChatCanada* was founded as a secure, Canadian-based platform, supported by Cancer Journey and housed at the BC Cancer Agency. It now operates in five provinces (British Columbia, Alberta, Manitoba, Ontario and Nova Scotia) and offers:

- Professionally led online support groups for patients and family caregivers
- Telephone and Internet access
- A secure site ensuring privacy and confidentiality
- Peer discussion boards
- Provincial pages with links and contacts
- Professional pages for research and development of online support

To date, over 514 participants with various types of tumours have contacted the program and participated in 79 groups. Nearly three-quarters of these people have been enrolled in, or are on a waiting list for, a professionally led online support group. Over 70% of participants are patients or survivors and just under 30% are family caregivers. Targeted groups have been created to meet the specific needs of young and rural

breast cancer survivors, patients with metastatic disease, and family caregivers, as well as post-treatment survivors.

### *Findings*

Researchers evaluated data collected through document reviews and focus group discussions as well as interviews with NAPSCO members, the program lead, current program staff and members of the *CancerChatCanada* Leadership Group. The evaluation considered three factors:

- **Feasibility:** Is it possible to develop and operate professionally led pan-Canadian online support groups for cancer patients and caregivers? Can the groups conform to organizational and professional requirements and preferred clinical practices?
  - It is feasible to conduct professionally led online support groups in Canada that meet professional and ethical standards and best practices.
  - Privacy and data security issues can be resolved with appropriate technology, staff training and patient education.
  - Risk management and ethical guidelines have been successfully addressed.
- **Acceptability:** Are patients participating in and satisfied with the support groups? In particular, is there added value in using an online format?
  - The vast majority of participants found the group format and the professional facilitation very beneficial.
  - The online format was highly valued for its convenience, privacy and anonymity, and the use of writing as a form of expression. Many participants assessed the quality of the online modality as equal or superior to in-person support.
- **Implementation:** Is pan-Canadian support for a partnership model possible and is the program sustainable? This phase included questions about best practice standards, suitability for the Canadian context, communications and involvement of stakeholders and the public.
  - Building on feasibility and acceptability, the team was able to operationalize the program to best practice standards. The website has been enhanced and training materials developed according to evidence-based standards.
  - Buy-in has been garnered for a pan-Canadian partnership model from psychosocial oncology leaders at cancer centres in eight provinces. Plans for a sustainable national model are underway.

### **Lessons Learned**

Following participant feedback, some operational elements of *CancerChatCanada* were enhanced. For example, in response to requests for more information, the website was equipped with links to other websites and discussion boards for information exchange. Enrollment protocols were also modified to better inform participants about the purpose and intent of the groups.

The evaluation identified several key factors in the program's success, including:

- Systematic development and a commitment to evaluation and quality improvement
- National support and investment from like-minded professionals across Canada
- Development of a community of practice with trained facilitators
- Development of a strong knowledge and research base for education and promotion regarding this form of support

Some operational and logistical challenges are to be expected in a national program. The following challenges are likely to be met as a pan-Canadian program is developed and implemented:

- Addressing cross-jurisdictional issues of professional capacity
- Working with different provincial funding models and administrative requirements
- Recruiting from underserved populations (this will require more promotion and better awareness of the program at regional and provincial cancer centres)

As a result of extensive evaluation, the program has gained national support for a Canada-wide expansion, which is underway. Researchers and supporters believe *CancerChat-Canada* is sustainable.

## **The Return to Work Projects**

The National Survivorship Working Group identified a significant gap in knowledge and research about the challenges facing cancer survivors when they return to work. This became a priority area for the final year of the Cancer Journey Portfolio's mandate. The key objective of this set of investigations was to build a comprehensive understanding of the needs of, as well as current resources and supports available to, cancer survivors as they return to the workplace during or following treatment.

This work consisted of three projects:

- An environmental scan to investigate supports, training and resources related to workplace issues for cancer survivors as they return to work
- A literature review and consultations to examine Canadian information about challenges encountered by those returning to work
- Research and consultations to determine challenges for the workplace and employers of those affected by cancer

## Environmental Scan

The environmental scan had two main objectives:

- To create a comprehensive list of any or all of the support services, education, training programs or online resources that address workplace issues for people living with cancer and other chronic diseases as they return to work
- To interview key developers and providers of these supports and services

The scan was conducted in two phases: 1) a web-based review and synthesis of return-to-work resources related to cancer and chronic disease in Canada, and of those related only to cancer internationally; 2) 16 in-depth interviews with representatives of 21 programs in cancer, HIV/AIDS and mental health.

Findings from the web-based review indicate that:

- Resources are mainly programs, guides, information sheets, services, reports, publications and booklets.
- The field of mental health has produced the most work on the subject that is available on the Internet.

The key informant interviews revealed that:

- Programs range from information or education to psycho-educational groups to one-on-one counselling and are delivered through various means (e.g., telephone, in person, videoconference and online).
- Content from Canada and four other English-speaking countries covers a similar range of topics (e.g., disclosure, stigma, job preparation, financial information, workplace accommodations, stress, side effects and legal information).
- Most programs are offered to individuals who have completed their treatment, indicating a gap in support for persons returning to work earlier.
- Most programs focus on getting people back to work, not on issues faced once they return.

### *Recommendations and Directions for Future Work*

- Provide funding for pilot programs involving individuals with cancer, health care professionals and employers. Projects should incorporate return-to-work support across the cancer trajectory, embrace multiple issues, including workplace reintegration and follow-up, and have a strong evaluation component.
- Fund an expert panel of return-to-work professionals to inform and advise on best practices, evaluation design and long-term sustainability.
- Establish mechanisms for knowledge transfer among employers, health professionals and providers of support for cancer patients and their caregivers.
- Support information exchange with organizations within and outside of the cancer community (e.g., HIV/AIDS and mental health).

## Literature Review and Consultations

This project aimed to investigate current Canadian information about the challenges encountered by people living with cancer and their caregivers as they return to the workplace.

The project consisted of three phases:

- **Phase I:** A literature review and interviews to assess information in Canada concerning return-to-work challenges for people living with cancer and caregivers
- **Phase II:** Based on the literature, a national online survey for people living with cancer and caregivers to identify return-to-work concerns
- **Phase III:** Focus groups to expand on survey findings

Researchers designed the online survey to reflect key challenges identified in the literature. The survey was completed by 470 participants (410 individuals with cancer and 60 caregivers). Descriptive and bivariate analyses were completed. Two focus groups were also held with 16 participants from three cities.

The following summarizes responses from survey and focus group participants who had a cancer diagnosis:

- In the 12 months following diagnosis, 60% of survey respondents self-reported a decrease in their income. Those who continued to work through their cancer treatment or who needed to return early cited financial needs for doing so.
- During treatment, over three-quarters of survey participants relied on income supports: short-term disability, long-term disability or employment insurance (EI). The period of EI is sometimes insufficient for those undergoing lengthy cancer treatments.
- Of survey respondents, 40% left work for more than six months to undergo treatment. Of respondents, 50% returned to work gradually and 18% returned immediately to full-time work.
- Those who worked for large organizations (over 500 employees) were more likely to receive accommodations such as working from home or paid time off for medical appointments than were those working in smaller organizations.
- Participants reported changes such as working less, reducing workload, reducing stress by commuting less and better work-life boundaries.
- The majority of participants reported that their main work-related challenge was side effects following treatment (e.g., fatigue, loss of energy and cognitive problems).

The following summarizes responses from caregivers:

- Over 40% of caregivers fulfilled their role for over six months. Care included tasks that required physical presence and time away from work (e.g., transportation, help with daily activities, home management).
- Caregivers reported that they experienced stress and needed time off for caregiving and to take care of themselves.
- Of the caregiver respondents, 90% reported missing some work and a decrease in income, and 63% did not receive support from the workplace to leave or to work flexibly. To leave work, caregivers used sick days, adopted a flexible schedule or reduced their hours.
- The main work-related issues were loss of concentration and productivity, stress and lack of support from colleagues.

### *Recommendations and Directions for Future Projects*

- Consult with all stakeholders regarding what resources are necessary. Resources should address both those who leave work and those who stay at work.
- Create a website or information pamphlet about income supports.
- Create awareness about critical illness and disability insurance for self-employed workers.
- Create workplace accommodation information for employers in small companies.
- Develop information about the possible side effects individuals might experience that could affect work and direct them to rehabilitation programs.
- Create rehabilitation resources to address concerns about side effects.
- Create a working group of individuals with cancer, insurance representatives, employers and cancer care professionals to create resources about workplace accommodations and side effects.
- Create workplace accommodation information for employers of caregivers.
- Partner and strategize with interested organizations to improve:
  - eligibility criteria and length of EI sickness benefits and
  - eligibility criteria and length of compassionate care benefits.
- Conduct further research with participants recruited through cancer centres and with those who have lower levels of education (high school or less).

## Research and Consultations on the Workplace

This project set out to determine challenges encountered by employers and to identify any supports offered by the workplace for managers of employees affected by cancer. This research was carried out in two stages:

- **Stage I** consisted of in-depth interviews with senior staff from workplace organizations, including employers, insurers, law firms and unions. Recruiting considerations included size of firm, sector, level of employee physical activity and location.
- **Stage II** consisted of three focus groups with employers. All participants were from organizations with over 100 employees and were senior managers or held a senior human resources position within their organization.

Most employers reported that they experienced or knew about few cases of cancer among employees and did not have specific strategies or policies in place to support return to work following cancer treatment. Most small and mid-sized organizations did not offer short-term disability, and most part-time/non-salaried workers do not have benefits. A variety of gaps in income support and employer accommodation contribute to financial stress for many cancer patients.

### *Recommendations and Directions for Future Projects*

- Create a communication program to raise the profile and importance of being prepared to accommodate chronic illnesses such as cancer in the workplace.
- Develop educational material for managers covering issues such as communication with employees, health care workers and insurers; what to expect from employees undergoing treatment; how to build a back-to-work program; and how to manage workload and productivity.
- Facilitate or provide training sessions about similar issues for human resources managers, including the legal responsibilities of employers and available resources.
- Build a toolkit of relevant resources, including packages for both employees and physicians with the necessary information, forms (including return-to-work forms) and accommodation policies.
- Provide access to external professionals with expertise in accommodation and the development of return-to-work plans.
- Compile and provide online access to a list and description of community services that could assist employees and employers who have workers with diminished capacity related to a chronic illness such as cancer.
- Explore the feasibility of providing an incentive or tax break for select employers who incur costs related to accommodation.
- Assess the extent to which inadequate financial support impedes a successful return-to-work process (e.g., forces employees back before they are ready or induces considerable stress).

- Consider quantifying some of the findings in this research by conducting further research. The following are possible research questions:
  - What percentage of Canadian workers have poor short-term and long-term coverage? What groups of employees are financially vulnerable?
  - What employers (e.g., sector, size) are most interested in accessing training regarding return-to-work issues for their managers? What would the expected uptake be? What is the best way to deliver these services?

## Findings

The *Return to Work* projects contributed valuable information about cancer survivors' needs as they return to work, particularly regarding gaps in available programs and resources. These findings highlight the newness of this field of investigation and make it clear that bolstering awareness of survivorship needs among employers is an imperative first step.

## Conclusion

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The body of work on survivorship care summarized in this report has enabled Cancer Journey to both verify and promote the need for extensive further research, education and programming about survivorship issues in Canada. While diverse in their aims, scope, target audiences and activities, the projects undertaken to date illustrate the landscape of survivorship care, which encompasses:

- Understanding the needs and challenges of survivors, families, caregivers and health care providers
- Understanding requirements and barriers within the cancer system
- Raising awareness of needs and challenges, targeting the appropriate and most influential change leaders
- Setting priorities for research, education and programming
- Developing evidence-based program models
- Implementing and evaluating programs
- Creating resources for information and support
- Developing and evaluating practices for determining individual needs (e.g., Screening for Distress)
- Developing and sustaining resources to meet the needs identified
- Facilitating appropriate referrals to services and resources
- Targeting and adapting resources and services to specific populations and individuals
- Creating streamlined, coordinated models of care

A key element in sustaining this body of work will be an emphasis on partnerships and links to both communities and complementary programs. The development of research and an evidence base for survivorship planning must be shared with cancer patient advocacy groups and community organizations, many of which have offered programs or are in the process of developing services. In turn, such groups can provide essential survivor perspectives and knowledge gained from community-based programs to inform both research priorities and care planning within the cancer system.

At another level, the benefits of developing strong links to other types of programming, such as Navigation and Screening for Distress, seem apparent. Screening for Distress tools have already been used in some survivorship care programs. This field of programming has flagged times of transition in the cancer journey as particularly important and lends itself to post-treatment care planning. The field of cancer patient navigation also encompasses the entire trajectory of cancer care and thus will benefit from the available evidence on appropriate care planning to address survivorship needs.

Based on the work accomplished to date, the National Survivorship Working Group is now planning for another five-year mandate in which survivorship has been designated a key priority. The working group's recommendations emphasize the need to:

- Develop a knowledge transfer framework that includes innovative strategies to reach various audiences
- Produce standard communication materials to promote awareness of the survivorship work to be presented by working group members at conferences and workshops
- Develop appropriate evaluation metrics to incorporate in all future projects
- Align with the Partnership's 2012-17 mandate to address the needs of rural and remote populations
- Further promote communication about return-to-work issues among health care providers, human resource departments and specialists in chronic disease
- Plan to rigorously assess feasibility, efficiency and value for investment in survivorship initiatives

## References and Resources

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### Environmental Scans and Survivorship Workshops

Ristovski-Slijepcevic, S. (April 2008). Environmental Scan of Cancer Survivorship in Canada: Conceptualizations, Practice and Research. Toronto, Canada: ReBalance Focus Action Group (now Cancer Journey Portfolio), Canadian Partnership Against Cancer.

Scalzo, K. (May 2009). A Brief Review of Survivorship Care Plans in Canada and the United States. Toronto, Canada: National Survivorship Working Group, Cancer Journey Portfolio.

National Invitational Workshop: Toward an Agenda for Cancer Survivorship. Report and related resources available at:

<http://www.partnershipagainstcancer.ca/resources-publications/cancer-journey/national-invitational-workshop-towards-an-agenda-for-cancer-survivorship-related-resources/>

Pan-Canadian Invitational Workshop: Identifying Priorities for Cancer Survivorship Research. Report available at:

<http://www.bccancer.bc.ca/Search.htm?query=Pan-anadian+Invitational+Workshop%2c+Identifying+Priorities+for+Cancer+Survivorship+Research>

### Guidance on Survivorship Services

Howell, D, Hack, TF, Oliver, TK, Chulak, T, Mayo, S, Aubin, M, et al. (2011). *Pan-Canadian Guidance on Organization and Structure of Survivorship Services and Psychosocial-Supportive Care Best Practices for Adult Cancer Survivors*. Toronto, Canada: Canadian Partnership Against Cancer (Cancer Journey Action Group) and the Canadian Association of Psychosocial Oncology. Available at: <http://www.capo.ca/>

### Cancer Transitions and EMPOWER

Cancer Survivorship: Creating Uniform and Comprehensive Supportive Care Programming in Canada. Cancer Transitions: Moving Beyond Treatment. Report available at:

<http://www.partnershipagainstcancer.ca/resources-publications/cancer-journey/reports/>

Cancer Transitions and EMPOWER information and resources available at:

<http://www.bccancer.bc.ca/RES/ResearchPrograms/SBR/Programsforsurvivors.htm>

### CancerChatCanada Online Support Groups

Information and registration form available at:

<http://cancerchatcanada.ca/>

## “Return to Work” Reports

Environmental Scan of Programs and Resources to Facilitate Return to Work for People with Cancer or other Chronic Diseases. Report available at:

Literature Review and Consultation about Return to Work Concerns Faced by People Dealing with Cancer and Caregivers. Report available at:

Research Related to Workplace Support for Cancer Survivors. Report available at:

## Other Resources

“The Truth of It.” Video Series available at Cancer View Canada:

[www.cancerview.ca/thetruthofit](http://www.cancerview.ca/thetruthofit)

CancerBridges program resources available at:

<http://www.cancerbridges.ca/research/care-plan-demonstration-project/>

For Survivors and Professionals:

- Care Plan Template for Breast Cancer Survivors
- Care Plan Template for Head and Neck Cancer Survivors

For Professionals:

- Care Plan Evaluation Form (Survivor Version)
- Care Plan Evaluation Form (Medical Professional Version)
- Nurse Training Manual

Howell, D, Hack, TF, Oliver, TK, Chulak, T, Mayo, S, Aubin, M, et al. (2011). Survivorship services for adult cancer populations: a pan-Canadian guideline. *Current Oncology*, 18(6), 265-81.

Coyle, D, Grunfeld, E, Coyle, K, Julian, JA, Pond, GR, Folkes, A, et al. (2011). Cost-effectiveness of a survivorship care plan for breast cancer survivors. *Journal of Clinical Oncology*, 29(15 suppl), abstr 6082.

Grunfeld, E, Julian, JA, Pond, G, Maunsell, E, Coyle, D, Folkes, A, et al. (2011). Evaluating survivorship care plans: results of a randomized, clinical trial of patients with breast cancer. *Journal of Clinical Oncology*, 29(36), 4755-62.

Grunfeld, E, and Earle, CC. (2010). The interface between primary and oncology specialty care: treatment through survivorship. *Journal of the National Cancer Institute Monographs*, 40, 25-30.

Institute of Medicine. (2006). From Cancer Patient to Cancer Survivor, Lost in Transition. Hewitt, M., Greenfield, S., Stovall, E., eds. Washington, DC: The National Academies Press.

Supporting the Role of Primary Care in Cancer Follow-Up. Report prepared for Canadian Association of Provincial Cancer Agencies available at:

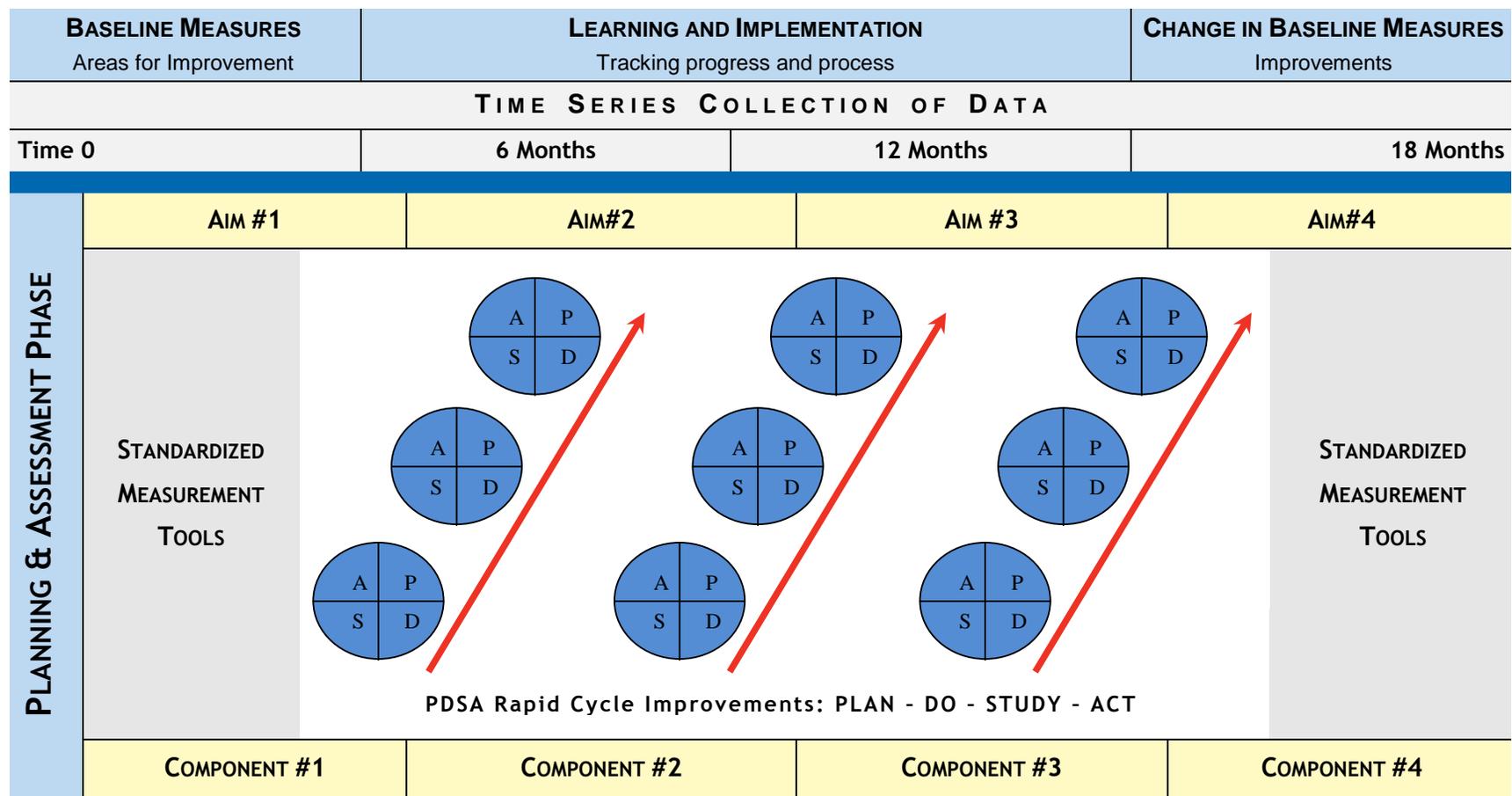
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Young Adult Cancer Canada. Online support and information available at:

<http://www.youngadultcancer.ca/>

## Appendix A: Quality Improvement and Evaluation Framework for Survivorship Care

Cancer Journey Portfolio, Quality Improvement Design Framework for a Person-Centred Approach to Screening for Distress / Navigation / Survivorship



Adapted from the Improvement Guide, Ontario Health Quality Council (2009).

**Cancer Journey Portfolio: Quality Improvement Design Framework for a Person-Centred Approach to Survivorship Care**

BASELINE MEASURES Areas for Improvement		LEARNING AND IMPLEMENTATION Tracking progress and process		CHANGE IN BASELINE MEASURES Improvements		
TIME SERIES COLLECTION OF DATA						
Time 0		6 Months	12 Months	18 Months		
<b>PLANNING &amp; ASSESSMENT PHASE</b>	<b>AIM #1 :</b> <ul style="list-style-type: none"> <li>• Strategy in place to address 90% of barriers identified in the design and use of survivorship care plans</li> </ul>	<b>AIM #2 :</b> <ul style="list-style-type: none"> <li>• 90% of targeted staff will have the knowledge to address the physical and psychological issues pertinent to cancer survivorship</li> <li>• 90% of targeted staff will have the competencies and skills required to take action to change their practice</li> </ul>	<b>AIM #3:</b> <ul style="list-style-type: none"> <li>▪ 90% of survivors targeted have a survivorship care plan</li> <li>▪ 90% of survivors have scores acknowledged by health care provider</li> <li>▪ 90% of survivors needs are further assessed and/or appropriate referrals are made</li> <li>▪ 90% of team members engaged in collaboration and integrated care team planning using evidence-based approaches</li> </ul>	<b>AIM #4:</b> <ul style="list-style-type: none"> <li>▪ 90% of targeted survivors/families are satisfied with the process of care</li> <li>▪ 90% of patients will have a reduction in distress overtime</li> </ul>		
	<b>Data Collection Tools:</b> <ol style="list-style-type: none"> <li>1. Care Plan</li> <li>2. Staff Knowledge and skills</li> <li>3. Staff satisfaction</li> <li>4. Patient satisfaction/ experience</li> </ol>				<b>Data Collection Tools:</b> <ol style="list-style-type: none"> <li>1. Care Plan</li> <li>2. Staff knowledge and skills</li> <li>3. Staff satisfaction</li> <li>4. Patient satisfaction/ experience</li> <li>5. Organizational</li> </ol>	
	<b>PDSA Rapid Cycle Improvements: PLAN - DO - STUDY - ACT</b>					
	<b>COMPONENT #1:</b> Strategy for the ongoing follow-up care of cancer survivors	<b>COMPONENT #2:</b> Staff Education and Training	<b>COMPONENT #3:</b> Teamwork and Collaboration	<b>COMPONENT #4:</b> Survivor Engagement		

**Template for Implementing Survivorship Care**

*\*Activities not limited to those listed here.*

Goal: To facilitate the transition of cancer survivors and their caregivers into the survivorship phase, improving quality of life (social, psychological and physical wellbeing) by using evidence-based guidance.

<p><b>Implementation of Navigation</b></p> <p><b>Objective:</b> To organize and plan implementation of survivorship care plans.</p> <p><b>Activities*:</b></p> <ul style="list-style-type: none"> <li>• Develop a detailed project implementation plan (to include readiness assessment, plans for field preparation, stakeholder assessment, marketing, etc.)</li> <li>• Incorporate core concepts of person-centered care in implementation plan</li> <li>• Implement quality improvement and evaluation data collection processes (systematic measurement and feedback cycle)</li> <li>• Identify the barriers to the design and use of survivorship care plans in Canada</li> </ul> <p><b>Process Outputs:</b></p> <ul style="list-style-type: none"> <li>• Detailed implementation plan</li> <li>• Data collection and reporting system</li> <li>• Strategy to overcome barriers</li> <li>• Best practices in Canada</li> </ul> <p><b>Process Outcomes:</b></p> <ul style="list-style-type: none"> <li>• Implementation and evaluation of a survivorship care program within a model of continuous quality improvement</li> <li>• Overcoming barriers to the design and use of survivorship care plans</li> </ul> <p><b>End Outcome:</b></p> <ul style="list-style-type: none"> <li>• Infrastructure that supports a person-centered approach to survivorship care</li> </ul>	<p><b>Staff Education and Training</b></p> <p><b>Objectives:</b> To develop the skills, knowledge, and core competencies to equip health professionals to address the physical and psychosocial issues pertinent to cancer survivorship.</p> <p><b>Activities:</b> Conduct education and training in the following:</p> <ul style="list-style-type: none"> <li>• Person-centered approach</li> <li>• Survivorship issues, comprehensive assessment and care planning</li> <li>• Evidence-based practice guidelines, assessment tools and screening instruments</li> <li>• Quality improvement</li> </ul> <p><b>Process Outputs:</b></p> <ul style="list-style-type: none"> <li>• Education and training materials</li> <li>• # and type of educational sessions</li> <li>• # and category of staff attending sessions</li> <li>• # of staff who have competencies and skills</li> </ul> <p><b>Process Outcomes:</b></p> <ul style="list-style-type: none"> <li>• Increased knowledge about and skills to address survivorship issues</li> <li>• Increased awareness and integration of key attributes of person-centered care</li> <li>• Increased knowledge about the core competencies required to deal with survivorship issues</li> </ul>	<p><b>Teamwork and Collaboration</b></p> <p><b>Objective:</b> To establish interprofessional collaboration in planning and coordinating care to manage the medical and psychosocial difficulties experienced by cancer survivors.</p> <p><b>Activities:</b></p> <ul style="list-style-type: none"> <li>• Develop capacities to work in an interprofessional team (expand team scope and communication)</li> <li>• Use guidelines, assessment tools and screening instruments to inform care planning process (best practices)</li> <li>• Assess patients’ key concerns and make referrals, as appropriate</li> <li>• Delineate roles and responsibilities of team members</li> </ul> <p><b>Process Outputs:</b></p> <ul style="list-style-type: none"> <li>• Interprofessional model for survivorship care</li> <li>• Uptake of guidelines, best practices</li> <li>• Staff satisfaction</li> <li>• # of survivorship care plans developed</li> <li>• # of survivors screened for distress</li> </ul> <p><b>Process Outcomes:</b></p> <ul style="list-style-type: none"> <li>• Increased adherence to evidence-based guidelines to inform practice</li> <li>• Improved team collaboration</li> <li>• Provision of accessible and comprehensive survivorship care</li> </ul> <p><b>End outcomes:</b></p> <ul style="list-style-type: none"> <li>• Improved coordination, continuity and integration of survivorship care</li> <li>• Practice change</li> </ul>	<p><b>Survivor Engagement</b></p> <p><b>Objective:</b> To improve the experience of the survivor and their family as they transition to the survivorship phase of the cancer trajectory.</p> <p><b>Activities:</b> Implement processes to ensure that survivors are:</p> <ul style="list-style-type: none"> <li>• Part of the health care team (involved in the conversations)</li> <li>• Participating meaningfully in decision-making and priority setting for ongoing follow-up care</li> <li>• Provided with timely, complete and accurate information</li> <li>• Having their key concerns discussed and addressed as soon as possible</li> </ul> <p><b>Process Outputs:</b></p> <ul style="list-style-type: none"> <li>• Survivor and family satisfaction</li> <li>• % of survivors with decreased distress scores</li> </ul> <p><b>Process Outcomes:</b></p> <ul style="list-style-type: none"> <li>• Increased survivor satisfaction with and experience of ongoing follow-up care</li> <li>• Increased awareness of supportive care services</li> <li>• Increased knowledge about self-management and self-care</li> </ul>
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## Appendix B: Cancer Journey — Survivorship Care Plan Program Logic Model

Source: PricewaterhouseCooper

Components	Planning & Assessment	Staff Selection, Training & Support	Teamwork & Collaboration	Organizational Capacity Building	Patient Engagement	Monitoring, Evaluation & Reporting	Dissemination
Resources			• Staffing	IS/IT	• Facilities		
Activities	<ul style="list-style-type: none"> <li>Assessment of:                             <ul style="list-style-type: none"> <li>Problem/local situation</li> <li>Individual staff perceptions/motivation</li> <li>Existing social supports</li> <li>Organizational capacity for innovation</li> </ul> </li> <li>Barriers to implementation</li> <li>Tailoring of innovation to local context</li> <li>Creation of implementation plan</li> </ul>	<ul style="list-style-type: none"> <li>Select/recruit staff</li> <li>Conduct education and training in:                             <ul style="list-style-type: none"> <li>person-centered approach</li> <li>best practices</li> <li>integration of innovation into workflow and culture</li> <li>quality improvement and plan/do/study/act cycles</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Develop capacities to work on an interprofessional team by expanding scope and communication</li> <li>Use guidelines, standards and algorithms to inform care planning process</li> <li>Promote positive social influences</li> </ul>	<ul style="list-style-type: none"> <li>Identify and promote champions and other positive social influences</li> <li>Develop policies and boundaries</li> <li>Secure human and financial resources</li> <li>Develop intra-organizational communication mechanisms</li> </ul>	<ul style="list-style-type: none"> <li>Materials/Documents</li> <li>Create, implement processes to ensure patients:                             <ul style="list-style-type: none"> <li>Are involved in conversations as part of the health care team</li> <li>Participate meaningfully in decision-making and priority setting</li> <li>Receive timely, complete and accurate information</li> <li>Have concerns identified and discussed</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Measurement development</li> <li>Tracking and progress reporting</li> <li>Barrier management</li> <li>Sharing results</li> </ul>	<ul style="list-style-type: none"> <li>Creation of mechanisms to share results and lessons learned with internal stakeholders</li> <li>Development of products to share lessons learned with external stakeholders</li> <li>Participation in conferences, collaborations, etc.</li> </ul>
Outputs	<ul style="list-style-type: none"> <li>Documentation of rationale for need</li> <li>Best practice guidelines</li> <li>Implementation plan</li> <li>Barrier mgmt strategy</li> <li>Tailored innovation components/elements</li> </ul>	<ul style="list-style-type: none"> <li>Education/training materials and sessions</li> <li># of staff attending and rationale for selection</li> <li>Person-centered educational modules</li> </ul>	<ul style="list-style-type: none"> <li>Interprofessional model for survivorship care planning</li> </ul>	<ul style="list-style-type: none"> <li>Champions</li> <li>Policy documents</li> <li>Resource allocation documents</li> </ul>	<ul style="list-style-type: none"> <li>Patient information sessions and consultations</li> <li>Patient concerns are addressed</li> </ul>	<ul style="list-style-type: none"> <li>Data collection and reporting system</li> <li>Progress reports</li> </ul>	<ul style="list-style-type: none"> <li>Knowledge products</li> <li>Collaborations</li> <li>Conferences</li> <li>Publications, presentations</li> </ul>
Process Outcomes	<ul style="list-style-type: none"> <li>Increased preparation/readiness for implementation</li> <li>Overcoming the barriers for implementation</li> </ul>	<ul style="list-style-type: none"> <li>Increased knowledge, skills, capacity to address distress (screening, assessment, referrals), navigation and survivorship</li> <li>Increased awareness, integration of key attributes of person-centered care</li> <li>Increased knowledge of core competencies for screening for distress, navigation and survivorship</li> </ul>	<ul style="list-style-type: none"> <li>Increased adherence to evidence-based guidelines to inform practice</li> <li>Improved collaboration and service coordination</li> <li>Provision of safe and accessible care</li> <li>Staff satisfaction with teamwork and collaboration</li> </ul>	<ul style="list-style-type: none"> <li>Improved infrastructure to support innovation</li> </ul>	<ul style="list-style-type: none"> <li>Patients and families increasingly involved in all aspects of the care process</li> </ul>	<ul style="list-style-type: none"> <li>Continued implementation of quality improvement and plan/do/study/act cycle</li> </ul>	<ul style="list-style-type: none"> <li>Internal and external stakeholders increasingly aware of existence of innovation</li> </ul>
Short-Term Outcomes	<ul style="list-style-type: none"> <li>Program implemented as designed</li> </ul>	<ul style="list-style-type: none"> <li>Enhanced staff competencies and capacity for person-centered approach to survivorship</li> </ul>	<ul style="list-style-type: none"> <li>Improved coordination, continuity and integration of care</li> <li>Team working toward person-centered care</li> </ul>	<ul style="list-style-type: none"> <li>Enhanced infrastructure that supports implementation</li> </ul>	<ul style="list-style-type: none"> <li>Increased knowledge, awareness, involvement in, and understanding of the process of care</li> </ul>	<ul style="list-style-type: none"> <li>Increased understanding of innovation and necessary modifications at individual, team and organizational levels</li> </ul>	<ul style="list-style-type: none"> <li>Increased understanding of innovation by internal and external stakeholders including challenges and opportunities</li> </ul>
Intermediate Outcomes	<ul style="list-style-type: none"> <li>Increased patient and family satisfaction with the experience of care</li> </ul>		<ul style="list-style-type: none"> <li>Increased patient and family awareness of supportive care services and resources</li> </ul>		<ul style="list-style-type: none"> <li>Increased patient and family knowledge about self-management and self-care</li> </ul>		
Long-Term Outcomes	<ul style="list-style-type: none"> <li>Widespread diffusion of innovations</li> </ul>	<ul style="list-style-type: none"> <li>Sustainability of innovations</li> </ul>	<ul style="list-style-type: none"> <li>Reduced patient and family stress and increased quality of life</li> </ul>			<ul style="list-style-type: none"> <li>Reduced costs to cancer care system</li> </ul>	