Living Beyond Cancer:
Summary of the Expert Roundtable on Survivorship
November 7, 2008, Toronto, Ontario

Prepared by:
Dana Wilson-Li, Research Policy Analyst, CQCO Secretariat
Katya Duvalko, Director, CQCO Secretariat

December 19, 2008
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When planning the 2007 Signature Event on the patient experience in the peri-diagnostic phase of the cancer journey, working group members identified the post-acute-treatment phase (survivorship) as another high priority area for discussion and further development. As a result, Cancer Quality Council staff were asked to research key issues involved in survivorship care and to bring together experts for a roundtable discussion.

Definition and scope
There are a variety of different ways of defining survivorship. Historically, survivors were patients who remained disease-free for 5 years (Rowland et al. 2006) but in the last several years multiple definitions have been offered (see figure 1).

For the purposes of this work, CCO is adapting the definition from the Institute of Medicine’s report, Lost in Transition: the phase of the cancer trajectory following diagnosis and treatment and prior to recurrence of subsequent cancers or death. In other words, our focus is after completion of the acute phase of treatment until treatment is needed again, or until the patient dies.

Adapted from Lost in Transition: following diagnosis and treatment and prior to recurrence of subsequent cancers or death.

Figure 1: Representation of the scope of various definitions of survivorship

It is not within our scope to review cancer patient needs around palliative and end-of-life care or the care of family members/caregivers.
Why look at survivorship?

Goal Four of the Ontario Cancer Plan is to improve the patient experience along every step of the cancer journey. As many cancer treatments improve and survival rates increase, the numbers of those living beyond cancer continue to grow.

There are well documented occurrences of late-effects, cancer recurrences, and second primary cancers following treatment (Hewitt et al. 2006) and research has noted dissatisfaction by survivors with their follow-up care, particularly in areas related to psychosocial care (Mallinger et al. 2005; Ganz 2006; Hewitt et al. 2006). Yet, survivorship remains relatively under-developed and unevaluated area of care (Ayanian 2006).

The leaders in studying patient needs post-treatment have been in the United States, where, in the last several years, several prominent cancer organizations have issued major reports with recommendations for action, the most notable being the influential report of the Institute of Medicine, *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al. 2006).

Closer to home, the survivorship agenda in Canada is gaining momentum as awareness of the issue is raised within several leading cancer care agencies, healthcare organizations, and policy makers.

Key Issues: Challenges and Gaps

The fundamental question for living beyond cancer is how the optimal care should be delivered, by whom, in what setting, to what guidelines and best practices? (Rowland 2006) A review of the survivorship literature and a jurisdiction scan found several challenges and gaps.

Provider and patient experiences of survivorship

Cancer patients comprise 2.5% of the patient population and many patients receive cancer follow-up care from more than one physician, including their primary care physician. However, approximately 10-25% of primary care provider visits by cancer survivors deal with cancer related issues (Del Giudice et. al. 2006, Del Giudice manuscript in preparation).

While there is evidence that primary care physicians are willing to provide exclusive cancer follow-up care and they feel rewarded by providing this care, they report experiencing frustration due to the ambiguity of their role, a lack of guidelines, and poor communication (Del Giudice manuscript accepted for publication; CMA, CFPC, RCPSC 2007; Wood, 1993; Nissen 2007).
Along with recounting feelings of uncertainty about the future and a sense of being lost (Hewitt et al. 2006), for their part, patients have reported a lack of clarity regarding which physician is in charge of their follow-up care and what that care might encompass (Miedema et al. 2004). Dissatisfaction and uncertainty related to follow-up care has direct impact on overall perceptions of quality (Sandoval et al, 2006).

Survivors of childhood cancers have their own unique and complex issues. The relative survival rate for childhood cancer is high (82%), but a significant proportion of these survivors experience adverse late effects for remainder of lives (Canadian Cancer Society 2008).

As many as 35% of childhood cancer survivors are unaware that their cancer treatment may have serious effects on long-term health (Kadan-Lottick 2002) and research has found that patients with longer follow-up are more likely to become lost to follow-up care (Blaauwbroek 2007). As a result, these survivors may not be getting optimal care exactly when the risk of late-effects increases (Shaw 2006).

**Tools and enablers of survivorship care**

The strongest themes emerging from the literature focus on communicating with and educating providers and patients and clarifying roles and responsibilities. Several tools and enablers have emerged to bridge this gap including evidence-based guidelines for follow-up, communication enablers such as treatment summaries and care plans, and support for survivorship-focused education and training.

There is little evidence of acceptability, impact or cost effectiveness of these tools. A jurisdiction scan found that components of survivorship care are offered in some provinces but efforts remain largely uncoordinated and dependent on province, hospital or program. There is some guidance available about appropriate site-specific surveillance but availability is uneven and few guidelines address the broader psycho-social aspects of follow-up care (Grunfeld 2006).

Those programs in place nationally and internationally have yet to be fully evaluated.

**Expert Roundtable**

The purpose of gathering together experts in the field of survivorship was to explore the question, “What is the most effective and appropriate role, if any, for a cancer agency in improving this phase of the cancer patient experience?” Since the majority of cancer agencies have yet to fully integrate survivorship care within their cancer plans, we wanted to ensure that our participants held a diversity of experiences and interests.
Through a review of relevant literature, a jurisdictional scan and interviews, we identified and invited to our ½ day discussion provincial, national, and international experts in:

- survivorship program design, development and delivery;
- models and approaches to survivorship care;
- evaluation and research; and performance monitoring.

Additionally, we sought out representatives from the patient/care-giver sphere along with CCO and Ontario cancer region representation. In total, the roundtable hosted thirty participants.

Goals and objectives
The goals of the roundtable discussion were to:

- Review cancer agency experience; US, Canada and provinces
- Gather information about who is doing what and explore partnerships
- Seek a critical appraisal of participant experiences in the delivery, research, and evaluation of survivorship care

Themes from expert roundtable discussion
The half-day discussion was divided into three modules: care enablers, research and innovation, and measurement. Participants engaged in a wide-ranging discussion resulting in the emergence of three notable challenges for the cancer system.

Coordination with national priorities
We set the context of the expert roundtable through presentations offering a national, provincial and U.S. perspectives. It was clear that there is engagement in this issue across many jurisdictions and at numerous levels. Equally apparent for the Ontario cancer system was the need to be aware of opportunities for coordination in order to avoid duplication of work, especially in the case of a national strategy.

For example, the Canadian Partnership Against Cancer (CPAC), through their Cancer Journey Action Group, has identified survivorship as one of their priorities for 2008-09. Following an invitational workshop on survivorship in the spring of 2008, CPAC identified the need to engage in work related to guidelines and national standards, research, communication and knowledge translation, and care mapping (models of care and care plans).

Models of care
Throughout the discussion, the issue of how to manage the care of those living beyond cancer was frequently highlighted by participants. Participants acknowledged that there are a variety of views on the appropriateness of each model.

Two specific U.S. survivorship care clinics were described by Craig Earle and Mary McCabe: the Dana Farber Cancer Centre and the Sloan Kettering Memorial Cancer Centre, respectively. Both, which are lead by nurse-
practitioners, are stand-alone cancer centres that offer psychosocial after care and ongoing surveillance for cancer recurrence and/or late-effects. The Memorial Sloan-Kettering Cancer Centre also provides healthy living recommendations about diet, exercise and cancer screening. The Dana Farber’s multidisciplinary approach allows pediatric survivors to see several specialists in one visit to the clinic.

Participants heard that these centres, at lease initially, relied heavily on philanthropic support and fundraising for financial sustainability. Both have developed a business model to ensure long-term stability.

Group medical visits were suggested as a relatively new and innovative means of managing survivorship care. Group medical visits have been initiated for managing chronic diseases such as hypertension and diabetes. It was suggested that cancer survivorship, which is suited to the chronic disease management framework, would lend itself well to this type of care.

Regardless of the approach to survivorship care, there was general acceptance that levers would need to be established to integrate survivorship care into cancer care. Suggested examples of these levers could include policy changes, episode-based funding and accreditation.

**Tracking patients**
The ability to locate former cancer patients has implications for recruitment in research studies and for follow-up when new side-effects of treatment are discovered. The lack of ability to track patients once their treatment and initial follow-up care is complete was raised as a question for the cancer system. This gap is particularly evident for survivors of childhood cancer or young adult survivors who frequently change contact information as they move into adulthood.

Roundtable participants involved in research and follow-up care noted the challenge of locating former cancer patients through the administrative databases available. There was acknowledgement of the need for a coordinated approach to resolving this question.

**Outcomes**
It was evident that there is much activity and enthusiasm for survivorship work. This work includes substantial activities in the areas of community based programming, guideline development, and research. Since engagement around care plans, treatment summaries, shared care models, and guidelines already exists, there is no need for CCO to duplicate this work.

There was general concurrence that it will be critical to engage all stakeholders and capture diverse points of view while acknowledging the need to also be attentive to those who haven’t spoken yet.
Areas for Cancer Care Ontario consideration include:
- Facilitate and support innovative models of care
- Strengthening evidentiary base, balanced with outcomes that are relevant to survivors
- Report on evaluation and knowledge transfer and exchange activities

Potential Cancer Quality Council of Ontario roles may encompass
- Measurement and reporting (performance and quality indicators through CSQI)
- Assessment of evidentiary base as needed
- Providing external advice and an international perspective

What’s Next?

Through a combination of research methods and drawing from the literature review, the jurisdiction scan, key informant interviews, and feedback from the roundtable, a final report will be issued in February. This report will draw out the lessons learned from our study of survivorship and will make recommendations for the Executive Team of CCO.
<table>
<thead>
<tr>
<th>Time</th>
<th>Item</th>
<th>Lead</th>
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<tbody>
<tr>
<td>12:00</td>
<td>Welcome and Introduction</td>
<td>Helen Angus</td>
</tr>
<tr>
<td>12:15</td>
<td>Review of Agenda</td>
<td>Bernita Drenth (facilitator)</td>
</tr>
<tr>
<td>12:20</td>
<td>Setting the Context - CCO perspective</td>
<td>Carol Sawka</td>
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<tr>
<td>12:30</td>
<td>National Perspective</td>
<td>Heather Bryant and Leanne Kitchen Clarke</td>
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<td></td>
<td>Provincial Perspective</td>
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<td>12:45</td>
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<tr>
<td></td>
<td>Nova Scotia</td>
<td>Theresa-Marie Underhill</td>
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<tr>
<td>1:00</td>
<td>Manitoba</td>
<td>Jeff Sisler</td>
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<tr>
<td>1:15</td>
<td>US Perspective</td>
<td>Craig Earle</td>
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<tr>
<td>1:30</td>
<td>Group discussion/Q and A</td>
<td>Bernita Drenth</td>
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<tr>
<td>2:00</td>
<td>BREAK</td>
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<tr>
<td>2:15</td>
<td>Roundtable discussion</td>
<td>Bernita Drenth</td>
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<tr>
<td>2:15</td>
<td>1. Tools and enablers</td>
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<tr>
<td>3:00</td>
<td>2. Evaluation and measurement</td>
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<tr>
<td>3:45</td>
<td>3. Research and Innovation</td>
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<tr>
<td>4:30</td>
<td>Putting it together</td>
<td>Bernita Drenth</td>
</tr>
<tr>
<td></td>
<td>Reflections on the day</td>
<td>Carol Sawka</td>
</tr>
<tr>
<td>5:00</td>
<td>Adjourn</td>
<td></td>
</tr>
</tbody>
</table>
### Expert roundtable participants

1. **Heather Bryant**  
   Vice-President Cancer Control, Canadian Partnership Against Cancer (CPAC)

2. **Nancy Baxter**  
   Assistant Professor of Surgery, Li Ka Shing Knowledge Institute, St Michael's Hospital, University of Toronto

3. **Leanne Kitchen Clarke**  
   Vice-President Strategy, Performance Measures and Communications, CPAC

4. **Donna Czukar**  
   Director, Cancer Information and Support, Canadian Cancer Society, Ontario Division

5. **Brenda Carter**  
   Regional Vice-President, Windsor Regional Cancer Program

6. **Pam Catton**  
   Medical Director of the Breast Cancer Survivorship Program at PMH

7. **Richard Doll**  
   Provincial Director, Sociobehavioural Research and Cancer Rehabilitation, British Columbia Cancer Agency.  
   Member of the CPAC Cancer Journey Action Group

8. **Craig Earle**  
   Lead, Health Service Research, CCO; formerly of Director of Lance Armstrong Foundation Adult Survivorship Clinic at the Dana Farber Cancer Institute.

9. **Janine Giese-Davis**  
   Lead, Cancer Survivorship Initiative  
   Alberta Cancer Board

10. **Mark Greenberg**  
    Medical Director/Chair, Pediatric Oncology Group of Ontario (POGO)  
    Senior Staff Oncologist, HSC

11. **Eva Grunfeld**  
    Director, Knowledge Translation Network, CCO and Ontario Institute for Cancer Research (OICR)

12. **Trevor Johnson**  
    Patient representative, adult survivor of childhood cancer

13. **Beth Kapusta**  
    Patient representative, cancer survivor

14. **Cheryl Levitt**  
    Provincial Clinical Lead Primary Care, CCO

15. **Mary McCabe**  
    Director, Cancer Survivorship Program Memorial Sloan-Kettering Cancer Centre

16. **Margaret Mottershead**  
    CEO, Ontario Association of Community Care Access Centres (OACCAC)

17. **Bertha Paulse**  
    Regional Vice President, North East Regional Cancer Program

18. **Scott Sellick**  
    Associate Research Scientist in Psychosocial Oncology and Director of Supportive Care at the Thunder Bay Regional Health Sciences Centre.

19. **Jeff Sisler**  
    Director of Primary Care Oncology, Cancer Care Manitoba
| 20. Anne Smith          | Regional Vice President, South East Regional Cancer Program  
                        | Provincial Pediatric Oncology AfterCare Program, Kingston General Hospital |
|-------------------------|---------------------------------------------------------------|
| 21. Jonathan Sussman   | Investigator, Supportive Cancer Care Research Unit, Juravinski Cancer Centre; Radiation Oncologist. |
| 22. Theresa Marie Underhill | Chief Operating Officer, Cancer Care NS |

**Along with Working Group members:**

**Executive Team Sponsors:**

<table>
<thead>
<tr>
<th>23. Helen Angus</th>
<th>VP Planning and Strategic Implementation, CCO</th>
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<td>24. Carol Sawka</td>
<td>VP Clinical Programs, CCO</td>
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**Members:**

| 25. Lisa Del Giudice    | Family Physician  
                        | Assistant Professor, Family and Community Medicine U of Toronto |
|-------------------------|---------------------------------------------------------------|
| 26. Deborah Dudgeon    | W. Ford Connell Professor of Palliative Care, Queen’s University 
                        | Provincial Program Head, Palliative Care, CCO |
| 27. Katya Duvalko      | Director, CQCO Secretariat,                                  |
| 28. Esther Green       | Provincial Program Head, Nursing and Psychosocial Oncology, CCO |
| Audrey Friedman (unable to attend) | Director of Patient Education, PMH,  
                        | Provincial Lead Patient Education, CCO |
| 29. Barb Johnson       | OPACC – Ontario Parents Advocating for Children with Cancer |
### Jurisdiction scan

**Current or Planned Survivorship Initiatives and Programs (non-exhaustive)**

<table>
<thead>
<tr>
<th>Type of Initiative</th>
<th>Source</th>
<th>Details or Plan</th>
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<tbody>
<tr>
<td><strong>NORTH AMERICA</strong></td>
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<tr>
<td><strong>CANADA</strong></td>
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<tr>
<td>Guidelines</td>
<td>Steering Committee on CPG for the Care and Treatment of Breast Cancer</td>
<td>2005 update to guidelines included several additional recommendations&lt;sup&gt;1&lt;/sup&gt;</td>
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<tr>
<td><strong>Ontario</strong></td>
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<tr>
<td>Care Summaries</td>
<td>Breast Cancer Surviviorship Centre/PMH</td>
<td>Patients provided with online tools to track treatment and care; coordinated approach under development.</td>
</tr>
<tr>
<td>Follow-up Care plans</td>
<td>ELLICSR/Toronto General Hospital CCO Regional Cancer Centres PMH</td>
<td>Focus on follow up care for survivors</td>
</tr>
<tr>
<td>Guidelines Delivery of Care</td>
<td>Program in Evidence-Based Care (PEBC)&lt;sup&gt;2&lt;/sup&gt; Variety of models of care&lt;sup&gt;3&lt;/sup&gt;</td>
<td></td>
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<tr>
<td><strong>Manitoba</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care Summaries</td>
<td>Cancer Care Manitoba</td>
<td>Discharge summaries; use is discretionary</td>
</tr>
<tr>
<td>Delivery of Care</td>
<td>Cancer Care Manitoba</td>
<td>Uniting Primary Care and Oncology (UPCON)&lt;sup&gt;5&lt;/sup&gt;</td>
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<sup>2</sup> Since 2002, the cumulative number of reports introduced has more than doubled (CSQI 2008), many of which are supportive care guidelines specifically directed at late or long-term effects, including depression, of several cancers and cancer treatments. However, none of the guidelines offer comprehensive follow-up care.


<sup>5</sup> The UPCON initiative, supported by Cancer Care Manitoba, is an innovative approach to encouraging relationships between family physicians and the cancer agency. Following the cancer coach model, within each of the 24 family practices which are part of the network, one provider is designed the lead clinician in oncology. This lead may be a physician or a nurse practitioner. UPCON also provides education and outreach about the program across Manitoba and has established a hotline, available to network practice for advice about cancer related issues and offers full day workshops to physicians and nurse practitioners on a variety cancer care topics including follow-up care and how health care providers can better navigate the cancer system. ([Cancer Care Manitoba](http://www.cancercare.mb.ca/home/health_care_professionals/information_for_health_care_professionals/upcon/education/) Accessed May 15, 2008 and Personal conversation with Jeff Sisler, MD, Cancer Care Manitoba.)
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<tr>
<th>Type of Initiative</th>
<th>Source</th>
<th>Details or Plan</th>
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<tbody>
<tr>
<td>Patient Education, Information, Support</td>
<td>Cancer Care Manitoba</td>
<td>Professionally led support groups</td>
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<tr>
<td>British Columbia</td>
<td></td>
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<tr>
<td>Follow-up Care Plan (Survivorship Care Plan)</td>
<td>B.C. Cancer Agency</td>
<td>Chronic condition flow sheets</td>
</tr>
<tr>
<td>Saskatchewan</td>
<td></td>
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<tr>
<td>Care Summaries</td>
<td>Saskatchewan Cancer Agency</td>
<td>Discharge summaries with or without psycho-social component</td>
</tr>
<tr>
<td>Follow-Up Care Plan</td>
<td>Saskatchewan Cancer Agency</td>
<td>Patients assist in writing their own life plan; monthly workshops</td>
</tr>
<tr>
<td>Patient Education, Information, Support</td>
<td>Saskatchewan Cancer Agency/CCS</td>
<td>• Monthly survivorship workshops, group counselling, therapy</td>
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<td></td>
<td></td>
<td>• Workload capture database</td>
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<tr>
<td>Nova Scotia</td>
<td></td>
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<tr>
<td>Follow up care plan</td>
<td>Cancer Care NS</td>
<td>Individualized long-term follow-up care plans a priority goal of Survivorship Roundtable.</td>
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<tr>
<td>Guidelines</td>
<td>Cancer Care NS</td>
<td>Committed to developing evidence-based long-term follow-up guidelines for all types of cancers.</td>
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<tr>
<td>Patient Education, Information, Support</td>
<td>Cancer Care NS</td>
<td>Psychosocial care a priority goal following Survivorship Roundtable.</td>
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<tr>
<td>UNITED STATES</td>
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<tr>
<td>Care Summaries</td>
<td>ASCO/Cancer.Net</td>
<td>Treatment summary templates</td>
</tr>
<tr>
<td>Follow up care plan</td>
<td>LAF Centres of Excellence</td>
<td><a href="http://www.Cancer.Net">www.Cancer.Net</a> Researching several issues related to survivorship care including the Survivorship Care Plan</td>
</tr>
<tr>
<td>Patient Education, Information, Support</td>
<td>National Coalition for Cancer Survivorship</td>
<td>• Cancer Survivor Toolbox (online)</td>
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<tr>
<td>Guidelines</td>
<td>Lance Armstrong Foundation</td>
<td><a href="http://www.canceradvocacy.org/toolbox/">http://www.canceradvocacy.org/toolbox/</a></td>
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6 This database, developed by the Saskatchewan Cancer Agency, gathers information about psychosocial care. For example, the database tracks how many patients experience post-traumatic stress disorder following treatment, how many patients have been assisted by developing a life plan, and the length of time a patient spends in counselling. (Personal communication with Deb Arsenault, Provincial Leader of Supportive Care, Saskatchewan Cancer Agency, January 18, 2008.)

7 Cancer.Net, has developed treatment summary templates, readily available to the public and providers. While the available templates are not comprehensive to all types of cancer, they do cover a range of the most common cancers. (American Society for Clinical Oncology, Cancer.NET http://www.cancer.net/portal/site/patient. Accessed May 21, 2008.)


9 Lance Armstrong Foundation’s website has a section geared toward survivor support with detailed information about cancer, where to find one on one support, and the materials needed to organize your cancer experience, such as worksheets and journals. (Livestrong.org http://www.livestrong.org/site/c.khLXK1PxHmF/b.2661019/k.8FE9/Cancer_Support.htm#. Accessed May 20, 2008.)
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<thead>
<tr>
<th>Type of Initiative</th>
<th>Source</th>
<th>Details or Plan</th>
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</table>
| Guidelines         | National Cancer Institute (NCI) | Physician’s Data Query (PDQ)¹¹
| Guidelines         | Children’s Oncology Group       | Exhaustive guidelines for follow-up of survivors of childhood cancer, organized by treatment the patient received. ¹² [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org) |
| INTERNATIONAL       |                                   | |
| United Kingdom      |                                   | |
| Delivery of Care    | National Health Service and National Health Service Cancer Plan | Currently researching establish best practices (model, format, type of setting, type of clinician, and patient/clinician preferences) in follow up care for cancer survivors. Joint training of professionals to improve communications with patients. Follow-up care discussed for specific disease sites.¹³ |
| Guidelines         | National Institute of Clinical Excellence (NICE) | |
| Australia           |                                   | |
| Patient Education, Information, Support Guidelines | New South Wales Cancer Plan National Cancer Control Initiative (NCCI) | Counselling services will be documented and enhanced. Survivorship component to guideline focusing on psychosocial and quality of life care concerns.¹³ |
| New Zealand         |                                   | • Establish a working group to develop guidance on supportive care and rehab services for adults, children, and adolescents with cancer
• Develop a database of services available in each network, a system to disseminate the information and another to ensure currency of the information.
• Identify core principles and criteria to guide the development of a national standard and formal endorsement of consumer information
• Implement and evaluate a pilot survivorship programme for the long-term follow-up of children and adolescents with cancer. |

¹¹ National Cancer Institute Physician’s Data Query (PDQ) offers peer-reviewed care summaries which provide information about care and treatment of common complications of cancer and cancer therapy. (See above Ferrell and Winn 2006)
¹³ Grunfeld E. Looking beyond survival: How are we looking at survivorship? Journal of Clinical Oncology 2006; 24:5166-5169.
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<th>Type of Initiative</th>
<th>Source</th>
<th>Details or Plan</th>
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Bibliography


60. National Cancer Institute, Office of Cancer Survivorship  
http://cancercontrol.cancer.gov/ocs/definitions.html  
Accessed August 31, 2008

61. National Coalition of Cancer Survivorship  
http://www.canceradvocacy.org/about/org/history.html  
Accessed August 31, 2008

“Views of primary care providers on follow-up of cancer patients,”  

63. K.C. Oeffinger, M.S. McCabe, “Models for Delivering Survivorship Care,”  

64. K.C. Oeffinger, L.L. Robison, "Childhood Cancer Survivors, Late Effects,  
and a New Model for Understanding Survivorship,"  

65. C. Parry, "Embracing Uncertainty: An Exploration of the Experiences of  
Childhood Cancer Survivors,"  

66. L.W. Pedro, “Quality of Life for Long-Term Survivors of Cancer:  
Influencing Variables,”  

67. L. Persson, I.R. Hallberg, “Lived Experience of Survivors of Leukemia or  
Malignant Lymphoma,”  

Coughlin, E. Stovall, D. Ulman, “Cancer Survivorship: A New Challenge in  
Comprehensive Cancer Control,”  

69. President’s Cancer Panel, 2003-2004 Annual Report:  Living Beyond  
Accessed December 3, 2008

70. President’s Cancer Panel, 2005-2006 Annual Report:  Assessing Progress,  
Advancing Change (2006).  
http://deainfo.nci.nih.gov/advisory/pcp/pcp06rpt/pcp06rpt.pdf  
Accessed November 23, 2007

Delivering Quality Cancer Care,”  


**Speaker presentations**

1. Leanne Kitchen Clarke and Heather Bryant, Canadian Partnership Against Cancer.

2. Theresa-Marie Underhill, Cancer Care Nova Scotia

3. Jeff Sisler, Cancer Care Manitoba

4. Craig Earle, Institute for Clinical and Evaluative Sciences (ICES)
Creating New Opportunities for Survivorship

Cancer Care Ontario
November 7 2008

Refining the strategy – key areas of focus

- Emphasize specific subjects within the cancer control continuum
- Generate tangible and sustainable advancements in these areas
- Support and strengthen the ability of the Partnership and others to influence change
- Cut across the cancer control continuum, affecting multiple areas

Foundational Focus Areas
- Support and strengthen the ability of the Partnership and others to influence change
- Cut across the cancer control continuum, affecting multiple areas

Content Focus Areas
- Multi-year projects
- National in scope
- Measurable impact
- Defined and accepted need and potential to impact
- Potential to integrate across cancer control continuum, between partners and jurisdictions
- Adds value to ongoing efforts of others

Program concepts, projects and studies are generated through Action Groups
- Committee-review of proposals, as well as universities, cancer agencies, NGOs, hospitals for program co-sponsorship

Impact through strategic investment

- To achieve measurable outcomes and sustainable change in cancer control, we focus on areas where significant outcomes in cancer control are in reach while building a foundation and legacy for future efforts
  - Multi-year projects
  - National in scope
  - Measurable impact
  - Defined and accepted need and potential to impact
  - Potential to integrate across cancer control continuum, between partners and jurisdictions
  - Adds value to ongoing efforts of others

Program concepts, projects and studies are generated through Action Groups
- Committee-review of proposals, as well as universities, cancer agencies, NGOs, hospitals for program co-sponsorship

Key area of focus

Highlights:

Patient navigation programs: Help patients & families move through the system and access support

Screening for Distress: Identify those needing peer, online & professional support to decrease emotional burden through the cancer journey

Survivorship: National Survivorship Working Group to prioritize and focus on recommendations

Priorities in palliative care: Access to palliative & end of life care when active treatment ends

What’s been achieved so far

- 84 attended including 34 cancer survivors
- An environmental scan was completed prior to the workshop; “Environmental Scan of Cancer Survivorship in Canada, Conceptualization, Practice and Research”
- Identified seven priorities for a Canadian survivorship agenda

Cancer Journey Action Group

2007-08
- Vision for person-centred care
- Screening for distress and navigation
- Professional education
- Guidelines
- Survivorship

2008-09
- Integrated person-centred care with a focus on screening for distress, navigation and transition to palliative and end-of-life care
- Survivorship
Priorities identified

1. Models of survivorship care
2. Care plans for survivors
3. National standards and guidelines
4. Survivorship focused research
5. Knowledge translation, education, training and uptake of survivorship programs
6. A national survivors’ voice, to interact with policy-level funders, decision-makers, and health care providers
7. Communications plan about survivorship issues

Currently underway

- Creation of a National Survivorship Working Group that will be co-chaired by a survivor and a “support” professional
  - 15 nominations received
  - Most downloaded file on website in October
- The mandate will be to investigate programs and focus on a few priorities that can be advanced by the Partnership (eg. survivorship models of care and care plans)
  - Find the gems and mine them

Foundational work to support survivorship

- The Cancer Journey Action Group Standards/Guidelines/Indicators working group is starting the development of Canadian survivorship guidelines
- Also in development is a Canadian psychosocial guideline, working in collaboration with the Guidelines Action Group through the ADAPTE project

Interest is growing

A few examples…..

- First Canadian workshop on cancer survivorship research will be held in November in Vancouver, lead by BCCA, supported by the Partnership, CIHR
- Increasing attention to the topic of survivorship: the Ontario Division of the Canadian Cancer Society is holding a “Surviving Cancer and Living Well” conference in Toronto on November 14-16

Next steps

- NSWG meeting in January 2009
- Establish priorities to advance and focus on implementation
- Build on current best practices, existing knowledge
- Create new opportunities through partnerships
Cancer Survivorship – Nova Scotia Perspective

Theresa Marie Underhill
Chief Operating Officer

Overview

- Cancer Services Delivery in Nova Scotia
- Survivorship approach
- Roundtable Process
- Outcomes, Directions and Impacts

NS Context: Cancer Services Delivery

Nova Scotia Department of Health

Standards / Models / System Performance
Clinical Service Delivery

9 District Health Authorities + IWK Provincial Cancer Network District Cancer Committees Community Health Boards

- Established Fall 1998 to create integrated system for cancer control – policy, programs & providers
- Purpose is to coordinate, strengthen and evaluate cancer services in Nova Scotia
- Programs spectrum inclusive of prevention, early detection/screening, education, treatment, follow-up care, palliation, and surveillance

CCNS Role

Provincial Agency Knowledge Broker Policy, Standards & Monitoring

Monitoring/Evaluation
Implementation
Information Management
Service Delivery
Quality Review / Long Term - Accreditation

DHA Role

Care Delivery Funding Levels of Care District Programs

NS Context: Health Services Delivery
CCNS Survivorship Approach

- Build a responsive and inclusive structure – Cancer Patient and Family Network
- Address Survivors supportive care and advocacy/engagement needs
- Create an environment of hope through community development –

Roundtable – A Change Management Tool

- Cornerstone of CCNS change management strategy
- Applied to effect changes in structure & in process
- Examples: develop district cancer program structures; define and implement Cancer Patient Navigation; action planning for Palliative Care and for Prevention

Roundtable Description

- Diverse groups brought together to work collectively for change
- A discussion of groups on equal terms
- Varied perspectives make better informed decisions
- Vehicle for providing advice
- Facilitator-led group

Survivorship Roundtable Purpose

To develop an action plan for the survivorship agenda for Nova Scotia

Survivorship - Definition

- “Living with, through and beyond a cancer diagnosis” \( \text{LAF} \)
- “The period of health and well-being experienced by survivors after active cancer treatment”, \( \text{NCCS} \)
- Pediatrics: 5 year post treatment, off medication with no evidence of disease
- Focus is on post-active treatment

Four Phase Building Process

- Action Plan
- Roundtable Consensus Building
- Survey: Engage and Identify Priorities
- Consultation to Concept Document
Phase I - Consultation to Concept Document

- Literature Review
- Definition of Survivorship
- Evidence-base for actions
- Advisory Group appointed for Roundtable development

Phase II – Survey: Engage and Identify Priorities

- Survey respondents included: Nurses, Family Physicians, Oncologists, Patients/Survivors, Family Members, Researchers, Health Professionals, Government/Policy, Voluntary Agencies
- High degree of consensus
- Consolidation to reduce duplication and focus discussion

Four Priorities

- Navigating long term follow up care
- Addressing psychosocial and physical concerns
- Education & awareness for health care professionals, survivors and their families
- Clinical standards and guidelines

Phase III - Roundtable

- 110 in attendance: practitioners, survivors, policy makers, volunteers, care givers
- Consensus-building through facilitated process
- Action Plan created

Phase IV - Action Plan

- Develop evidence-based long term follow-up guidelines for all types of cancers
  Action: Disseminated report to all Cancer Site Teams. Developing a common template for f/u guidelines

- Develop, implement and evaluate individualized follow-up care plans for primary care physicians and cancer survivors
  Action: Roundtable April 2009 to focus on Primary Care. Site Teams developing template for long term care plans for transition of care.
Phase IV - Action Plan

- Make psychosocial care a key component of the follow-up care plan

**Action:** Leveraging CPAC Supportive Care initiatives, Distress Screening; scoping supportive care needs provincially 2009/2010

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Many Hearts, Many Minds, One Goal

The CCNS Motto will be at the forefront as we move forward the action plan for Cancer Survivorship in Nova Scotia
Bridging the gap between primary care and the cancer system: 
**UPCON at CancerCare Manitoba**

Jeff Sisler  MD MClSc FCFP  
Pat McCormack-Speak RN MBA  
Lynne Savage  
November 7, 2008

**Introduction:**  
The problem in cancer care

- The cancer system is poorly integrated with primary care
- Cancer is infrequent in a FP’s practice and poorly taught
- FPs often feel like “outsiders”

**The problem in cancer care**

- Cancer centres used “to do it all,” but this is breaking down
- Higher profile of FPs & primary care
  - Growth of screening
  - Evidence that FPs can provide high quality follow-up care

**UPCON Program**

- Global Primary Care Outreach  
  - “Be a CancerPro” system orientation sessions  
  - Provincial Newsletter  
  - Website  
  - Orientation of new Manitoba Physicians

- The UPCON Network  
  - 24 clinics with a closer relationship with CCMB

**Be a CancerPro**  
*Cancer System Essentials for Primary Care*

- Full day cancer system navigation day for primary care providers
- Events 3-5 times a year in Winnipeg and all RHAs
- Screening to Palliation

**PROGRAM STAFF**

Pat McCormack-Speak RN MBA  Program Manager 1.0 EFT  
Dr. Jeff Sisler  Medical Lead 0.6 EFT  
Lynne Savage  Admin Assist 1.0 EFT  
Professional Development Coordinator 0.5 EFT
The UPCON Network

- 16 Winnipeg sites:
  - 9 Fee for Service
  - 5 Community/Academic Clinics
- 8 rural/northern sites:
  - Oakbank, Dauphin, Russell, Steinbach, Morden, Winkler, Hamiota

Goals of the UPCON Network

- Better integrated care for patients
- Timely and complete information sharing for physicians
- Equip a local “go-to” person
- Improve cancer care knowledge of FPs
- Build relationships
- Promote role of primary care

Our Partner Clinics

- Interested in playing an active role in the care of their cancer patients
- Willing to support their Lead Clinician in their liaison role and in attending CME

1. Education

Of Lead Physicians

- Small group learning sessions
- Clinical Exposure
- Of all staff in UPCON Clinics
- Educational handouts
- Lunch ‘n Learn Sessions
- Annual symposia for FPs & RNs
- Newsletters

Small group Mainpro-C CME

- Supportive Care
- Advanced Care Planning
- Failing Bone Marrow
- Neuropathic Pain
- Lymphoma
- Breast Cancer Surgery
- Pediatric Cancer
- Brain Tumours
  - Polycythemias
  - Prostate Cancer
  - Skin Cancer
  - Radiation Therapy
  - Delving into DVT
  - Biopsy Skills
Lunch ‘n Learn Sessions

- Psychosocial Care
- WRHA Breast Health
- Palliative Care
- CCMB Referrals
- Manitoba Prostate Centre

2. Sharing the Provincial Cancer System EHR

- Supplied hardware and internet
- Trained 75 UPCON clinic staff
- Linked 3000 patient charts with UPCON clinics

3. Building Relationship

- UPCON Fax sheets
- Website
- >230 patients placed
- Accessibility Initiative
  - Contact info for UPCON FPs and Oncologists
- Profiling primary care at CCMB

  2003 – 42% charts with FP listed
  2006 – 81% charts

- Support from the UPCON Cancer HelpLine

  226-2262
  (CCM-CCMB)

Program Evaluation

1. UPCON Patient Survey
2. UPCON Clinic Physician Survey
3. FP Comparison Survey
   - UPCON and non-UPCON

UPCON Patient Survey
Research Methodology

- Survey of all patients with no FP referred to UPCON clinics from program inception in 2004 to June 2006
- Probe Research contacted 86 patients by phone in January 2007
- 60 / 86 or 70% response rate

Participant Demographics

<table>
<thead>
<tr>
<th>AGE</th>
<th>% of Total (n=66)</th>
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<tr>
<td>18-34</td>
<td>5</td>
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<td>35-44</td>
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<td>45-54</td>
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<td>55 to 64</td>
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<tr>
<td>65 years or older</td>
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<table>
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<tr>
<th>GENDER</th>
<th>% of Total (n=66)</th>
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<tbody>
<tr>
<td>Men</td>
<td>23</td>
</tr>
<tr>
<td>Women</td>
<td>77</td>
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</tbody>
</table>

Length of Relationship with FP
- Less than 6 months: 17
- 6-12 months: 33
- More than one year: 60

Years since cancer diagnosis: 83% more than 3 years

Patient Perception of Care Coordination

- Tests not unnecessarily repeated
- Know which MD does what
- FP aware of tests
- Consistent info from FP and CCMB
- Care well organized
- FP and specialists communicating
- Clinic aware of FP’s tests

Satisfaction with FP’s Help

(n=45) 74% rated their overall satisfaction as 9 or 10 / 10

Drivers of Satisfaction with FP Care
UPCON Clinic Physician Survey

Survey Methodology

- Probe Research surveyed FPs in 12 UPCON medical clinics
- Phone interviews in the summer of 2006
- In total 29/86 physicians (34%) completed the survey
  - 8 Lead Physicians
  - 21 Non-Lead Physicians

Respondent Profile

<table>
<thead>
<tr>
<th>Physician Status</th>
<th>Respondents (n=29)</th>
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<tbody>
<tr>
<td>Lead Physician</td>
<td>28</td>
</tr>
<tr>
<td>Non-Lead</td>
<td>72</td>
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<table>
<thead>
<tr>
<th>Familiarity with UPCON</th>
<th>Respondents (n=29)</th>
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<tr>
<td>High</td>
<td>52</td>
</tr>
<tr>
<td>Medium</td>
<td>21</td>
</tr>
<tr>
<td>Low</td>
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<table>
<thead>
<tr>
<th>Received ARIA Training</th>
<th>Respondents (n=29)</th>
</tr>
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<tbody>
<tr>
<td>Yes</td>
<td>55</td>
</tr>
<tr>
<td>No</td>
<td>45</td>
</tr>
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</table>

Overall FP Evaluation of UPCON

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree (5)</th>
<th>Somewhat Agree (4)</th>
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</thead>
<tbody>
<tr>
<td>Effective in improving working relationship</td>
<td>31%</td>
<td>28%</td>
</tr>
<tr>
<td>Has improved care</td>
<td>10%</td>
<td>52%</td>
</tr>
<tr>
<td>Has helped to improve communication</td>
<td>21%</td>
<td>34%</td>
</tr>
<tr>
<td>Has improved knowledge of who to contact</td>
<td>11%</td>
<td>41%</td>
</tr>
</tbody>
</table>

Seeking Help from Lead Physician

“How many times have you sought information or advice regarding cancer-related issues and treatments from your UPCON lead physician over the past 12 months?” (n=20)

- Never: 45%
- Twice: 20%
- Three times or more: 25%
- Once: 15%

Information Sought from Lead Physicians

“Which of the following types of information or advice were you looking to obtain?” (n=12)

- Name of person at CancerCare: 69%
- How to make a referral: 69%
- Information about treatments/follow-up: 69%
- Work-up information: 69%
- Pain/Symptom management: 69%
- Information about counseling/support services: 69%
- Cancer screening information: 17%
Usefulness of Having an UPCON Lead Physician in the Clinic

“On a scale of 1 to 5, with 5 being very high, please rate how useful it has been to have an UPCON Lead Physician in your clinic” (n=20)

Low (1, 2) | Moderate (3) | High (4, 5) | Unsure

FP Comparison Survey
UPCON and non-UPCON

Lessons Learned
- Discussion of the successes and challenges with this model of primary care outreach
Living Beyond Cancer: U.S. Perspective

Craig Earle, MD

Survivorship care models

- PCP follow up
- Dedicated survivorship clinics
- Shared care/survivorship care plans

Survivorship clinics

- Consultative
  - DFCI, UCLA
- High volume follow up
  - MSKCC, VCU
- Multidisciplinary follow up
  - Pediatric, BMT, H&N

Survivorship care planning

- Flexible
- Actionable
- Empowering

Why are there communication problems in cancer in particular?

- Multidisciplinary care
  - An average of > 3 cancer doctors/patient
- Complex
  - Treatment takes place in a variety of settings (inpatient, outpatient, specialized facilities) across time and space
  - Multiple medical records
- Often takes place in isolation from PCPs

Barriers: Lack of...

- Awareness/buy-in among providers
  - Evidence base
  - Content, Detail, Format
  - Adherence
- Time
- Money
- Incentive
**Levers**

- IOM: standard of care
- Templates available
  - ASCO, LAF
- Kennedy-Hutchison Bill

**Real levers:**
- Episode-based funding
- QOPI accreditation

**CCO opportunities**

- CSQI
  ⇒ opportunity to improve data capture
- ?episode-based funding

**Conclusion**

In most cases, more important than the specifics is that everyone involved (patient and providers) be clear on:
- what has been done
- what should be done going forward
- who is going to do it