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## Ontario's Approach to Survivorship: What do patients need?

presented by:  
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 at:  
 ISQua - Dublin 2009

*Better cancer services every step of the way*

## Why Focus on Survivorship?

The annual number of cancer diagnoses is increasing



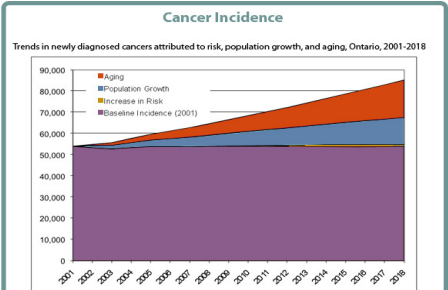
# 83,220

The yearly total of Ontarians expected to be diagnosed with cancer in 2017.  
 This breaks down to 228 per day, compared to 172 per day in 2007.

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## Why Focus on Survivorship?

The number of the people living with Cancer is increasing



**Cancer Incidence**  
 Trends in newly diagnosed cancers attributed to risk, population growth, and aging, Ontario, 2001-2018

- Next 10 years Ontario to see 40% increase in people living with cancer
- By 2017, the estimated number near half a million (406,000)


## Why Focus on Survivorship?

Explicit goal to improve patient experience across cancer journey

**Goal n°4: Improve the patient experience along every step of the cancer journey**

### The cancer journey

*Better cancer services every step of the way*



**Integral part of patient journey**

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## Why Focus on Survivorship?

Survivors face unique issues and are dissatisfied with current care


### Lessons from the literature:

- Well documented occurrence of late-effects, cancer recurrences, second primary cancers following treatment (Hewitt et al. 2006)
- Dissatisfaction by survivors with their follow-up care (Wattlinger et al. 2005; Ganz 2006; Hewitt et al. 2006)
- Patients report feelings of uncertainty of future and a sense of being lost (Hewitt et al. 2006)
- Relatively under-developed and unevaluated area of care (Ayanian 2006)

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## Survivorship has clearly reached a tipping point

Unmentioned topic until 2004; "zero to sixty" almost overnight



**www.caringvoices.ca**

**2004 2005 2006 2007 2008 2009**

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### -2M Web hits for cancer support / survivor

The screenshot shows two Google search results. The first is for 'cancer support' with approximately 2,000,000 results. The second is for 'cancer survivor' with approximately 1,800,000 results. Both results show a list of relevant websites and snippets of text.

### CCO convened an Expert Roundtable to look for some answers: *November 7, 2008*

**Objectives:**

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

### What is the role for a cancer agency?

Expert Roundtable group recommended three main areas of focus

**Survivorship roundtable group consisted of:**

- Specialists,
- FP physicians
- Patients
- Researchers
- Clinic managers
- Agency executives

**Three main areas of focus defined:**

- Exploring innovative models of care
- Establishing standardized follow-up practice in accordance with evidence
- Evaluation and reporting

### Newly formed expert panel diving into core issues underlying each focus area

Focus Area	Core issue
1 Innovative Models of care	<b>Specialist follow-up not a sustainable model</b> <ul style="list-style-type: none"> <li>Current and projected shortage of medical oncologists in Ontario</li> <li>Reimbursement incentives must be aligned with other follow-up models</li> </ul>
	<b>Specialists not best equipped for many aspects of follow-up care</b> <ul style="list-style-type: none"> <li>Many late effects of cancer and treatment (e.g. bone health for breast cancer) not part of oncologist's expertise and training</li> </ul>
2 Standardized practice	<b>Specialist "hand-off" to family physician model not ideal</b> <ul style="list-style-type: none"> <li>Family physicians have small number of cancer patients (1500 patient practice may see 1 lung cancer patient every year or two)</li> </ul>
	<b>Follow-up care practices / testing extremely variable</b> <ul style="list-style-type: none"> <li>Guidelines contain different recommendations</li> <li>Ad-hoc use of care plans</li> </ul>

### 1 Innovative Models of Care

Technology has major role, but can't solve all issues

Methods of outreach	What we heard
<p><b>Please join us TONIGHT (8 p.m. ET) on www.CaringVoices.ca</b></p> <p>Have your say with Cancer Care Ontario (CCO) and be part of turning ideas into action - Live Chat with Dr. Carol Sanka, VP of Clinical Programs and Quality Initiatives at CCO.</p> <p>Selected Survivor Interviews</p> <p>Disease Pathway Management Patient/Family advisory groups</p>	<ul style="list-style-type: none"> <li><b>Social networking tools helpful in meeting psychosocial, supportive care needs</b> <ul style="list-style-type: none"> <li>Not a solution for everyone</li> </ul> </li> <li><b>Interaction w/ clinician in follow-up care still required</b> <ul style="list-style-type: none"> <li>Results and Information portals can increase need for interaction</li> <li>E-mail, videocon, phone, in-person</li> </ul> </li> <li><b>Prefer roadmap of what lies ahead and a clear point person</b></li> </ul>

### 1 Innovative models of care

Exploring potential replacements for outdated models

	Description	Barriers	Enabler
Group Visits	<ul style="list-style-type: none"> <li>Borrows from chronic disease (cardiac, ortho)</li> <li>Small groups similar follow-up</li> <li>Led by specialist / allied health</li> <li>Brief 1-on-1 w/ specialist</li> </ul>	<ul style="list-style-type: none"> <li>Reimbursement</li> <li>Patient privacy / acceptance</li> </ul>	Therapeutic Patient Education
Allied health led model	<ul style="list-style-type: none"> <li>Specialist / APN partnership</li> <li>APN discusses key issues (e.g. bone health)</li> <li>Specialist follows-up on issues, brief 1-on-1 on</li> </ul>	<ul style="list-style-type: none"> <li>Reimbursement</li> <li>Billing code</li> <li>HR shortages</li> </ul>	
Survivorship e-tool	<ul style="list-style-type: none"> <li>Based on Dx tool in development</li> <li>Patient survivorship pathway</li> <li>Appointments, test results available to patient, providers</li> <li>Access to support info resources</li> </ul>	<ul style="list-style-type: none"> <li>Provider adoption</li> <li>Some patients need more</li> </ul>	

## 2 Standardized Practice

Current follow-up practices extremely variable

**Follow-up Practice Patterns Cohort Studies - Grunfeld *et al.*<sup>1</sup>**

- Examined follow-up practices for Breast Cancer, Hodgkin's Lymphoma, Endometrial Cancer and Colorectal Cancer patient cohorts in Ontario
  - Cohort sizes ranged from 2,300 to > 11,000 patients

**Key Themes**

- Number of follow-up visits within cohorts variable**
  - Some cohorts >50% patients had more (or fewer) than guideline recommended visits
- Follow-up imaging within cohorts variable**
  - Many patients more imaging tests than guideline recommended imaging tests
- Screening for relevant secondary cancers within cohorts variable**
  - Higher than expected numbers of unscreened patients in some cohorts

1. Kron *et al.* Obstetrics and Gynecology (2009), and Grunfeld submitted and unpublished data

## 2 Standardized Practice

Current follow-up practices extremely variable

- Involvement of family practice physician in follow-up care varies markedly within Canada and especially Ontario

Grunfeld *et al.* J Clin Onc (2006)

## 2 Standardized practice

Exploring best way to standardize follow-up

	Description	Barriers
Standardize follow-up planning process	<ul style="list-style-type: none"> <li>Develop / adopt follow-up care plan, process and format</li> <li>Structural indicators, reporting</li> <li>Expand to psychosocial, once momentum built</li> </ul>	Reimbursement - plan devpt
Standardize follow-up testing recs	<ul style="list-style-type: none"> <li>Adopt / adapt follow-up care guidelines</li> <li>Consensus process</li> <li>Measure and report on concordance</li> </ul>	Consensus - existing guidance variable
Electronic imaging triage tools	<ul style="list-style-type: none"> <li>Computer algorithm, signs/symptoms entered imaging tests recommended (evidence based)</li> </ul>	Technology adoption

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## Takeaway Messages

- CCO to take focused survivorship care role
  - Can't be all things to all people
- Growing survivor populations and physician shortages make Ontario's current follow-up care model unsustainable
  - Is your jurisdiction in the same predicament?
- New innovative models should better incorporate use of
  - Therapeutic patient education
  - Allied health professionals
  - Appropriate technologies
  - Standardized practices

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