A Focus on Adolescents and Young Adults

Margaret Fitch PhD
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Disclosures

- Nothing to disclose
Plan for the presentation

Highlight selected results from two key Canadian reports focused on adolescents and young adults:

- Person-centered Perspective Indicators in Canada
- Experiences in Transitions: Survivors Perspectives
Canadian Partnership in Cancer

- Since 2007, works with Canada’s cancer community

- Grounded in and informed by the experiences of those affected by cancer, works with partners to support multi-jurisdictional uptake of evidence that will help to optimize cancer control planning and drive improvements in quality of practice

- Supports the work of the collective cancer community in achieving long-term population outcomes: reduced incidence of cancer, less likelihood of Canadians dying from cancer, and an enhanced quality of life of those affected by cancer.
Why We Need Measurement

- Measurement allows identification of those with difficulties and monitoring of their status over time.
- Important to be able to measure the impact of interventions in a standardized way.
- Measurement facilitates comparisons and quality improvement.
- “If you can not measure it, you can not improve it” ~Sir William Thomson
Measurement and response at multiple levels

Reporting pathways . . .

Response at each level

National – bench-marking and comparison across jurisdictions

Regional/provincial – standardize best practices; resource allocation

Program - evaluating/adjusting programs

Clinical – guide practice, communication with patient
Performance Indicator
Definition

numerical measures that can be used as a guide to monitor performance

data often requires further investigation to isolate actual problem/pinpoint solution
Person-centered Perspective
Indicators in Canada (2017)

- Palliative and End-of-Life Care
- Patent-reported Outcomes and Experiences
- Outcomes and Care for Adolescents and Young Adults
We may be rare, but we are here. ’
AYA survivor
Indicators (feasible at the time)

- Incidence (types and distribution)
- Wait times
- Satisfaction with care
- Place of death
- Educational attainment
- Return to work
- Research funding gaps
- Clinical trial enrolment
Incidence

In Canada, approximately 7,600 INDIVIDUALS (aged 15 to 39) were diagnosed with cancer in 2013.¹
### Types and distribution

**Figure 1**
Most common cancers by age

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Years</th>
<th>Cancers</th>
</tr>
</thead>
</table>
| 0–14      | 2006–10 | - Leukemia  
- Central nervous system  
- Lymphoma  
- Neuroblastoma and other peripheral nervous cell tumours |
| 15–29     | 2009–13 | - Thyroid  
- Testis  
- Hodgkin lymphoma  
- Melanoma  
- Bone & soft tissue sarcoma  
- Non-Hodgkin lymphoma |
| 30–39     | 2009–13 | - Thyroid  
- Breast  
- Melanoma  
- Colorectal  
- Cervix  
- Testis |
| 40+       | 2016   | - Lung  
- Colorectal  
- Breast  
- Prostate |

*Figure 1
Based on rates age-standardized to the 2011 Canadian population.
Data exclude the territories.
QC: Data were not available for 2011, 2012 and 2013. The 2010 data were therefore used for 2011, 2012 and 2013.
Data Source: Statistics Canada, Canadian Cancer Registry; *Canadian Cancer Society, Canadian Cancer Statistics.
Between 1992 and 2013, there was an increase in the age-standardized incidence rate of cancer for the AYA population.

- Ages 15–29: 18.2%
- Ages 30–39: 11.9%
- Ages 40+: 2.2%
FIGURE 3
Five-year relative survival ratios increasing for adolescents and young adults – 1992–96 vs. 2004–08

15–29 year olds

<table>
<thead>
<tr>
<th>Region</th>
<th>1992–96</th>
<th>2004–08</th>
</tr>
</thead>
<tbody>
<tr>
<td>West</td>
<td>+8.3%</td>
<td></td>
</tr>
<tr>
<td>Central</td>
<td>+3.7%</td>
<td></td>
</tr>
<tr>
<td>ON</td>
<td>+5.6%</td>
<td></td>
</tr>
<tr>
<td>East</td>
<td>+5.7%</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>+6.2%</td>
<td></td>
</tr>
</tbody>
</table>

30–39 year olds

<table>
<thead>
<tr>
<th>Region</th>
<th>1992–96</th>
<th>2004–08</th>
</tr>
</thead>
<tbody>
<tr>
<td>West</td>
<td>+9.4%</td>
<td></td>
</tr>
<tr>
<td>Central</td>
<td>+6.0%</td>
<td></td>
</tr>
<tr>
<td>ON</td>
<td>+10.7%</td>
<td></td>
</tr>
<tr>
<td>East</td>
<td>+7.5%</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>+9.8%</td>
<td></td>
</tr>
</tbody>
</table>

Figure 3
West includes AB and BC; Central includes MB and SK; East includes NB, NS, NL and PE. Data exclude QC and the territories.
Data source: Statistics Canada, Canadian Cancer Registry.
Wait times

![Percentage of women starting treatment within specified wait times after diagnosis, by age at diagnosis — 2012–14 diagnosis years](image)
Satisfaction with care

FIGURE 5.1a

Percentage of patient responses (aged 18-29) that were negative across dimensions of care, all provinces combined, by gender — from 2012–16

<table>
<thead>
<tr>
<th>Patient Experience Dimensions</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to Care</td>
<td>3.8</td>
<td>5.3</td>
</tr>
<tr>
<td>Coordination &amp; Continuity of Care</td>
<td>2.4</td>
<td>2.8</td>
</tr>
<tr>
<td>Emotional Support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information, Communication &amp; Education</td>
<td>6.9</td>
<td>11.7</td>
</tr>
<tr>
<td>Physical Comfort**</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Respect for Patient Preferences</td>
<td>6.4</td>
<td>7.5</td>
</tr>
<tr>
<td>Overall Quality of Care**</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Percent (%)

50
45
40
35
30
25
20
15
10
5
0
Place of death

Percentage of deaths of cancer patients occurring in a hospital, by age group and time period, Canada — 2000–04 and 2007–12 combined

<table>
<thead>
<tr>
<th>Age Group</th>
<th>2000–04</th>
<th>2007–12</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–14</td>
<td>66.9</td>
<td>57.1</td>
</tr>
<tr>
<td>15–19</td>
<td>79.7</td>
<td>71.1</td>
</tr>
<tr>
<td>20–29</td>
<td>80.7</td>
<td>73.3</td>
</tr>
<tr>
<td>30–39</td>
<td>81.3</td>
<td>73.4</td>
</tr>
<tr>
<td>40–49</td>
<td>80.6</td>
<td>72.6</td>
</tr>
</tbody>
</table>
Educational attainment

Percentage of adolescents and young adults (aged 20–39 years) reporting ever having had cancer who reported achieving post-secondary education, by age group, Canada — 2007–14 reporting years combined.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Had Cancer</th>
<th>General Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>20–24</td>
<td>52.4</td>
<td>46.4</td>
</tr>
<tr>
<td>25–29</td>
<td>67.6</td>
<td>71.0</td>
</tr>
<tr>
<td>30–34</td>
<td>62.8</td>
<td>73.8</td>
</tr>
<tr>
<td>35–39</td>
<td>73.5</td>
<td>75.1</td>
</tr>
</tbody>
</table>
FIGURES
Employment and income for young adults with cancer – 2007–14 reporting years combined

- Had cancer
- General population

<table>
<thead>
<tr>
<th>Age Group</th>
<th>X%</th>
<th>Y%</th>
</tr>
</thead>
<tbody>
<tr>
<td>20–24</td>
<td>13.2E</td>
<td>69.5</td>
</tr>
<tr>
<td>25–29</td>
<td>15.7E</td>
<td>59.9</td>
</tr>
<tr>
<td>30–34</td>
<td>16.5</td>
<td>54.0</td>
</tr>
<tr>
<td>35–39</td>
<td>16.5</td>
<td>54.0</td>
</tr>
</tbody>
</table>

Percentage who did not report working at a job in the past year

Percentage who reported a personal income below $40,000 per year

Figure 5
Data are nationally representative overall, but the number of respondents considered adolescent and young adult cancer survivors is relatively small; must be interpreted with caution.

1: Interpret with caution owing to large variability in the estimate.

Data do not include people who currently have cancer.

Data source: Statistics Canada, Canadian Community Health Survey.
Investment in research

<table>
<thead>
<tr>
<th>Investment type</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>All cancer research (millions of dollars)</td>
<td>374.7</td>
<td>391.3</td>
<td>442.4</td>
<td>488.7</td>
<td>564.1</td>
<td>549.1</td>
<td>569.0</td>
<td>550.8</td>
<td>498.2</td>
</tr>
<tr>
<td>% of all cancer research that includes AYAs</td>
<td>1.6%</td>
<td>2.7%</td>
<td>2.6%</td>
<td>2.6%</td>
<td>2.3%</td>
<td>2.4%</td>
<td>1.9%</td>
<td>2.4%</td>
<td>3.7%</td>
</tr>
<tr>
<td>% of all cancer research that is AYA-specific</td>
<td>0.7%</td>
<td>0.4%</td>
<td>0.3%</td>
<td>0.3%</td>
<td>0.3%</td>
<td>0.4%</td>
<td>0.4%</td>
<td>0.3%</td>
<td>0.4%</td>
</tr>
</tbody>
</table>

Data source: Canadian Cancer Research Alliance.
Participation in clinical trials

**Figure 6.2a**
Percentage of therapeutic clinical trials currently recruiting for the most prevalent cancers in adolescents and young adults aged 15–39 years, new cancer cases (2005–13) and cancer deaths (2000–12), by disease site – June 2016

- **Breast**: 16.4%
- **Leukaemia**: 18.6%
- **Oesophageal Tumours**: 4.1%
- **Germ Cell**: 20.3%
- **Colorectal**: 13.1%
- **Melanoma**: 6.1%
- **Non-Hodgkin Lymphoma**: 6.5%
- **Female genital Tract**: 1.8%
- **Hodgkin Lymphoma**: 5.8%
- **Sarcoma**: 4.6%
- **Thyroid**: 0.3%

Legend:
- **New Cases**
- **Deaths**
- **Treatment Trials Available**
AYA-SPECIFIC DATA REQUIRED:

Psychosocial support
- Types of psychosocial supports needed
- Level of distress among AYAs regarding issues most relevant to them

Diagnosis and treatment
- Wait times from symptoms to diagnosis
- Measurement of fertility preservation consultations
- Factors affecting AYAs’ decisions to undergo fertility preservation (e.g., cost)

Research and education
- Best practices for cancer control
- Factors affecting access to clinical trials
- Factors affecting research investment

Palliation and symptom management
- Quality of symptom management and end-of-life care provided

Survivorship
- Factors that influence AYAs’ ability to complete their education and obtain employment after treatment
- Late effects of cancer and/or its treatment
- Availability of rehabilitation services and their ability to meet survivors’ needs (e.g., physical, psychosocial, occupational, educational)
- Factors affecting the transition or establishment of survivors in the workforce
- Measures of quality of life
- Effective models of care for survivors
Need for the Transitions Study

To make necessary system change, we need to better understand:

1. What are the biggest unmet needs for survivors?
2. Who are the most vulnerable survivors?
3. What factors/system resources are correlated with needs being met?

Based on survey findings, to develop actionable recommendations on how to better integrate the cancer care delivery and survivorship care systems
**Acknowledgements:**

**CPAC Team:** Rami Rahal, Esther Green, Raquel S. Moxam, Susana Huang, Margaret Fitch, Gina Lockwood, Cheryl Louzado, Alexander Lim, Sarah Zomer, Heather Bryant

**Transition Study Expert Panel**

**Provincial Partners & Principal Investigators**
Cancer Survivorship

# OF CANCER SURVIVORS: 1,600,000

# OF SURVIVORS ELIGIBLE FOR THE STUDY: 93,000

# OF SURVIVORS SAMPLED: 40,790

# OF RESPONSES: 13,258

RESPONSE RATE = 33%
Inclusion Criteria

A survey of 40,000+ survivors in ten provinces
• 1 to 3 years after treatment has ended

**AYA**
- Ages 15 to 29
- All cancers

**Adults**
- Ages 30+
- Non-metastatic cancers: breast, colorectal, hematological, prostate, melanoma
Scope of the Survey

- Influencers
- Types of care & support
- Enablers & barriers in health system

Physical
Emotional
Practical
Informational
Summary of Completed Surveys – AYAs only

Total AYA Completes: 575
AYA response rate: ~20%

Overall Demographic Breakdown

- Male: 38%
- Female: 61%

Demographic Breakdown:
- 18-24 years old: 20%
- 25-29 years old: 37%
- 30-34 years old: 43%

Completed Surveys by Province:
- PEI: 64
- BC: 93
- AB: 22
- MB: 21
- QC: 54
- NB: 17
- NB: 23
- NS: 28
- SK: 279
- NFLD: 17

BC, AB, MB, ON, QC, NS, PEI, SK, NFLD
### Most Recent Type of Cancer

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hematology cancer*</td>
<td>24%</td>
</tr>
<tr>
<td>Thyroid</td>
<td>16%</td>
</tr>
<tr>
<td>Testicular</td>
<td>13%</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>9%</td>
</tr>
<tr>
<td>Melanoma skin cancer</td>
<td>8%</td>
</tr>
<tr>
<td>Gynaecological</td>
<td>7%</td>
</tr>
<tr>
<td>Brain/Central Nervous System</td>
<td>6%</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>4%</td>
</tr>
<tr>
<td>Colorectal cancer</td>
<td>2%</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>&lt;1%</td>
</tr>
<tr>
<td>Other type of cancer</td>
<td>10%</td>
</tr>
<tr>
<td>Response left blank</td>
<td>4%</td>
</tr>
</tbody>
</table>

Selected two or more cancer types: 2%
Blank: 4%
Selected ONE cancer type: 94%

Bars total >100% due to respondents choosing multiple selections. *Other blood cancers included but do not fit within the “qualifying criteria”
Q16. What type(s) of cancer treatment did you receive for this cancer, if any? n=575

- Surgery: 66%
- Chemotherapy (intravenous or oral): 52%
- Radiation therapy: 33%
- Drug therapy: 12%
- Alternative medicine: 5%
- Bone marrow or stem cell transplant: 4%
- Other: 1%
- Not received treatment / no plan for...: <1%
- Not received treatment but closely...: 1%
- Response left blank: 1%
Q32: After completing your cancer treatment, was there a particularly challenging period(s) in terms of your ability to live your life the way you want to? n =575

- Yes, 6 months to <1 year after: 39%
- Yes, 1 to < 2 years after: 16%
- Yes, 2 to < 3 years after: 7%
- Yes, 3 + years after: 2%
- All periods were equally challenging: 12%
- There were no challenging periods: 24%
- Not applicable: 4%
- Response left blank: 1%
Q10. Which, if any, of the following chronic conditions did you have before you were diagnosed with cancer? Base: n=575.
Physical Challenges – AYA

Most prevalent concerns

- Fatigue: 78%
- Hormonal/Fertility: 50%
- Changes in concentration/memory: 49%
Physical Challenges – AYA

Severity of concerns

- Fatigue
- Hormonal/Fertility
- Changes in concentration/memory

Small concern
Moderate concern
Big concern
Physical Challenges – AYA

Seeking help

- Fatigue: Sought help (80%) vs. Did not seek help (20%)
- Hormonal/Fertility: Sought help (40%) vs. Did not seek help (60%)
- Changes in concentration/memory: Sought help (30%) vs. Did not seek help (70%)
Physical Challenges – AYA

Seeking help

- **Fatigue**: 40% did not get any help or had difficulty getting help
- **Hormonal/Fertility**: 35% did not get any help or had difficulty getting help
- **Changes in concentration/memory**: 45% were told it was normal to expect and thought nothing could be done
Emotional Challenges – AYA

Most prevalent concerns

- Anxiety about cancer returning: 84%
- Depression & sadness: 66%
- Changes in body image: 64%
Emotional Challenges – AYA

Severity of concerns

- Anxiety about cancer returning
- Depression & sadness
- Changes in body image

Big concern
Moderate concern
Small concern
Emotional Challenges – AYA

Seeking help

<table>
<thead>
<tr>
<th></th>
<th>Sought help</th>
<th>Did not seek help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety about cancer returning</td>
<td>80%</td>
<td>20%</td>
</tr>
<tr>
<td>Depression &amp; sadness</td>
<td>60%</td>
<td>40%</td>
</tr>
<tr>
<td>Changes in body image</td>
<td>50%</td>
<td>50%</td>
</tr>
</tbody>
</table>
Emotional Challenges – AYA

Seeking help

- Anxiety about cancer returning
- Depression & sadness
- Changes in body image

35% did not get any help or had difficulty getting help
47% did not want to ask
23% felt embarrassed to ask
Practical Challenges – AYA

Most prevalent concerns

<table>
<thead>
<tr>
<th>Concern</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Returning to work or school</td>
<td>62%</td>
</tr>
<tr>
<td>Difficulty getting health / life insurance</td>
<td>41%</td>
</tr>
<tr>
<td>Getting to &amp; from appointments</td>
<td>37%</td>
</tr>
</tbody>
</table>
Practical Challenges – AYA

Severity of concerns

Percentage distribution:
- Returning to work or school
- Difficulty getting health/life insurance
- Getting to & from appointments

Severity levels:
- Small concern
- Moderate concern
- Big concern
Practical Challenges – AYA

Seeking help

- Returning to work or school
- Difficulty getting health / life insurance
- Getting to & from appointments

Sought help

Did not seek help
Practical Challenges – AYA

Seeking help

- Returning to work or school: 60%
- Difficulty getting health/life insurance: 40%
- Getting to & from appointments: 30%

44% did not get any help or had difficulty getting help.
33% did not want to ask.
32% thought no services were available.
Q23. To the best of your memory, thinking about issues related to your follow-up cancer care, how many times did you visit or speak to each of the following?
Q65. After your cancer treatment, did you have someone close to you, such as a friend or family member, who helped provide support for your follow-up cancer care needs (emotional, physical or practical needs)? N=566
Q64. Below is a list of ways a cancer patient can get support or counselling during the first few years of follow-up cancer care. Please indicate which of the following best describes your experience with the type of support or counselling in each row.

<table>
<thead>
<tr>
<th>Support Type</th>
<th>Aware of</th>
<th>Participated in</th>
</tr>
</thead>
<tbody>
<tr>
<td>One-on-one counselling with a support therapist, psychologist, social worker, etc.</td>
<td>72%</td>
<td>28%</td>
</tr>
<tr>
<td>Face-to-face peer support group</td>
<td>57%</td>
<td>8%</td>
</tr>
<tr>
<td>Ongoing online peer support through social media, such as a Facebook group</td>
<td>57%</td>
<td>12%</td>
</tr>
<tr>
<td>Telephone peer support group</td>
<td>52%</td>
<td>2%</td>
</tr>
<tr>
<td>A professionally led online peer support group</td>
<td>49%</td>
<td>4%</td>
</tr>
<tr>
<td>Wellness program in your community</td>
<td>48%</td>
<td>6%</td>
</tr>
<tr>
<td>Support group retreat weekends</td>
<td>46%</td>
<td>4%</td>
</tr>
<tr>
<td>One-on-one peer mentorship program</td>
<td>43%</td>
<td>2%</td>
</tr>
</tbody>
</table>
Next steps

- AYA National Network: mechanism to engage the cancer care system in working to improve outcomes

- Membership:
  - Representatives from each provincial cancer agency
  - Provincial ministries of health
  - Adolescents and young adults and their family members
  - National stakeholder groups
In their words...

- “At the end of treatment you are wondering, ‘what now?’ You are really redefining yourself, asking yourself, ‘who am I now?’ Everything is different. It’s a lot to handle as a young person.”
  Bronwen Garand-Sheridan, survivor, Manitoba

- “Follow-up is important. You should be setting this age group up for life. You have been taken out of the race for a time and it is hard to find how to get back in, in healthy ways. You need help to do it.”
  Mike Lang, survivor, Alberta