

Evolution of adolescent and young adult oncology in Canada

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BACKGROUND

In the context of cancer, adolescents and young adults (AYAs) were defined by the Progress Review Group convened in 2005 by the U.S. National Cancer Institute and the LIVE-STRONG Foundation as falling into the age range 15–39 years¹. That definition was then adopted by EURO-CARE, in which the population-based cancer registries of 27 European countries participate².

There is increasing recognition that AYAs with cancer are a population distinct from younger and older patients and survivors. The distribution and biology of their malignant diseases characterize the differences in this age group³. Furthermore, the effects of a diagnosis of cancer and its treatment add considerably to the challenges that young people face in the transition from early adolescence to life as an independent adult⁴. And yet, the demanding needs of AYAs with cancer are poorly met⁵. The personal, societal, and socioeconomic effects of cancer in this age group are enormous, and the number of years of life affected are greater than in children and older adults⁶.

A burgeoning interest in AYA oncology is reflected in the establishment of a Society and two journals devoted to the topic, as well as the emergence of a textbook, similarly focused, now in its 2nd edition⁷. Moreover, national initiatives to address the needs of AYAs with cancer have been mounted in Australia, the United Kingdom, the United States, Italy, and elsewhere in Europe⁸. It is sobering to realize that the 15–39 age group encompasses 3 billion people—some 40% of the world's population—and contributes approximately 1 million incident cases of cancer annually⁹. A global assessment of cancer in AYAs has been reported¹⁰.

Against that backdrop, the 2009 annual report from the Canadian Cancer Society included the special topic of cancer in AYAs, who were defined on that occasion as those 15–29 years of age¹¹. Each year in Canada, more than 2500 new cancers are diagnosed in that age group, and using the expanded age range of 15–39 years, the number of incident cases rises to more than 8000¹². A special report from the Steering Committee for Canadian Cancer Statistics about AYAs with cancer in Canada, published in 2011, focused on opportunities to improve coordination and level of care¹³.

THE CANADIAN TASK FORCE

In 2008, the Canadian Task Force on Adolescents and Young Adults with Cancer (TF) was formed with funding from

the Canadian Partnership Against Cancer, together with the support of CI7, the consortium of Canadian pediatric cancer centres. The goal of developing an AYA-specific cancer control strategy was to improve all outcomes in the AYA cancer population. The TF was headquartered at McMaster University and had a small administrative secretariat under the direction of three co-chairs. All participated in teleconferences every two weeks, thus facilitating nimble advances and sustained productivity. Ultimately the TF included more than 60 individuals providing diverse professional and regional representation, as well as representation from survivors and family members. Working groups were formed to address key issues identified during two international workshops held by the TF. During its existence from 2008 to 2017, the TF provided guidance for best care on many fronts and drew attention to deficiencies in AYA cancer care and cancer control in Canada that required process and structural improvements.

Specific TF accomplishments between 2008 and 2015 include (Figure 1)

- a national survey of existing AYA cancer services in Canada to describe the unique needs of AYAs with cancer and the lack of resources, staff, and collaborative activities dedicated to AYAs with cancer throughout Canada, in both pediatric and adult centres. Results of the survey were published in the *Journal of Adolescent and Young Adult Oncology*¹⁴.
- an international workshop in 2010, which brought together survivors, supporters, health care professionals, and administrators. Their discussions of priority issues in AYA oncology were summarized and published as a supplement to *Cancer*¹⁵.
- development and publication of principles and recommendations about priority issues for AYAs with cancer in Canada, published in 2011 in the *Journal of Adolescent and Young Adult Oncology*, based on discussions between stakeholders at the 2010 workshop (Table 1)¹⁶.
- a second international workshop held in 2012 developed a framework for action on AYA cancer care and control and launched regional action partnerships to promote action to effect improvements. The deliberations were also published in the *Journal of Adolescent and Young Adult Oncology*¹⁷.
- description of key factors that affect the many different transitions that occur during the AYA cancer journey, and the need for developmentally appropriate services for

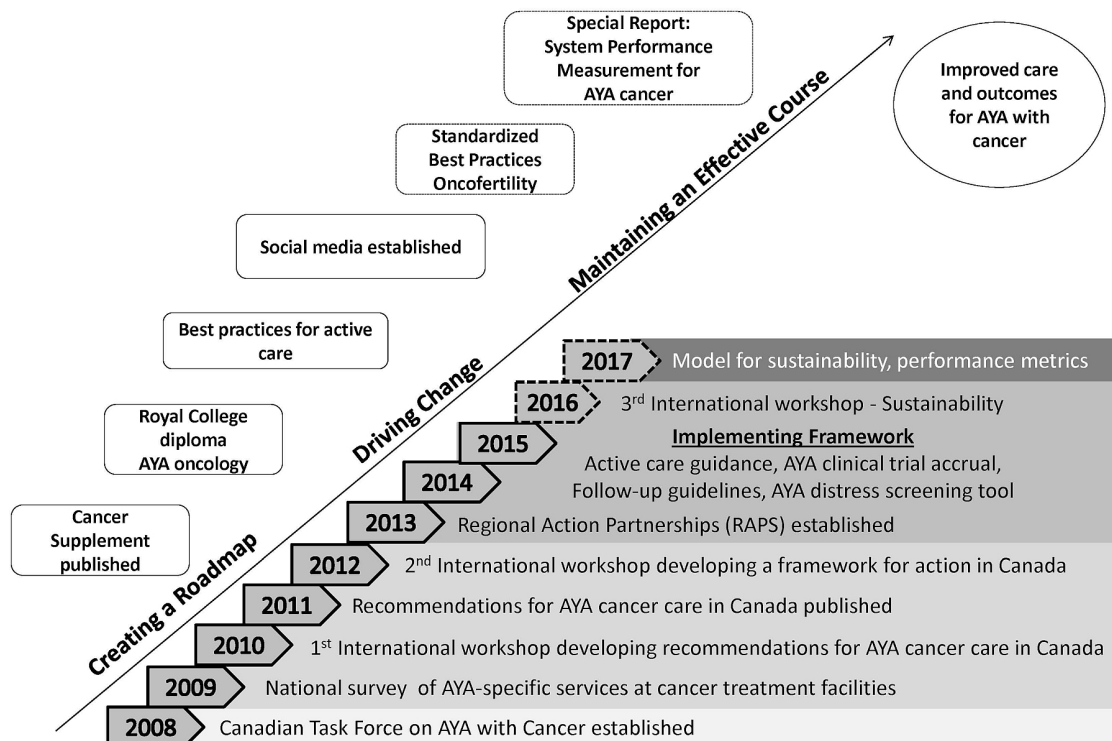


FIGURE 1 Canadian Task Force on Adolescents and Young Adults with Cancer timeline: milestones and accomplishments. AYA = adolescent and young adult.

TABLE I Priority issues in adolescent and young adult (AYA) oncology, as determined by stakeholders, including AYA cancer survivors

Active therapy and supportive care
Psychosocial needs
Palliation and symptom management
Survivorship
Research and metrics
Awareness and advocacy

AYAs with cancer that consider both systemic and individual transition issues. The resulting recommendations are broad enough to be applicable in various settings¹⁸.

- development of guidance for the care of AYAs with cancer in Canada (based on a systematic search for, and review of, existing guidelines and guidance), published in 2016 in *Current Oncology*¹⁹.
- bringing attention to the paucity of data about Canadian clinical trial accrual rates for AYAs with cancer. Clinical trials participation rates are widely accepted as a surrogate measure of quality of care, underlined by the tremendous impact of improved survival rates in recent decades in children less than 15 years of age and in older adults (more than 29 years of age). Relevant information was published in *Current Oncology*²⁰.
- creation of strategies for increasing the accrual rates of AYAs to clinical trials in partnership with the NCIC's Canadian Cancer Trials Group and the Children's Oncology Group²¹.

- initiation of an international effort to produce an AYA-specific psychosocial distress screening tool for better assessment of distress in AYAs with cancer. The tool would enable implementation of risk-based interventions to improve quality of care and outcomes for AYAs with cancer²².
- development of the 1-year diploma program in AYA oncology from the Royal College of Physicians and Surgeons of Canada as an Area of Focused Competence, established in 2016.
- exploration of possible models of future governance for efforts to promote better care of AYAs with cancer in Canada (presented to stakeholders at a 3rd international workshop in 2016).

During the final 2 years of its tenure, from 2015 to 2017, TF members and many other representatives of the broader AYA cancer community addressed three urgent priorities for improving cancer control for AYAs with cancer, as described in the subsections that follow.

Creating System Performance Measurement Capacity

Improving outcomes for AYAs with cancer will not only enable individuals to reach their full potential as productive members of society, but will also help maximize the efficient use of scarce health system resources. System performance measurement is needed to determine the overall costs and benefits of AYA-specific cancer initiatives. A model for formal economic evaluation of AYA cancer care in Canada has been presented (Hedden L,

Peacock S. *Measuring the Economic Impact of Adolescent and Young Adult (AYA) Cancer Programs* [research report for the Canadian Centre for Applied Research in Cancer Control], 2012).

Measurement of outcomes, including patient-reported outcomes, is essential for identifying opportunities to improve the quality of care and benchmarks to achieve short-, medium-, and long-term goals in outcome improvement. Development of indicators specific to the AYA cancer population, including specifications for the required data, is needed to direct and evaluate projects and system changes being undertaken to improve overall care and outcomes for AYAs with cancer.

In 2017, the first-ever report of national system performance for AYAs with cancer was released: *Adolescents and Young Adults with Cancer*²³. This detailed and broad-ranging report is the first of its kind. The information it contains has been instrumental in increasing awareness about the need for, and challenges associated with, system performance measurement for AYA cancer care, in Canada and internationally.

These highlights of the 2017 AYA system performance report for Canada are listed according to the main themes identified by the TF in 2011 as critical to advancing the care of AYAs with cancer¹⁶:

- **Incidence and survival**
Since the early 1990s, cancer cases in 15- to 29-year-olds have increased by 18.2%, and 5-year survival has increased by 6.2% and 9.8% in the 15–29 and 30–39 age groups respectively.
- **Palliation**
Most AYA cancer deaths occur in hospital (73%).
- **Psychosocial issues**
Emotional support was rated negatively by a substantial number of male AYAs (24.1%) and female AYAs (26.2%).
- **Survivorship**
Compared with the general population, AYA cancer survivors had similar achievements in postsecondary education, but higher unemployment.
- **Research, including available clinical trials**
Cancer research specific to AYAs represented 0.4% of cancer research funding in Canada; 32.9% of trials were for a cancer prevalent among AYAs.

In addition, a group of 26 experts who are representatives of most provinces and all stakeholder groups created a network of individuals committed to developing system performance parameters for AYA cancer care. In a modified Delphi process, the network recently (October 2018) finalized a complete ranked list of indicators for AYA cancer care. The indicators are linked to priorities and recommendations identified during two TF stakeholder workshops (in 2010 and 2012) that laid the groundwork for the 2012 action plan for AYA cancer care in Canada. The results of the network's efforts have been submitted for publication, and findings

have been presented at scientific conferences as well as at the various institutions represented by network members.

Oncofertility

An Oncofertility Stakeholder Workshop held 16 May 2016 gathered AYA survivors, clinicians, researchers, policy-makers, and representatives of nongovernmental organizations from across Canada to discuss the development of pan-Canadian oncofertility best practices and a framework for an oncofertility action plan to address barriers to best care and future options for fertility preservation. Four main priorities in oncofertility in Canada were tackled:

- Local champions (mainly health care professionals) are needed in cancer centres to raise awareness of, provide accurate information about, and challenge their peers to identify patients at risk and to promote oncofertility referrals. The Champions Report highlighted 3 recommendations relating to oncofertility champions:
 - A group of champions should include an oncologist, a social worker or nurse, a patient, and a fertility specialist.
 - Champions will need the support of administrative and managerial staff to formally acknowledge and advocate for the role of champion.
 - Champions will have to be equipped with standardized tools and knowledge about fertility preservation to support the oncofertility agenda in cancer centres.
- A Canadian Oncofertility Charter was created to assist champions and anyone else interested in improving access to oncofertility services for AYAs (Table II).
- A framework to develop a customizable oncofertility toolkit was established to target barriers to fertility preservation referrals before the start of cancer treatment in AYA patients. Each barrier is addressed with a selection of existing tools identified by a national working group. Further funding for the creation and implementation of new standardized tools is needed to address current gaps in the Canadian oncofertility landscape and to disseminate the tools across Canada. A Web site is proposed to host all the tools and resources available for patients, families, and cancer clinics.
- The oncofertility working group conducted a survey of all private fertility centres in Canada to report on costs and services provided, subsidies available, and other sources of financial assistance for patients. Survey data collection and analysis have been reported^{24,25,a}.

Data about AYA oncofertility referrals, services accessed, and outcomes are needed. In 2015, the Cancer Knowledge Network and the Canadian Fertility and Andrology Society collaborated to establish a database to collect the needed data, which will inform planning to improve AYA oncofertility care.

^a Canadian Task Force on Adolescents and Young Adults with Cancer. *Oncofertility Cost Report*. 2017. Available from the authors on request.

TABLE II Canadian Oncofertility Charter: a 10-point plan for adolescents and young adults, 8 January 2018

1.	Cancer clinicians should discuss the possible effects of cancer treatment on a patient's fertility, including that of children, before the start of any treatment, irrespective of the patient's prognosis.
2.	Identification of appropriate patients can be facilitated by the appointment of oncofertility "champions" in cancer centres.
3.	Cancer clinicians should give patients an opportunity to discuss their future fertility by offering a referral to a fertility specialist (reproductive endocrinologist, andrologist, or gynecologist) who can discuss fertility preservation strategies as well as fertility and reproductive health follow-up after cancer treatment.
4.	Educational toolkits should be developed and available for clinicians and patients to facilitate these interactions.
5.	Cancer centres should have a clear and timely referral pathway between the centres and fertility preservation services to ensure that a fertility preservation consultation and a suitable procedure can be organized in a timely manner when it is deemed appropriate to do so, before the start of cancer treatment.
6.	A national oncofertility database should be established to enable the development and implementation of standardized referral pathways and identification of suitable facilities for the provision of oncofertility services and to provide a resource for education, research and advocacy.
7.	Oncofertility care should be incorporated into the training curriculum for cancer and fertility health professionals of all disciplines at both undergraduate and postgraduate levels to ensure that oncofertility care becomes standard practice in Canada.
8.	A national initiative should aim to secure equity of access to public and philanthropic funding support of fertility preservation procedures for cancer patients of reproductive age.
9.	Fertility preservation strategies and storage of gonadal tissue (including sperm and oocytes) and embryos should be affordable and equitable for all cancer patients of relevant age, independent of ethnicity, sexual orientation, place of residence or socioeconomic factors.
10.	Fertility-related psychosocial support should be available to all appropriate patients during and after cancer therapy, regardless of whether they choose to pursue fertility preservation strategies. Information should also be provided about contraception and safe sexual practices during treatment.

Sustainability

The Canadian Task Force on Adolescents and Young Adults with Cancer consisted of survivors, supporters, health care professionals (including psychologists, social workers, nurses, and doctors), researchers, and senior administrators from across the country who all volunteered their time to contribute to the success of TF activities. Beginning in 2008, the Task Force made important progress toward improving outcomes for AYAs with cancer.

To ensure the continued functioning and sustainability of the AYA cancer movement in Canada, a Governance Committee was formed in early 2014 to plan for the sustainability of efforts on behalf of AYA cancer patients and survivors of cancer in childhood, adolescence, or young adulthood. That effort is required to measure progress toward the goal of improved outcomes. The committee developed possible models of future governance that were reviewed and finalized with input from all stakeholders at the TF workshop held in February 2016^b. The overall outcome of the workshop on sustainability was agreement that a wider scope of effort is needed to advance the cause of improving cancer care for AYAs in Canada. There was support for the idea of strong national leadership within a new, inclusive, and collaborative organization. Workshop participants recommended an evolutionary approach, moving, in the long term, toward a formal nonprofit structure with professional management. Collaborations and partnerships will be an essential element of the structure. A vital role was seen for AYAs living with cancer, as well as for health care professionals and advocacy groups across the cancer care continuum. A business case was created to support the proposed long-term governance model.

Funding from Canadian Partnership Against Cancer for the TF was ended in 2016 in favour of a systems-integrated approach in the near term. The Partnership's Adolescents and Young Adults National Network, founded in 2017, consists of representatives from all provincial cancer agencies and health ministries, together with interdisciplinary health care providers. They are focused on engaging stakeholders in co-creation and implementation of a framework for action to improve AYA cancer care in Canada. The core leadership group of the TF has not been included in the Adolescents and Young Adults National Network in a membership or advisory role, resulting in a considerable loss of corporate memory, experience, and expertise. Hopefully, the Network will build on the ground-breaking work done by the Canadian AYA TF from 2008 to 2016. The expertise and experience gained, which led to the principles and recommendations created by the TF, will form a strong foundation for building an AYA network in Canada that will be important in improving overall care and cancer control for AYAs with cancer in this country and beyond.

UNFINISHED BUSINESS

Efforts to create a paradigm shift in AYA cancer treatment and supportive care are well underway in other developed countries, primarily Australia and the United Kingdom. Similar systemic efforts will be needed in Canada to coordinate action and to guide change because of the small

^b Canadian Task Force on Adolescents and Young Adults with Cancer. *AYA Stakeholders' Workshop*. 2016. Available from the authors on request.

number of AYAs with cancer and the wide distribution of the population generally in the country, as well as the uneven distribution of sites of care (pediatric and adult cancer services, and sites outside the cancer systems). The economic benefits of providing optimal care for patients in this age group at risk of many potential years of life lost must be elaborated, because the cost of not providing comprehensive care is large.

Since about 2010, several informal networks were developed based on interests in clinical trials focused on AYA cancer, system performance measurement, oncofertility, distress screening, and other topics. In addition, the possibility of training oncologists to manage the care of AYA patients is now available through the Royal College of Physicians and Surgeons of Canada training program in AYA oncology mentioned previously. That foundation must not be lost, but rather built upon to improve the overall care of AYAs with cancer to achieve better outcomes for this special population that continues, at present, to be underserved.

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CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare that we have none.

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