

# SUSTAINABLE ACTION FOR IMPROVED OUTCOMES IN ADOLESCENTS AND YOUNG ADULTS (AYA) WITH CANCER IN CANADA – THE CANADIAN TASK FORCE ON AYA WITH CANCER: 2015 AND BEYOND

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## Objective

- While cancer is relatively uncommon among AYA (ages 15 to 29 years) compared to older adults, its personal, societal, and socioeconomic impact is disproportionately greater.
- The needs of AYA with cancer, unique to this age group, are being met poorly by the conventional dichotomy of Canadian pediatric and adult health care systems, particularly their psychosocial needs.
- The objective of the Canadian Task Force (TF) on AYA with Cancer is to mitigate the current disparities of care for AYA with cancer, including survivors, and survivors of cancer in childhood through advances in treatment and research, respecting the unique circumstances and needs of this population, across all health care jurisdictions in Canada.

## Approach

- In 2008, the TF was created with funding from the Canadian Partnership Against Cancer, with support from C<sup>17</sup> (the consortium of Canadian pediatric oncology centres).
- The TF conducted a national survey of cancer care facilities in 2009. Results showed a wide diversity of care and service models across Canada for AYA patients and survivors, as well as little availability of AYA-specific care (*Journal of Adolescent and Young Adult Oncology. 2011;1:140-144*).
- Two international workshops on AYA with cancer were held in March 2010 and March 2012; attendees included survivors and supporters, health care professionals, administrators, and international experts. The proceedings of the first workshop are published (*Cancer. 2011;117(Suppl 10):i-ii, 2239-2354*).
- The first workshop produced 6 broad recommendations for care of AYA with cancer highlighting the need for age-appropriate psychosocial, survivorship, palliative and medical care to redress inequities in the care provided to this group relative to younger and older cancer patients (*Journal of Adolescent and Young Adult Oncology. 2011;1:53-59*).
- The second workshop led to the development of the Framework for Action on Recommendations for Care of AYA with Cancer. This road map is being used to develop strategies to implement the recommendations at the local, regional, provincial/territorial, and national levels.
- Regional Action Partnerships (RAPs) were formed in 2012 to take the lead in implementing the Framework in their provinces and territories.
- In 2013, four national working groups were formed to address AYA-specific needs in active care, follow-up care, clinical trial accrual, and distress screening.

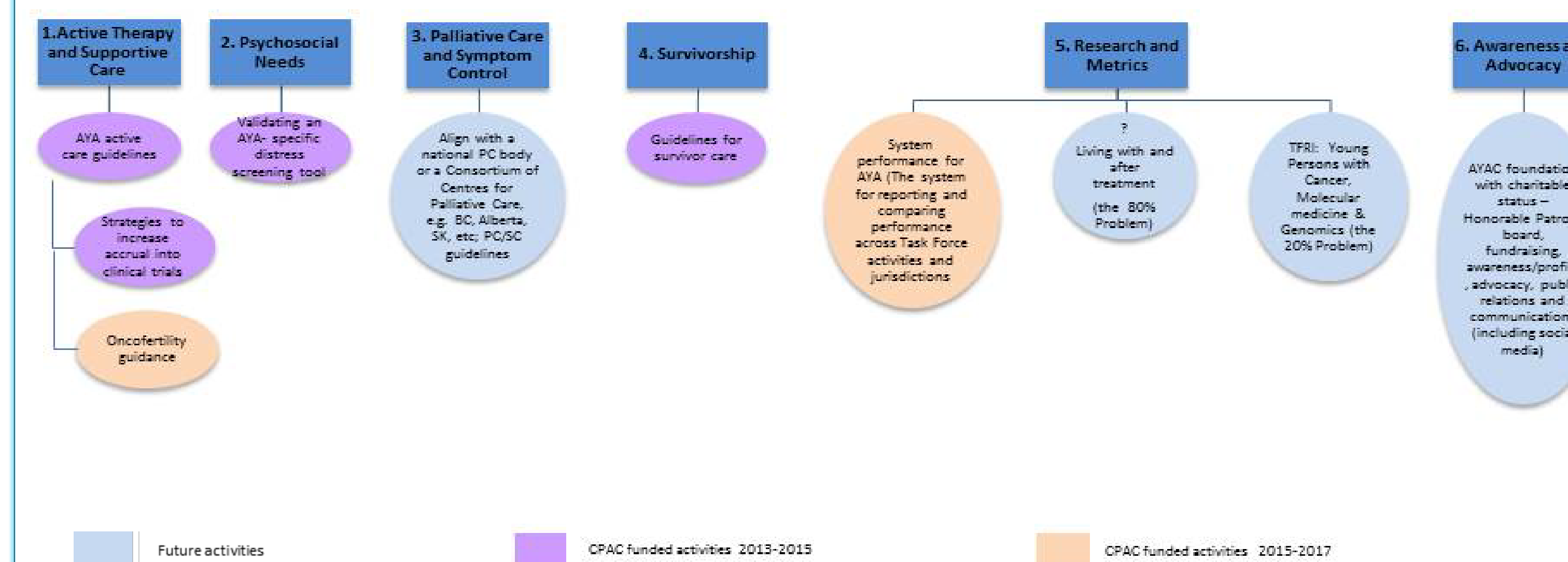
## Results

In June 2015, national working groups will complete:

1. Guidance for active care of AYA with cancer
2. Guidelines for breast cancer surveillance of survivors who received chest radiation during treatment
3. An analysis of accrual of AYA with cancer to clinical trials in Canada
4. An AYA-specific distress screening tool as part of an international collaboration

The Canadian Task Force on Adolescents and Young Adults with Cancer

### Strategic Priorities and Activities March 25, 2015



## Sustainability

- An effective cancer control plan for AYA and sustainable action to promote implementation of the plan involves 6 key components:
  - Improving active therapy
  - Meeting psychosocial needs
  - Enhancing palliative care
  - Increasing surveillance among survivors
  - Promoting research and associated metrics
  - Stimulating awareness and advocacy
- An effective pan-Canadian operational entity must be created to succeed the TF, with a new defined, accountable governance structure and function.
- A Governance Committee has conducted an environmental scan of AYA cancer organizations internationally (USA, UK, Australia, and Italy).
- Possible models will be presented for discussion by stakeholders at a third workshop planned for September 2015.

## Results (cont'd)

### Third international workshop

- A third stakeholder workshop is planned for September 2015.
- Stakeholders from across Canada will be invited to discuss future priorities and directions, and future governance of the AYA cancer movement in Canada.
- Stakeholders will include survivors and supporters, health care professionals, administrators, researchers, and policy-makers.
- International experts will provide input based on AYA cancer activities in their jurisdictions.
- Collaborative and purposeful action by all stakeholders is needed to build awareness of AYA cancer issues.

### System Performance Measurement and Oncofertility

- System performance evaluation has proven to be a powerful tool for the identification of failings in the health care system, and a driving force for collaborative efforts to redress inequities of care.
- Indicators will be identified and prioritized with stakeholder input.
- Fertility issues are often not addressed at the time of cancer diagnosis in AYA, yet this is an issue of great importance to them.
- Stakeholders will be brought together to develop best practices for fertility preservation and related considerations for health care providers treating AYA cancer patients, including:
  - identification of patients whose fertility may be at risk;
  - description of fertility-preserving procedures and referral processes;
  - development and provision of educational information for patients, including sources of funding support, in both electronic and written form.

## Conclusions

- The AYA TF has laid the groundwork for a Canadian AYA cancer control plan.
- System performance measurement is required to evaluate and refine the cancer control plan for AYA.
- Stakeholders will determine a new sustainable governance structure for the AYA cancer movement in Canada.