

# Setting Priorities for a Provincial Adolescent & Young Adult Oncology Program

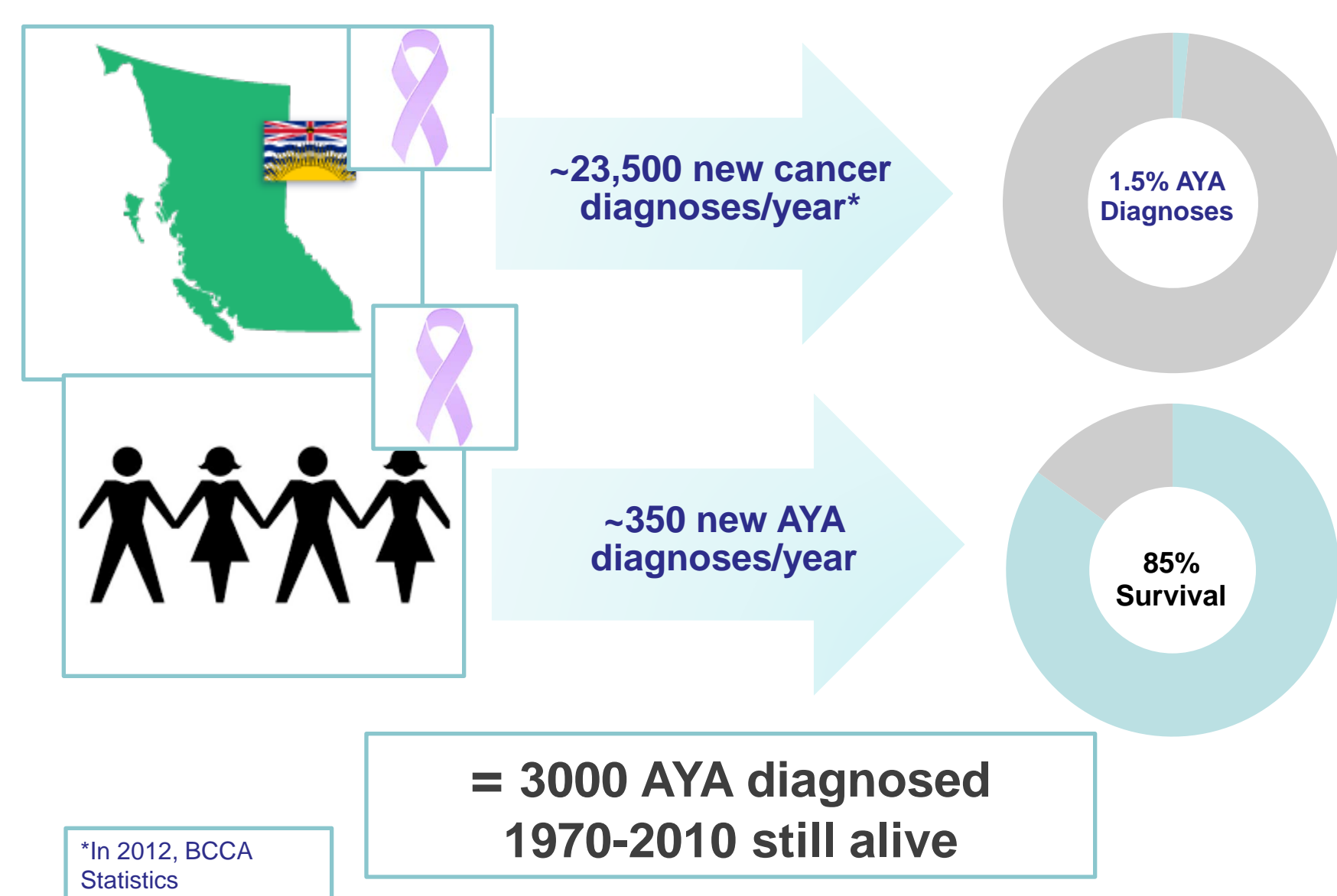
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## Introduction

### Background

Approximately 1.5% of new cancer diagnoses in BC each year are among adolescents and young adults (AYA) aged 15-29 years. With a survival rate of over 85%, 3,000 AYA patients diagnosed between 1970 and 2010 are still alive in BC. AYA are in a period of key development for milestones fundamental to a person's overall lifelong wellbeing, including the development of values and personal identity, formation of strong personal relationships, and attaining financial independence.



Progress in outcomes for AYA with cancer lag behind other age groups due to:

- Delays in diagnosis
- Geographically distributed care across British Columbia
- Lack of referral guidelines to BC Cancer
- Lower participation in and access to clinical trials
- Poor understanding of the unique biological characteristics of cancers in AYA
- Lack of appropriate psychosocial screening tools
- No access for providers to AYA education and training
- Higher degree of psychosocial distress among AYA compared to other age groups
- Inadequately met psychosocial needs and biomedical risks

### Objectives

BC Cancer and BC Children's Hospital created a Steering Committee to develop recommendations to address the gaps in care for AYA. A priority setting exercise with health care providers, patient and family representatives and administrative professionals was undertaken to determine core program components to best meet the needs of AYA patients in BC.

## Methods

The prioritization exercise consisted of two parts: a modified Delphi technique and stakeholder engagement session.

### Delphi Survey

Eight core program components were identified through a literature review, national consensus documents and expert opinion. The core program components include (1) health care provider education, (2) patient and family education, (3) patient care implementation, (4) program expansion and sustainability, (5) research strategy, (6) multidisciplinary tumour board review, (7) evaluation strategy, and (8) program mission and goals.



The eight core program components were further broken down into 79 distinct items. A modified Delphi technique was used through two iterations administered online to AYA stakeholders, asking them to score each of the 79 items on a scale of 1 to 5. Consensus on an item was defined as a mean score of less than 2.0 (indicating not important) and 4.0 or greater (indicating important).

### Stakeholder Engagement Session

Stakeholders were brought together in a one day session to review results of the Delphi technique and further discuss AYA program components, priorities and activities. Participants were assigned to groups of 5 or 6 individuals and provided with discussion guides as well as Delphi survey results, and were requested to discuss the identified program component as a small group and report back to the larger group. Each small group also discussed program mission and goals.

## Results

### Demographics

Sixty provincial AYA stakeholders completed the first iteration of the Delphi survey, and 27 completed the second iteration and attended the stakeholder session.

Location of Work	Round 1	Round 2 & participants
	% responses	% responses
BC Cancer - Abbotsford	5.0%	3.7%
BC Cancer - Prince George	8.3%	7.4%
BC Cancer - Kelowna	6.7%	11.1%
BC Cancer - Surrey	3.3%	3.7%
BC Cancer - Vancouver	5.3%	22.2%
BC Cancer - Victoria	10.0%	3.7%
BC Children's Hospital	6.7%	18.5%
BC Cancer Provincial Office	5.0%	14.8%
Vancouver General Hospital	0.0%	3.7%
Patient/Caregiver Advisor	n/a	11.1%
No Response	1.7%	0.0%
Total	100.0%	100.0%

Respondents worked in administration, oncology, nursing, psychosocial services, radiation therapy, pain and symptom management, nutrition, psychiatry and speech language pathology. Respondents worked and lived across the province of BC.

Area of Work	Round 1	Round 2 & participants
	% responses	% responses
Administration	6.7%	3.7%
Oncology	26.7%	37.0%
Nursing	26.7%	14.8%
Psychosocial & Therapeutic Services	21.7%	18.5%
Radiation Therapy	1.7%	0.0%
Pain & Symptom Management	6.7%	0.0%
Nutrition	1.7%	0.0%
Patient/Caregiver Advisor	1.7%	14.8%
Psychiatry	1.7%	3.7%
Nurse Practitioner	1.7%	3.7%
Speech Language Pathology	1.7%	0.0%
Vocational Rehabilitation	0.0%	3.7%
No Response	1.0%	0.0%
Total	100.0%	100.0%

### Program Mission & Goals

The following program mission and goals were endorsed by all survey respondents:

- **Program Mission:** Create a provincial interdisciplinary cancer program for AYA aged 15-29 years that will regionally implement recommendations across at BC Cancer sites in partnership with BC Children's Hospital.
- **Goal 1:** Develop health care provider education curriculum based on a formal learning needs assessment with clinical teams.
- **Goal 2:** Facilitate clinical consults with referral pathways to other services and flexible access to interventions.
- **Goal 3:** Integrate access to AYA specific psychosocial distress screening and fertility preservation screening and referral
- **Goal 4:** Develop multidisciplinary tumour board case reviews supported by BC Cancer and BC Children's Hospital
- **Goal 5:** Create evidence-based quality improvement and program evaluation plans
- **Goal 6:** Introduce patient reported outcome measurement to improve patient experience
- **Goal 7:** Support patients and families through education and peer support network

Additional feedback regarding the program mission suggested that the age be increased from 29 to 39 to align with national definitions of AYA. Numerous participants also noted the importance of an AYA Survivorship Program.

Consensus was not obtained for the eighth goal, development of a comprehensive AYA research agenda.

### Program Priorities

Participants were asked to prioritize program component implementation, ranking each component on a scale of 1 to 7, where items ranked 1 should be implemented first, and 7 last. Implementation priorities are as below:

1. Patient Care Implementation
2. Health Care Provider Education
3. Patient and Family Education
4. Program Expansion & Sustainability Plan
5. Identifying Research Priorities & Research Agenda
6. Program Evaluation Strategy
7. Multidisciplinary Tumour Board Review Plan

## Conclusions & Future Directions

There is widespread support amongst BC Cancer and BC Children's Hospital employees for the development of a provincial AYA oncology program; however, additional resources are required to fully implement a robust program.