



CANADIAN  
FRAMEWORK

FOR THE CARE AND SUPPORT  
OF ADOLESCENTS AND YOUNG  
ADULTS WITH CANCER

2019

CANADIAN PARTNERSHIP  
AGAINST CANCER



PARTENARIAT CANADIEN  
CONTRE LE CANCER

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# ACKNOWLEDGEMENTS

The Canadian Partnership Against Cancer (the Partnership) was created in 2007 by the federal government. Since then, our primary mandate has been to move Canada’s cancer control strategy into action and to help it succeed through coordinated system-level change across the full cancer care continuum. To do this, the Partnership works closely with national, provincial and territorial partners.

Developing the *Canadian Framework for the Care and Support of Adolescents and Young Adults with Cancer* (the Framework) would have been impossible without the participation and dedicated efforts of the members of the Adolescents and Young Adults with Cancer National Network (AYANN). The Partnership would like to acknowledge the significant contributions of the AYANN and the numerous expert advisors and leaders, educators, clinicians, patients and family members, policy makers, researchers, health service planners, and cancer control organizations that have helped shape the Framework.

The Partnership is grateful to the AYAs and their families who have shared their personal photographs with us. We have intentionally used these photographs throughout the Framework to reflect and honor their experiences.

The Partnership would like to acknowledge CanTeen Australia for permission to adapt the 2017 Australian Youth Cancer Framework for the Canadian context and for their ongoing advice and assistance.

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In April 2017, the Canadian Partnership Against Cancer (the Partnership) released its first ever system performance report that focused on a subset of indicators on cancer care for adolescents and young adults with cancer (AYAs; see Appendix B for ‘Glossary of Terms’), providing for the first time a national view on the entire continuum of cancer control in AYAs—from diagnosis, palliative care and treatment, to long-term survivorship and end-of-life care.

The report also identified areas in which efforts could be targeted to improve AYA-focused cancer control at a national level, such as enhancing collection and use of data and prioritizing research on AYAs and survivors to better understand the unique biological and psychosocial needs of this population.<sup>1</sup>

Given the lack of information about AYAs in Canada and the high degree of unmet needs in this population, the Partnership worked with the Adolescents and Young Adults with Cancer National Network to develop the *Canadian Framework for the Care and Support of Adolescents and Young Adults with Cancer* (the Framework). The Framework articulates our national vision, co-developed with provincial and territorial governments, provincial cancer agencies, national health professional associations, community organizations, providers, patients and families, and focuses on addressing the unique needs of AYAs. Guided by the Framework, individual, service and system-level action within and beyond the healthcare system will allow the greatest number of AYAs to access high quality care and comprehensive survivorship support that is crucial for long-term quality of life.

At the system-level specifically, key actions will be required to achieve the vision of the Framework. These include i) developing a national plan for adapting the healthcare environment in a manner that harnesses emerging technologies, e-health and personalized medicine approaches to improve traditional service delivery models; ii) establishing critical partnerships across the country to transfer experience, evidence and knowledge; iii) supporting the training and development of healthcare professionals who provide developmentally-appropriate and supportive care for AYAs; iv) creating the mechanisms for ongoing data monitoring and program evaluation; and, v) facilitating models to support research to address the unmet needs of Canadian AYAs.

In the summer of 2019, the Partnership launched the refreshed *Canadian Strategy for Cancer Control*. The refreshed Strategy offers opportunity to support the Framework and move its vision into action. The refreshed Strategy is grounded in five priorities, which include supporting people living with cancer with resources and information and eliminating barriers to getting care. A specific action in the Strategy calls for better support for children, adolescents and young adults through expanded access to a wide range of integrated services to address the unique challenges faced by AYAs living with cancer. As the Strategy’s steward, the Partnership will work with key partners to move the Strategy into action.

Over the coming years, the Framework will inspire future policy direction, investment and action to ensure Canada can meet new challenges in an evolving healthcare landscape, and so that every young Canadian with cancer has access to the best practice, developmentally-appropriate care and support they need to optimize their health, well-being and survival, and facilitate meaningful participation across all aspects of life. While the Framework helps set the direction, this is just the beginning. Additionally, a Peoples-specific First Nations, Inuit and Métis AYA framework must be developed through respectful engagement and development of action plans that are responsive to regionally diverse protocols and priorities. Effective leadership, commitment and action plans will be required to achieve our collective vision to improve the care and support of the entire AYA community in Canada.

## CANCER AND YOUNG CANADIANS

Every year, 7,600 Canadians aged 15 to 39 years are diagnosed with cancer. The most frequent types of cancers in AYAs are thyroid cancer, breast cancer, Hodgkin lymphoma, non-Hodgkin lymphoma, testicular cancer and melanoma.<sup>2</sup> The overall incidence rate of cancer in AYAs has increased since 1992, however, the five-year relative survival ratio has dramatically increased, with survivors living 50-60 years beyond their diagnosis and treatment.<sup>2</sup>

Adolescence and young adulthood encompass many key developmental milestones that affect a person's overall long-term well-being. These include the development of values and personal identity, formation of strong personal relationships and attainment of financial independence. Embarking on a cancer journey—from diagnosis, palliative care and treatment, to long-term survivorship and where needed, end-of-life care—means more complex challenges to navigate during this already complicated time.

Cancer diagnosis brings distress and anxiety, fueled by the prospect of facing early death, grappling with disruptions to social life, returning to live with parents and suffering through fear of cancer recurrence or long-term complications of treatment such as the inability to have children. AYAs also experience a more intense symptom burden, may have under-developed coping mechanisms and depend on family and caregivers to help them make sound decisions. Family members of AYAs also experience distress, which can compromise their ability to support their AYA family member. Feelings of isolation are often exacerbated by the lack of other AYAs present in cancer centres during appointments and treatment sessions.

Following treatment, AYAs have to deal with a unique set of challenges. Given the relatively high survival rates for AYAs and children diagnosed with cancer, there is a growing population of survivors that attempt to attend or return to school or the workforce. These can be challenging times for AYAs generally and even more so for those with cancer who have been away due to treatment and must deal with the uncertainty of potential recurrence, without the level of peer social support that an AYA without cancer can count on.

*"During chemo treatments, I didn't ever see another young person. I just lay in bed and went to sleep. There was no point in being awake as there was nobody else to talk to."*

*-Chris*

Cancer survivors in young adulthood may experience difficulty in obtaining employment, and of those who do find work, they are more likely than the general population to make less than \$40,000 per year. They are also more likely to be under-employed and to be reliant on social assistance programs.<sup>2</sup> Further, the economic impact of cancer is not limited to the survivor. There is also a significant economic burden experienced by families, the healthcare system and broader society in the form of healthcare costs, out-of-pocket expenses, forfeited income, additional education costs and long-term diminished employment opportunities.

*"After cancer treatment you don't just slide back into your old life as if it's been waiting for you. There is really no support after chemo. All follow-ups are medical-based and they get you in and out."*

*-Samantha*

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An Australian study estimated the total lifetime costs for AYAs was \$1.3 million per person: \$0.6 million in burden of disease costs, and \$0.7 million in health costs, productivity losses and informal care.<sup>3</sup> Adequate resources and support are needed to better enable AYAs to fully participate in and contribute to society.

If we are to ensure their optimal survival, health, well-being and positive contribution to society, AYAs must have their unique clinical, psychosocial and practical needs met across the cancer journey. Instead, AYAs often find themselves in services designed for either younger children or older adults that do not address the unique needs of AYAs. And even when dedicated support services do exist, such as peer-support networks, AYAs are not always informed about them at the appropriate time during their journey. Moreover, AYAs are not provided with needed palliative care early enough to optimize quality of life. Early integration of palliative care into a person's cancer journey leads not only to an improved quality of life—better symptom control, reduced anxiety and pain, and more support for emotional, social and spiritual needs—but also to greater satisfaction with care.<sup>4</sup>

Remedying these issues requires specialized developmentally-appropriate care, support beyond the walls of a cancer clinic and research dedicated to studying biological and psychosocial dimensions of cancer in AYAs.



## EFFORTS TO ADDRESS THE UNMET NEEDS OF AYAS WITH CANCER: AN EVOLUTION

A Canadian Task Force on Adolescents and Young Adults with Cancer (the Task Force) was formed in 2008 with funding from the Partnership and the support of the C17, a consortium of Canadian pediatric cancer centres. The Task Force succeeded in drawing attention to gaps in cancer care for AYAs in Canada and laid the groundwork for future efforts by the Partnership. Its accomplishments include:

- A national survey of AYA cancer services, identifying the diversity of care and service models.
- International workshops in 2010, 2012 and 2016 that brought together stakeholders and led to:
  - Establishment of principles and recommendations for care of AYAs in Canada.<sup>5</sup>
  - Development of the Framework for Action on AYA cancer care and to launch Regional Action Partnerships (RAPs) to improve care and support for AYAs.<sup>6</sup>
  - Creation of a plan for future governance of efforts to improve AYA cancer care in Canada.
- A Supplement to the journal *Cancer* in 2011 that includes in-depth descriptions of the unique needs of AYAs.<sup>7</sup>
- Detailed strategies for care of AYAs in the medical, psychosocial and research domains;<sup>8</sup> surveillance of survivors; clinical trial enrolment;<sup>9</sup> and screening for distress in AYAs.
- Development and establishment, in 2016, of a post-Fellowship AYA Oncology diploma program of the Royal College of Physicians and Surgeons for pediatric, medical and radiation oncologists.
- A multi-stakeholder workshop in May 2016 to establish a national action plan for onco-fertility.

These achievements provide a strong foundation for the next phase of national action designed to ultimately improve outcomes for young Canadians with cancer and enhance their quality of life.

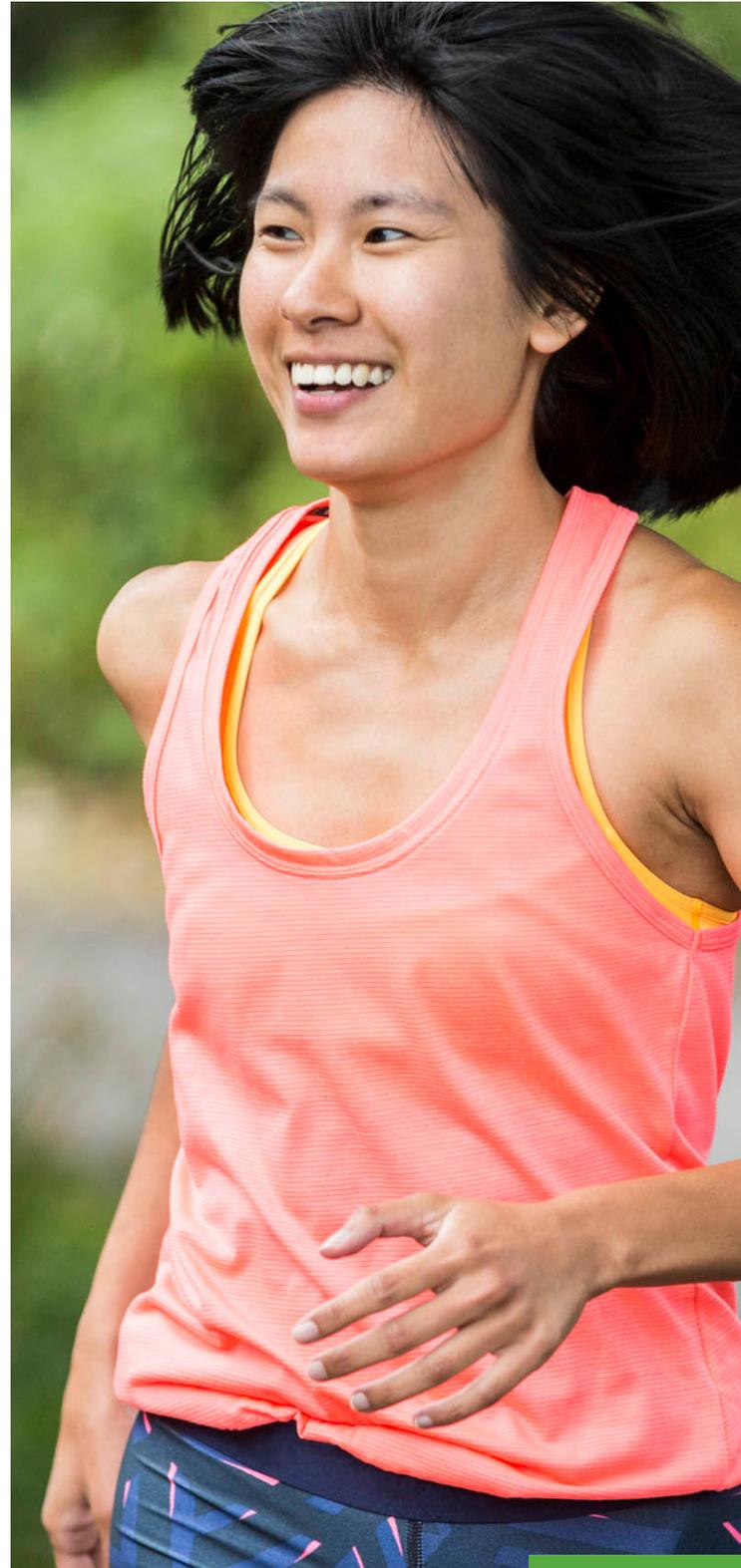


# THE CANADIAN FRAMEWORK FOR THE CARE AND SUPPORT OF AYAS WITH CANCER

## CONTEXT

*The Canadian Framework for the Care and Support of Adolescents and Young Adults with Cancer (the Framework)* describes a national vision for the care and support of AYAs with this distressing disease. It was created to ensure AYAs experience meaningful participation, and achieve the best outcomes, throughout care and survivorship, as well as compassionate end-of life support when needed. It was also created to address the unique needs that AYAs experience given their vulnerable and highly dynamic life stage. The Framework was developed in collaboration with, and based on input from, national leaders and experts in cancer and in consultation with AYAs and their families. The Framework was adopted and adapted from the Australian Youth Cancer Framework.<sup>10</sup>

The Framework sets out key **strategic priorities** and **supporting platforms** that each have defined actions that move us closer to our common ambitions for all AYAs. The actions are intentionally broad so that individual jurisdictions or organizations have flexibility to adapt their approach according to local context and systems capacity. The Framework is intended to complement and enhance national and local efforts, including related regional cancer plans and policies that improve outcomes for AYAs both in terms of the disease itself and the broader psychosocial and mental health and social challenges faced during care and survivorship.



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## ELEMENTS OF THE FRAMEWORK EXPLAINED

### VISION

The vision describes the desired future state of care and support provided to AYAs with cancer and their families, following successful implementation of the Framework.

### ASPIRATION

The aspiration for the plan outlines the intention of the Framework for leadership across Canada.

### STRATEGIC PRIORITIES

The four strategic priorities are intended to focus current activity, targeting key areas of unmet need. They may change over time.

### SUPPORTING PLATFORMS

The four supporting platforms of the Framework cut across and underpin the strategic priorities and support their achievement. They will remain integral to the Framework over time.

### ACTIONS

Under each of the strategic priorities and supporting platforms are high-level, strategic actions to support delivery and provide direction.

Actions and activities are described at three different levels:

- *Individual level* refers to actions to improve direct interactions between the care team, which includes health professionals or other service providers, and AYAs.
- *Services level* refers to interventions that apply across whole services, including health services, community support and other organizations important to an AYA's well-being, including education, capacity-building, vocational, financial and counselling services.
- *Systems level* refers to “bigger picture,” higher level interventions that are broader than the local service context (often national) and cut across geographic regions, services and/or sectors.

### WHAT SUCCESS WILL LOOK LIKE

These are a suite of multidimensional factors that are linked to the actions and are intended to reflect success at a national, service and individual level.



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## VISION AND ASPIRATION

### VISION

All AYAs with cancer in Canada receive optimal, developmentally-appropriate care and comprehensive survivorship support that lead to improved outcomes and high-quality life.

### ASPIRATION OF THIS FRAMEWORK

To provide national leadership to, and promote alignment among, stakeholders regarding the critical priorities that will bring all AYAs, their families and caregivers closer to the shared Vision.



# STRATEGIC PRIORITIES AND SUPPORTING PLATFORMS

## STRATEGIC PRIORITIES

The Framework has defined four strategic priorities that will guide the evolution of optimal, developmentally-appropriate care and comprehensive survivorship support for AYAs according to their specific needs. The strategic priorities are to:

- 1. Integrate an AYA-centred experience throughout care and survivorship:** AYAs and their families and caregivers are engaged as true partners, and services and support plans are adapted to the needs of the individual.
- 2. Deliver interdisciplinary, integrated and comprehensive care and survivorship support that address the unique needs of AYAs with cancer:** AYAs are cared for and strengthened by a team of healthcare professionals and support networks that address needs specific to AYAs both within and outside the health system.
- 3. Increase access to cutting-edge approaches to care and survivorship support for AYAs with cancer:** Opportunities to receive the best care and to participate in relevant clinical trials are available to all AYAs in an equitable manner.
- 4. Drive evidence-based improvements for AYAs with cancer:** Decision-making is based on sound evidence and informs optimal delivery of care and support, resourcing and evaluation, as well as relevant research tailored to this age group.

## SUPPORTING PLATFORMS

These strategic priorities are enabled by cross-cutting supporting platforms, which include:

**Partnerships:** Collaborations at all levels, both across and outside of the health system, are used to leverage resources, share insights and improve care and outcomes for AYAs.

**Workforce:** A team of qualified healthcare professionals and support staff are educated on and skilled to address the specific needs of AYAs.

**Research:** Studies, including clinical trials, are designed to address the unique needs of AYAs and evolve our approaches to care and survivorship for this age group.

**Data:** Information and datasets of relevance to AYAs are collected, evaluated and used by stakeholders across the priorities and at all levels for improved decision-making.

Taken together, the priorities and platforms work in harmony to move individuals, services and systems both within the clinic and the community toward more optimal, developmentally-appropriate care and comprehensive survivorship support for all AYAs.

Each **strategic priority** and **supporting platform** is associated with a set of actions to be considered at the individual, service and system level. The following framework depicts these actions in their appropriate context; subsequent sections elaborate on what success should look like following implementation.



# THE CANADIAN FRAMEWORK FOR THE CARE AND SUPPORT OF ADOLESCENTS AND YOUNG ADULTS WITH CANCER

<b>VISION</b>	All AYAs with cancer in Canada receive optimal, developmentally-appropriate care and comprehensive survivorship support that lead to improved outcomes and high-quality life.			
<b>STRATEGIC PRIORITIES</b>	1. Integrate an AYA-centred experience throughout care and survivorship	2. Deliver interdisciplinary, integrated and comprehensive care and survivorship support that address the unique needs of AYAs with cancer	3. Increase access to cutting-edge approaches to care and survivorship support for AYAs with cancer	4. Drive evidence-based improvements for AYAs with cancer
<b>ACTIONS</b>	<ul style="list-style-type: none"> <li> Create true alliances with AYAs with cancer and their families and caregivers</li> <li> Provide information and resources tailored to the AYA's perspective and context</li> <li> Develop services that can adapt to the unique circumstances of AYAs</li> <li> Facilitate self-management support outside of a cancer centre for improved coping and disease management</li> <li> Consolidate information for AYAs with cancer to support shared decision-making</li> </ul>	<ul style="list-style-type: none"> <li> Develop interdisciplinary, specialized care and survivorship plans to meet the needs of all AYAs</li> <li> Support AYAs in navigating the health system and beyond for long-term survivorship support</li> <li> Facilitate capable, specialized care and support networks for AYAs with cancer</li> <li> Support developmentally-appropriate design of facilities and services</li> <li> Identify opportunities, remove barriers and scale best practices to establish integrated systems for AYAs with cancer</li> </ul>	<ul style="list-style-type: none"> <li> Increase awareness and participation among AYAs in clinical trials</li> <li> Facilitate equitable access to research and clinical trials of relevance to AYAs with cancer</li> <li> Facilitate equitable access to care and support for AYAs with cancer</li> <li> Reduce barriers for AYAs to participate in clinical trials and research</li> <li> Facilitate access to technologies, treatments and approaches to survivorship support</li> </ul>	<ul style="list-style-type: none"> <li> Measure and monitor the experience of AYAs with cancer</li> <li> Create mechanisms that enable the use of data to inform improvements related to services, care, access and equity for AYAs with cancer</li> <li> Evaluate data to develop best practices and national guidances for AYAs with cancer</li> </ul>
<b>SUPPORTING PLATFORMS</b>	<b>PARTNERSHIPS</b>			
	Coordinate activities across the care and survivorship support pathways for AYAs with cancer	Participate in AYA-focused collaborations locally, regionally, nationally	Enable effective AYA-focused collaborations nationally and internationally to share experience, evidence and knowledge	
	<b>WORKFORCE</b>			
	Participate in continuous learning dedicated to AYAs with cancer	Ensure sustainable, capable workforce with expertise relevant to AYAs with cancer	Support capacity-building efforts to establish a sustainable and accessible AYA-focused workforce	
	<b>RESEARCH</b>			
Generate evidence for best practice treatment, access and support for AYAs with cancer	Advocate to expand existing research efforts toward AYAs with cancer	Advocate to expand national research capacity for AYAs with cancer	Inform health research agendas to target efforts to AYAs with cancer	
<b>DATA</b>				
Collect and contribute data related to care and support of AYAs with cancer	Implement systems to collect and share data related to AYAs with cancer	Leverage existing, or where needed develop, national datasets to create AYA-relevant data	Collect and report on performance indicators for AYAs with cancer	

Individual Level Action

Service Level Action

Systems Level Action

## PRIORITY #1: INTEGRATE AN AYA-CENTRED EXPERIENCE THROUGHOUT CARE AND SURVIVORSHIP

To provide the best care and survivorship support, AYAs and their families must be true partners among the team of healthcare professionals and community experts that influence their lives. This experience may last for years, beginning with initial testing, diagnosis and treatment, palliation and AYA-specific survivorship support that extends to long-term follow-up. For this reason, engagement with AYAs must occur consistently at all stages of care and survivorship with an appreciation for the pillars that form positive experiences (see figure below).

"Engaging with AYAs is super important. The age range is very diverse, with 15 year-olds thinking about university and 39 year-olds thinking about or already having kids. There is a need for getting lots of feedback across the group of AYAs."

-Samantha



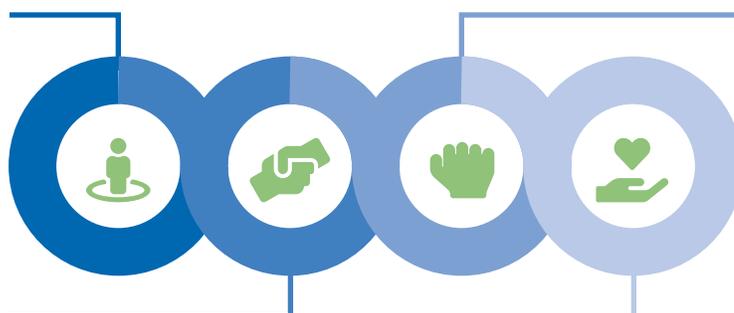
### PILLARS OF POSITIVE EXPERIENCE AND WHAT THEY MEAN

#### I AM A UNIQUE INDIVIDUAL

To be seen as an individual with unique preferences and a broader life beyond my disease (family, work, and culture).

#### I AM RESPECTED

To receive consistently delivered care that considers my time and preferences.



#### I AM EMPOWERED

To participate actively in my care by receiving tailored information that facilitates decision making and promotes self-care.

#### I AM SUPPORTED

To receive support for physical, emotional and practical needs in a way that alleviates my concerns and is culturally sensitive.

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## INDIVIDUAL LEVEL ACTION

### CREATE TRUE ALLIANCES WITH AYAS WITH CANCER AND THEIR FAMILIES AND CAREGIVERS

Stakeholders involved in AYA care and support should listen to, and work alongside AYAs and their families, including parents, siblings, children or other caregivers, and appropriately adapt their approach to care and survivorship support. This partnership must acknowledge individuality and cultural perspectives, a person's own clinical care and broader support needs as well as unique challenges to AYAs, including fertility, sexuality, relationships, mental health, cognition, education, employment and/or finances.

### PROVIDE INFORMATION AND RESOURCES TAILORED TO THE AYA'S PERSPECTIVE AND CONTEXT

Information based on solid evidence should be crafted and provided in a manner that acknowledges the variability in health literacy among AYAs and their caregivers. Information should provide life-stage, culturally-relevant detail in a manner that is easily consumed by patients and their families/caregivers and allow for knowledgeable decision-making by AYAs.

#### What success will look like for AYAs

AYAs and their families:

- Are communicated with about their specific care and needs at every stage across the cancer care pathway and are aware of potential impacts of treatment.
- Are aware of potential impacts of treatment to fertility and the fertility preservation options available to them.
- Feel listened to, empowered, informed, respected and supported to make decisions.
- Are aware of the support systems and resources available to them within and outside of the health system.

## SERVICE LEVEL ACTION

### DEVELOP SERVICES THAT CAN ADAPT TO THE UNIQUE CIRCUMSTANCES OF AYAS

Given different circumstances can exist among persons 15-39 years, services must have built-in flexibility to adapt. For this reason, organizations, within the healthcare system and beyond, should incorporate steps into their processes that consider a person's, family's and caregivers' own strengths, financial means, education or employment standing, fertility, relationship status, mental well-being, beliefs, culture, physical location, preferences and supportive needs to tailor care and survivorship support. Tools should be developed to capture this information systematically, support assessments and inform individualized plans that span care, follow-up, survivorship and if necessary, high-quality end-of-life support.

"Peer connection is so key...for me it was six months into treatment before I met a guy in the waiting room my own age. We had an incredible conversation."

-Michael

### FACILITATE SELF-MANAGEMENT SUPPORT OUTSIDE OF A CANCER CENTRE FOR IMPROVED COPING AND DISEASE MANAGEMENT

Since health outcomes and quality of life will be influenced by an AYA's ability to cope and manage when not within a cancer centre, organizations should empower independence with self-managed care and support options. These options must account for the capabilities and resilience of AYAs, especially for follow-up, palliation, survivorship challenges and upcoming life transitions that are unique to the person's development. They should also reinforce the power of peer networks, which bring an understanding of what it truly means to face cancer as an AYA and can provide that much needed personal connections.

#### What success will look like for AYAs

- The AYA's needs and preferences are heard, documented and appropriately adapted to.
- Information and tools to support AYAs in self-management are developed and made available.
- Timely provision of fertility information and referral for fertility preservation.
- AYAs should have access to peer support to connect with those facing similar challenges.

## SYSTEM LEVEL ACTION

### CONSOLIDATE INFORMATION FOR AYAS WITH CANCER TO SUPPORT SHARED DECISION-MAKING

System-level stakeholders will play a vital role in ensuring evidence-based resources and tools that cover the specific needs of AYAs are available and accessible, reporting best practices and empowering AYAs with the knowledge they need for shared decision-making about cancer care and beyond.

#### What success will look like for AYAs

- Relevant, evidence-based information and tools are available, accessible and used by AYAs.
- Access to fertility information and affordable fertility preservation options.

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## SUMMARY OF STRATEGIC PRIORITY #1: INTEGRATE AN AYA-CENTRED EXPERIENCE THROUGHOUT CARE AND SURVIVORSHIP

### INDIVIDUAL LEVEL

- Create true alliances with AYAs with cancer and their families and caregivers
- Provide information and resources tailored to the AYA's perspective and context

### SERVICE LEVEL

- Develop services that can adapt to the unique circumstances of AYAs
- Facilitate self-management support outside of a cancer centre for improved coping and disease management

### SYSTEM LEVEL

- Consolidate information for AYAs with cancer to support shared decision-making



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## PRIORITY #2: DELIVER INTERDISCIPLINARY, INTEGRATED AND COMPREHENSIVE CARE AND SURVIVORSHIP SUPPORT THAT ADDRESS THE UNIQUE NEEDS OF AYAS WITH CANCER

Given their rapidly changing, sometimes vulnerable, life stage, AYAs are unique, requiring a more comprehensive approach to care and support both within and beyond the walls of the health system. This also applies to survivors of childhood cancer transitioning into adolescence who require ongoing psychosocial and/or mental health support that can last for years. There is a need for interdisciplinary and integrated efforts that address these challenges across the care and survivorship journey.

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### INDIVIDUAL LEVEL ACTION

DEVELOP INTERDISCIPLINARY, SPECIALIZED CARE AND SURVIVORSHIP PLANS TO MEET THE NEEDS OF ALL AYAS

Upon diagnosis, AYAs and their families should have dedicated teams with, at minimum, nursing, medical and mental health expertise, to co-develop a plan with the patient and advise on treatment recommendations. For those with limited access to comprehensive support teams, virtual care options should be provided. Treatment and customized palliative care plans that leverage best-practices for the specific diagnosis should be clearly documented and shared in accordance with principles of Strategic Priority #1. A plan to transition into follow-up and survivorship, including ongoing screening and prevention of recurrence and/or secondary cancers should also be created (see next action).

*"For me, it wasn't the physical part that was so hard, it was the psychosocial... The whole thing throws your life for a loop. It is unexpected."*

*-Michael*

SUPPORT AYAS IN NAVIGATING THE HEALTH SYSTEM AND BEYOND FOR LONG-TERM SURVIVORSHIP SUPPORT

AYAs and survivors of previous childhood cancer often do not know what supplementary services are available to them. Within a cancer centre, teams must themselves be knowledgeable and take the time to raise awareness regarding available resources that an individual can use (e.g. gym, exercise equipment, library, peer support) to improve their experience and potential outcomes. Teams must also raise awareness for support outside of the cancer centre, including broader and ongoing mental health, vocation, education and peer support. And, because the needs or priorities of AYAs evolve over time, the availability of these resources should be frequently reemphasized.

#### What success will look like for AYAs

- AYAs have documented, individualized care plans to support seamless, coordinated care, including clearly documented plans for patients with transitions across rural-metropolitan locations, public-private sectors and/or pediatric-adult services.
- AYAs have access to and receive the right treatment, care and support by the right professionals, at the right time, taking into account their unique circumstances.
- AYAs receive psychosocial and mental health support to cope with a diagnosis, address personal developmental issues and social impacts (e.g. isolation), as well as guidance for engagement with education or work, or when needed, end-of-life care.

## SERVICE LEVEL ACTION

### FACILITATE CAPABLE, SPECIALIZED CARE AND SUPPORT NETWORKS FOR AYAS WITH CANCER

Leadership within the provincial/territorial ministries of health/cancer control agencies should play a role in organizing and coordinating networks of cross-sector services and teams to provide developmentally-appropriate, culturally-safe, interdisciplinary care across the cancer care pathway and broader survivorship journey for AYAs. This should include educating health professionals to increase awareness, knowledge and relevant referral pathways required to deliver this level of care.

### SUPPORT LIFE STAGE APPROPRIATE DESIGN OF FACILITIES AND SERVICES

When AYAs enter cancer clinics, they are unique compared to typical cancer patients who tend to be older. This creates a sense of unease, anxiety and tension that can impact patients psychologically. For this reason, spaces within cancer clinics should be designed to suit the needs of AYAs and their families.

#### What success will look like for AYAs

- AYAs experience a system that is coordinated and linked to community organizations that address the crucial support needed outside of the health system.
- Networks of healthcare professionals focused on AYAs and spanning specialized services are established to ensure exchange of information of relevance to this age-group and establish referral mechanisms to address comprehensive care and support needs.
- Cancer clinics are designed to suit the needs of AYAs and their families.

"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."

—Bronwen



## SYSTEM LEVEL ACTION

### IDENTIFY OPPORTUNITIES, REMOVE BARRIERS AND SCALE BEST PRACTICES TO ESTABLISH INTEGRATED SYSTEMS FOR AYAS WITH CANCER

Leaders can support this priority by identifying and removing barriers and scaling up best practices. The implementation of national and provincial/territorial policy and strategic plans should prioritize and facilitate the integration and access to comprehensive care and support, including calling on the pediatric and adult systems to work collaboratively. Integrated systems should also include monitoring of late effects from treatment, screening for early detection of recurrence and/or secondary cancers, linking with mental health support, education, employment and other contributors to long-term well-being and promoting healthy behaviours.

#### What success will look like for AYAs

- Resources across the system leverage knowledge of best practices for AYA care and support, and deliver improved coordination and navigation across the system.
- Variation of AYA care and survivorship support is minimized across the continuum of care and support.

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**SUMMARY OF STRATEGIC  
PRIORITY #2: DELIVER INTERDISCIPLINARY,  
INTEGRATED  
AND COMPREHENSIVE CARE  
AND SURVIVORSHIP SUPPORT  
THAT ADDRESS THE UNIQUE  
NEEDS OF AYAs WITH CANCER**

**INDIVIDUAL LEVEL**

- Develop interdisciplinary, specialized care and survivorship plans to meet the needs of all AYAs
- Support AYAs in navigating the health system and beyond for long-term survivorship support

**SERVICE LEVEL**

- Facilitate capable, specialized care and support networks for AYAs with cancer
- Support developmentally-appropriate design of facilities/services

**SYSTEM LEVEL**

- Identify opportunities, remove barriers and scale best practices to establish integrated systems for AYAs with cancer



## PRIORITY #3: INCREASE ACCESS TO CUTTING-EDGE APPROACHES TO CARE AND SURVIVORSHIP SUPPORT FOR AYAS WITH CANCER

Stakeholders involved in cancer care and survivorship support for AYAs have a role to play in ensuring access to best practices, the latest treatments and clinical trials designed to improve health outcomes and quality of life for AYAs with cancer.

### INDIVIDUAL LEVEL ACTION

#### INCREASE AWARENESS AND PARTICIPATION AMONG AYAS IN CLINICAL TRIALS

Healthcare professionals should discuss the potential benefit for AYAs and their families to participate in clinical trials using a shared decision-making process. AYAs and their families should also be aware of the risks associated with clinical trial participation, and healthcare professionals will ideally place emphasis on aspects covered during the consent process such as unrealistic expectations and false hope. Appropriate counseling should be provided to not aggravate an already stressful experience.

#### What success will look like for AYAs

- Health professionals have heightened awareness of relevant clinical and mental health research and clinical trials for AYAs.
- AYAs and their families are aware of opportunities to participate in clinical trials and research along with the potential benefits and risks.
- Discussions and decisions about participation in research and clinical trials are documented in care plans designed for AYAs.

### SERVICE LEVEL ACTION

#### FACILITATE EQUITABLE ACCESS TO RESEARCH AND CLINICAL TRIALS OF RELEVANCE TO AYAS WITH CANCER

Organizations that oversee and run clinical trials must encourage clinical studies and other research efforts to focus on the needs of AYAs and ensure equitable access to these efforts at a local level, particularly for underserved populations. Coordinated advocacy related to the focus of trials can drive multi-institutional efforts toward areas of greatest need for AYAs, helping to address the key barriers that currently exist at the institutional levels, including the small size of the patient population.

#### FACILITATE EQUITABLE ACCESS TO CARE AND SUPPORT FOR AYAS WITH CANCER

Organizations must work to identify and reduce barriers that prevent equitable access to the best care and support for AYAs and families. This is particularly important for underserved populations, including: First Nations, Inuit and Métis communities; LGBTQ communities; individuals in rural and remote locations, with culturally and linguistically diverse backgrounds; low socio-economic status or special healthcare needs. The use of virtual tools should be integrated when and where appropriate.

#### What success will look like for AYAs

- Access and recruitment of AYAs to trials is equitable compared to other age groups.
- National and international clinical trials/studies are accessible to AYAs in Canada.
- Networks leverage services and partnerships to facilitate access for underserved groups.
- Expanded use of technology to engage with and support AYAs.
- AYAs from underserved groups have equitable access to culturally and linguistically appropriate cancer services and survivorship support, and importantly have equitable outcomes.

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## SYSTEM LEVEL ACTION

### REDUCE BARRIERS FOR AYAS TO PARTICIPATE IN CLINICAL TRIALS AND RESEARCH

Barriers such as enrolling patients (e.g. AYAs under 18 years are unable to participate in adult trials), establishing networks of trial sites, and ensuring equitable access to trials should be examined, and appropriate solutions, such as incentives to public and private sector organizations should be developed and scaled across the country to enhance the opportunity for AYAs to participate in research.

### FACILITATE ACCESS TO TECHNOLOGIES, TREATMENTS AND APPROACHES TO SURVIVORSHIP SUPPORT

Stakeholders with influence over access to technologies, treatments and approaches to survivorship support should advocate for the increased availability, with a focus on key challenges unique to AYAs.

#### What success will look like for AYAs

- AYAs are represented in cohorts for clinical trials as barriers such as age are removed.
- AYAs have access to cutting-edge approaches which improve their care and survivorship support.



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## SUMMARY OF STRATEGIC PRIORITY #3: INCREASE ACCESS TO CUTTING-EDGE APPROACHES TO CARE AND SURVIVORSHIP SUPPORT FOR AYAs WITH CANCER

### INDIVIDUAL LEVEL

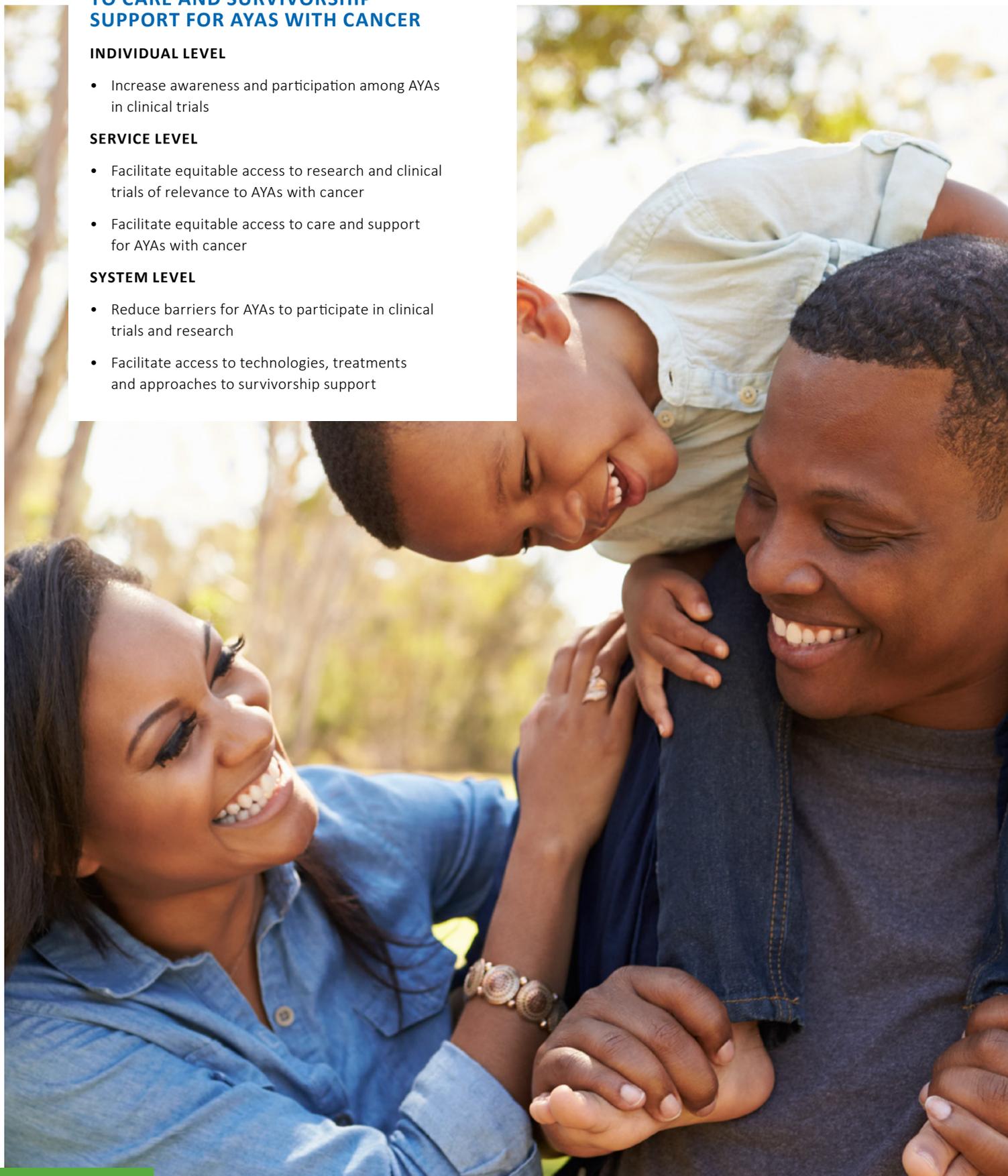
- Increase awareness and participation among AYAs in clinical trials

### SERVICE LEVEL

- Facilitate equitable access to research and clinical trials of relevance to AYAs with cancer
- Facilitate equitable access to care and support for AYAs with cancer

### SYSTEM LEVEL

- Reduce barriers for AYAs to participate in clinical trials and research
- Facilitate access to technologies, treatments and approaches to survivorship support



## PRIORITY #4: DRIVE EVIDENCE-BASED IMPROVEMENTS FOR AYAS WITH CANCER

Routinely collected and reported data and indicators on the care and support of AYAs should drive evidence-based care and survivorship support, appropriate resourcing, effective program evaluation and research.

### INDIVIDUAL LEVEL ACTION

MEASURE AND MONITOR THE EXPERIENCE OF AYAS WITH CANCER

During the course of treatment and survivorship, health care professionals should seek feedback from AYAs and their families about their experiences, self-reported outcomes and needs across the cancer care pathway.

#### What success will look like for AYAs

- Tools are available for AYAs to capture their care and survivorship experience and quality of life outcomes.
- Individual care plans for AYAs are adjusted based on patient reported outcomes and experiences.

### SERVICE LEVEL ACTION

CREATE MECHANISMS THAT ENABLE THE USE OF DATA TO INFORM IMPROVEMENTS RELATED TO SERVICES, CARE, ACCESS AND EQUITY FOR AYAS WITH CANCER

Tools and mechanisms should be developed to measure, track and evaluate the effectiveness of new AYA cancer programs against key indicators and report findings to support decision-making. AYA-reported outcomes and feedback inform service improvements, gaps and priorities.

#### What success will look like for AYAs

- A system of information exchange is established.
- Data and indicators about AYAs are regularly monitored, reported, reviewed and communicated.
- Policies and processes are in place to support integrated and real-time information exchange.

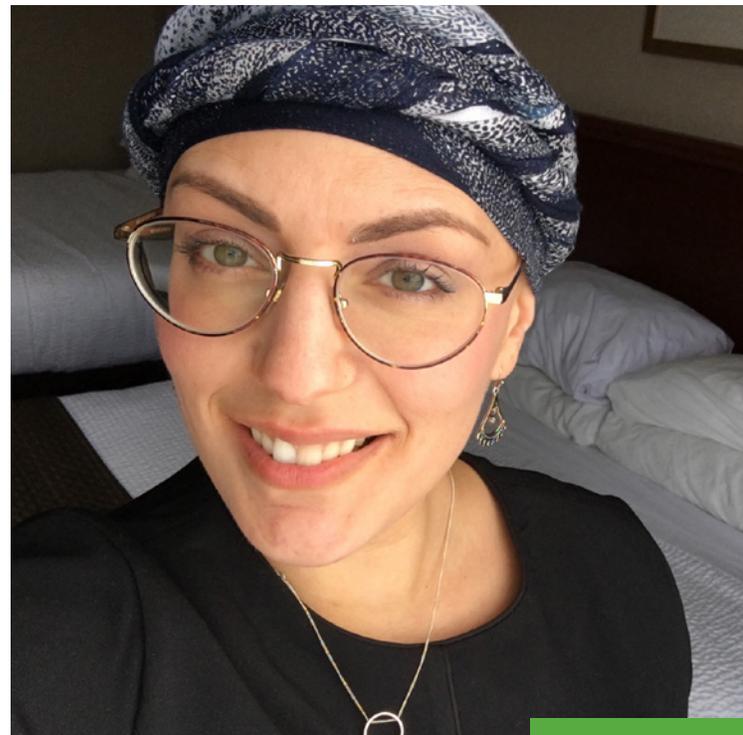
### SYSTEM LEVEL ACTION

USE DATA TO DEVELOP BEST PRACTICES AND NATIONAL GUIDELINES FOR AYAS WITH CANCER

To deliver best practice care, better understand the patient experience, inform continuous improvement and decrease variation in care, mechanisms must be established to review and monitor qualitative and quantitative data.

#### What success will look like for AYAs

- Data and indicators on AYAs can be compared and promising practices are identified and scaled up jurisdictionally and across the country.
- Data and information drive improvements in the quality of cancer systems and outcome improvements.



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## SUMMARY OF STRATEGIC PRIORITY #4: DRIVE EVIDENCE-BASED IMPROVEMENTS FOR AYAs WITH CANCER

### INDIVIDUAL LEVEL

- Measure and monitor the experience of AYAs with cancer

### SERVICE LEVEL

- Create mechanisms that enable the use of data to inform improvements related to services, care, access and equity for AYAs with cancer

### SYSTEM LEVEL

- Use data to develop best practices and national guidelines for AYAs with cancer



## PLATFORM #1: PARTNERSHIPS DEDICATED TO AYAS WITH CANCER

Community, regional and provincial/territorial partnerships within and outside the health system must be established, nurtured and leveraged to accelerate efforts aimed at improving the experience and outcomes for AYAs.

### INDIVIDUAL LEVEL ACTION:

COORDINATE ACTIVITIES ACROSS THE CARE AND SURVIVORSHIP SUPPORT PATHWAYS FOR AYAS WITH CANCER, inclusive of healthcare professionals working with relevant primary and specialist care providers and extending to survivorship support circles inclusive of organizations focused on, for example, housing, mental health, social services, education, vocation, among other areas of need for AYAs. *Together, partnerships can ensure that efforts and resources are not duplicated, and efficient care referrals and comprehensive support networks are solidified to improve care for AYAs.*

### SERVICE LEVEL ACTION:

PARTICIPATE IN AYA-FOCUSED COLLABORATIONS LOCALLY, REGIONALLY, NATIONALLY by implementing processes, systems and tools that allow groups to share experience, evidence, knowledge and research findings and take advantage of progress made in various jurisdictions. *These collaborations can lead to feedback loops on services and programs that inform continuous improvement and lead to more effective and comprehensive service delivery models.*



### SYSTEM LEVEL ACTION:

ENABLE EFFECTIVE AYA-FOCUSED COLLABORATIONS NATIONALLY AND INTERNATIONALLY TO SHARE EXPERIENCE, EVIDENCE AND KNOWLEDGE by engaging with organizations that touch on different dimensions of need for AYAs during treatment and throughout survivorship, capturing best practices of relevance to AYAs in Canada and scaling them appropriately to achieve consistency. *These efforts should facilitate the synthesis and distribution of best practices throughout Canada.*

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## PLATFORM #2: WORKFORCE TRAINED TO ADDRESS THE NEEDS OF AYAS WITH CANCER

Qualified professionals with deep knowledge of age, development and disease specific care needs of AYAs will ultimately lead to more person-centred care. Efforts to foster the workforce and engage in continuing education will be beneficial.

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### INDIVIDUAL LEVEL ACTION:

PARTICIPATE IN CONTINUOUS LEARNING DEDICATED TO AYAS WITH CANCER. Individuals who provide support and care for AYAs seek out opportunities to improve practice, understand the latest research related to care and survivorship and participate in multidisciplinary mentorship opportunities. *These efforts should ultimately increase the quality of care and support for AYAs as well increase workforce competency.*

### SERVICE LEVEL ACTION:

ENSURE SUSTAINABLE, CAPABLE WORKFORCE WITH EXPERTISE RELEVANT TO AYAS WITH CANCER by facilitating knowledge sharing and by promoting multidisciplinary mentorship and learning. These efforts should include general oncologists as well as specialists in AYA oncology.<sup>11</sup> For example, support can be provided to the workforce to participate in continuing professional education programs dedicated to topics of interest to AYAs. *These opportunities should enhance the general knowledge and skills for working with AYAs, including respecting their autonomy, improving stakeholders' understanding of developmental and age-related issues and increasing awareness for appropriate referrals to comprehensive care and survivorship supports.*



"There could be more teaching about the AYA population so healthcare professionals know how to change their approach before they walk into a room with an AYA with cancer."

-Kirsten

### SYSTEM LEVEL ACTION:

SUPPORT CAPACITY-BUILDING EFFORTS TO ESTABLISH A SUSTAINABLE AND ACCESSIBLE AYA-FOCUSED WORKFORCE by creating professional development frameworks and competencies establishing multi-level strategies to address skill gaps, linking specialist teams with local community clinicians, forming national and international collaborations to avoid duplication, creating opportunities for mentorship for healthcare professionals, and scaling proven education and knowledge mobilization models such as learning communities comprised of AYA experts and other healthcare professionals to share experiences, knowledge, and best practices. *These efforts should result in decreased variation and increased consistency in good, high quality care for AYAs.*

"The diagnosis took time, very much so; I did not think I had a problem I was young and did not think anything was serious; so did others. They tried to rule out other things first."

-Bronwen

## PLATFORM #3: RESEARCH FOCUSED ON THE NEEDS OF AYAS WITH CANCER

AYAs remain an under-studied group. Research on the biology and epidemiology of cancers in this age group is limited, and enrollment of AYAs in clinical trials in Canada is insufficient.

### INDIVIDUAL LEVEL ACTION:

GENERATE EVIDENCE FOR BEST PRACTICE TREATMENT, ACCESS AND SUPPORT FOR AYAS WITH CANCER by conducting the appropriate health services research. This research would ideally be supported by collaboration and partnership across the country and with patients and their families. *It will, enhance the scale and scope of the efforts, increase the impact of research, contribute valuable data to national datasets and boost Canada's contribution to the international literature on AYA cancer care.*

### SERVICE LEVEL ACTION:

ADVOCATE TO EXPAND EXISTING RESEARCH EFFORTS TOWARD AYAS WITH CANCER by designing and implementing mechanisms and models to support research within relevant organizations. *These mechanisms should focus and incentivize efforts to address unmet needs of AYAs and build an evidence base that can be translated to the frontlines of care and support using best practices.*

### SYSTEM LEVEL ACTION:

ADVOCATE TO EXPAND NATIONAL RESEARCH CAPACITY FOR AYAS WITH CANCER by partnering and advocating with Canadian and international research bodies to extend the age-eligibility criteria of existing and proposed oncology research to include AYAs. *Ideally, these efforts will increase the number of cancer research studies and clinical trials including 15–39 year-olds in their patient cohorts.*

INFORM HEALTH RESEARCH AGENDAS TO TARGET EFFORTS TO AYAS WITH CANCER by dedicating resources to identify research gaps and priorities, supporting high-quality research proposals across dimensions such as health services, health economics and cost-effectiveness. *These efforts should ultimately aim to deliver a comprehensive, sustainable and innovative national research agenda for youth cancer and ensure that Canadian researchers are part of a global research agenda for AYAs.*



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## PLATFORM #4: DATA RELEVANT TO AYAS WITH CANCER

For AYAs, there remain many critical data gaps, including AYA-focused transition statistics into survivorship or end-of-life care, deeper socioeconomic impact statistics and clinical trial data. These gaps impair our ability for sound decision-making, advocacy and resource allocation.

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### INDIVIDUAL LEVEL ACTION:

COLLECT AND CONTRIBUTE DATA RELATED TO CARE AND SUPPORT OF AYAS WITH CANCER with an aim to gather statistics across the continuum of care and prioritization on key indicators. Efforts to gather data from patients through Patient Reported Outcomes (PROs) should also be prioritized and will provide a deeper understanding of health outcomes and quality of life from those who experience them. *These efforts will contribute to improved decision-making and patient-centred care.*

### SERVICE LEVEL ACTION:

IMPLEMENT SYSTEMS TO COLLECT AND SHARE DATA RELATED TO AYAS WITH CANCER with a focus on seamless, effective tools integrated within cancer care and support services and utilized through the cancer journey—during treatment, palliation, survivorship, life-long follow-up, surveillance and end-of-life care. *Efforts will lead to continuous improvement within patient care and services.*



### SYSTEM LEVEL ACTION:

LEVERAGE EXISTING AND/OR DEVELOP NATIONAL AYA DATA with partners. Data will be useful for measuring effectiveness of cancer care for AYAs at the local, national and international level. *This data should be consistently collected for monitoring, measuring, reporting and evaluating programs, clinical outcomes and gaps in care.*

COLLECT AND REPORT ON PERFORMANCE INDICATORS FOR AYAS WITH CANCER leveraging new data collection opportunities and incorporating these into a broader national evaluation framework. This information should leverage broader jurisdictional, national and international data initiatives and linkage opportunities and be benchmarked to global comparators. *In the end, national indicators will be mapped to the cancer care pathway, and analysis of national youth cancer data will identify areas where Canada is leading or lagging.*

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## SUMMARY OF SUPPORTING PLATFORM ACTIONS

### INDIVIDUAL LEVEL

- Coordinate activities across the care and survivorship support pathways for AYAs with cancer (partnerships)
- Participate in continuous learning dedicated to AYAs with cancer (workforce)
- Generate evidence for best practice treatment, access and support for AYAs with cancer (research)
- Collect and contribute data related to care and support of AYAs with cancer (data)

### SERVICE LEVEL

- Participate in AYA-focused collaborations locally, regionally, nationally (partnerships)
- Ensure sustainable, capable workforce with expertise relevant to AYAs with cancer (workforce)
- Advocate to expand existing research efforts toward AYAs with cancer (research)
- Implement systems to collect and share data related to AYAs with cancer (data)

### SYSTEM LEVEL

- Enable effective AYA-focused collaborations nationally and internationally to share experience, evidence and knowledge (partnerships)
- Support capacity-building efforts to establish a sustainable and accessible AYA-focused workforce (workforce)
- Advocate to expand national research capacity for AYAs with cancer (research)
- Inform health research agendas to target efforts to AYAs with cancer (research)
- Leverage existing and/or develop national AYA data with partners (data)
- Collect and report on performance indicators for AYAs with cancer (data)



## WHAT OVERALL SUCCESS LOOKS LIKE

What success looks like

The actions recommended in the Framework are aimed at ensuring that all AYAs in Canada and their families receive optimal, developmentally-appropriate care and comprehensive survivorship support that leads to improved survival and healthy, high-quality life. To envision what this will look like for an AYA at different stages of his or her cancer journey, let's use the example of a hypothetical patient called Anna.

Anna starts to feel unwell and sees her family doctor who, taking her symptoms seriously, refers her for some preliminary investigations and then on to an appropriate specialist who makes a diagnosis of cancer. She quickly sees an oncologist who is aware of the special needs of young patients with cancer and the resources they may require. Anna's specialist explains the type of cancer Anna has and the optimal treatment options available—as well as associated risks such as potential impact on fertility. At the same time, Anna is introduced to the rest of her care team: a nurse, a social worker and a system navigator who have been trained in supporting AYAs. Anna works with her care team and her family to draft a care and support plan detailing her palliative care and treatment regimen and the psychosocial and/or mental health support activities Anna will receive. Anna is also informed about the importance and use of Patient-Reported Outcomes (PROs) for monitoring her progress and helping the field learn more about cancer in AYAs and is provided with tools to capture these insights. Through the system navigator, Anna's family doctor is also looped into the process for visibility and to promote smooth transitions between care settings.

Anna talks to her care team about her school and work situation, as well as social or financial issues that could impact her treatment. Anna is also referred to a peer-support network where she can share her experience and learn from other AYAs. Because there is a lot to process and because Anna's situation will evolve over the course of her journey, Anna's care team follow up frequently to monitor her cancer, and to revise her care and support plan based on her situation and new research studies on cancer in AYAs. When appropriate, Anna is also informed of AYA-specific clinical trials across Canada—which have grown in number due to advocacy and a stronger commitment to research—that she could enroll in to gain access to new investigational therapies regardless of the province or territory that she resides in. These follow-ups, which can be conducted virtually through tools like telehealth, will also provide her team with opportunities to understand Anna's life outside the cancer centre and to remind her of the different support resources available to her.

After her final treatment, Anna checks in with her care team, as well as her family doctor, to plan her follow-up appointments and ensure access to AYA-specific survivorship support, including peer support and psychosocial and/or mental health support and for help with engaging in school and work to ensure her optimal quality of life.

Throughout her journey, Anna feels like a true partner in her care and survivorship support—listened to, informed and supported—enabling Anna, her family and caregivers and her team of healthcare professionals to provide her with the best possible developmentally-appropriate care and survivorship support that optimizes her quality of life.

AYAs face a unique and daunting set of challenges. AYAs are reaching major life milestones like living away from parents, going to high school or post-secondary education, entering the workforce, cultivating social and romantic relationships and having children. These milestones are often coupled with strong emotional, social and financial challenges that can exacerbate the management of cancer diagnosis, treatment and survivorship.

This Framework articulates the vision for improving care and survivorship support for AYAs in Canada and outlines strategic priorities and supporting platforms as well as recommended actions to help achieve the vision. Actions have been purposely described at a high level in order to inspire the implementation of tailored policies, programs and resources at various levels across Canada.

*"Everyone involved in treating AYAs with cancer is doing a good job but as professionals, patients and advocates, we can always do better. Let's make a commitment and invest in areas that will really make a difference for AYAs that have to face this difficult journey."*

—Chris

It is hoped that everyone involved in the care and support of AYAs—patients and their families, peers, oncologists, nurses, social workers, healthcare and research administrators and government policymakers—will use the Framework to inspire and guide the design, execution and scale up, evaluation and improvement of policies, programs and resources. It will take all stakeholders working together to champion and bring required efforts to life in order to drive much-needed improvements in the engagement of, and care and support for, AYAs across all stages of their cancer journey and beyond.



Stakeholders should use this Framework to accelerate their efforts aimed at alleviating the unique burdens faced by AYAs and to ensure that all AYAs in Canada and their families receive optimal, developmentally-appropriate care and comprehensive survivorship support that lead to improved survival and healthy, high-quality life.

# APPENDIX A: INDIVIDUAL-, SERVICE- AND SYSTEM-LEVEL SPECIFIC ACTIONS

## CANADIAN FRAMEWORK FOR THE CARE AND SUPPORT OF ADOLESCENTS AND YOUNG ADULTS WITH CANCER: SUMMARY OF INDIVIDUAL LEVEL ACTIONS

<b>VISION</b>	All AYAs with cancer in Canada receive optimal, developmentally-appropriate care and comprehensive survivorship support that lead to improved outcomes and high-quality life.	
 <b>Individual Level Actions by Priority and Supporting Platform</b>		
<b>STRATEGIC PRIORITIES</b>	<b>1. Integrate an AYA-centred experience throughout care and survivorship</b>	Create true alliances with AYAs with cancer and their families and caregivers Provide information and resources tailored to the AYA's perspective and context
	<b>2. Deliver interdisciplinary, integrated and comprehensive care and survivorship support that address the unique needs of AYAs with cancer</b>	Develop interdisciplinary, specialized care and survivorship plans to meet the needs of all AYAs Support AYAs in navigating the health system and beyond for long-term survivorship support
	<b>3. Increase access to cutting-edge approaches to care and survivorship support for AYAs with cancer</b>	Increase awareness and participation among AYAs in clinical trials
	<b>4. Drive evidence-based improvements for AYAs with cancer</b>	Measure and monitor the experience of AYAs with cancer
<b>SUPPORTING PLATFORMS</b>	<i>Partnerships</i>	Coordinate activities across the care and survivorship support pathways for AYAs with cancer
	<i>Workforce</i>	Participate in continuous learning dedicated to AYAs with cancer
	<i>Research</i>	Generate evidence for best practice treatment, access and support for AYAs with cancer
	<i>Data</i>	Collect and contribute data related to care and support of AYAs with cancer

## CANADIAN FRAMEWORK FOR THE CARE AND SUPPORT OF ADOLESCENTS AND YOUNG ADULTS WITH CANCER: SUMMARY OF SERVICE LEVEL

<b>VISION</b>	All AYAs with cancer in Canada receive optimal, developmentally-appropriate care and comprehensive survivorship support that lead to improved outcomes and high-quality life.
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### Service Level Actions by Priority and Supporting Platform

		<b>Service Level Actions by Priority and Supporting Platform</b>
<b>STRATEGIC PRIORITIES</b>	<b>1. Integrate an AYA-centred experience throughout care and survivorship</b>	<p>Develop services that can adapt to the unique circumstances of AYAs</p> <p>Facilitate self-management support outside of a cancer centre for improved coping and disease management</p>
	<b>2. Deliver interdisciplinary, integrated and comprehensive care and survivorship support that address the unique needs of AYAs with cancer</b>	<p>Facilitate capable, specialized care and support networks for AYAs with cancer</p> <p>Support developmentally-appropriate design of facilities and services</p>
	<b>3. Increase access to cutting-edge approaches to care and survivorship support for AYAs with cancer</b>	<p>Facilitate equitable access to research and clinical trials of relevance to AYAs with cancer</p> <p>Facilitate equitable access to care and support for AYAs with cancer</p>
	<b>4. Drive evidence-based improvements for AYAs with cancer</b>	Create mechanisms that enable the use of data to inform improvements related to services, care, access and equity for AYAs with cancer
<b>SUPPORTING PLATFORMS</b>	<b>Partnerships</b>	Participate in AYA-focused collaborations locally, regionally, nationally
	<b>Workforce</b>	Ensure sustainable, capable workforce with expertise relevant to AYAs with cancer
	<b>Research</b>	Advocate to expand existing research efforts toward AYAs with cancer
	<b>Data</b>	Implement systems to collect and share data related to AYAs with cancer

## CANADIAN FRAMEWORK FOR THE CARE AND SUPPORT OF ADOLESCENTS AND YOUNG ADULTS WITH CANCER: SUMMARY OF SYSTEM-LEVEL ACTIONS

<b>VISION</b>	All AYAs with cancer in Canada receive optimal, developmentally-appropriate care and comprehensive survivorship support that lead to improved outcomes and high-quality life.
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### System Level Actions by Priority and Supporting Platform

<b>STRATEGIC PRIORITIES</b>	<b>1. Integrate an AYA-centred experience throughout care and survivorship</b>	Consolidate information for AYAs with cancer to support shared decision-making
	<b>2. Deliver interdisciplinary, integrated and comprehensive care and survivorship support that address the unique needs of AYAs with cancer</b>	Identify opportunities, remove barriers and scale best practices to establish integrated systems for AYAs with cancer
	<b>3. Increase access to cutting-edge approaches to care and survivorship support for AYAs with cancer</b>	Reduce barriers for AYAs to participate in clinical trials and research Facilitate access to technologies, treatments and approaches to survivorship support
	<b>4. Drive evidence-based improvements for AYAs with cancer</b>	Evaluate data to develop best practices and national guidances for AYAs with cancer
<b>SUPPORTING PLATFORMS</b>	<b>Partnerships</b>	Enable effective AYA-focused collaborations nationally and internationally to share experience, evidence and knowledge
	<b>Workforce</b>	Support capacity-building efforts to establish a sustainable and accessible AYA-focused workforce
	<b>Research</b>	Advocate to expand national research capacity for AYAs with cancer Inform health research agendas to target efforts to AYAs with cancer
	<b>Data</b>	Leverage existing, or where needed develop, national datasets to create AYA-relevant data Collect and report on performance indicators for AYAs with cancer

## APPENDIX B: GLOSSARY OF TERMS

### **ADOLESCENTS AND YOUNG ADULTS WITH CANCER (AYAS)**

This refers to people aged 15 to 39 years when diagnosed with cancer, with flexibility to accommodate developmentally younger or older people to meet an individual patient's needs. AYAs include survivors of childhood cancer.

The age range of 15 to 39 years is also appropriate for and consistent with epidemiological studies and data collection practices.

### **CANCER CARE PATHWAY**

Describes all stages of the cancer care journey, from prevention and diagnosis, palliative care and treatment through to monitoring, survivorship issues, end-of-life care, late effects of treatment and life-long support within and beyond the healthcare setting.

### **CANCER SURVIVORSHIP**

Cancer survivorship has different phases and means different things to different people. For the purpose of this Framework, cancer survivorship refers to anyone who has finished and is recovering from their active cancer treatment, is on maintenance therapy, is having ongoing treatment for cancer that is stable and slow growing, is on active surveillance or is in remission.<sup>12</sup> It is important to note that there are various definitions of cancer survivorship.<sup>13</sup> Some organizations adopt a much broader definition than the definition used for the Framework. Regardless, early integration of survivorship planning and care is important.

### **CANCER SURVIVORSHIP CARE PLANS**

Cancer survivorship care plans are individualized plans of care that are constructed through a holistic assessment and implemented at the conclusion of cancer treatment. Survivorship care plans are intended to facilitate communication and information sharing related to survivorship care and can be provided to both survivors and other healthcare providers caring for the survivor. The AYA care plan should include a summary of treatment and a detailed plan for ongoing care based on the type of cancer, including follow-up schedules for visits and testing, as well as recommendations for early detection and management of treatment-related effects and other health problems. It may include information to help meet the emotional, social, legal and financial needs of the AYA survivor, as well as referrals to specialists and recommendations for a healthy lifestyle.

### **END-OF-LIFE**

End-of-life care is supportive and compassionate care that focuses on comfort, quality of life, respect for personal healthcare treatment decisions, support for the family, and psychological, cultural and spiritual concerns for people with advanced progressive disease and their families.<sup>14</sup>

### **FAMILY**

The Framework refers to both AYAs and their family – families play a critical role in supporting AYAs through their cancer care and survivorship journey. The concept of family is broad and unique to each individual. It can represent a broader set of close family members other than parents, such as siblings, grandparents, extended family members or a partner or spouse.

### **FOLLOW-UP**

Cancer follow-up care consists of monitoring for signs of recurrence, management of adverse effects of treatment and the detection and management of comorbid conditions (e.g., cardiac conditions and mental health).<sup>15</sup>

### **INTERDISCIPLINARY CARE**

Interdisciplinary care happens when medical, nursing and allied health professionals involved in a patient's treatment together consider all treatment options and personal preferences of the patient and collaboratively develop an individual care plan that best meets the needs of that patient.

### **MENTAL HEALTH**

Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.<sup>17</sup>

### **PALLIATIVE CARE**

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.<sup>17</sup>

### **PEERS**

Include individuals currently living with or having survived cancer, who bring a wide range of related experiences and can share insights and provide support to other AYAs on their cancer journey.

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## PERSON-CENTRED CARE

To best support AYAs and their families – from the moment they start wondering if they have cancer to post-treatment care – it is essential to treat them as individuals with a reality that extends beyond being a cancer patient. A healthcare system guided by a person-centred approach recognizes this and establishes a partnership among everyone involved – healthcare providers, patients and loved ones.

In Canada’s cancer control system, shifting toward person-centred care means

- 1. Expanding from “episodes of care” to an extended care continuum.** Throughout the course of diagnosis, treatment and follow-up care, living with cancer is a continuous experience for patients and families. Delivering integrated care that coordinates services across all phases of the cancer journey – while being considerate of travel concerns, barriers to accessing services and cultural preferences – is an essential element of person-centred care.
- 2. Recognizing that the patient experience is a dimension of quality and empowering patients to be co-designers of care services.** The patient experience is recognized internationally as one of the foundations of high-quality care. Providing a positive patient experience should therefore be top of mind during the design, planning and delivery of cancer care services. Patients and families have fundamental knowledge about what their cancer experience is like and what is needed to improve their quality of life. The healthcare system should therefore look for opportunities to involve patients when identifying, implementing and evaluating improvement to healthcare services.
- 3. Aligning patient’s and clinician’s concepts of what a positive experience is.** A gap often exists between what patients and their families want and what health care providers think they want. A relationship between the person with cancer and the clinicians who provide care should be based on reciprocity, active listening and sharing of the knowledge and preferences of everybody involved. It is crucial that clinicians hold discussion that encourage patients to express their personal needs and preferences, paying particular attention to complex needs of individuals in low-income, Indigenous, immigrant and rural groups, among others. This enables a personalized approach to care to create the best possible experiences, as defined by all individuals concerned.

## PSYCHOSOCIAL CARE

Psychosocial care is a whole-person approach to cancer care, addressing the social, psychological, emotional, spiritual and functional aspects of the patient journey. AYAs can experience changes in how they think, in their feelings, moods, beliefs and ways of coping and in their relationships with family, friends and co-workers. There are different kinds of psychosocial supports that can help cancer patients, including counseling, education, group support and spiritual support.

## WORKFORCE

In the context of the Framework, workforce refers to people engaged in actions whose primary intent is to enhance the health of AYAs. The workforce can include clinical staff, such as oncologists, primary care physicians, nurses, pharmacists, as well as others that provide care and support for AYAs, such as social workers and system navigators. The workforce also includes those who address mental health and psychosocial care and support.

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