



VICTORIAN  
COMPREHENSIVE  
CANCER CENTRE

Overcoming Cancer Together

## **Paediatric-Adult Oncology Collaboration Framework**

A guide to the establishment of collaborative craft groups across paediatric and adult oncology (AYA Craft Groups) to advance the care of young people with cancer



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# 1. Introduction

## 1.1 Objectives

The primary objective of this Framework is to describe a mechanism through which improved communication and collaboration can be achieved between adult and paediatric oncology. This will support:

- Improved awareness of AYA treatment standards across the oncology sector
- Improved awareness of adolescent and young adult (AYA) clinical trials open across paediatric and adult oncology centres
- Improved access to clinical trials for AYA through collaborative decision making around appropriate oncology care pathways
- Improved availability of clinical trials open across the AYA age range of 15 – 25 years via collaborative trial development
- Reduced duplication of research efforts between paediatric and adult oncology
- Improvements to AYA treatment standards over time

## 1.2 Context

In Victoria, around 300 people aged between 15 and 25 years are diagnosed with cancer each year (Source: Victorian Cancer Registry data 2015 – 2017, Cancer Council Victoria). These adolescents and young adults (AYA) sit on the boundary between paediatric and adult oncology care. There is a significant division between paediatric and adult health care in Australia, where access to clinical care at a paediatric hospital is generally limited to those aged under 18 years. Conversely, care in an adult hospital is limited to those aged 16 years and above.

However, cancer biology does not follow these relatively arbitrary age divisions. AYA are diagnosed with a diverse spectrum of cancer types, and several cancers peak in incidence in the AYA years. Adolescents can develop cancers that more commonly occur in adults, and conversely, young adults can develop cancers that are considered more paediatric in nature (1). This presents challenges for the provision of care, where the most appropriate oncology expertise may not easily be accessed due to age-based hospital access policies. As an extension of this, relevant cancer clinical trials may not be accessible for similar reasons (2).

It is well recognised internationally that AYA enrolment in cancer clinical trials occurs at a frequency that is lower than for younger children, and for older adults (3). This is considered a consequence of a lack of trial availability and access due to division between adult and paediatric oncology. Where a cancer type occurs more commonly in adult patients, clinical trials are usually led by adult oncologists, may have an age eligibility that is restricted to those 18 years of age and over (despite the cancer also occurring in adolescents), and are often only opened in adult cancer centres where access for younger adolescents may be restricted by hospital access policies.



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Conversely, young adults may face barriers in accessing a clinical trial focussed on a paediatric-type cancer, led by paediatric oncologists, and open only in paediatric cancer centres. Additionally, awareness of the existence of an appropriate clinical trial will likely be lower if the trial is open on the other side of the paediatric-adult clinical divide from which the AYA is receiving care (4).

The AYA cancer clinical trial access problem is multifaceted and founded in long-established health care policy. Significant effort internationally has so far failed to identify a broadly effective solution (3). However, it is clear that creating a ‘bridge’ between adult and paediatric oncology care would assist to lessen the problem through improved communication regarding the most appropriate care pathways and open clinical trials in both settings. Additionally, such a bridge should encourage increased research collaboration, promoting the establishment of clinical trials with broader age eligibilities that are accessible by AYA across the 15 – 25 year age range, and reducing potential for duplication of age-siloed research efforts. As such, this framework sets out to describe a paediatric-adult oncology liaison (‘AYA Craft Group’) model to promote and support key opportunities for effective communication across oncology services, with the broad aim of improved clinical care for AYA with cancer.

### **1.3 Purpose of the AYA Craft Group Framework**

The purpose of the Framework is to facilitate improved communication and collaboration between paediatric and adult oncology in order to promote improvements in cancer clinical care for young people diagnosed with cancer between the ages of 15 and 25 years.

The vision is to facilitate regular and deliberate paediatric-adult oncology knowledge-sharing around current and upcoming clinical trials that may be relevant to the AYA population, and to create an environment that encourages collaboration in the design of future AYA clinical trials.

This collaborative framework will assist in addressing the strategic priorities of the Australian Youth Cancer Framework for Adolescents and Young Adults with Cancer (5), particularly as they relate to clinical trial availability and equity of access.

### **1.4 Victorian Comprehensive Cancer Centre Program Support**

The AYA Craft Group Model has developed from the work of two cancer programs currently (2019) run by the Victorian Comprehensive Cancer Centre (VCCC), with the support of the Victorian Government. These are:

- Increasing AYA Access to Cancer Clinical Trials Program. The aim of this program is to identify the local barriers to clinical trial access for AYA and develop solutions to these barriers. A Steering Committee, and three Working Groups, have focussed on solutions to barriers related to clinical trial access, availability and ethics. Development of the Framework has been a focus of the Availability Working Group.
- Research and Education (R&E) Leads Program. This program aims to systematise collaboration across the VCCC Alliance Partners in order to better integrate research, education, and clinical care. A key element is building leadership and networks for tumour streams and cancer themes. Current R&E Lead Streams/Themes of most relevance to AYA oncology include:

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- Sarcoma
  - CNS and Brain
  - Haematology
  - Genitourinary

Themes not yet specifically incorporated in the R&E Leads Program, but of relevance to AYA include Early Drug Discovery/Molecular Sequencing.

## **2 Description of the Craft Group Framework**

### **2.1 Logic model**

Figure 1 sets out a logic model for the AYA Craft Group, including required inputs, key activities, products of the model, and desired short- and longer-term outcomes. All aspects of the model lead to the long-term goals of advancements in AYA standard care and increases in AYA cancer survival.

### **2.2 Tumour streams**

It is recommended that AYA Craft Groups be established within tumour streams of relevance to AYA oncology. This is because expert consideration and discussion of clinical trial availability and emerging research collaboration opportunities must be targeted and highly informed to be effective.

Consideration of clinical trial opportunities for AYA across multiple tumour types would require a broad membership and extensive agenda and would become unwieldy.

Tumour streams of most relevance to AYAs include:

- Sarcoma
- Brain
- Leukaemia
- Lymphoma
- Germ Cell
- EDD/Molecular sequencing

### **2.3 Membership**

For each tumour stream within which an AYA Craft Group is established, membership should include the following:

- Paediatric oncologist(s)
- Adult oncologist(s)
- VCCC R&E Lead

Optionally, based on need, membership might additionally include:

- AYA oncology representation
- Clinical trial pathway representation
- VCCC Program Manager(s)
- Other multidisciplinary team members when relevant

## 2.4 Terms of Reference Template

(Tailor where indicated to meet the specific needs of each established AYA Craft Group)

### 2.4.1 Establishment

The Adolescent & Young Adult (AYA) (**Insert Tumour Stream**) Craft Group is established (**Insert Date**) as an ongoing committee.

### 2.4.2 Nature

Communication and collaboration.

### 2.4.3 Purpose

The function of the AYA Craft Group is to bridge the gap in communication and collaboration between adult and paediatric oncology through regular discussions regarding AYA treatment standards, clinical trial availability and access, future research directions, and other relevant issues. Unlike a multidisciplinary meeting, it is not intended that craft groups be focussed on specific patients.

### 2.4.4 Roles and responsibilities of the group

Craft Groups will be conducted as a partnership between the VCCC Increasing AYA Access to Clinical Trials Program (AYA Program) and the VCCC Research & Education (R&E) Lead Program. The champion and members of the Craft Group will be responsible for driving the group and reporting to the VCCC R&E Lead for the (**Insert Tumour Stream**) Stream. The VCCC AYA Program will be responsible for providing monitoring and management support at an appropriate level.

Members of the Craft Group will act in accordance with the VCCC's Equal Opportunity Policy and VCCC Bullying Prevention Policy.

#### 2.4.4.1 Scope

- To gather and disseminate information on availability of clinical trials relevant to AYA diagnosed with (Insert cancer types)
- To work collaboratively to plan future research directions focussed on improvements to AYA standards of care
- To encourage the inclusion of broader age eligibilities that encompass the AYA age range of 15-25 years in future trial protocols
- To discuss clinical trial pipelines relevant to AYA
- To ensure avoidance of trial duplication for rare cancer subtypes
- To perform a basic audit of the patient population including clinical trial recruitment 15-25yo within the craft group on an annual basis

#### 2.4.4.2 Areas of expertise

Members of the group will bring expertise in paediatric, adult, and where possible, AYA oncology relevant to (Insert Tumour Stream). It is important that members also bring thorough and current knowledge of clinical trial availability in order to share this knowledge with other group members.

### **2.4.5 Period**

The Craft Group shall convene on an ongoing basis.

### **2.4.6 Membership**

- The Craft Group will comprise the following:
  - Expertise in paediatric oncology relevant to the tumour stream
  - Expertise in adult oncology relevant to the tumour stream
  - VCCC R&E Lead for the tumour stream
- The Craft Group membership may additionally include:
  - Expertise in AYA oncology relevant to the tumour stream (where available)
  - Paediatric oncology clinical trial manager or clinical research associate
  - Adult oncology clinical trial manager or clinical research associate
- The VCCC AYA and/or R&E Lead Program Manager will provide support and attend Craft Group meetings but will not be identified as an expert member of the Group.

### **2.4.7 Leadership and chair**

Leadership of the Craft Group shall be identified through stakeholder nomination. The member identified as the Craft Group Leader will act as meeting Chair. Where the Chair is unavailable for any meeting, it is their responsibility to identify another attending member to Chair in their place.

### **2.4.8 Quorum**

A quorum will be met where at least one representative each from paediatric and adult oncology is present at the meeting, either in person, or via teleconference.

### **2.4.9 Meetings**

#### **2.4.9.1 Frequency**

Meetings will be held every (Insert frequency).

#### **2.4.9.2 Agenda and papers**

Agenda and papers will be distributed by the Steering Group secretariat at least one week prior unless extenuating circumstances.

### **2.4.10 Reporting**

The Craft Group will report, via the regular reporting methods of both the AYA Program and the R&E Lead Program, through to the VCCC Cancer Research Advisory Committee (CRAC), VCCC Executive Director, and Department of Health and Human Services (the AYA Program and R&E Lead Program funder).

### **2.4.11 Minutes**

Minutes of meetings will be distributed to members of the Craft Group during the period in which they are active, as a draft by email after each meeting. Minutes will be approved at the subsequent meeting.



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#### **2.4.12 Conflicts of interest**

Written declarations of conflict of interest will be submitted on appointment to the Craft Group and as any new conflict is identified, using the VCCC Conflict of Interest Declaration Form. A record will be kept by the Craft Group secretariat.

#### **2.4.13 Review**

The Craft Group will continue to monitor its performance against the scope and responsibilities outlined in the TOR. The CRAC may conduct a review on the effectiveness, procedures, terms of reference and membership on an as needs basis.

#### **2.4.14 Contact/Secretariat**

- Contact and Secretariat: VCCC AYA and/or R&E Lead Program Managers
- VCCC contact number: 03 8559 7160

## AYA Craft Group Logic

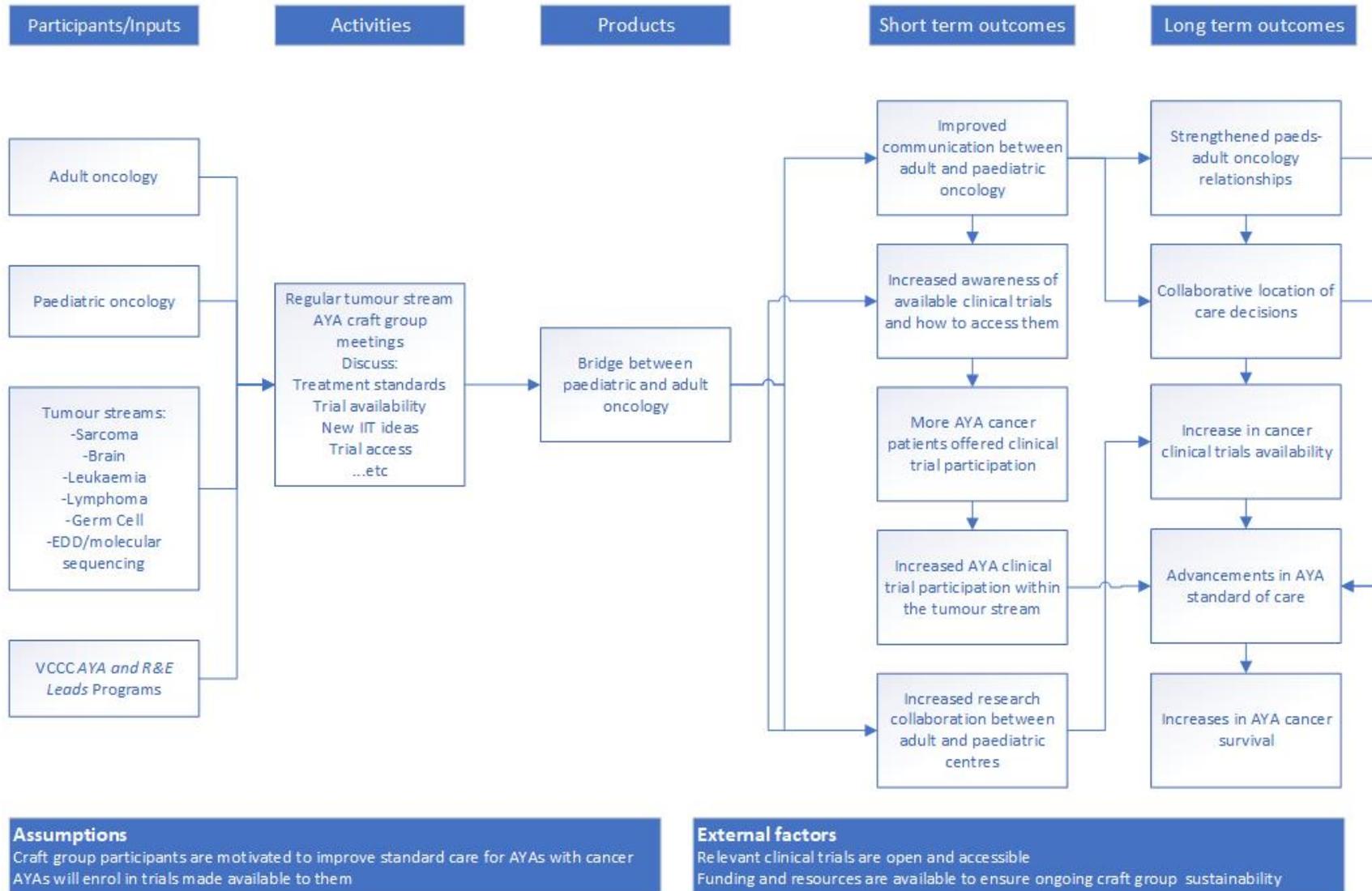


Figure 1: AYA Craft Group Logic Model demonstrating the inputs, activities and products that are proposed to lead to short-term improvements in communication, awareness and collaboration between paediatric and adult oncology, which in turn are proposed to lead to longer-term improvements in AYA clinical care and survival.



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### 3 Evaluation (Measuring Success)

At commencement, it is recommended that each Craft Group document measures of:

- Current clinical trial availability relevant to AYAs for the tumour stream, along with the age eligibility and sites where the trials are open
- Current AYA enrolments in the trials mapped above
- Current level of engagement between paediatric and adult oncology relevant to the tumour stream, including shared/transferred care, multidisciplinary team meeting interactions, knowledge dissemination, and research collaboration
- Any other items deemed relevant to the local setting, and to the tumour stream.

Measures should focus on trial availability and paediatric-adult oncology engagement within the institutions or local area encompassed by the Craft Group membership.

At each anniversary of the Craft Group establishment, the measurements should be repeated to identify any changes to trial availability and paediatric-adult oncology interaction since Craft Group establishment and over time. This evaluation process should be used to guide the ongoing direction of the Craft Group agenda in order to maximise impact on downstream improvements to AYA standards of care.



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## 5 Acknowledgements

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