



# AYA Cancer Network Aotearoa Annual Work Programme

July 2021 – June 2022

# BACKGROUND

On average 190 young people are diagnosed with cancer every year in New Zealand. While this makes up less than 1% of the total population diagnosed, for young people it is the leading cause of disease-related death.

Young people tend to sit on the periphery of cancer care, often falling into a “no-man’s land” between paediatric and adult cancer services. Adolescents and young adults (AYAs) have distinct and often unmet needs and the spectrum of AYA cancers that present in this age group differ to child and adult cancers, as do tumour and host biology factors. In addition, the psychosocial care needs of AYAs with cancer tend to be broader in scope and intensity than children or older adults due to the many emotional, developmental and social changes occurring during this stage.

To determine and direct improvements in cancer services for young people the AYA Cancer Network Aotearoa was established in 2013. The Network provides strategic direction and clinical leadership of AYA cancer care in New Zealand and is contracted directly to Te Aho o Te Kahu (the Cancer Control Agency) to undertake this role. The Network is a membership organisation that connects hands-on health professionals and support providers from many disciplines and organisations. The aim of the Network is to find new and innovative ways of delivering care to all AYAs diagnosed with cancer and ultimately, to improve outcomes.

Over the last decade, New Zealand has seen improved survival rates for AYAs, this achieved through a number of complex and intertwining factors. But while this is significant and reassuring, we must not become complacent. Still existing are unacceptable disparities, inequities and variation in cancer care outcomes for young New Zealanders, particularly for Māori. To continue to support and guide on-going improvements, the AYA Cancer Network has developed the NZ AYA Cancer Action Plan 2020 to 2025. The plan is aimed at both government and non-government organisations involved in programme development funding, planning, policy and delivery of AYA cancer support services.

The plan was developed in response to the insight provided and obtained by the Network since its establishment. This includes an extensive review of literature and reports relevant to AYA cancer care, a number of research projects, a self-review process undertaken by all 20 District Health Boards (DHBs) specific to AYA cancer, and a national patient experience survey which 200 young people with cancer across the country completed. It is therefore a collective representation of significant consumer and provider input.

Described throughout this programme are key components of work and activity from the Action plan scheduled for the period July 2021 to June 2022. The annual work programme will adapt in response to emerging and developing priorities as they arise.

# OVERVIEW OF THE ANNUAL WORK PROGRAMME

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## 1. The prioritisation and establishment of key projects and initiatives

### Schedule of activities:

- Develop a national AYA cancer pathway of care that promotes localised cancer care delivery where possible, with a centralised decision-making and monitoring process.
- Agree on nationally approved protocols and management for AYAs diagnosed with ALL and sarcoma.
- Develop a national guideline for optimal procedural analgesia and sedation for AYA cancer patients.
- Develop a national AYA cancer tiered framework for the guidance and delivery of psychosocial care.
- Develop tools to support national consistency of care in New Zealand for young people
  - Newly diagnosed checklist
  - A standardised psychosocial care plan/ template
  - A risk identification tool
- In collaboration with whānau, partners, communities and the broader social networks of AYAs, seek feedback on existing services and supports currently available to them. Collaborate to identify areas for improvement and implementation strategies.
- Re-establish the Fertility Preservation Working Group to be tasked with reviewing and updating the 2014 New Zealand Fertility Preservation Guidelines/Pathways of Care.
- Establish an AYA Cancer Palliative Care Working Group tasked with making recommendations and providing expert oversight in the area of AYA palliative care.
- Develop the following national AYA cancer resources and educational materials for young people
  - NZ end of life care document
  - AYA survivorship and reintegration resource
  - Nutrition resource
  - Emotional health wellbeing resources and tools
  - Substance use and cancer resource

## 2. Data Monitoring to drive change

### Schedule of activities:

- Develop a NZ AYA Cancer data plan for the period 2021 to 2025.
- Develop processes to provide new patient notifications to the AYA Key Workers and ensure all Key Workers have up-to-date records of young people that they are supporting.
- Establish a national cancer data set to support clinical case management service planning and clinical performance monitoring.

### **3. Infrastructure to support the success and on-going sustainability of the Network**

#### **Schedule of activities:**

- Continue to evolve the AYA Cancer Network website to become a centralised one stop "AYA cancer website" for health and support providers.
- Expand the AYA Cancer Network website to include a specific section tailored to the needs of young people through the inclusion of information, resources and relevant support contacts.
- Strengthen utilisation of social media platforms and continue to engage with the wider sector through these means to promote and drive the work of the Network.
- Facilitate effective communication and consultation with key stakeholders i.e. regular newsletters and create easy-to-access opportunities for meaningful participation i.e. working groups, consultation.
- Maintain registry of stakeholders with an interest in AYA cancer care.
- Provide logistical/secretarial support to working groups and projects.
- Strengthen and support the AYA Cancer Consumer Advisory Group to shape, design and contribute to policy, network activities, network governance and the development of AYA Cancer services.
- Create opportunities for young people to be involved in influencing, shaping, designing and contributing to policy, network activities/research and the development of AYA Cancer services.
- Maintain visibility at conferences / forums/meetings to raise the profile, awareness and understanding of AYA cancer as a clinical priority area.
- Foster good working relationships with DHBs, PHOs, and other cancer support providers.
- As opportunities arise build international collaboration.
- The AYA Cancer Network will reflect their core value of being youth focused, in all their communications, regardless of the intended audience i.e. where relevant will use real life examples to help show information from a young person's point of view, utilise creative approaches to presenting information.

## **4. AYA Cancer Network Governance**

### **Schedule of activities:**

- Continue to meet twice a year, with ideally one face to face.
- Approve the annual work plan and provide budget and finance management.
- Produce reports for Te Aho o Te Kahu within agreed time frames.
- Support chairpersons from the AYA Cancer Consumer Advisory Group to present and contribute to governance meetings.
- Agenda and papers circulated 2 weeks prior to meetings.
- Minutes recorded and circulated.
- Budget/Finance Management.

## **5. AYA Standards of Care Online Self Review Process**

### **Schedule of activities:**

- Continue to support and monitor the implementation of each DHB's AYA Cancer Service Development Plan.
- Introduce additional prioritised standards of care to the online self-review process.
- Complete the next run of the DHB self-review process meetings for the AYA Standards of Care.

## **6. Advocacy and Advice**

### **Schedule of activities:**

- Provide advice and information on AYA Cancer Service issues to Te Aho o Te Kahu (Cancer Control Agency).
- Provide an AYA cancer expert perspective into guiding documents regionally, nationally and internationally.
- Ensure representation on groups where work will impact AYAs with cancer.
- Clinical Leader to act as media spokesperson in consultation with Chair of the Governance group for the AYA Cancer Network and its workstreams.
- Progress forward a national proposal/business case to Te Aho Kahu (Cancer Control Agency) for endorsement and resourcing to redefine the AYA age group to extend to 29 years.

## 7. Research

### Schedule of activities:

- Provide support for researchers to disseminate and actualise their research findings.
- Facilitate the development of a NZ specific AYA cancer research project directory.
- Identify priority areas of research in New Zealand for AYA cancer.
- Ensure the sector has good access to outcome data, publications, and reports from AYA cancer research in NZ.
- Support research collaborations with a focus on AYA cancer.
- Establish a national five year prospective study to investigate timelines to diagnosis with the potential associations to mortality and reoccurrence of disease.
- Explore further work that could be undertaken to identify potential contributors to the survival disparities for AYA diagnosed with central nervous system tumours.

## 8. Workforce Development and Professional Development

### Schedule of activities:

- Promote training opportunities and resources relevant to AYA cancer on the Network website.
- Explore avenues to support health professionals to obtain postgraduate qualifications in AYA cancer care.
- Develop teaching resources and templates that can be utilised by the wider AYA cancer team for teaching purposes.
- Define and strengthen the role of the AYA regional and service cancer champions.
- The development and implementation of a culturally responsive national AYA cancer workforce knowledge and skills framework.

## 9. AYA Keyworkers Working Group

### Schedule of activities:

- Support the implementation of the annual AYA Key Worker Working Group Plan.
- Promote national consistency in the delivery of care by the AYA Key Workers.
- The development of a guiding document for keyworker support for different prognostic groups.
- The development of information sheets for young people who may not routinely require AYA Key Worker support, such as those diagnosed with localised melanoma, neuroendocrine tumours and thyroid cancer.