



# AYA Cancer Network Aotearoa Annual Work Programme

July 2023 – June 2024

# BACKGROUND

On average 190 young people aged 12–24 years are diagnosed with cancer every year in New Zealand. While this makes up less than 1% of the total population diagnosed with cancer, it is nevertheless the leading cause of disease-related death for young people.

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.

The AYA Cancer Network Aotearoa was established in 2013 to determine and direct improvements in cancer services for young people. 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 to raise awareness about the unique challenges faced by AYA cancer patients and to develop and promote best practices for their care. The Network employs a small operational team and hosts the AYA Governance Group, the AYA Consumer Advisory Group, and numerous working and project groups. The Network works closely with the six regional AYA Cancer Services teams to find new and innovative ways of delivering high quality and equitable 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 AYA Cancer Action 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 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 2023 to June 2024. We are a small team, and so not all 18 priorities will be a focus in this single year. 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. Reducing unwarranted variation in AYA cancer care

- Continue to progress the development of a national AYA cancer pathway of care that promotes localised cancer care delivery where possible, with a centralised decision-making and monitoring process.
- Convene the AYA ALL Working Group to develop and implement the National AYA ALL Pathway by 2025 which will follow extensive consultation and formal endorsement.
- Work in partnership with Te Whatu Ora–Te Toka Tumai to develop and implement a designated National AYA Sarcoma Service.
- Collaborate with the AYA governance group, Te Aho o Te Kahu and the sector to explore the future role and structure of the AYA Cancer Network and AYA Cancer Services in light of the recent health reforms.
- Complete the development of recommended best practice guidelines for procedural analgesia and sedation for AYA cancer patients.
- As a part of the self-review process for the AYA Standards of Care, review the implementation of the AYA Cancer Service Development Plan for each region. The six AYA Cancer Centres will be the first to receive site visits, followed by the regional centres that have been identified as priorities by the host centres.
- Engage with Pharmac to ensure equity of access to pharmaceutical treatments for AYAs under rule 8.1b: the funding of paediatric cancer treatments.

## 2. Achieving equity in outcome by levelled psychosocial care provision, 'the stepped care model approach'

- Refine and implement the national AYA cancer tiered framework for the guidance and delivery of psychosocial care including the newly diagnosed checklist, the standardised psychosocial care plan/template, and the risk identification tool.
- Support the efforts of the Consumer Advisory Group and NGO partners in advocating for improved travel & accommodation supports for AYAs and their whānau through the National Travel Assistance Scheme.

## 3. Ensuring the on-going effectiveness and sustainability of the AYA cancer Key Worker model

- Proactively communicate with Key Workers and provide timely support for any service issues.
- To reduce isolation and ensure sustainability for key workers, create a handbook that clarifies their responsibilities and provides support to those in both temporary and permanent positions.
- Where opportunities arise, advocate for adequate resourcing of the AYA Key Worker role.
- Provide operational support to the AYA keyworker working group, including hosting the annual face-to-face meeting, supporting the development and implementation of their annual work plan, providing support to meetings, and creating a national repository of resources for the group.

#### **4. Data Monitoring to drive change**

- Continue implementing Phases 2 and 3 of the Network's 2020–2025 Data Plan
- Identify opportunities for data monitoring/evaluation including capturing patient-reported experience measures, in new initiatives such as the AYA Survivorship Reintegration Programme, National AYA Sarcoma Service, and the AYA ALL National Pathway.
- Undertake the 2023 annual reconciliation of AYA notifications to the New Zealand Cancer Registry to ensure the accuracy of our data and consistency in reported case numbers.

#### **5. Redefining the age range for AYA by extending the upper range to 29 years**

- With endorsement from the governance group continue advocating for the expansion of the AYA age range up to 29 years. This includes seeking feedback and exploring opportunities to deliver this to prioritised groups such as Māori and Pacific rangatahi.
- Include 25–29 year olds wherever possible in Network work streams (e.g. the Fertility Guidelines, the AYA ALL National Pathway, the National AYA Sarcoma Service, and AYA clinical trial initiatives).
- Present data for 25–29 year olds in AYA snapshots and presentations for regional AYA cancer services so that each service can be aware of the volumes and needs of older AYAs.

#### **6. Improving access to clinical trials**

- Explore opportunities to improve clinical trial access for AYAs with central nervous system tumours with the newly formed New Zealand Aotearoa Neuro-Oncology Special Interest Group (NANO-SIG).
- Support access to tumour-specific trials through the development of the National Pathway for AYA with ALL and the National AYA Sarcoma Service.
- From 2024 begin tracking ALL participation in clinical trials, including tumour biology and registry studies.

#### **7. Understanding the current gaps in survivorship within the AYA cancer population**

- Preparations for the next AYA survival analysis will begin in late 2024 in anticipation of the new AYA Cancer Action Plan beyond 2025.
- Liaise with the Neuro-Oncology Special Interest Group (NANO-SIG) and Brain Tumour Support NZ regarding the establishment of a national registry for CNS tumours which could help us better understand the lack of survival improvements for AYAs with CNS tumours.

#### **8. Caring, supporting and involving whānau, partners and the community**

- Conduct a preliminary survey of whānau experiences and needs through the Consumer Advisory Group. Collaborate with them to develop a guide specifically for whānau.
- Enhance the Network website by creating a dedicated section for whānau, partners and the community.

## 9. Workforce development

- Complete the development of four e-learning modules for healthcare providers working with young people. Make them available on national health care e-learning platforms including Ko Awaeta LEARN
- Define and strengthen the role of the AYA Cancer Champions, including the development of an AYA Cancer Champion handbook, champion database and facilitate opportunities for champions to complete the post graduate AYA cancer qualification
- Explore hosting an AYA Champions Study Day in 2024 with the support of the AYA Key Workers.
- The AYA Cancer Network website, newsletters and social media will continue to actively promote professional development opportunities, including education opportunities, scholarships, new resources/research outputs, and webinars on AYA-related topics.
- Support the Canterbury-Waitaha AYA Radiation Therapist Professional Supervision Pilot Programme and explore learnings that could be applied nationally.

## 10. Fertility preservation

- Under the guidance of the fertility preservation working group create an easy-to-use patient flow pathway and checklist tool for clinicians based on the national fertility guidelines.
- In collaboration with fertility providers and AYA Key Workers, create a standardised national fertility referral form.
- Advocate for increased access to fertility preservation outside major centres.

## 11. Early identification

- Continue to seek opportunities to improve awareness and referral practices for AYA cancer among youth health and primary care providers.

## 12. Survivorship

- Promote the newly created AYA Life After Cancer Resource and make individual chapters and templates of the Life After Cancer Resource downloadable from the Network website for ease of use.
- With the support of funding from the Wayne Francis Charitable Trust scope and develop an AYA Survivorship Reintegration Programme. The project will involve recruiting a project manager to oversee the development, establishing a stakeholder reference group, consulting with consumers and stakeholders to develop a programme, and creating an evaluation framework along with relevant tools and resources.

## 13. Palliative care

- Under the direction of the AYA Palliative Care Working Group develop an end-of-life resource for adolescents and young adults (AYAs) with cancer when a cure is no longer an option. The group will also create a guideline to support professionals who work with young people in a palliative care situation.
- Provide an online platform on the AYA cancer network website to share up-to-date resources, services, and education opportunities for AYA Palliative Care.

## **14. Age-appropriate information**

- Continue to develop and enhance the Network website as a "one-stop-shop" for cancer resources for young people.
- Ensure that resources are easily accessible by providing links through QR codes.
- Develop information sheets for young people who may not routinely require AYA Key Worker support (such as those diagnosed with localised melanoma, and neuroendocrine tumours).
- Support the Consumer Advisory Group in creating audio-visual content (videos, curated YouTube channels, podcasts) for their passion projects.

## **15. Traditional and complementary therapy**

- Undertake a scoping exercise with the Consumer Advisory Group to determine the resources and delivery formats that would have been helpful for them regarding traditional and complementary therapy.

## **16. Holistic wellbeing**

- Develop a repository of resources and services on the website to support the emotional well-being of young people throughout their cancer journey

## **17. Increased collaborative AYA cancer specific research**

- Continue to develop the AYA research repository on the Network website and establish connections across the sector
- Facilitate opportunities to progress and prioritize research areas within the work programme, such as AYA-ALL ALL specific research and evaluation of survivorship reintegration programme work

## **18. Age-appropriate treatment environments**

- Support hospitals and services in the development and design of dedicated age-appropriate facilities and spaces.
- Advocate for the opening of the AYA Cancer Unit at Waipapa Hospital in Christchurch and seek updates on its progress.

# OVERVIEW OF ONGOING NETWORK ACTIVITIES 2023–2024

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## The AYA Governance Group

- Meet twice a year, with ideally one face-to-face meeting to oversee the strategic direction of the AYA Cancer Network. Ensuring that the projects and activities undertaken by the network align with and support the overall objectives of the network
- Provide approval for the annual work plan and budget as well as financial management.
- Produce reports for Te Aho o Te Kahu within agreed time frames.

## The Consumer Advisory Group

- Maintain an active membership of 20 members, including at least 50% Maori and Pasifika representation, and ensure that the membership comprises individuals from diverse backgrounds and experiences..
- Regularly convene the Consumer Advisory Group via Zoom and plan/run the annual face-to-face weekend meeting.
- Ensure that the Consumer Advisory Group is represented in both working groups and governance groups.
- Involve young people in all activities of the network and encourage them to provide their input and feedback.
- Support the Consumer Advisory Group in developing their own self-initiated passion projects,
- Explore ways to develop consumer representatives as leaders and share their stories and ideas in a way that suits them.

## Advocacy, Advice & Communications

- Provide advice and information on AYA Cancer Service issues to Te Aho o Te Kahu, The Cancer Control Agency
- Provide an AYA cancer expert perspective into guiding documents regionally, nationally and internationally.
- Collaborating with NGO partners on areas of shared interest, including the continuation of regularly scheduled meetings with CanTeen, LBC and others.
- Ensure representation on groups where work will impact AYAs with cancer.
- Provide consistent and regular communications through our newsletter and social media platforms.