AYA Cancer Network Aotearoa Work Programme

January - June 2025

BACKGROUND

On average 190-200 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 medical-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 2014 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 2020-2025 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 work plan are key components of work and activity from the AYA 2020-2025 Action Plan.

OVERVIEW OF THE WORK PROGRAMME

When producing the previous 6-month workplan, it was anticipated that there would be Clinical Lead in place in the later part of 2024 and that the rest of the structure of the Network Operations Team would have been finalised. Due to delays in recruitment, we have elected to once again produced a six-month workplan. This will bring the next annual workplan back in line with our financial year. The annual workplan will include an extensive review and consultation process in order to prepare the next National AYA Cancer Action Plan.

In this six month period, we will continue to advance the 18 priorities for AYA outlined in our current action plan. However, a priority for this period will also be to rebuild the Network Operations Team, Governance Group and Consumer Advisory Group, as outlined below.

Network Operations Team

- Following the new Clinical Lead commencing their role, provide them with a comprehensive induction. Communicate their appointment through the Network newsletter.
- Meet with AYA cancer services around the country, NGOs, and Te Aho o Te Kahu to discuss new developments and to share views on the challenges and opportunities in the sector.
- Identify gaps in reach and complete a comprehensive update of the Network database at a regional and national level.
- Create a Network Handbook as a single source for key information including passwords, processes, and background documents.
- Conduct a though review, archive, and cull of the 10 years of Network documents and resources on the Te Toka Tumai N drive to make it easier for new staff members to navigate and ensure that are not lost.
- Commence recruitment for additional Network positions once the Clinical Lead has settled into their role and following discussions with Te Aho o Te Kahu, Governance, and Te Toka Tumai,

AYA Cancer Network Governance Group

- Review the Governance Group Terms of Reference.
- Fill current vacancies, identifying potential new members to approach to ensure that the group has the right composition and expertise and representation from across the cancer sector.
- Meet twice in this period, ideally at least once face-to-face, to oversee the strategic direction of the AYA Cancer Network and provide support for the newly-appointed Clinical Lead.
- Review the Network's hosting arrangements if directed to by Te Aho o Te Kahu.

AYA Consumer Advisory Group

- Establish a designated role for CAG coordination within the Network operations team.
- Prioritise the CAG 'passion projects' that can be completed in the first half of 2025, in line with the Network's AYA Cancer Plan.
- Regularly convene the group via Teams.
- Gradually rebuild the CAG group membership to 20 AYAs who have recent experience with AYA cancer services, ensuring the group includes at least 50% Maori and Pasifika representation, and comprises of individuals from diverse backgrounds and experiences.
- Ensure that the Consumer Advisory Group is represented in working groups and the Governance Group and encourage them to provide their input and feedback.
- Set a date and explore venue options for the next AYA CAG weekend for early 2026.
- Support individual members in progressing their own passion projects where capacity allows.
- Promote opportunities for participation in a number of upcoming research projects, including the joint Network-University of Auckland Nutrition masters' projects.

OVERVIEW OF THE WORK PROGRAMME ACCORDING TO THE PRIOTITIES OF THE 2020-2025 AYA ACTION PLAN

The focus of this work plan is on completing the AYA end of life resources, AYA fertility preservation guidance, Pharmac's review of 8.1b, the AYA e-learning modules, and evidence-based guidance to improve the supports available for AYAs undergoing medical procedures. These have been written in blue.

In addition, we will endeavor to make further progress towards our 18 current priorities in this, our final year of the 2020-2025 AYA Cancer Action Plan.

PRIORITY 1. Reducing unwarranted variation in AYA cancer care

- Work with Pharmac to finalise the briefing document and supporting data for their proposal to the Pharmac board to extend 8.1b for AYAs with paediatric malignancies.
- Establish a short-term working group to review and support the implementation and recommendations contained in the Guidance for AYAs Undergoing Medical Procedures, including the development of a number of supporting documents and educational materials
- Work with the Te Whatu Ora-Te Toka Tumai North Island Sarcoma Service to progress the implementation of the National AYA Sarcoma Service, with a focus on ensuring equity of supports for AYAs located in the South Island.
- Advocate for the implementation of the AYA ALL National Pathway, while recognising the challenges in progressing this due to the pressures the health system is currently facing.

PRIORITY 2. Achieving equity in outcome by levelled psychosocial care provision

- Continue to refine and monitor the use of the National AYA Cancer Tiered Framework for the Guidance and Delivery of Psychosocial Care with the AYA Keyworkers, including the New Patient Checklist, the Standardised Psychosocial Care Plan, and the Risk Identification Tool.
- Support the efforts of the CAG and NGO partners in advocating for improved travel & accommodation supports for AYAs and their whānau through the NTA Scheme.

PRIORITY 3. Ensuring the on-going effectiveness and sustainability of the AYA Keyworker model

- Proactively communicate with the Keyworkers and provide timely support for any service issues.
- Where opportunities arise, advocate for adequate resourcing of the AYA Keyworker role.
- Develop a transfer form for patients permanently moving between regions and those who are treated in more than one centre.
- Support the AYA Keyworker Working Group, including the provision of resources, providing secretariat support for their regular meetings, planning and hosting the annual face-to-face meeting in December, and the development and implementation of their annual work plan.

PRIORITY 4. Data Monitoring to drive change

- Continue implementing Phases 2 and 3 of the Network's 2020-2025 Data Plan.
- Promote consistent use by the Keyworkers of Network-developed tools in order to improve the quality of data collection and for the Network to be better able to identify needs and advocate for AYAs at both a regional and national level.
- Identify ways to have Network checklists and tools available on more electronic health records (c.f. paper copies in some regions) for greater visibility and ease of handover.
- Hold a workshop with the AYA Keyworkers to explore developing a monthly reporting template of patient referrals, status, and a brief update on their region.
- Identify opportunities for data monitoring/evaluation, including capturing patient-reported experience measures, in all new Network initiatives.

PRIORITY 5. Extending the upper range for AYA to 29

- Include 25-29 year olds wherever possible in Network projects (e.g. Palliative Care Resources, Guidance for AYAs Undergoing Medical Procedures, Fertility Guidelines, and the National AYA Sarcoma Service).

PRIORITY 6. Clinical trial participation

- Prioritise work with Pharmac on rule 8.1b and the AYA ALL National Pathway, both of which have the potential to improve AYA access to clinical trials.

PRIORITY 7. Understanding the current gaps in AYA survivorship

- Work with Dr Jason Gurney to analyse and report on the findings of recent child and AYA ethnicity data which they recently presented.

PRIORITY 8. Caring, supporting and involving whānau, partners and the community

- Promote palliative care supports available to whānau and partners within the palliative care printed resources and in the newly created directory to be hosted on the Network website.

PRIORITY 9. Workforce development

- Complete the development of the final e-learning module (on AYA cancer) for healthcare providers working with young people.
- Work with Counties Manukau Centre for Youth Health to make all AYA e-learning modules available on national healthcare e-learning platforms including Ko Awatea LEARN.
- Develop an AYA cancer workforce knowledge and skills framework and workforce development strategy for implementation in the next workplan.
- Present at the South Island Haematology Shared Care Day and Haematology National Conference in March.
- Promote palliative care resources, including presenting at the Paediatric Palliative Care Forum in May.
- Proactively seek out other national and regional forums to present the work of the Network at and advocate for our young people.
- Promote the semester 2 post-graduate AYA cancer qualification at Auckland University and administer the LBC scholarship.
- Continue to promote professional development opportunities, including education opportunities, scholarships, new resources/research outputs, and webinars on AYA-related topics in on the AYA Cancer Network newsletters, on our website and on social media.
- Work with the AYA Keyworkers to plan an AYA Education Day for the final quarter of 2025.

PRIORITY 10. Fertility preservation

- Widely promote the Fertility Preservation Guidelines, Preservation Pathway, Checklist, and referral forms, including meeting with key sector representatives.
- Identify key contacts around the country who might be involved in fertility referrals for AYAs (e.g. CNSs) and distribute printed copies of the guidelines, pathway, and checklist to them. This may require producing a bespoke database, as there don't appear to be existing national lists.
- Identify fertility referral forms used nationally, and provide links on the Network website.
- Produce and promote a list of fertility provider contacts in each region which will be available on the Network website.

PRIORITY 11. Early Identification

- Review materials shared by international colleagues at AYA Congress to identify successful initiatives.
- Include a section on early identification in the AYA Cancer e-learning module
- Consider the learning needs and educational delivery options for primary healthcare providers to learn more about early identification for AYA patients as part of the workforce development strategy.

PRIORITY 12. Survivorship

- With funding from the Wayne Francis Charitable Trust, begin the next phase of the development of an AYA Survivorship Reintegration Programme. This will involve commencing the recruitment of a project manager (Note: this will not occur until the Clinical Lead has been appointed and settled into their role).
- In partnership with PINC & STEEL and Canteen, pilot an online survivorship rehabilitation programme. Include evaluation measures in order to incorporate these learnings into the survivorship reintegration programme.

PRIORITY 13. Palliative care

- Working closely with the AYA Palliative Care Working Group, complete and release the two end-of-life resource documents for AYAs with an incurable illness. This includes producing a supporting Medical Decision Making Form for uploading to their electronic medical record.
- Complete a small print run for Keyworkers to provide the end-of-life resources to their young people. Collate feedback of any changes required prior to wider release in 2025.
- Create a comprehensive palliative care directory for young people and their families to be hosted on the AYA Cancer Network website.
- Provide an online platform on the AYA Cancer Network website to share up-to-date resources education opportunities for clinicians involved in AYA palliative care.
- Renew the Palliative Care Working Group to include wider stakeholder representation to implement phase 2 of the project - i.e. widespread promotion and education around AYA palliative resources and developing best practice guidelines for introducing palliative care to young people.

PRIORITY 14. Age-appropriate information

- Continue to develop and enhance the Network website as a "one-stop-shop" for cancer resources for young people.
- Develop a separate password-encrypted section of the website to store resources which are more relevant to healthcare professionals or need to be introduced sensitively (e.g. end of life resources and patient checklists).
- Using the localised melanoma information sheet as a model, develop an information sheet for young people with neuroendocrine tumours who may not routinely require AYA Key Worker support.
- Develop range of age-appropriate resources for young people undergoing medical procedures as part of their cancer diagnosis and treatment.

PRIORITY 15. Traditional and complementary therapy

- Incorporate advice around traditional and complementary therapy into the end-of-life resources and medical treatment procedures resources.

PRIORITY 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, with a particular focus on developing a section for those who have been told that their cancer is incurable.

PRIORITY 17. Increased collaborative AYA cancer-specific research

- Partner with Dr Sue MacDonnel and her colleagues from the University of Auckland Nutrition Masters Programme, to supervise student projects involving needs assessments and interventions to support the nutrition needs of AYAs with cancer. Have a view of presenting this work in appropriate forum(s) in the future - e.g. publications and presentations.
- Meet with international colleagues who first developed the 'voicing my choices' end-of-life resources, with a view towards future collaborations in AYA palliative care research.
- Continue to develop the AYA research repository on the Network website, establish connections across the sector, and respond to / promote new opportunities as they arise.

PRIORITY 18. Age-appropriate treatment environments

- Where opportunities arise, 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 regular updates on its progress.

Advocacy, Advice & Communications

- Provide advice and information on AYA Cancer Service issues to Te Aho o Te Kahu.
- Visit Te Aho o Te Kahu to share updates and knowledge and to explore opportunities for greater collaboration on projects of importance to both organisations.
- Provide an AYA cancer expert perspective into guiding documents regionally, nationally and internationally.
- Collaborate 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 the work will impact AYAs with cancer.
- Provide consistent and regular communications through our newsletter and social media platforms.