AYA CANCER NETWORK AOTEAROA

ADVANCING CANCER CARE FOR 12-24 YEAR OLDS

AYA Cancer Network Work Programme

July 2020 to June 2021

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 Ministry of Health announced additional funding to establish the AYA Cancer Network Aotearoa 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, through a number of complex and intertwining factors. 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 is focusing on the development of a five year national plan.

OVERVIEW OF THE ANNUAL WORK PROGRAMME

Below are the key components of work and activity planned for the period July 2020 to June 2021. The work programme will adapt in response to emerging and developing priorities as they arise.

KEY AREAS	SCHEDULE OF ACTIVITIES
Development of the National Action Plan for AYA Cancer Care in NZ	• Draft and disseminate for stakeholder consultation, a proposed 5- year National Action Plan for AYA Cancer Care in NZ • Publish and launch the National Action Plan
The prioritisation and establishment of key projects and initiatives	• Work with key stakeholders to prioritise key projects and initiatives to be established from the national 5 year AYA cancer action plan.
Design and development of a minimum AYA cancer data set	• Establish the requirements and investigate the feasibility of a national AYA cancer data set to support clinical case management, service planning, clinical performance monitoring and research. • Develop a set of data quality indicators for AYA cancer care
Infrastructure to support the success and on-going sustainability of the network	• Continue to evolve the AYA cancer network website to become a centralised one stop “AYA cancer website” for health and support providers • 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. • Young people supported in accessing age appropriate services and information • 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 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.

AYA Cancer Network Governance	• AYA Cancer Network governance group meets four times a year, half of which are face to face when possible. • Agenda and papers circulated 2 weeks prior to meetings • Minutes recorded and circulated • Budget/Finance Management • Annual work plan and budget agreed on and signed off • Reports provided to Te Aho o Te Kahu (the cancer control agency) within agreed time frames • Support chairpersons from the AYA Cancer Consumer Advisory Group to present and contribute to governance meetings
AYA Standards of Care online self-review process	• 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
Advocacy and Advice	• 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 • 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 works streams • Present a national proposal/business case to Te Aho Kahu (Cancer Control Agency) for endorsement to redefine the AYA age group to extend to 29 years.
Research	• Present a discussion document to Te Aho Kahu (Cancer Control Agency)on a potential clinical trial pathway for improving clinical trial access for young people in New Zealand • Facilitate and support the Clinical Trials Working Group to develop strategies and tools to improve/support access and participation onto clinical trials for AYA cancer patients. • Provide support for researchers to disseminate and actualise their research findings. • Facilitate the development of a directory of research projects being undertaken in AYA Cancer care in NZ. • 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 • Complete an incidence and survival analysis of NZ AYA cancer between 2008-2017, with a plan to disseminate the findings
Workforce Development and Professional Development	• Promote training opportunities and resources relevant to AYA cancer on the network website • Explore avenues to support health professionals to obtain post grad qualifications in AYA cancer care • Identify junior doctors and explore International Fellowship opportunities to specialise in AYA cancer care • Develop teaching resources and templates that can be utilised by the wider AYA cancer team for teaching purposes

AYA Key Workers Working Group	• Support the implementation of the annual AYA key worker working group plan • Promote national consistency in the delivery of care by the AYA keyworkers. Priority for 2020/2021 is the development of a national AYA psychosocial assessment tool and care plan. • Establish a process to improve early identification for AYA identified at high suspicion of cancer or newly diagnosed to the regional AYA cancer keyworker • Attendance and secretariat support provided by the network at the monthly teleconferences and annual face to face meetings

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