

TERMS OF REFERENCE **AYA Palliative Care Working Group**

The AYA Cancer Network Aotearoa supports a series of working groups, involving a diverse range of health and voluntary sector professionals. The Network has an on-going commitment to Te Tiriti o Waitangi and a working partnership with Maori individually and collectively to achieve inclusive and equitable outcomes for all young people with cancer in Aotearoa. They provide advice, recommendations and action plans on specific areas of service delivery across the continuum of Adolescent and Young Adult cancer care.

Purpose of the AYA Cancer Palliative Care Working Group

Conveyed strongly in the work undertaken by the Network to date, is the need for improved timelines and early referral to palliative care services for young people with cancer, along with the current lack of age-appropriate and adequately resourced services.

According to results of the AYA Cancer Network Patient Experience Survey undertaken in 2018, 32% of young people undergoing treatment had not been given the opportunity to discuss what would happen if their treatment were unsuccessful and would have liked this opportunity.

Review SOC 6.2

Background

This working group comprised of health professionals and representatives from the ngo sector, with the support of the Network, aims to work collaboratively to identify and implement projects & initiatives that respond to the needs of AYA at the end of their life.

Purpose/Role

The role of the working group is to oversee and monitor implementation of the action steps identified in the AYA Cancer Action Plan for Palliative Care:

1. Development of guidelines/pathways promoting early access to palliative care services when prognosis is guarded at diagnosis, when curative treatment cannot be offered, or if curative treatment is declined.
2. Development of AYA specific tools/resources to assist health providers, AYAs and their whānau in palliative care discussions and decision-making around palliative care needs and support.
3. Support the development and provision of an AYA specific palliative care education programme for those working with young people in either a palliative or cancer care capacity.
4. Make further recommendations and provide expert oversight in this area

Te Tiriti o Waitangi and achieving equity

The AYA Palliative Care Working Group recognises the central importance of its Te Tiriti o Waitangi obligations, including working in partnership with Māori with a clear focus on achieving equity for Māori in terms of AYA palliative care services and outcomes.

In partnership with Māori and other groups most affected by unequal outcomes, the AYA Palliative Care Working Group will take a broad and systematic approach to addressing systems and processes that disadvantage such groups, and endeavour to support the monitoring and evaluation of their programmes of work to ensure achieving equity is a priority.

Membership

Membership of the working group is open to any individual (health-professional or supportive care professional) employed in role working directly with AYA with cancer and with an interest or experience in palliative care. Individuals can send expressions of interest to the working group convener at any time.

In addition to open membership of interested parties, representatives from the following professional groups or organisations are being actively sought:

- Hospice
- Regional Representation
- NGO providers
- Primary Care
- Māori/Pacific Health
- Palliative care services
- AYA Cancer Services

While the intention of the Working Group is to remain inclusive, the Working Group Chair may elect, in consultation with existing members, to close membership in order to maintain a workable quorum.

Working Group members must demonstrate active involvement through attendance at the majority of meetings held. These will be held every 2 -3 months for a period of 1-2 hours. To maximize participation a yearly schedule will be completed. Membership is for a 24 month period.

Membership will also include the National Clinical Leader and a Project Manager for the AYA Cancer Network.

Should a member wish to resign from the Working Group they must provide email notification to the Working Group Chair and give one month's notice from the previous meeting.

Individual Roles and Responsibilities

A chair will be assigned to the working group. The chair is responsible for developing and reporting on an annual work plan, chairing Working Group meetings and acting as the Working Group's spokesperson as appropriate.

The AYA Cancer Network Project Manager will provide administrative and secretarial support to the Working Group. This includes, but is not limited to:

- Organising meetings;
- Producing minutes;
- Undertaking research and consultation on behalf of the Working Group;
- Assisting with the development and implementation of an annual work plan; and
- Monitoring of expenditure.

Confidentiality

All group members will maintain confidentiality of agenda material, documents and other matters provided to them.

Planning and Reporting

The Chair, in consultation with the Working Group and with the support of the Networks Operational Team, is responsible for producing an Annual Work Plan. The Work Plan must include:

- Current membership and role holders;
- Prioritised, planned activities;
- Rationale for planned activities;
- Expected outcomes of planned activities;
- Timeframes for activities;
- Suggested dates for planned meetings to be held during year
- Detailed proposal for any project activity that has a monetary cost

The Chair is responsible for providing a 6 monthly report against the agreed annual Working Group Work Plan.

Meeting Arrangements

- Virtual Meetings will be 1 -2 hours in duration (this can change with group consensus)
- Date and time of meetings will be based on the majority vote/availability