

TERMS OF REFERENCE

AYA Keyworker Working Group

The AYA Cancer Network Aotearoa supports a series of working groups, involving a diverse range of health and voluntary sector professionals. They provide advice, recommendations, and action plans on specific areas of service delivery across the continuum of AYA cancer care.

1. Background

In New Zealand in 2007, six regional AYA Cancer Care Keyworkers were established, based in the larger treatment centres. The work of keyworkers is highly valued and has largely contributed to the success of the AYA cancer services in New Zealand to date.

The keyworker role is necessarily broad and specific components depend on local variables such as caseload, geographical spread of the service, and infrastructure within the region.

The keyworker role may include:

- Case-management and triaging the care needs of young people and their families/whānau as they move between care settings along the patient pathway.
- Ensuring provision of coordinated services for the delivery of age-appropriate specialised healthcare for adolescents/ young adults with cancer.
- Assessing young people for their psychosocial needs and strengths.
- Promoting a holistic assessment and approach to psychosocial and educational care and support for adolescents/young adults with cancer and their families and whānau.
- Empowering young people to address their developmental needs and well-being.
- Coordinating and organising the cancer centre and supra-regional AYA multi-disciplinary teams' meetings.
- Liaising with and educating health and social care agencies and professionals in the community, including the primary care and shared care teams.
- Promoting and providing skill development opportunities for staff working with AYAs, including training workshops and mentorship.
- Interacting with the other keyworkers to ensure consistency and enhancement of services for AYA with cancer.

- Advocating for AYAs to have access to equitable and developmentally-appropriate care as described in the AYA Standards of Care. This includes, but is not limited to, areas such as clinical trial participation; fertility preservation; palliative care; and survivorship.

Keyworkers are sole practitioners, working across multiple services/teams, all with different team dynamics. There is the potential for these roles to be isolating. The population that keyworkers are caring for means that the role can be both emotionally draining and challenging.

2. Purpose of the National AYA Keyworker Working Group

1. Provide support, collegiality, and mentoring to one another.
2. Provide opportunities for national networking, support, education, research, and collaboration.
3. Source, promote, and develop evidence-based resources for AYA patients, their families, and other providers of care.
4. Promote national consistency in care across New Zealand, no matter where the patient lives.
5. Identify and address issues that arise in AYA cancer care delivery.
6. Ensure an AYA Keyworker national perspective is included in all service planning and development.
7. Support the professional development of the AYA cancer workforce.
8. Promote evidenced based care for AYA cancer patients and their whānau.
9. Collaborate closely with the AYA Cancer Network to share information and offer expert advice on Network activities to maximise impact and streamline efforts across the sector.
10. Highlight the gaps and needs of AYAs at a national level, and identify ways to collectively advocate for AYAs to have equitable access to high quality and age-appropriate services and supports.

3. Membership

Membership of the working group includes keyworker representation from the below regions:

- Auckland-Northland
- Midland
- MidCentral
- Capital and Coast
- Canterbury
- Southern

Other health practitioners in a specialized AYA cancer role can be invited to join the group if nominated by a keyworker and agreed on by a majority vote by the Keyworker Working Group members.

Fifty percent of the above membership plus one must be in attendance for a meeting to proceed and group decisions to be made.

Membership will also include the National Clinical Lead and Programme Manager for the AYA Cancer Network as ex officio. Ex officio members do not have voting rights.

4. Roles and Responsibilities

Working group members must demonstrate active involvement through attendance at 80% of meetings held unless exceptional circumstances prevent participation. There will be one face-to-face meeting a year and four-weekly videoconferences. To maximise participation, a yearly schedule will be completed.

The working group will be chaired by one of the keyworker members. The Keyworker Working Group Chair is responsible for writing the meeting agenda, chairing the meeting, drafting the annual workplan and providing a six-monthly update to the Network, and acting as the working group's spokesperson as appropriate.

The election of the AYA Keyworker Working Group Chair will take place on an annual basis, coinciding where possible with the annual face-to-face meeting. If more than one keyworker wishes to put themselves forward for the role, then voting will be conducted anonymously with votes counted by a non-voting member.

Apologies are to be communicated to the Chair in advance of the meeting. If unable to attend, members will forward any comments, concerns, and queries to the Chair prior to the meeting. If the Chair is unable to attend a meeting or needs to step down, an Acting Chair will be agreed upon by a majority vote of the working group.

The AYA Cancer Network Aotearoa will provide administrative and secretariat support to the working group. This includes, but is not limited to:

- Organising meetings (An agenda and papers are to be circulated 5 working days prior to the meeting or as close to this as possible).
- Producing minutes (these are to be distributed 14 working days after the meeting or as close to this as possible).
- Undertaking research and consultation on behalf of the working group.
- Assisting with the development of an annual workplan.

5. Planning and Reporting

The Chair, in consultation with the AYA Keyworker Working Group and with the support of the Network's Operational Team, is responsible for producing the AYA Keyworker Working Group Annual Workplan. The workplan must include:

- Current membership and role holders.
- Prioritised, planned activities.
- Rationale for planned activities.
- Expected outcomes of planned activities.
- Timeframes for activities.
- Budget proposals for project activities if required.

The Chair is responsible for providing a six-monthly report against the agreed annual AYA Keyworker Working Group Workplan to the Network.

6. Review

An annual review of the Terms of Reference will take place at the first working group meeting of each year. Revisions to these Terms of Reference require majority agreement and acceptance by the AYA Keyworker Working Group. Any changes should be made through a formal change control process, and this can be requested at any time in addition to the annual review.