



TERMS OF REFERENCE AYA Key Worker 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 Adolescent and Young Adult cancer care.

1. Background

In NZ in 2007, six regional AYA cancer care keyworkers were established based in the larger treatment centres. The keyworker role is central to the AYA cancer service. The work of key workers is highly valued and has largely contributed to the success of the AYA cancer services in NZ to date.

The role is necessarily broad and specific components depend on local variables such as:

- caseload
- geographical spread of the service including shared care centres within the region and
- infrastructure within the DHB, for example pre-existing AYA service, AYA Unit.

The Key Worker role may include:

- case-managing 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

- liaison with health and social care agencies and professionals in the community, including the primary care team and Shared Care Centres
- providing skill development opportunities for staff working with adolescents/ young adults in conjunction with a recognised youth health trainer
- interacting with the other Key Workers to ensure consistency and enhancement of services for adolescents/young adults with cancer.

Key workers 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 keyworkers are caring for can be both emotionally draining and challenging.

2. Purpose of the National AYA Key Worker 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 NZ, no matter where the patient lives.
5. Discuss and progress issues that arise in AYA cancer care delivery
6. Ensuring 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 family

3. Membership

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

- Auckland/Northland
- Midland
- Midcentral
- Capital and Coast
- Canterbury
- Southern

Fifty percent of the core membership plus one (four keyworkers) must be in attendance for a meeting to go ahead and group decisions to be made.

Membership will also include the National Clinical Leader for the AYA Cancer Network as ex-officio.

4. Roles and Responsibilities

Working Group members must demonstrate active involvement through attendance at the majority of meetings held. This will be one face to face meeting a year and monthly videoconferences. To maximise participation a yearly schedule will be completed.

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

The chairing of the meeting will be shared among the keyworkers on a quarterly rotation. Any apologies to be communicated to 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

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

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

Annual revisions to these TOR require agreement and acceptance by the AYA Key Workers working group. Any changes should be made through a formal change control process and this can be requested any time.

5. Planning and Reporting

The Convener, in consultation with the Working Group and with the support of the Network's 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 Convener is responsible for providing a 6monthly reports against the agreed annual Working Group Work Plan to the network.