

Adolescent and Young Adult Cancer Group

New Zealand AYA Service Specification

Introduction

The New Zealand Department of Health has established a working party to develop a Service Specification to govern the future care of Adolescent and Young Adult (AYA) cancer patients in New Zealand. The working party is work-in-progress and is in the process of consulting with the wide variety of stakeholders that will be affected and involved in the future service; however, the Chair of the working party has given permission for the release of this progress summary.

Note that none of the details in this document are final and all are subject to change as the working party completes its consultation process.

Service Specification – Key Elements

The Service Specification under development for adolescent and young adult cancer services will be linked to NZ's overarching Tier 1 Specialist Medical and Surgical Services and Tier 2 Paediatric Oncology service specification.

It will be linked to secondary and tertiary adolescent and young adult oncology haematology services, funded by District Health Boards (DHBs) and delivered by the DHB's provider arms.

Service Objectives

The objective of the Adolescent and Young Adult Oncology Haematology Service is to partner the existing paediatric and adult oncology tertiary services, whilst enhancing care directed to the specific needs of adolescent and young adult cancer patients, in particular, their unique psychosocial needs and entry onto age-appropriate clinical trials.

The **primary objectives** of the Service are:

- to maximise the cure rate for adolescents/young adults with cancer, whilst
- minimising the psychosocial sequelae to the patient and their family/whanau

The Service is guided by important **principles**:

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| <ul style="list-style-type: none"> • patient <i>and</i> family/whanau focussed • safe and effective services as locally as possible (<i>not</i> local services as safely as possible) • provided to achieve equity of outcome • based on international best practice, research and education | <ul style="list-style-type: none"> • monitored and evaluated regularly • integrated with other health services • culturally safe • fiscally responsible |
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Central to the Adolescent and Young Adult Oncology Haematology Service are multidisciplinary teams (MDTs) and the Adolescent/Young Adult (AYA) Key Worker, linking all the components of the service to provide a seamless journey for the adolescent/young adult and their family/whanau.

The Service will also cater to the particular needs of AYA patients in cultural groups including Maori and Pacific Islanders.

Service Users

This service specification applies to adolescents and young adults – the precise age range is to be determined. However, in recognising that adolescence and young adulthood represent developmental stages that cannot be defined accurately in chronological terms, it may be appropriate to treat some young people:

- within the Service despite their age falling outside of the age range, or
- outside the Service despite their age falling within the age range.

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Service Components

Details of a management model for the service are under development. The service may include:

- A national advisory group, consisting of representatives from regional services, Key Workers, and representatives from medical, nursing and psychosocial backgrounds, overseeing service delivery nationally.
- Regional and/or local management groups, ensuring compliance with service specifications and providing leadership and direction for coordinated services locally. Membership would include representation from haematology, medical & radiation oncology, surgical & paediatric oncology, psychosocial, nursing, DHB management, consumers and Key Workers.

Multi-disciplinary Teams

The proposed Adolescent and Young Adult Oncology Haematology Service is premised upon MDTs within each of the 6 Cancer Centres with clear lines of communication between:

- AYA MDTs within a region, for example between teams in Wellington and Palmerston North, and
- MDTs in the shared-care centre, a hospital close to the patient's place of residence where aspects of treatment may be provided.

The Role of the AYA MDT within each Cancer Centre would include (but not be limited to) assessment of patient eligibility for treatment within the service, a role in referral decisions, coordinating age-appropriate psychosocial care, and transition to late effects programs/palliative care etc.

The team's composition at any point in a patient's journey would vary and reflect needs at that time. Some professionals would attend all the AYA MDT meetings whereas others may be engaged intermittently.

Key Worker

The Key Worker is central to the proposed Adolescent/Young Adult Oncology Haematology Service. The role would include leadership in providing coordinated services for the delivery of age-appropriate health care, promoting a holistic approach to psychosocial and educational care and support, coordinating and organising the defined AYA MDTs, interacting with the other Key Workers to ensure consistency and enhancement of services, liaison with health and social care agencies and professionals in the community, including the primary care team and Shared Care Centres, and case-managing the care needs of the young person and their family as they move between care settings along the patient pathway.

Settings

Care for adolescents and young adults should be delivered in age-appropriate facilities in order to achieve the best possible health outcomes. Care may be delivered in a variety of settings:

- initial diagnostic work-up and intensive therapy undertaken in a Cancer Centre
- less intensive chemotherapy and management of intercurrent, treatment-related conditions may be carried out at a shared care centre
- palliative care is usually undertaken in the community with involvement of primary carers in association with the secondary /tertiary centre.

Age-appropriate facilities could include:

- a dedicated Adolescent/Young Adult Cancer Unit
- dedicated space on a ward
- a non-clinical social "hang-out" rooms
- access to computers/laptops, internet, games, e-mail, and room telephones.