

Service Provision for Adolescent and Young Adult Cancer Patients in New Zealand including Standards of Care

2016

THE VOICE OF A YOUNG PERSON



*"Mauri ora kit e rangi,
"We greet the spiritual realm"*

*Mauri ora kit e whenua
We greet the physical realm"*

*Na te rangatahi te ao
The world belongs to the youth"*

*Maana apopo e whakairo."
They will shape tomorrow."*

Kia ora, I'm Esther Grace Pekepo.

I am one of many (too many).

I was a pre-mature young lady trying to make a plan to move forward, to find my fit in this big world, only to have my life turned backwards, when I was diagnosed with the "Big C".

It wasn't part of my dream at 17, but like many, I had to adjust to the new normal of my reality. My 13 years of education did not prepare me for the transition that took over the past five years of my unexpected journey. Life had never been so fragile and the rawest of emotions were deeply felt and exposed.

Through the rings of fire, I am grateful to say that I am now in remission. I have gone from planning my last wishes to planning my future. I thank and salute all my carers within and outside the hospital, for it is they that hold the cup for my great honour. Thank you. My value and appreciation for life has been elevated.

Along my journey I have met and grown with so many others who are dealing with the harsh reality of the Big C in all its forms, as well as sadly losing (one too many) a brother or sister from this thief of a disease.

It pains me that there are many like myself who unwillingly have to face the brutality of this sickness. But knowing that something like this now exists to navigate and enhance the care we as rangatahi receive has me eternally grateful.

I am truly humbled and grateful for all the effort and hard work that has been undertaken in supporting youth like myself in the development of these Standards of Care.

On behalf of our young people we thank you all immensely for echoing your volume of support to provide us with the best care possible. Thank you.

"Nau te rourou, naku te rourou ka ora ait e iwi"

"With my food basket and your food basket the people will prosper"

"He aha te mea nui o te ao? He tangata, he tangata, he tangata"

"What is the most important thing in the world? It is people, it is people, it is people."

Esther's cancer journey provides just one example of the need for these broad standards. Her story can be found on the AYA Cancer Network Aotearoa website.

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INTRODUCTION

Every year 180-200 Adolescent and Young Adult (AYA) New Zealanders are told that they have cancer. Survival rates for New Zealand adolescents lag behind international comparisons by 7%. This means in the past 10 years, 49 more 15 – 19 year old New Zealanders have died of cancer than we would expect. 34 (69%) of these deaths were Māori or Pacific youths, even though they account for less than 30% of cancer diagnoses in this age group.⁽¹⁾

These statistics come from the Adolescent and Young Adult (AYA) Advisory Group's Report back to Cancer Treatment Advisory Group in 2013. In response to these findings, the Minister of Health announced additional funding over the next two years for AYA cancer care, to determine and direct improvements in cancer services for AYAs. A key result of this funding was the establishment of the AYA Cancer Network Aotearoa, which provides strategic direction and leadership of AYA cancer care.

A key focus for the network is to develop a five-year national strategy for AYA cancer care. This strategy will include a proposed model of care that ensures young people diagnosed with cancer have equitable access to high-quality medical and supportive care regardless of where they live.

The development of the strategy will be informed by the standards, these based on strong evidence and best practice. The document sets out the level of service that young people with cancer should have access to. It will help guide quality improvement initiatives locally and nationally. The standards of care set out in this document will sit alongside the Ministry of Health's 11 National Tumour Standards, to ensure that AYA patients with particular tumour types receive both best practice and age-appropriate care.

“Why have we been able to **equalise outcomes** for 0-14-year-old Pacific and Māori kids but not for AYAs?”

~AYA Advisory Group
member

AYA CANCER NETWORK AOTEAROA

Connecting professionals, patients, carers and other stakeholders with an interest in improving AYA cancer outcomes
Leading collaboration for service development, across the continuum of cancer care for AYA



WHO ARE AYA?

Terms such as 'youth', 'rangatahi', 'teenagers', 'adolescents', 'young adults' and 'young people' are used interchangeably to describe both the whole group and various subgroups of people from age 10 to their late 20s.

The age group focus of these standards is between 12 and 24 years. This is consistent with the age group defined in two key documents from 2002: The Ministry of Youth Affairs' Youth Development Strategy Aotearoa² and the Ministry of Health's Youth Health: A Guide to Action.³ The upper age limit should be indicative, rather than absolute, dependent on the disease type and developmental needs of the individual; sometimes, this guidance will be appropriate for those aged up to 30 years.

PURPOSE OF THIS DOCUMENT

It is widely recognised internationally and in New Zealand that the AYA cancer population have distinct and unmet needs. Adolescents and Young Adults with cancer are currently understudied and underserved.^{4,5} They tend to sit on the periphery of cancer care, and they often fall into a "no man's land" between paediatric and adult cancer services.⁴

This document aims to set the standard of care for AYAs with cancer in New Zealand. It describes the core elements of AYA cancer care, supported by an international and (where available) national evidence base.

These standards represent a move away from a model of care that traditionally centred on trying to fit AYAs with cancer into existing structures and services. The evidence suggests that this does not work, and that we need to explore innovative ways of delivering services to reach and meet the distinct needs of the AYA population, including through collaboration across individuals, groups, services and organisations. We must continue to ask ourselves: "how can we do better?"

AUDIENCE

The intended audience for this document includes all organisations and institutions that work with AYAs with cancer, including within the education sector, the health sector, social services and non-governmental organisation (NGO) providers. Together we can make a real difference.

This document is not designed or intended for consumer use. A series of short video clips have been developed, in consultation with young people, to provide consumers with a user-friendly summary of these standards. These videos are available on the Network website <https://www.ayacancernetwork.org.nz>.

HOW WERE THE STANDARDS DEVELOPED?

A skilled working group representing the wider multidisciplinary/multiagency AYA cancer care workforce developed these standards. A lead clinician chaired the group, and had access to expert advisors in key content areas. The group sought consumer input through a nationally representative youth advisory group facilitated by CanTeen.

These standards recognise the need for evidence-based practice. In creating them, the working group reviewed and made use of international and national literature, guidelines and existing national tumour standards. Where no clear evidence was available, it sought expert opinion.



A COMMITMENT TO ACHIEVING EQUITY

Health inequalities or health inequities (the terms are used interchangeably) describe differences in the health status of groups of people that are avoidable, unnecessary and unjust.⁶

The working group that developed these standards recognises that AYA cancer patients in New Zealand face health inequities. These include differences in health outcomes compared to other high-income countries, as well as differences in outcomes within the AYA population (eg Māori and Pacific AYAs are 13 to 15% more likely to die of their cancer than non-Māori/non-Pacific Peoples)⁷

The working group used the Health Equity Assessment Tool (HEAT) in developing these standards of care.⁸ The HEAT tool enabled the assessment and strengthening of individual standards, with a particular focus on reducing health inequities. The group applied the tool in consultation with senior equity and cultural advisors, and as part of the process of developing these standards also conducted equity workshops with both providers of care and consumers. The section “What distinguishes AYA cancer care from paediatric and adult cancer care?” below outlines in more detail the factors that contribute to AYA inequities.

REVIEW

As the speciality of AYA cancer care in New Zealand develops and services progress, the standards of care will change. They will stay live; revisions will capture new evidence and approaches to care as it becomes available. A group will review the standards every two years.

MONITORING AND EVALUATION

A national framework is necessary to ensure consistent and cohesive care is provided to the relatively small numbers of AYAs diagnosed with cancer who are widely spread across the country. The AYA Cancer Network Aotearoa is responsible for the clinical oversight and leadership of these standards of care, including development and ongoing monitoring and evaluation. The Network has developed an online self-review tool to support these standards. The tool is designed to help service providers understand what aspects of the support and care they provide to AYAs in their region is working well and to identify areas where service improvements are required. The tool encourages sector-wide collaboration and the development of local service development plans that link with the national strategy for AYA cancer care. It is not intended to be a compliance tool for bench marking or making regional comparisons.

FUTURE RESOURCES AND LINKAGES ON THE AYA CANCER NETWORK AOTEAROA WEBSITE

A large proportion of the good practice points within these standards involve references to resources of various services (eg, oncology training resources, psychosocial screening tools and surveillance guidelines), and linkages between services (eg, appropriate multidisciplinary meeting (MDM) referrals). Links to these resources will be available on the AYA Cancer Network Aotearoa website.

WHAT DISTINGUISHES AYA CANCER CARE FROM PAEDIATRIC AND ADULT CANCER CARE?

Internationally, over the past 20 years, improvement in survival rates for the AYA cancer population have not been as significant as those seen in either paediatric or adult cancer care.^{9,10,11,12} There are many reasons for this “survival lag”. They can be divided into “specific factors related to the tumour and to the patient, as well as access to and use of health care resources”.¹³ Furthermore, a survival disparity exists when comparing New Zealand AYA cancer patients to international AYA cohorts.⁷ The sections below describe the factors that may contribute to this disparity.





DIFFERENCES IN DISEASE BIOLOGY.

Cancers of AYA patients are biologically different to paediatric and older adult cancers. The spectrum of cancers that present in this age group is different; so are some tumour and host biology factors.

From 2000 to 2009, the five most common cancers affecting AYA patients in New Zealand were (in descending order) melanoma, gonadal germ cell tumours, Hodgkin lymphoma, acute lymphoblastic leukaemia and non-Hodgkin lymphoma.⁷ This incidence profile is different to that of both paediatric oncology, which includes significantly higher numbers of embryonal tumours (eg, neuroblastoma and nephroblastoma), and that of older adult oncology, in which epithelial cancers (eg, breast and colorectal carcinoma) account for more than 85% of the total cancers.¹⁴ Peak incidence rates of Hodgkin lymphoma, testicular cancer and Ewing's sarcoma occur during the AYA years.¹³

Distinct tumour biology factors in AYA tumours include the following.¹³

- Younger breast cancer patients are more likely to have less hormone-sensitive tumours of a high grade and a higher frequency of lymph node spread.
- Younger colorectal cancer patients have the highest incidence of microsatellite instability and heritable forms of colorectal carcinoma.
- When compared to paediatric patients, AYA patients with acute lymphoblastic leukaemia (ALL) have a higher incidence of ALL subtypes associated with a poorer prognosis; these include: T-cell ALL, Philadelphia-positive ALL and Philadelphia-like ALL.¹⁵

TOLERANCE OF THERAPY

Research has identified age-related differences in host biology in AYA cancer patients. Patients in this age group with ALL have different treatment toxicity profiles when compared to younger patients, such as higher rates of osteonecrosis.¹⁶ Treatment toxicities specific to this group have been associated with pharmacokinetic differences in hormone regulation, physiological differences with volume of distribution (eg, adipose vs lean body weight), protein binding and hepatic and renal function.¹⁴

LOW ACCRUAL ONTO CLINICAL TRIALS AND INVOLVEMENT IN RESEARCH

Clinical trial enrolment is associated with improved survival among cancer patients.¹⁷ However, enrolment rates for New Zealand AYAs with cancer remain low. Relevant barriers include a lack of age and diagnosis-specific clinical trials, poor referral rates, and policy and regulatory barriers regarding age and access.¹⁸ Poor clinical trial enrolment in the AYA age group also results in a lack of donated tissue specimens for research. This hampers knowledge about AYA tumour biology.

OPTIMAL TREATMENT SITE AND DIFFERENCES IN TREATMENT STRATEGIES

Emerging evidence suggests that where an AYA patient is treated influences their survival outcome; patients treated within specialist centres have better overall rates of survival.^{19, 20} Enhanced clinical trial enrolment opportunities are one perceived benefit of receiving care in a specialist treatment centre.¹³

The consideration of a range of treatment strategies for AYA patients with a particular disease can improve the probability of cure. A good example of this is AYA patients with ALL, where a range of evidence-based philosophies exist. Some research reports enhanced survival when AYA patients are treated on "paediatric-style" protocols;^{21, 22} other evidence shows that adult-style treatment can be associated with equivalent survival when a patient is treated in a specialist treatment centre.²³ Best practice involves collaboration between departments to ensure the most appropriate treatment is delivered in the most appropriate treatment site.



DIAGNOSTIC DELAY

When compared to paediatric and older adult patients, AYA cancer patients are more at risk of diagnostic delay.^{24, 25} This is due to a number of factors, which may include insufficient education of cancer symptom awareness to the AYA population, resulting in poor health literacy; delays in seeking medical attention due to access issues; and due to its rarity in this population, a lower level of suspicion of cancer by health care providers.^{26, 27}

DEVELOPMENTAL STAGE AND ADHERENCE

The psychosocial care needs of AYAs with cancer tend to be broader in scope and intensity than in younger and older patients. This is due to the many emotional, developmental and social changes that occur during this stage of life. This factor impacts on the overall management of AYAs with cancer. Adherence becomes more of an issue during the adolescent years; some studies report that up to one-half of AYAs are non-adherent with oral chemotherapy.^{28, 29}

ETHNICITY

An analysis of cancer incidence and survival data for New Zealand cancer patients aged between 0 and 24 years of age during 2000–2009 found that ethnic disparities in survival outcomes arise from the age of 15 years.⁷ The study found five-year relative survival by ethnicity for 15–24-year-old cancer patients to be significantly lower for Māori (69.5%) and Pacific peoples (71.3%) than it was for non-Māori/non-Pacific peoples (84.2%). However, it found equitable outcomes when looking at ethnic groups in the 0–14-year age group.⁷

The reasons for this disparity are likely to be multiple; no single factor appears to explain it. We do know from existing New Zealand youth health and wellbeing research that a disproportionate number of Māori and Pacific youth identify with multiple risk factors that increase the likelihood of their experiencing difficulties in life and poor health and wellbeing.³⁰ These same risk factors are associated with non-adherence and disengagement from cancer services and treatment.

Collectively, these contributory factors are important issues, and this document acknowledges them as such. Addressing these issues will be paramount to creating a functional and relevant AYA cancer service framework.

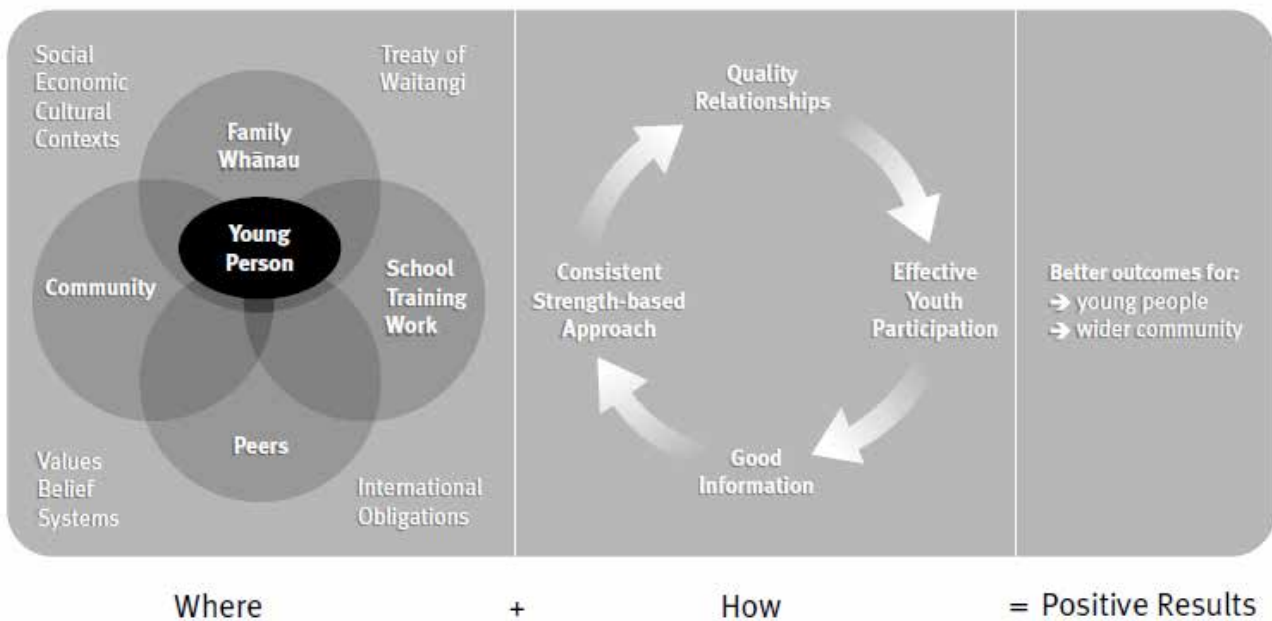
IMPROVING OUTCOMES FOR MĀORI AND PACIFIC AYA PATIENTS

In part, the development of these standards of care has been driven by the poorer health outcomes seen in Māori and Pacific AYA cancer patients compared with the general population. The standards have been influenced by the principles of a number of documents and policies that outline partnership and/or commitment to improving Māori and Pacific health in New Zealand,^{31,32,33} including:

- the Treaty of Waitangi
- the guide to He Korowai Oranga: Māori Health Strategy 2014³¹
- Equity of Health Care for Māori: A framework³²
- the key government policy area of Whānau Ora³⁴
- 'Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2014–2018.³³

As illustrated below, the youth development approach³⁵ has also guided the development of these standards. This approach to care is consistent with a kaupapa Māori approach. It aligns with existing Māori and Pacific models, including holistic-based models such as the Te Whare Tapa Whā model, the Meihana model and the Pacific Fonofale model.

Figure 1: The Youth Development Approach³⁵



“Culture to me means **purpose and belonging**. Like a tree rooted in the ground it helps me identify where and who I am. Without it I would find myself lost, **question the meaning of life** and unable to relate to people. In Maori paradigms culture is distinctly embedded or at least should be to help **assist in healthy wellbeing**. I practice culture in many forms: Spiritually, language, fashion, how I conduct myself. I look back on my culture with the beliefs it carries to help **make choices in life**, as if I am representing a world class organisation. I don't want to depict myself as being culturally sensitive but it assists me in **knowing where I stand and where I'm headed**”

~AYA patient



FORMAT OF THESE STANDARDS

This document is in three sections, equally important and designed to complement each other.

Section 1, **The AYA cancer trajectory**, focuses on aspects of care that ensure that all AYAs with cancer, regardless of domicile, receive best-practice clinical management and treatment for their disease.

Section 2, **Developmentally appropriate care**, focuses on aspects of care that ensure that all AYAs with cancer receive comprehensive and developmentally appropriate care that facilitates best medical and psychosocial outcomes.

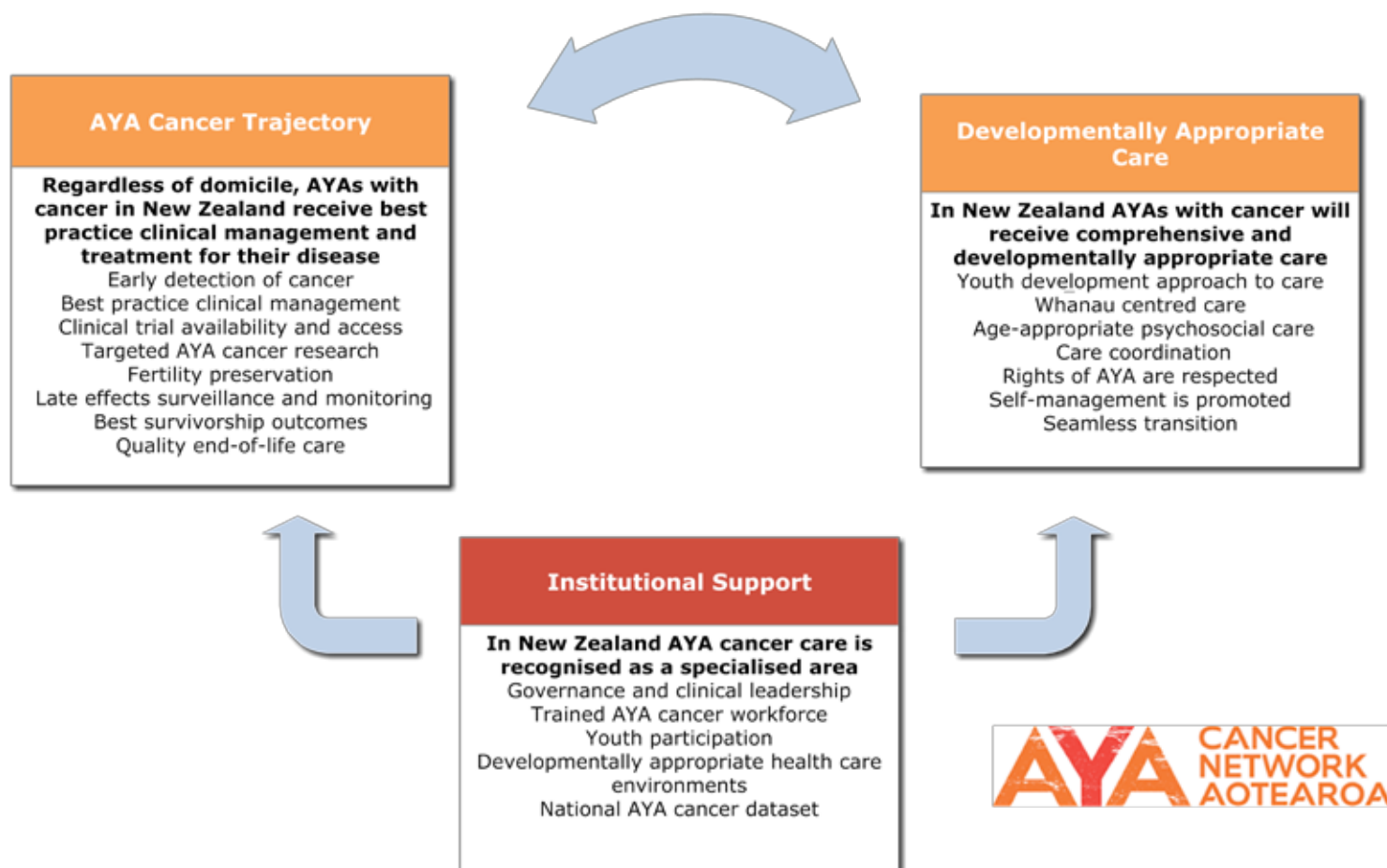
Section 3, **Institutional support**, focuses on the systematic changes required to ensure that we recognise AYA cancer care as a specialised area of cancer care.

The diagram below summarises these components.

Figure 2 : Key components of best practice for AYA cancer patients in New Zealand

Service Provision for Adolescents and Young Adult Cancer Patients in New Zealand

Aim: To achieve excellence in AYA cancer care in New Zealand with the goal of improving survival outcomes and supporting AYAs to transition to healthy functioning adults.



SUMMARY OF STANDARDS

This section summarises the set of standards as a whole.

SECTION 1: THE AYA CANCER TRAJECTORY

Prevention and early identification

Standard 1.1 Cancer prevention education and interventions will be clearly communicated to AYAs, whānau and health care providers.

Standard 1.2 Early symptoms of cancer will be recognised by AYAs and health care providers.

Referral to the right expertise

Standard 2.1 When a cancer diagnosis is suspected, AYAs will be referred to the appropriate tumour group expertise and Multi-Disciplinary Meeting (MDM)

The diagnostic process

Standard 3.1 Investigations undertaken during the diagnostic stage will comply with best practice recommendations as described in the national tumour standards.

Standard 3.2 Sedation and other techniques to reduce procedural distress will be made available to all AYA cancer patients.

The treatment plan

Standard 4.1 All AYA cancer patients will have a documented treatment plan that adheres to best practice recommendations.

Standard 4.2 All AYA patients referred urgently with a high suspicion of cancer will receive their first cancer treatment or other management within 42 days.

AYA targeted cancer research

Standard 5.1 All AYA cancer patients will be offered the opportunity to participate in targeted AYA cancer research.

Standard 5.2 All AYA cancer patients will be offered the opportunity to enrol in available diagnostic and therapeutic clinical trials.

Fertility preservation

Standard 6.1 Prior to treatment, all AYA cancer patients will be informed about the potential risks of treatment-related infertility, and, where appropriate, fertility preservation procedures will be completed.

End of life care

Standard 6.2 AYA cancer patients will have access to palliative care services. Where appropriate, access will start at diagnosis.

Survivorship

Standard 7.1 Following completion of treatment, all AYA cancer patients will have a structured follow-up plan that focuses on the multifaceted health issues of survivorship.

Standard 7.2 All AYA cancer patients and relevant health care providers will be provided with an end-of-treatment summary document.



SECTION 2: DEVELOPMENTALLY APPROPRIATE CARE

Psychosocial assessment and care

Standard 8.1 All AYA cancer patients will have a psychosocial assessment at diagnosis which will be updated at regular intervals to inform their care.

Standard 8.2 All AYA cancer patients will have access to psychological support from diagnosis.

Standard 8.3 The spiritual needs of AYA cancer patients and their whānau will be proactively considered and addressed along the cancer journey.

Developmental milestones

Standard 9.1 All AYA cancer patients will receive support and care to optimise their normal developmental process as they continue through their cancer journey.

Caring for whānau, partners and the community

Standard 10.1 Whānau, partners and the support network of an AYA diagnosed with cancer will have their practical, cultural and emotional needs identified and assistance provided to address these.

AYA cancer patients identified at risk of non-adherence

Standard 11.1 AYA cancer patients with risk factors associated with increased non-adherence will be identified and prioritised for intensive case management

Self-management

Standard 12.1 All AYA cancer patients will be supported to self-manage their own health care as they mature.

Standard 12.2 All AYA cancer patients and their whānau will be provided with developmentally appropriate cancer-related information.

“

I was numb. I mean what did cancer mean for my plans for **university**? I was already planning my courses. What about **life and marriage and even kids**? I hadn't thought about kids before but now I had to. And I had to think about how to tell my **girlfriend**. What would it mean for our **relationship**?

”

~AYA patient



Transition

Standard 13.1 All AYA cancer patients will be supported as they transition across services.

Confidentiality/rights/respect and trust

Standard 14.1 The rights of AYA cancer patients will be respected. A key focus is to establish confidentiality and trust.

Care coordination

Standard 15.1 All AYA cancer patients and whānau will be provided with access to a nominated health care professional who will coordinate their care.

Standard 15.2 All AYA cancer patients will have access to co-ordinated multidisciplinary and multiagency care.

SECTION 3: INSTITUTIONAL SUPPORT

Governance and clinical leadership

Standard 16.1 There will be a governance structure with identified clinical leadership that provides direction and oversight for AYA cancer care.

Workforce development

Standard 17.1 Health care professionals and the supportive care workforce who work with AYA cancer patients will be trained to deliver developmentally appropriate care.

Youth participation

Standard 18.1 AYA cancer patients are provided with the opportunity to actively participate in the development, implementation and evaluation of regional and national AYA cancer care programmes and services.

Age-appropriate environments

Standard 19.1 AYA cancer patients will be treated in a health care environment that is developmentally appropriate.

Clinical performance & monitoring

Standard 20.1 A nationally agreed AYA cancer dataset will be collected within each district health board (DHB).



SECTION 1

THE AYA CANCER TRAJECTORY

Over the past 20 years, the improvement in survival rates for the AYA cancer population has **not been as significant** as those in either paediatric or adult cancer care. Differences in biology, diagnostic delay, tolerance to therapy, location of treatment and discrepancies in treatment strategy all contribute to **poorer outcomes**. This section focuses on aspects of **clinical management and care** for AYAs with cancer, with a focus on best practice, starting before diagnosis through treatment, survivorship and, where necessary, end-of-life care.

PREVENTION AND EARLY IDENTIFICATION

STANDARD 1.1

Cancer prevention education and interventions will be clearly communicated to AYAs, whānau and health care providers.

RATIONALE

A number of cancers are associated with preventable risk factors relevant to AYAs in New Zealand. Although many of these cancers tend to affect the older age groups, behaviours associated with them can begin during the AYA years. Lung cancer, cervical cancer and melanoma are examples.

Lung cancer

New Zealand Health Survey data shows that smoking rates for 15–24-year-olds dropped from 23.4% in 2006/7 to 18.5% in 2014/15.³⁶ However, lung cancer remains New Zealand's leading cause of cancer death.³⁷ On average, young people in New Zealand start smoking at 13–14 years of age.³⁸

Family members are their main source of tobacco (the legal minimum age to purchase tobacco is 18 years).³⁹

Cervical cancer

Human papillomavirus (HPV) infection affects an estimated 80% of sexually active women. The peak incidence of infection occurs in women between 16 and 20 years old.⁴⁰ In the majority of cases, the HPV infection will spontaneously clear. However, for a small number, the HPV infection progresses, to cause changes in cells that can subsequently develop into cancer.⁴¹ Over 99% of all cervical cancer is linked to genital infection with HPV.⁴⁰

Internationally, efforts to reduce cervical cancer with HPV immunisation programmes have proven effective: a recent systematic review found maximal reductions of approximately 90% for HPV infection, and 85% for high-grade histologically proven cervical abnormalities.⁴²

In September 2008, the Ministry of Health launched a three-dose HPV immunisation programme for 12-year-old girls as part of the funded National Immunisation Schedule.⁴⁰ A recent effort to revitalise the programme resulted in a ten percent increase in immunisation rates to 65 percent for the most recent cohort to complete Year 8, however our rates remain lower than those in Australia and the United Kingdom.

Māori and Pacific women are less likely to access cervical screening, and are therefore at increased risk of developing and dying from cervical cancer when compared to the New Zealand European population.^{41,43} As a result, the Government has prioritised increased immunisation coverage for Māori and Pacific women since the outset of the programme. Pacific and Māori women have consistently achieved higher immunisation rates than other ethnic groups as a result.

Other HPV cancers

HPV can cause cancers to other body parts (genitals, anus, mouth and throat) and these affect men as well as women. The proportion of mouth and throat cancers caused by HPV has increased in recent years, and these cancers disproportionately affect men. From 1 January 2017, boys and young men will also be eligible for free HPV immunisation. An updated vaccine will reduce the number of required doses to two for those aged 14 and under, and it will protect against five additional types of HPV.



Melanoma

New Zealand has the highest incidence of melanoma in the world. Although melanoma rates are comparatively lower for the AYA population in New Zealand when compared to older age groups, repeated excessive sun exposure at a young age significantly contributes to melanoma risk in later life. Artificial tanning methods such as sunbeds have also been associated with melanoma, especially in those people who are exposed before 35 years of age.⁴⁴ The Government introduced legislation banning commercial sunbed use by people under 18 years of age in 2016; it will implement this from early 2017.

GOOD PRACTICE POINTS

1. Services should support existing health promotion/public health campaigns targeting AYAs in areas such as: cigarette smoking, alcohol use, sun exposure, safe sex practices, HPV immunisation, healthy eating and physical activity.
2. Health promotion campaigns should also target AYA's whānau and the wider community:
 - a. where health-related behaviours occur in the AYA's wider environment (eg, cigarette smoking in the household)
 - b. where whānau need to be aware of risk factors that predispose AYAs to future cancers (eg, sunscreen use, responsible drinking and safe sex).
3. Health providers working with AYAs (eg, school nurses) should undertake opportunistic health screening when appropriate, focusing on preventable cancer risk factors.
4. Immunisation providers should identify populations where HPV immunisation coverage is low. They should engage with these communities to understand their concerns and provide information. Use of "immunisation champions" within such communities to front local campaigns has been effective in previous childhood immunisation programmes.⁴¹
5. The AYA Cancer Network Aotearoa should support primary care and youth health initiatives focusing on reducing barriers to accessing health care services for AYA (eg, sexual health and drug and alcohol counselling).



STANDARD 1.2

Early symptoms of cancer will be recognised by AYAs and health care providers.

RATIONALE

AYA cancer patients are at increased risk of a delayed diagnosis. This risk is heavily influenced by AYAs' lack of awareness of cancer symptoms,^{26,27,45} which occurs as a result of poor education. In a recent study of 49,000 cancer patients in the United Kingdom, those patients in the 15–34-year age group, were noted to have the lowest rates of cancer symptom awareness when compared to older age groups; in turn, that age group had the highest number of identified barriers to presentation to health

care providers.²⁶ In an analysis of a younger patient cohort, an Italian study of presentation patterns in paediatric and adolescent solid tumour patients showed a significantly longer median symptom interval (137 days vs 47 days, $p < 0.001$) for those patients aged > 15 years, when compared to the 0–14-year age group.²⁵

Access to care barriers contribute to diagnostic delay for AYA cancer patients. A 2012 study investigating cancer awareness in 420 British adolescents identified emotional issues as the most common barriers to presentation. These included anxiety about what the doctor would find, embarrassment and fear. Other barriers included difficulties in communication with the doctor and practical barriers, such as transport issues.²⁶ Contextual factors such as ethnicity group, gender and level of socioeconomic deprivation can also affect AYA health-seeking behaviours.⁴⁶

Referral delay is influenced by the rarity of cancer in the AYA population, and the comparatively different cancers that present in this age group.⁴⁵ A Scottish study analysing over 6000 general practitioner (GP) consultations with adolescent patients showed that only 4% of consultations covered possible “early warning” cancer symptoms. The study suggested that a GP might only diagnose one AYA cancer during their working life.²⁷ For this reason, clinical suspicion can be low.

Health literacy skills training that includes cancer symptom awareness information has been proven to enhance cancer awareness in targeted populations, as evident in a recent randomised controlled trial investigating an AYA cancer symptom awareness programme delivered to secondary school students.^{47, 48}

GOOD PRACTICE POINTS

1. AYA cancer health literacy programmes should be developed and implemented. They should be evidence based, and incorporate youth health promotion principles that are culturally responsive and include an evaluation component.
2. A variety of national education, training and communication initiatives should be developed targeting youth health and primary care providers, to improve awareness of AYA cancer risk and referral practices.
3. The AYA Cancer Network should liaise with youth health and primary care providers to support initiatives that reduce barriers to accessing health care for AYA patients.

REFERRAL TO THE RIGHT EXPERTISE

RATIONALE

Timely access to specialist treatment centres can have a significant bearing on the survival outcomes of an AYA with cancer.^{19, 20, 49} Involvement of tumour group-specific expertise is essential, and is a key component of best practice in AYA cancer care. Where a suspected cancer diagnosis is rare and/or complex and no tumour-specific MDM exists, providers should seek national or international expertise and promote collaborative practice. Such practice includes sharing clinical knowledge across departments (eg, paediatric and adult services) and DHB boundaries.

STANDARD 2.1

When a cancer diagnosis is suspected, AYAs will be referred to the appropriate tumour group expertise and multidisciplinary meeting (MDM).

GOOD PRACTICE POINTS

1. Referrers should have access to a list of MDMs and tumour group specific experts. This should be easily locatable and updated regularly, and include information on referral processes, and contact information. Providers should be able to seek further advice and information through the AYA regional cancer service.
2. On a patient's referral to an MDM, an automatic notification should go through to the regional AYA cancer service. This ensures early involvement of an AYA cancer key worker, and facilitates the process of referral to the right tumour MDM or tumour-based experts.
3. To ensure efficient and timely service provision, health providers should submit complete referral information. Communications to the MDM should include:
 - a. demographic information: the patient's name, date of birth, National Health Index (NHI) number, ethnicities (providers can record up to three ethnicities, according to the total response ethnicity system),⁵⁰ GP, DHB of origin and contact details
 - b. clinical history
 - c. details of investigations already undertaken and their findings, and any outstanding requested investigations
 - d. identified psychosocial risk factors
 - e. notes on what has been explained to the patient and their whānau so far
 - f. whether other referrals have been made.
4. Lead clinicians should ensure that MDM outcomes are communicated to AYA patients and whānau, and should send documentation summarising the outcome to the AYA patient or whānau and their GP.
5. Where a suspected cancer is rare and/or complex, additional expertise might be necessary. In this case, health providers should invite professionals with appropriate expertise to attend MDM meetings. Key time points for involvement of such professionals include the diagnostic period, the initial treatment planning stage and key treatment review periods.
6. Multidisciplinary meeting locations should have video/telephone conferencing facilities to enable communication with remote health providers and non-local experts involved in the case.

THE DIAGNOSTIC PROCESS

STANDARD 3.1

Investigations undertaken during the diagnostic stage will comply with best practice recommendations, as described in the national tumour standards.

STANDARD 3.2

Sedation and other techniques to reduce procedural distress will be made available to all AYA cancer patients

RATIONALE

New Zealand tumour standards exist for 11 tumour groups, and set out the level of service that a person with cancer should have access to in New Zealand.⁵¹ Where a suspected cancer is not covered by these guidance documents, NCCN assistance is available for paediatric tumour types, and regional cancer services can offer guidance on rare adult tumour types.

Initial reference to the guidance set out in the tumour standards may prevent the requirement for re-biopsy and the risk of diagnostic delay. Examples of common AYA cancers for which the standards set out specific biopsy recommendations include lymphoma (the standards specify that excision nodal biopsy is preferred), sarcoma (the standards recommend initial consultation with a sarcoma surgeon, to ensure biopsy is undertaken within the planned resection field) and melanoma (the standards recommend a 2-mm excision margin).^{49, 52, 53}

A number of AYA cancer types (eg, sarcoma, breast cancer and colon cancer) are associated with germline mutations and cancer predisposition syndromes (eg, TP53 mutation and Li Fraumeni syndrome, APC mutation and familial adenomatous polyposis, and BRCA1/2 and hereditary breast-ovarian cancer syndrome).⁵⁴ During the diagnostic stage, awareness of the AYA cancer types associated with inherited cancer risk and knowledge of local referral pathways to genetics services are essential components of best practice.

Discovery of a cancer predisposition syndrome not only has significance for patients and their whānau with regards to screening; it may also change how a cancer is treated. An example of this is the avoidance of radiotherapy where possible with Li Fraumeni syndrome patients with breast cancer, due to their increased risk of radiation-induced secondary cancers.⁵⁵

During procedures, AYA patients can face anxiety, pain and general psychological distress. If left unrecognised, this can contribute to poor tolerance of procedures, and may result in changes in the way AYAs manage pain.⁵⁶ Procedural distress may also compromise the quality of biopsy specimens and imaging results. Both pharmacologic interventions (eg, analgesia and sedation) and non-pharmacologic interventions (eg, provision of preparatory information and psychological interventions) can reduce distress and provide a sense of predictability and control.⁵⁶

“When I was due for a Bone Marrow Aspirate I had to **psych myself up**. They were so painful and I was just **expected to manage it**.”

~AYA patient



GOOD PRACTICE POINTS

1. DHBs should ensure that appropriate imaging technologies including timely access to advanced imaging modalities such as positron emission tomography (PET) scans, are available to AYA cancer patients, as clinically appropriate.
2. A specialist pathologist affiliated to the appropriate MDM should review and confirm the diagnoses of all AYA cancer patients with a histological diagnosis of cancer.
3. When a histological diagnosis is not confirmed, health providers should send samples to national and international pathologists with expertise in the suspected tumour type for second opinions.
4. In the case of complex AYA cancer diagnoses, health providers should seek advice on investigations recommended for diagnosis from designated local and national AYA and tumour group-specific experts.
5. In the case of AYA cancer types that are linked to inherited cancer risk, where appropriate, health providers should undertake early discussion and referral to local genetics services during the diagnostic stage.
6. Health providers should consider, discuss and offer optimal procedural analgesia and sedation, including general anaesthesia, where appropriate, with all AYA cancer patients, ideally prior to the procedure. This is especially relevant in the case of specific diagnoses where procedures occur frequently (eg, intrathecal chemotherapy and bone marrow aspiration for leukaemia patients).
7. All AYA patients should have the choice to be referred to health providers with expertise in reducing procedural distress (eg, psychologists). Techniques may include cognitive behavioural therapy strategies, distraction, hypnosis, relaxation therapy and meditation.
8. The AYA cancer network should make available information on national and international laboratories that undertake emerging diagnostic techniques for AYA cancer types (eg, genomic sequencing, molecular and flow-based minimal residual disease analysis for ALL).
9. Prior to biopsy/resection, health providers should consult with AYA patients and their whānau to ensure personal and cultural views regarding storage and possible disposal of human tissue are acknowledged.

“The hardest thing of all is it has probably **taken away so many years of my life**, of what I wanted to do and has really **knocked my confidence**. I has taken away a lot of dreams.”

~AYA patient

THE TREATMENT PLAN

STANDARD 4.1

All AYA cancer patients will have a documented treatment plan that adheres to best practice recommendations.

STANDARD 4.2

All AYA patients referred urgently with a high suspicion of cancer will receive their first cancer treatment or other management within 42 days.

RATIONALE

For an AYA cancer patient, best practice treatment combines the most appropriate expertise, the most appropriate treatment environment and the most age-appropriate psychosocial care. In the case of a 16-year-old patient with metastatic melanoma, an adult medical oncology team might direct therapy, while a paediatric oncology team provides an age-appropriate treatment environment and out-of-hours support, and an AYA keyworker coordinates psychosocial care. The United Kingdom Teenage Cancer Trust's "Blueprint of Care" for Teenagers and Young Adults with Cancer advocates for flexibility and "significant changes in attitude" within the health system, to overcome historic barriers to cross-departmental collaboration.⁵⁷

There is strong evidence to demonstrate that patients treated within specialist centres have better overall rates of survival.^{19, 20, 49} A Canadian study in 2006 examined the treatment site for AYA cancer patients, and noted the most significant survival advantage for lymphoma patients if they were treated in a specialist treatment centre.¹⁷ It also identified higher clinical trial enrolment rates as a contributing factor. The success of care provided within a specialist centre is dependent on early and repeated communication between relevant services in a multidisciplinary team environment.⁵⁷

Comparative analysis of AYA cancer survival data shows that New Zealand AYA cancer patients, and especially those with bone tumours, soft tissue sarcomas and ALL, are dying with greater frequency than those in Europe, Canada and the United States.⁷ Furthermore, Māori and Pacific AYA cancer patients have poorer survival rates when compared to non-Māori and non-Pacific AYA cancer patients.⁷

This signals that improvements in the cancer treatment pathway for AYA cancer patients can be made - the status quo is not good enough. In acknowledgement, and in the light of the vast heterogeneity of AYA tumour types, Standard 4.2 shortens the Ministry of Health's existing Faster Cancer Treatment (FCT)* target for commencement of treatment following a "high suspicion of cancer" from 62 days to 42 days. This indicator is not part of the FCT programme. Ensuring timely access to treatment plays an important part in improving cancer outcomes.

The Ministry of Health's FCT programme commenced in 2012. It aims to reduce waiting times for appointments, tests and treatment, and also to standardise cancer care pathways.⁵⁸ The specific clinical details that should prompt a "high suspicion of cancer" referral vary according to tumour type.⁵⁹



GOOD PRACTICE POINTS

1. Treatment plans for AYA cancer patients should have a strong evidence base and reference subsidised medicines on the New Zealand Pharmaceutical Schedule. PHARMAC's Exceptional Circumstance Framework can assist treating teams in determining whether unlisted medications can be funded (eg, via the Named Patient Pharmaceutical Assessment pathway).
2. In planning treatment for patients with complex diagnoses health providers should review the existing tumour standards and consult with regional, national, or international tumour group experts.
3. For all AYA cancer patients, health providers should strongly consider transfer of medical care to a treatment centre specialising in the specific tumour type, or joint case management with a specialist treating team.
4. Certain key factors influence the decision-making process regarding where a patient is treated, including the type of cancer, clinical trial access, school attendance, reliance on parents for decision-making, geographical considerations and AYA/whānau preference. AYA Cancer services play a key role in supporting health professionals and AYA/whānau to make this decision.
5. Establish standardised best practice treatment for AYA cancers where there is current variation in practice.
6. Health providers should repeatedly invite members of different specialities with expertise relevant to particular AYAs with cancer to MDMs at different time-points of therapy, to provide a comprehensive treatment perspective.
7. Not all AYA patients will meet the 42-day onset of treatment indicator. Exceptions may be justified in the case of:
 - a. delay due to patient choice
 - b. biopsy samples requiring lengthy processing (e.g, deossification for bone tumour samples)
 - c. the need for rebiopsy
 - d. the need for second opinions (e.g, an international colleague's opinion of a diagnostic sample).
8. All AYA cancer patients should know who the clinical lead for their care is. A clinical lead co-ordinates and oversees the clinical management of an AYA's care across specialities and regions.
9. Health providers should send documentation summarising treatment plans to an AYA's GP, the AYA and where appropriate, their whānau.



AYA TARGETED CANCER RESEARCH

RATIONALE

Improved AYA cancer research is pivotal to attaining better long term outcomes for AYAs with cancer.^{60,61}

Recently, the Australian Youth Cancer Service recruited 101 health professionals and consumers to undertake a survey to evaluate AYA research priorities. Participants in the survey gave most priority to “biomedical and clinical medicine research”, and identified “cancer control and outcomes research”, “anticancer treatment” and “early detection, diagnosis and prognosis” as being specific areas of identified.⁶²

The Progress Review Group for AYA oncology (within the United States’ National Cancer Institute) have recommended five strategies to enhance knowledge of AYA research within the medical domain as follows.⁴

- Analyse AYA data in published AYA trials and databases
- Increase specimens available for translational research
- Increase clinical trial activity in AYA patients
- Focus on the cancers where research can have the most impact (e.g. prevalent AYA cancers which currently show the least amount of survival improvement over time).
- Improve understanding of host/tumour biology.

Psychosocial topics identified as requiring further research include survivorship, fertility, psychosocial assessment tools/care, palliative care, lifestyle management, and psychological and physical therapy efficacy.^{62,63,64}

Research into AYA health services includes analysis of the degree to which AYA-specific services add value to the existing oncology services.⁶³ To best assess efficacy, researchers need to use appropriate metrics.⁶⁵ Providing this evidence for the benefits of a new service in this way can enhance health care provider engagement at the clinician and administrator level.

However, AYA cancer researchers need to overcome a number of barriers, including comparatively small numbers, the heterogeneity of the AYA population with regards to tumour type and age range, low accrual numbers complicated by recruitment and retention, and bias associated with survey research.⁶⁴

GOOD PRACTICE POINTS

1. The health system should encourage health providers to undertake AYA research and clinical audit.
2. Providers should seek financial support for AYA research projects from available funding sources.
3. In contemplating potential research projects, researchers should consider collaboration with other departments, regional health services, and international AYA cancer service partners to enhance study participant numbers.
4. In collecting specimens for biological research, researchers should establish tissue banking protocols that acknowledge cultural perspectives on tissue banking. Compliance with existing guidelines regarding the handling, retention and disposal of Māori patient samples should be apparent in information and the consent form provided to research participants.⁶⁶
5. Researchers should prioritise targeting Māori and Pacific AYA cancer patients and their whānau in their work to reflect the high-level goal of reducing inequalities.
6. The AYA Cancer Network should consider establishing a national AYA research advisory group to provide advice and leadership.

STANDARD 5.1

All AYA cancer patients will be offered the opportunity to participate in targeted AYA cancer research.



STANDARD 5.2

All AYA cancer patients will be offered the opportunity to enrol in available diagnostic and therapeutic clinical trials.

RATIONALE

Gains in survival rates over the past 20 years have not been as marked in the AYA cancer population as they have been in the paediatric or adult cancer populations. Poor clinical trial enrolment rates are regularly cited for this.^{9,10,67,68}

There are a number of barriers to clinical trial enrolment for AYA cancer patients including the lack of available clinical trials at existing treatment site, poor health provider knowledge on the availability of clinical trials, lack of age appropriate clinical trial information and ineligibility for enrolment due to age.^{9,10,18} A recent systematic review of clinical trials in the United Kingdom found “little scientific evidence” for stringent age-eligibility criteria.⁶⁷

From a systemic perspective, strategies to improve clinical trial enrolment for AYA cancer patients include:

- enhanced collaboration between paediatric, adult and AYA cancer services to increase access and accrual to open clinical trials.⁹ In 2014, the National Clinical Trials Network (NCTN) was launched in the United States: it facilitates the running of clinical trials in partnership between tertiary and community oncology services and reduces regulatory barriers in opening paediatric oncology based clinical trials (e.g, Children’s Oncology Group (COG) trials) in adult institutions and vice versa.¹³
- modification of age-eligibility criteria. Since 2000, increased catchment of AYA patients in COG trials has been achieved for Hodgkin’s lymphoma, ALL and sarcoma patients by modifying age-eligibility criteria.^{67,68} The COG Adolescent and Young Adult Committee have contributed significantly to this process.
- the creation of targeted AYA clinical trials. An example is the intergroup ALL trial C10403 which tested a regimen based on the paediatric high-risk ALL approach from the COG in patients aged between 16 and 39 years of age.^{13,22}
- increased referrals of AYA patients to centres known to have open clinical trials.^{10,69}
- increased AYA oncology education in medical school and specialist training.¹⁰

GOOD PRACTICE POINTS

1. The health system should promote open communication between institutions, to create a collaborative environment that aims at advocating for, and increasing, enrolment of AYA patients in clinical trials.
2. Health providers should be aware of the clinical trials that their AYA patient may be eligible for (e.g, various American, United Kingdom and Australian research groups are currently undertaking or planning clinical trials for the treatment of AYA leukaemias). An ideal resource would be an AYA clinical trials database, like the one for New Zealand paediatric cancer patients facilitated by the NCCN.
3. Health providers should liaise with clinical trial groups to find out if an AYA with cancer can participate in a clinical trial that is outside their region of domicile.
4. Health providers should contact clinical trial groups directly to find out whether entry of AYA patients into clinical trials is possible outside of age-limit cut-offs.
5. Clinical trial units should provide age-appropriate and culturally appropriate information verbally and in writing, to AYA cancer participants, and offer further advice prior to any decision-making time point.
6. The AYA Cancer Network should consider developing a national clinical trials working group to implement strategies and tools to improve/support access to and participation in clinical trials among AYA cancer patients.

FERTILITY PRESERVATION

STANDARD 6.1

Prior to treatment, all AYA cancer patients will be informed about the potential risks of treatment-related infertility, and, where appropriate, fertility preservation procedures will be completed.

RATIONALE

Cancer patients in the AYA age group perceive information about their future fertility as a priority, yet they are often dissatisfied with how health providers address this topic.⁵ Up to 60% of cancer survivors do not recall the fertility discussions that took place at their diagnosis.⁷⁰ Health care professionals may not understand the effect some therapies have on fertility, which fertility treatment options are considered standard and available, and how to access fertility preservation therapies especially when they are urgently required.⁶⁸

Fertility-related distress is common in AYA cancer patients during their treatment and beyond it. Many describe the prospect of therapy-related infertility to be as distressing as the cancer diagnosis itself.⁷⁰ Among cancer survivors, an unfulfilled desire to have children is associated with poorer mental health for both men and women.⁷¹ As cure rates improve, this topic has become increasingly relevant.

Evolving priorities during adolescence and young adulthood provide a unique context for fertility discussions. Although AYA patients may state at the time of their diagnosis that they do not desire children in the future, a substantial number of AYA patients (17% in one AYA cancer survivor study) change their mind several years after treatment.⁷¹ This may be explained by embarrassment, by a clouding of understanding at the distressing time of diagnosis, or by the fact that an AYA had not previously considered family planning at the time of diagnosis.

GOOD PRACTICE POINTS

1. When looking for local fertility preservation guidance, health care providers should consult *Fertility Preservation for People with Cancer: A New Zealand Guideline*, published in 2014.⁷² This document outlines the fertility preservation techniques that are available and funded in New Zealand.
2. Health care providers should initiate fertility preservation discussions when they have a “reasonable suspicion” of cancer and offer repeated fertility discussions that are sensitive and take into account the developmental age of the AYA, while recognising time frames for starting treatment.
3. The discussion and documentation of fertility issues at the time of diagnosis is a mandatory component of informed consent prior to treatment commencement.
4. Health providers should hold discussions on fertility risk and preservation options with AYA patients and their whānau in age-appropriate language. Providers should acknowledge differences in understanding of longer-term consequences, and the possibility that patients may later change their views.
5. The mechanisms by which a cancer diagnosis and its treatment modalities and dose intensities can contribute to infertility risk are well known. Health providers should access “fertility risk calculators” via websites. Numerous publications exist to assist health providers in accurately discussing this issue.
6. Health providers should make every effort to acknowledge cultural and religious differences in communicating information about and facilitating of fertility preservation techniques such as storage of embryos.
7. Clear communication pathways should exist between treating teams and fertility services, to enable efficient transfer of clinical information and remove the risk of giving contradictory information to patients and whānau.

STANDARD 6.2

AYA cancer patients will have access to palliative care services. Where appropriate, access will start at diagnosis.

RATIONALE

There is currently a lack of age-appropriate and adequately resourced palliative care services for AYA cancer patients who may not survive their illness, and their whānau. Palliative care aims to 'improve the quality of life for AYA patients and their whānau by controlling symptoms and alleviating physical, social, psychological, and spiritual suffering'.⁷³

Palliative care team members have expertise in complex symptom management, and in particular pain management. When they are provided early in the treatment period, palliative care services can be greatly beneficial to AYA patients. Involvement of the palliative care team as part of the broader treating team at diagnosis can "normalise" the team's involvement, and reduce barriers to optimal palliative care in the longer term.⁷⁴

Health care providers can feel uncomfortable and under skilled in discussing palliative care-related issues with AYA cancer patients. Reasons for this include not being comfortable with what to say to the AYA or their whānau, not wanting to give the perception of 'giving up', or due to the belief that the AYA patient is 'best not knowing'.^{57,74}

Where curative therapy is no longer appropriate for a particular patient, it is essential that providers consider and discuss end-of-life care well before the need for it eventuates.^{73,74,75} A lack of conversation about end-of-life care can create a sense of isolation, fear, and anxiety in AYA patients.⁷⁶ Evidence suggests that AYA cancer patients are comfortable in talking about these issues.⁷⁷



GOOD PRACTICE POINTS

1. Health providers should offer all AYA cancer patients early access to palliative care services when there are complex symptom control issues, when prognosis is guarded at diagnosis, when curative treatment cannot be offered, or if curative treatment is declined.
2. Health providers should introduce a range of palliative care services such as hospice support and respite services early, and include them as part of the multidisciplinary team. This will reduce the stigma of such services, and allow the maximum time for relationship-building with the AYA patient and their whānau.
3. Health providers should ensure that AYA patients have access to palliative care clinicians with sufficient expertise in assessing symptoms, ensuring appropriate treatment to achieve comfort and enhancing quality of life.
4. Providers should offer AYA patients opportunities to talk about their cancer with appropriately skilled health care professionals and assure them that their values, wishes and beliefs will be upheld in the context of palliative care.
5. Providers should support AYA patients to plan proactively for their future irrespective of their prognosis.
6. Providers should recognise that palliative care services provide care not only for AYAs with cancer but also for their whānau, friends and healthcare professionals involved in their care.
7. Providers should recognise the impact a death of an AYA cancer patient can have on other AYA cancer patients and their whānau, especially for patients that had established friendships. Additional consideration and support should be provided.
8. Providers should give AYA patients and (where appropriate) their whānau the opportunity to discuss their needs and goals in the context of palliative care. They should develop an end-of-life care plan for individual AYA patients and provide the AYA, their whānau and key health care providers with a copy. Standard end-of-life care plans are available in New Zealand and internationally.^{78,79}
9. Services should offer health providers working with AYA patients resources and education on palliative care and end-of-life planning, with a specific focus on communication and the timing of palliative care support.
10. All those involved in end-of-life care should acknowledge specific cultural considerations in the context of death and dying (e.g. tikanga practices for Māori patients). Resources to assist providers to engage in culturally appropriate communication in end-of-life care are emerging: Northland DHB's "He Waka Kakarauri" communication model for Māori patients is one example.
11. Bereavement support for whānau, peers and people within AYA support networks is integral. Providers should ensure that this is available, and that it is delivered by appropriately qualified professionals.

STANDARD 7.1

Following completion of treatment, all AYA cancer patients will have a structured follow-up plan that focuses on the multifaceted health issues of survivorship.

STANDARD 7.2

All AYA cancer patients and relevant health care providers will be provided with an end-of-treatment summary document

RATIONALE

Following completion of treatment, AYA patients face numerous health risks. When compared to the non-cancer patient population, AYA cancer survivors have been shown to have a significantly higher prevalence of cigarette smoking, obesity, cardiovascular disease, hypertension, asthma, and poor mental health.⁸⁰ In addition, neurocognitive impairment, endocrine disorders, gonadal dysfunction and second malignancy are among a range of treatment-related complications that require regular follow-up.⁸¹

The health consequences of cancer treatment are relevant for many years beyond cure. In one large retrospective cohort study, at 25 years after their diagnosis, 66% of adult survivors of child and adolescent cancers (up to 21 years of age at diagnosis) were shown to have at least one chronic health; 33% had a chronic health condition classified as severe or life threatening.⁸²

Medical-follow up

Various models of survivorship care provide longitudinal medical follow-up. The established Late Effects Assessment Program (LEAP) is available to AYA patients treated in paediatric oncology services in New Zealand. Medical follow-up should include screening for both general health conditions and specific late effects of therapy.

The AYA cancer population is treated in a variety of institutions and locations; such as, flexibility in the provision of follow-up care is imperative. A tiered risk-based approach to survivorship care allows optimal use of service resources.^{83,84,85} Providers can plan appropriate follow-up care for AYA cancer survivors (in a hospital, through primary care services, or in a combination of both – the “hybrid” model) by allocating a risk group to them based on current medical issues and the level of risk stemming from prior treatment. Bidirectional communication and assistance with clinical management and provision of surveillance guidelines is recommended.⁸⁴ Successful survivorship programmes have demonstrated the benefits of a case manager to coordinate screening investigations, appointments and facilitate referrals.⁸⁵

Psychosocial follow-up

Cancer survivors in the AYA age group are at heightened risk of psychological late effects, including posttraumatic stress, depression and anxiety.⁶³ Psychosocial issues AYA patients face in survivorship include fear of recurrence, difficulties with the formation and maintenance of friendships/intimate relationships, forgetfulness and inattention, sexual concerns and fertility-related distress.^{63,86,87}

A major focus of survivorship is the re-entry into life without cancer. Key to this is the recommencement of work or education. One recent study in the United States found poorer employment rates among AYA cancer survivors compared to an age-matched non-cancer population (24% vs 14%).⁸⁷ Research shows that successful reintegration improves quality of life, reduces social isolation and increases self-esteem.⁸⁷

Providers need to recognise and address the psychosocial needs of AYA cancer survivors at the end of treatment and at regular intervals thereafter. An AYA patient's cancer experience will always be part of them, but should not become their sole identity. Services must finely balance the support they provide, to avoid AYA cancer survivors becoming overly dependent on services in the long term.⁴⁸



End-of-treatment summary documents

A formal end-of-treatment summary or “passport” that survivors and providers can both access facilitates easier transition into life without cancer. Topics in this document can include: the long-term effects of cancer and its treatment; identified psychosocial support resources in the community; guidance on follow-up care; prevention and health maintenance.⁸⁸ Clinicians who use formalised end-of-treatment care plans have reported improved conversations with survivors about potential late effects, and also improved adherence to surveillance recommendations.⁸⁹

GOOD PRACTICE POINTS

Medical follow-up

1. Providers should follow late effects surveillance guidelines such as those available at www.survivorshipguidelines.org or www.asco.org (the American Society of Clinical Oncology website) to provide surveillance guidance for each AYA patient.
2. Specialist long-term follow-up clinics should continue to regularly see AYA survivors identified as being at high risk of complications (e.g. bone marrow transplant patients)
3. Services should make an agreed contact person within the initial treating cancer team available to AYA patients to expedite re-referrals and answer questions.
4. Primary care providers and cancer specialists should collaborate to develop a model of care to address long-term follow-up that best meets the needs of AYA cancer survivors in New Zealand.
5. Providers should establish processes to identify and support AYA patients found to have disengaged from long-term follow-up.

Psychosocial follow-up

6. Providers should continue to offer or facilitate psychosocial care after treatment, with a focus on potential barriers to re-integration such as neurocognitive functioning, social isolation, academic and interpersonal difficulties, low self-esteem, fatigue management and the emergence of psychological symptom.
7. Providers should make educational and vocational support focusing on re-integration available as part of survivorship care. This may include a graduated return-to-school/study plan that supports people to make decisions on future vocational options and assists them with re-establishing their peer networks.
8. Services should establish or continue to support survivorship programmes for AYA cancer survivors that focus on topics such as healthy lifestyle, fatigue management, nutrition, increasing exercise tolerance, emotional wellbeing and self-management.
9. Health providers should provide access to neurocognitive testing and support to all at risk AYA cancer survivors.
10. Ongoing involvement of NGOs and community agencies should occur to address survivorship issues such as peer support, social support and financial assistance.
11. Health Providers should initiate or repeat oncofertility referrals after treatment, as per the *Fertility Preservation for People with Cancer: A New Zealand Guideline*.⁷²
12. Providers should make limitations clear to AYA cancer survivors when they begin to use follow-up services. For example, support groups might have a policy that membership is for up to three years after treatment. Providers may need to use a gradual process to disengage AYA from services.

End-of-treatment summary documents

13. The end-of-treatment document should include: a summary of treatment received, a late-effects surveillance plan, contact information for the treating team and community-based psychosocial support, and information on health prevention and self-management.
14. Health Providers should update the document regularly, and ensure it is able to travel with the AYA survivor (eg, on a USB or online).



SECTION 2

DEVELOPMENTALLY APPROPRIATE CARE

It is important that providers understand AYA patients' response to a cancer diagnosis from a **developmental perspective** to be able to care for them effectively and appropriately.^{4,5,90} The following paragraphs outline normal adolescent development and the impact a diagnosis of cancer can have on both the development of an AYA patient and the management of their cancer.

Adolescence and young adulthood is a **period of complex physical, cognitive and psychosocial change**, associated with the transition from childhood to adulthood. The tasks of adolescence include physical development, the formation of self-identity, school achievement, decisions about the future, the development of peer and sexual relationships, and achieving independence and autonomy from parents.^{5,29,84} Not only are AYAs with cancer susceptible to the pressure associated with developmental changes; they must also navigate the challenges associated with their disease and treatment. This can prevent or disrupt the successful accomplishment of developmental tasks.^{91,92,93}

An individual's particular developmental stage **impacts on the management of his or her cancer**. The available evidence suggests that a substantial proportion of AYAs with cancer experience challenges with **adherence**.^{28,29} Studies suggest that up to one half of AYA patient receiving oral chemotherapy are considered non-adherent.^{28,29}

Developmental priorities such as peer influence can compete with the demands of health care.⁸⁷ Up to the age of 25 years, **the cognitive and emotional capabilities of AYAs are still developing**. This may result in inconsistent thought processes, difficulties taking on others views, an inability to reason and weigh things up, preoccupation with the here and now, impulsivity and difficulty accepting cancer as part of their new reality.^{5,94} All of these may lead to an AYA rejecting the advice of health providers.

An inherent feature of AYA development is **experimenting and taking risks**. Risk-taking behaviours may include drug and alcohol use, unsafe sexual practices and engagement in riskier activities. For AYAs with cancer, the risk of engagement in these behaviours is greater than it is for their peers.⁵

In conclusion, AYA cancer patients have unique developmental needs that neither the paediatric nor the adult approach to management of cancer completely addresses.⁹¹ Because of the potentially negative consequences of non-adherence in AYA patients, providers need to focus on providing developmentally appropriate care alongside best practice medical management. The following standards describe the level of developmentally appropriate care that AYA patients should have access to.

PSYCHOSOCIAL ASSESSMENT AND CARE

RATIONALE

Age-based comprehensive psychosocial assessments and screening tools are essential elements of best practice for AYA cancer patients.^{5,92,95,96,97} Follow-up planning and interventions are more likely to be successful if they are based on a good understanding of the young person's social situation and functioning.^{90,97} Ongoing screening and assessment ensures early identification of issues, including those that contribute to non-adherence and poor emotional health.

Adolescents and young adults with cancer often want to know, but are reluctant to ask about topics such as sexual health and substance use. Evidence suggests that if providers ask AYA patients about these behaviours in confidence, patients are more likely to engage with health professionals and feel they can disclose and discuss concerns with them.^{5,92,95} Such discussions facilitate anticipatory advice and preventative care.

STANDARD 8.1

All AYA cancer patients will have a psychosocial assessment at diagnosis, which will be updated at regular intervals to inform their care.

GOOD PRACTICE POINTS

1. Health providers should complete an age-appropriate psychosocial assessment such as the HEEADSSS assessment⁹⁵ for all AYA patients on diagnosis and review it at regular intervals throughout their cancer journey
2. Health providers should undertake a psychosocial assessment at diagnosis, in the early treatment period, six months after diagnosis, after significant events in the young person's life (eg relationship break-ups), at treatment completion, at a point of relapse or a change in the treatment approach, and at points along the survivorship continuum.⁹⁶
3. In addition to assessment, validated screening tools such as the Australian Youth Cancer Service distress thermometer⁹⁶ may have a place in identifying issues. If providers identify significant distress, they should follow up the identification immediately with a more comprehensive psychosocial assessment.
4. Following assessment, the multidisciplinary team, in partnership with the AYA patient, should develop a care plan focused on addressing the needs of the AYA patient through referral, provision of information, standard AYA management principles and further assessment.

“I was too scared to ask my doctor about weed and chemo... so instead I kept quiet.”
~AYA patient

STANDARD 8.2

All AYA cancer patients will have access to psychological support from diagnosis.

STANDARD 8.3

The spiritual needs of AYA cancer patients and their whānau will be proactively considered and addressed along the cancer journey

RATIONALE

Low mood is an understandable and appropriate reaction to a cancer diagnosis. For many a low mood is a reasonable response to a very difficult situation. However, rates of significant depression and anxiety are consistently higher among AYAs with cancer in comparison to either children or adults diagnosed with cancer^{87,98} and in comparison to their healthy peers.⁹⁷ Rates of depression and anxiety in the AYA population diagnosed with cancer vary widely in the literature estimates of prevalence range from 16 to 42%.^{91,98,99} Poor psychological health in AYAs with cancer is associated with profound psychological suffering, impairments in quality of life, and higher rates of non-adherent and risk-taking behaviours, which in turn contribute to poorer health and social outcomes.^{4,28,98,100} Early psychological review of AYA cancer patients is important to differentiate low mood as a result of normal responses to a cancer diagnosis from the emerging development of clinically significant anxiety or depression.

It is not uncommon for AYA patients to think about, and question, the meaning and purpose of life after a diagnosis of cancer. This type of thinking may be described as philosophical, existential or spiritual.⁵⁷ At certain time points (eg, at diagnosis or relapse), such thinking may become more focused.¹⁰¹

Spirituality means different things to different people. It can include beliefs, values, a sense of meaning and purpose, identity, and religion.³³ For Māori and Pacific people, spirituality ("wairua" in Māori) is recognised as an important facet of wellbeing. 'Youth 2007', a New Zealand-based school health survey, found that spiritual beliefs were "very important" for 60% of Pacific students. This figure was more than double that noted for New Zealand European students. A similar proportion of Pacific students attended a place of worship weekly.¹⁰²

Health providers need to improve their awareness of psychological and spiritual concerns and the way they communicate with their patients and screen them for potential issues in this context. This will ensure early access to psychology and wider supportive care services (eg, chaplaincy, cultural support or spiritual advisors) where it is needed.^{57,91,103}

GOOD PRACTICE POINTS

1. Providers should ensure that AYA cancer patients who have high psychological health risks have early access to psychology or psychiatry specialists trained in providing age-appropriate therapeutic interventions.
2. Psychological input should be integrated and providers should view it as part of the routine care that AYA patients have access to from diagnosis. Ideally a mental health professional should be part of the treating team from diagnosis, normalising and destigmatising the involvement of psychological interventions and improving access to them.
3. Providers should ensure clear referral pathways for psychology, psychiatry and counselling services exist for AYA patients.
4. Providers should ensure that all relevant staff know about locally available support services and resources so they can refer AYA patients as needed.
5. Services should make use of secure online video streaming or telephone consultations in delivering psychological care to isolated AYA patients.
6. Providers should ask AYA patients and their whānau about their spiritual care needs and guide them to the appropriate services and supports
7. Providers should encourage and support AYA patients and their whānau to seek support from their own spiritual and cultural advisors, as well as from hospital based pastoral care and cultural support services.
8. The health workforce should maintain an appropriate level of cultural competency, to ensure the spiritual beliefs of Maori and Pacific AYA cancer patients are integrated into their care.

“I just could not take any more chemo - it was really getting me depressed. So after a lot of discussions with a lot of people, including my keyworker, I stopped
~AYA patient”



DEVELOPMENTAL MILESTONES

STANDARD 9.1

All AYA cancer patients will receive support and care to optimise their normal developmental process as they continue through their cancer journey.

RATIONALE

One focus of AYA cancer care is to minimise the amount of disruption caused by the cancer experience. Impacts of a diagnosis of cancer on development may include, a return to dependence on parents, a loss of autonomy, less peer interaction, body image concerns, increased social isolation, interruptions and setbacks in educational and vocational ambitions and difficulties maintaining romantic relationships.^{4,5,57,91}

We need to help AYA patients to maintain a sense of normality and to achieve their developmental milestones, with the goal of promoting good self-esteem, effective coping, good emotional health, adherence and reintegration back to healthy functioning after treatment.^{4,5,28,29,91,104}

Ultimately, the goal for AYAs with cancer is that they not only survive but thrive, and that we support them to become self-reliant, resilient, independent and productive members of society.^{5,105}

Providers need to incorporate access to age-appropriate resources and support into the care they provide, beginning at diagnosis and continuing through treatment, subsequent transitions to off-treatment survival and the end of life.

GOOD PRACTICE POINTS

Peer relationships and social support

1. To help them avoid social isolation, providers need to support AYA patients to maintain social contact with their usual peer group, through direct interaction, or other channels (eg, social media or the telephone).
2. Providers should offer AYA patients opportunities to spend time with other AYA patients and participate in extracurricular activities in the hospital and the community (eg, ward-based activities, meals out, or shared guitar lessons). Providers should consider and facilitate culturally relevant peer support.
3. Within the treatment schedule, health providers should make efforts to accommodate AYAs' attendance at significant events such as birthday parties, school balls and CanTeen organised camps.
4. Wherever possible, providers should ensure that AYA patients have access to social support (eg, a youth worker) who supports them to maintain social links and activities with peers.



Education, training and work

5. Providers should encourage and support AYA patients to continue their education and or/work where possible.
6. Where relevant, providers should refer school students to a regional health school, which will facilitate educational support for those patients who cannot continue to attend school.
7. Providers should facilitate support for AYA patients to liaise with tertiary education providers where necessary.
8. Health providers should work in partnership with AYA patients to arrange flexible treatment and consultation times to prevent disruption of normal activities.
9. Providers should support AYA patients to negotiate flexible working arrangements with employers.

Behaviour and risk taking

10. Providers should encourage AYA patients to discuss their risk-taking behaviours.
11. Providers should give AYA patients information, advice and support throughout their cancer journey on the impact cancer treatment may have on sexuality. This may cover intimacy, unprotected sex, the use of contraception and potential side-effects of cancer treatment on sexual functioning.
12. Providers should counsel AYA patients and give them information on the use of substances including tobacco, alcohol and marijuana while they are undergoing cancer treatment. Providers should refer AYA patients who require additional support to experts in smoking cessation or youth substance abuse.
13. Providers should promote and advocate healthy lifestyle choices, while remaining supportive and non-judgemental.

Body image

14. Providers should offer AYAs accurate and relevant information on the impact treatment may have on their appearance. They should consider outcomes such as hair loss, scarring, skin changes and weight loss or gain, and facilitate appropriate support and resources.
15. Where significant surgery (eg, amputation) is required providers should offer and facilitate a visit to the AYA patient from a healthy survivor of a similar surgery.

Supporting independence and autonomy

16. Providers should facilitate access to social workers or youth workers to ensure AYAs can access the full range of financial, accommodation, travel and practical support services they are eligible for.
17. Health providers should aim to create an environment in which AYA patients have some control over their care and treatment (eg, in the context of scheduling of procedures).

“Losing my hair during treatment was pretty hard. It was part of me and I just felt ugly. I look in the mirror now and all I see is someone going through hard times.”

~AYA patient

CARING FOR WHĀNAU, PARTNERS AND THE COMMUNITY

STANDARD 10.1

Whānau, partners and the support network of an AYA diagnosed with cancer will have their practical, cultural and emotional needs identified and assistance provided to address these.

RATIONALE

Many AYA cancer patients are reliant on their whānau and/or partner during treatment for practical, emotional and financial support. It is not uncommon for AYAs who had previously left home to return, and become dependent on parents.^{91,103} This can cause a significant economic and emotional burden for whānau.^{54,106,107} Some parents report higher levels of psychological distress than their child undergoing cancer treatment.¹⁰⁸ Siblings of AYA patients are also at risk of psychological distress, decline in academic performance, behavioural issues and disconnection from their peers.¹⁰⁹

Research shows that parental involvement, social support and whānau cohesion and functioning are some of the strongest predictors for good adherence.^{28,29} Thus, there is a need to foster parental involvement and provide support and resources

to meet the practical and emotional needs of whānau and partners.^{108,110}

There is a diverse range of ethnic communities within the New Zealand population. To work effectively with all whānau, services should be culturally responsive. Ethnic groups vary in terms of their beliefs, values systems, family structures and practices.

From an AYA's perspective, the role of their partner and (for some) their own children in their journey is often important. A cancer diagnosis is challenging, even in a robust and long-standing relationship. Younger partners may feel overburdened or, in contrast, isolated, depending on the reaction of the AYA cancer patient themselves to the diagnosis.⁵

Support networks for AYA patients extend to peers, teachers, sports teams and church communities. As appropriate providers should consider these people's own emotional needs, and provide them with information.

“ I don't get to spend as much **time with my kids** as I used to. My partner is very afraid ...**He couldn't quite handle it** and he had to get away from me.”
~AYA patient

“ The consultant was really interested in what mum had to say, and sat down and spent **4 hours speaking with her**, and that made a difference for Mum bringing me in for treatment.”
~AYA patient

GOOD PRACTICE POINTS

1. An AYA cancer patient's whānau may include people actually related to them and also those not related who they define as important to them; such people may offer equal or greater support. Providers should be aware of and acknowledge diverse definitions of "whānau".
2. Providers should take into account the practical needs of wider whānau and partners by:
 - a. providing them with information about their rights to government benefits/entitlements and assistance from charities and community agencies
 - b. identifying specific needs and facilitating support as appropriate in terms of transport, accommodation, advocacy with employers for flexible working arrangements, respite care and child care.
3. Providers should make available resources and supports for parents and carers on the challenges of parenting an AYA with cancer.
4. Providers should facilitate support for carers, parents, siblings and partners and make referrals to NGO support providers as appropriate. They should consider and facilitate culturally relevant peer support.
5. Providers should make use of school health and wellbeing teams as sources of support for school aged siblings and peers of AYA patients.
6. Providers should be alert to emotional and psychological distress in immediate carers, and refer them to support services as appropriate.
7. Providers should recognise the vital importance of whānau and partner involvement in the care AYA patients receive and the decisions they make. For example, they should ensure that AYAs are able to bring along significant whānau for support when providers deliver progress updates.
8. Where views between an AYA cancer patient and their whānau and/or partner are in conflict, providers should actively work to ensure collective support is maintained and conflict is resolved.
9. Providers should ensure that interactions with AYA and their whānau are respectful of cultural considerations and address the additional challenges that whānau may experience when they navigate mainstream health and support services.

Providers should demonstrate cultural competence, as follows.

 - a. Providers should proactively link whānau to services that are able to support their cultural needs, including Māori and Pacific providers.
 - b. Providers should demonstrate a respect for and appreciation of te reo and tikanga Māori practices in the delivery of health care for Māori. For example they could offer opportunities for karakia during care processes, make an effort to correctly pronounce names and terms and show respect for an AYA cancer patient's taonga (eg, by taping it to the body during surgery, rather than removing it).
 - c. Where English is a second language, providers should facilitate access to interpreters and translated information. Providers should not leave AYA cancer patients with the responsibility of translating conversations or information for their whānau.
 - d. Providers should encourage the participation of whānau in the care of an AYA cancer patient. For example, they could set aside additional time to meet with a patient's wider whānau; consider meeting in a non-traditional health care setting, such as a marae or church; identify a whānau spokesperson; engage a cultural advisor/advocate; or acknowledge and incorporate where possible traditional and complementary medicines important to the whānau into a care plan.
 - e. Providers should avoid stereotyping, including assumptions of ethnic identification and cultural preferences. In all cases, providers should ask AYA cancer patients and their whānau which ethnic group they identify with, and consult them on their needs accordingly.
 - f. In meeting the health needs of new migrants and their whānau, treating teams should consult with ethnic advisors. Young people from ethnic minority groups often talk of feeling caught between two cultures: their own and that of their new country.
10. Providers should offer programmes and resources to relevant peers and community groups following diagnosis of an AYA with cancer.

“The hospital sent the Samoan Cultural Liaison person in to support my mum because I have a Samoan last name, but my Mum is Maori ... so that didn't work very well. People always make assumptions”

~ AYA patient ⁴¹

AYA PATIENTS IDENTIFIED AT RISK OF NON-ADHERENCE

STANDARD 11.1

AYA cancer patients with risk factors associated with increased non-adherence will be identified and prioritised for intensive case management.

RATIONALE

A number of risk factors are associated with increased non-adherence in the AYA cancer population. These include family/parental dysfunction, multiple problems of disadvantage, poor health literacy and engagement, low self-esteem, psychological distress, parental mental health, substance abuse, being a teenage parent and not being engaged in training or work.^{28,29,108,111}

Early identification of those at risk of non-adherence and early intervention is likely to be most effective in supporting adherence and preventing abandonment.^{4,111}

GOOD PRACTICE POINTS

1. The regional AYA cancer service should have a process in place to identify and prioritise AYA patients at risk of non-adherence and disengagement from care. Where the service identifies this risk, AYA keyworkers/champion and the wider multidisciplinary/multiagency team should begin intensive case management as follows.
 - a. Providers should develop proactive ways of reaching and engaging the AYA patient such as home visits or flexible appointment times.
 - b. Providers should prioritise continuity of care for the patient; that is, make sure the same consultant, primary care nurse and MDT team members consistently see them. Designated consultants should update the AYA patient and whānau about their disease, any problems that might arise and planned treatment.
 - c. Where possible the AYA key worker should attend all appointments, to reinforce messages and monitor progress with plans.
 - d. Providers should maintain frequent contact and monitoring by phone, email or home visits.
 - e. In the case of an inpatient admission, the nursing team should work to ensure continuity of care.
 - f. Providers should recognise the practical difficulties for some AYA patient and whānau in accessing treatment involving transport, medications, accommodation and child care. They should endeavour to facilitate access and support where needed.
 - g. Providers should enlist "harm minimisation methods" to decrease the burden and risk of treatment (eg, simplifying the frequency of medication administration, supplying medications in a blister pack, providing a mobile phone top up to ensure contact can occur with health providers at all times, and arranging St John membership so transport worries are not a factor when a patient needs acute access to a hospital).
 - h. Providers should ground their assessments and delivery of health care in a strengths-based approach and avoid defining the AYA patient as "the problem". The focus should be on supporting and building the capacity of AYA patients to resist risk factors and enhance protective factors. (For further information on this, see the Youth Development Strategy Aotearoa.)²
2. Providers should update AYA patients primary care teams regularly and engage them to provide additional support.
3. Providers should prioritise collaboration and joint interventions between agencies (eg, NGO's, Work and Income, health services, housing services and social services). With the individual AYA patient's consent, collaboration could extend to support networks, such as their church or sports teams.
4. The wider multidisciplinary team should review AYA patients at regular intervals.

SELF-MANAGEMENT

STANDARD 12.1

All AYA cancer patients will be supported to self-manage their own health care as they mature.

STANDARD 12.2

All AYA cancer patients and whānau will be provided with developmentally appropriate cancer-related information.

RATIONALE

For AYAs with cancer, taking on and taking over self-management of their care is essential in the wider context of their transitioning into young adulthood. This responsibility may result in increased self-confidence, a more successful transition to adult health care, improved cancer outcomes, and improved quality of life.^{94,112} Acquiring skills for self-management requires significant support, and is a gradual process. Health providers can play a key role in this. Adolescent and young adult patients need to develop knowledge of their disease, and then need to accept responsibility for, and be motivated to take greater part in, their care. They need to learn to adhere to medication and management plans, maintain ongoing preventative health care and seek out health care and information services.⁹²

Research has revealed that AYA patients' need for age-appropriate information can be significantly unmet. The AYA Health Outcomes and Patient Experience study found that 53% of AYA cancer patients had high levels of unmet information need.¹¹³ AYA patients have a strong desire for comprehensive information that will inform their decision-making and allow them to fully understand their treatment.⁵ Effective methods for delivering information to AYA cancer patients include face-to-face contact with health care providers and patient educational materials, such as booklets, pamphlets, brochures and DVDs.⁵

In comparison to older patients, AYA cancer patients are more likely to use the internet as an important source of health information. Reviews of internet content show a paucity of reliable high-quality information for AYA cancer patients.^{114,115}



GOOD PRACTICE POINTS

1. In consultations with AYA cancer patients and their whānau, health providers should apply youth health literacy techniques; for example, they should:
 - a. explain concepts in a manner that is appropriate to the AYA's development, literacy and cultural needs
 - b. prioritise information
 - c. present information in logical simple steps
 - d. reinforce and emphasise key points
 - e. assess the AYA's understanding of what has been said
 - f. repeat and summarise information
 - g. use visuals, diagrams and practical application where appropriate.
2. Health providers should reinforce all verbal discussions with relevant written information developed specifically for the AYA age group. They might also consider digital video clips.
3. Services should develop preapproved lists of reliable websites to help AYAs safely sift through the information available on the internet.
4. Health providers should encourage AYA patients and whānau to discuss information they find on the internet with them: especially information that differs from that provided by the health care team.
5. Health providers should remain open and facilitate discussions regarding complementary, alternative and traditional therapies, with a specific sensitivity to cultural and religious backgrounds.
6. Health providers should encourage AYA patients to ask questions, give them time to prepare for conversations and suggest they write questions down prior to discussions.
7. Health providers should repeatedly offer AYA patients information throughout the cancer journey.
8. To assist AYA patients in self- management of their care, providers should ensure that consultations focus on skill-building tasks, through techniques such as role-playing scenarios, practical practice, support the development of problem solving techniques and anticipatory guidance.
9. Health providers should encourage AYA patients to use technology (eg, reporting symptoms via text message) to enhance engagement and self-management.
10. Health providers should use transition checklists to support AYA patients and their whānau to transition to more independent self-management. Such checklists set out indicators that serve as a prompt for health providers to assess and assist AYA patients in their self-management.

“The specialists were **so busy** and had their team with them - all poking at my leg - muttering to each other and I didn't feel like I could ask questions. **The doctors were very intimidating.**”

~AYA patient



STANDARD 13.1

All AYA cancer patients will be supported as they transition across services.

RATIONALE

The term "transition of care" refers to the transfer of care between paediatric and adult focused health care. There is literature available on the concept of transition of care for paediatric chronic diseases and disability.^{94,116} Less literature is available relating to transition of care in the context of cancer. However, it is thought that many of the principles established in other contexts can be applied to AYA cancer survivorship.

In recent decades, there has been a dramatic increase in the number of children and AYAs surviving their cancers and requiring transfer to adult-based care.¹⁰⁰ Adolescent and young adult patients requiring transition can be categorised into three subgroups: 1) survivors in need of long-term surveillance monitoring; 2) survivors with treatment-related late effects who require ongoing management; and 3) patients who have a relapsed, secondary or primary malignancy diagnosed in a paediatric setting.^{116,117}

There is generic evidence that AYA patients transitioning between paediatric and adult or primary care are at risk of feeling dissatisfied with their care, disengaging with services and dropping out of care. This may lead to worse disease outcomes.^{92,94} There are recognised transition-of-care models and widely available resources that can guide providers to support patients in transition. There is early evidence that development of transition programmes improves disease outcomes, cost-effectiveness and self-reported engagement in care.⁹²

Relapse or second malignancy in an older adolescent that is followed up in paediatrics or a late-effects monitoring programme can create significant challenges with regards to transition of care. It may call for creative strategies and closer collaboration between paediatric and adult cancer teams.¹¹⁷

Developing the capability to address the various types of transition should be a central goal of any AYA cancer service.

“I am constantly on the phone **chasing things up**. The nurses don't know what each other is doing. I have **better things to do with my life**.”

~AYA patient



GOOD PRACTICE POINTS

1. Services should ensure that they have a transition policy for AYA patients, with reference to the three sub-groups below:
 - a. survivors in need of long-term surveillance monitoring
 - b. survivors with treatment-related late effects who require ongoing management
 - c. patients who have a relapsed, secondary or primary malignancy diagnosed in a paediatric setting
2. Services should work to an evidence-based guideline for transition that covers the age of transfer, the rationale for transfer, the way services will work together to deliver care during the transition period, how information will be communicated and shared between the teams, and key contacts.⁹²
3. Good transition processes include ensuring AYA patients and their whānau are well-prepared for the transfer. This can be achieved by:
 - a. providing sufficient notice that transition will be occurring, to allow patients to prepare
 - b. giving patients and whānau the opportunity to visit the new ward/clinic and meet key members of the team
 - c. outlining differences in care and follow-up procedures between old and new services
 - d. facilitating a consultation/handover meeting between old and new providers and the AYA patient and whānau.
 - e. making sure resources (eg, brochures) are available to assist patients and whānau with the process.
 - f. making sure patients and whānau have a key contact who can help them navigate services, communicate preferences and access support resources throughout the transition period.
4. In the case of adolescents who have a relapsed, secondary or primary malignancy diagnosed in a paediatric setting and need urgent transfer to adult cancer services, health providers should take the following actions.¹¹⁷
 - a. Immediately educate the AYA patient and their whānau on the adult health care system.
 - b. Initiate a formal collaborative process (such as a face-to-face meeting) to achieve transition, involving at least the core members of the paediatric and adult cancer teams with the AYA patient and their whānau.
 - c. Immediately refer patients to specific age-appropriate psychosocial supports in the adult environment (eg, social workers, cultural support workers and peer support groups).
 - d. Temporarily assign a “key contact” from the paediatric team to accompany patients and whānau to initial tests and treatments.
 - e. Ensure that the consultative involvement of the wider paediatric team continues to assist the adult care team as needed.

CONFIDENTIALITY/RIGHTS/RESPECT AND TRUST

STANDARD 14.1

The rights of AYA cancer patients will be respected. A key focus is to establish confidentiality and trust.

RATIONALE

AYA patients are more likely to engage with health providers, disclose their concerns and contribute to decisions about their care if they feel a sense of trust and rapport with providers, and are assured of confidentiality/privacy.^{94,118,119,120} Providers who use effective, age-appropriate communication skills and work in partnership with the patients are more likely to successfully develop trust and rapport.^{5,57,95}

Providers must give AYA patients the opportunity to be heard, and must value their opinions. Involvement in decision-making and confidential access to health care are rights for all young people, regardless of their chronological age.¹²¹ Because of their age, increasing maturity and the seriousness of the consequences of decisions, working with AYA cancer patients potentially presents health professionals with a number of legal and ethical issues.¹²¹ For example, where a 15-year-old refuses to consent to further treatment against the wishes of her parents.

GOOD PRACTICE POINTS

1. Health services should visibly display information setting out AYA patients' rights, in language that will be understandable to AYAs and their whānau.
2. Providers should discuss confidentiality and its limits with every AYA patient and their whānau, reinforced by a youth-friendly written resource.
3. Providers should offer all AYA patients the opportunity to meet with them alone on a regular basis, even if it is only for part of the consultation.
4. Health providers should fully inform all AYA patients about their disease and decisions regarding their care, including consent to and refusal of treatment, making use of resources and standard processes.
5. Health providers should be aware of the rights of AYA patients including their right to be involved in decision-making about their care, and their right to confidential and private health care. Services should provide training in this area to all staff.
6. Ethical and legal dilemmas will arise in the AYA cancer age group. Services should ensure that processes are in place to support providers in approaching these situations. The 1998 Ministry of Health publication *Consent in Child and Youth Health: Information for Practitioners* serves as a guide.¹²¹
7. Providers should be familiar with and make use of developmentally appropriate communication techniques when working alongside AYA patients, such as: ^{54,60}
 - a. Taking a non-judgemental, respectful and empathic approach
 - b. Spend good quality time with the patient.
 - c. Be yourself; don't try to be cool.
 - d. Allow the patient time and space to process information.
 - e. Use good negotiation skills.
 - f. Be honest when you don't know the answer.
 - g. Adopt a personal approach; use of humour where it's appropriate.
 - h. Consider using technology(eg, text messaging) to enhance the patient's engagement with providers and their ongoing care.

“My oncologist and I always spent what felt like most of the appointment talking about silly things, like his shoes, which looked cooler than they actually were. That was cool - made the rest of the conversation really easy

~AYA patient

CARE CO-ORDINATION

RATIONALE

The needs of an AYA cancer patient cannot be met solely by one service or individual. It is not uncommon for an AYA patient to be seen by multiple health professionals/specialists, members of a multidisciplinary team, within/across multiple DHBs and in both public and private sectors. Adolescents and young adults with cancer and their whānau often report feeling overwhelmed by the number of people they come in contact with, the information they are offered and the need to navigate complex systems.

STANDARD 15.1

All AYA cancer patients and their whānau will be provided with access to a nominated health care professional who will co-ordinate their care.

Care co-ordination is essential in the delivery of AYA cancer care. Internationally, AYA co-ordinator/key worker roles are considered to be an integral component of best practice for AYA cancer care co-ordination.^{68,122} In New Zealand in 2007, six regional AYA cancer care key workers were established based in the larger treatment centres. The aim of the role is to provide specialised care co-ordination and oversight for the AYA age group.¹²³ A 2013 patient/whānau experience evaluation found that AYAs and whānau who had access to an AYA key worker reported decidedly more positive experiences than those that did not. The evaluation found positive outcomes identified with involvement of a key worker including better adherence to treatment; a reduction in did-not-attend numbers for outpatient clinic appointments; better psychosocial health and wellbeing among AYA patients and whānau; improved timeliness of access to services, supports and treatments; and improved oversight and continuity.¹²⁴

Access to a key worker is not always feasible (eg, in regions with higher caseloads, or in geographically isolated areas). The key message in this standard is that AYA cancer patients should have a nominated health professional, with some specialised AYA cancer care knowledge, who can provide care co-ordination as outlined in the practice points below. In a larger centre, this role maybe undertaken by a clinical nurse specialist with some training in AYA cancer care, supported by the keyworker and the wider AYA cancer services team. For the purposes of this standard, such roles will be referred to as AYA cancer champions.

“She would sit in on all my important appointments and then we’d go and talk about them afterwards to **make sure I understood** and didn’t miss anything. We’d then go over what was going to happen next, where I needed to be and what I needed to do. It was so good that I could understand.”
~AYA patient



GOOD PRACTICE POINTS

1. Health providers should refer all AYA cancer patients to the regional AYA cancer service during the diagnostic period.
2. Regional AYA cancer services should ensure that every AYA diagnosed with cancer has a nominated AYA key worker/cancer champion to co-ordinate their care. This person should provide support to the AYA patient while they are undertaking treatment and after their treatment is finished
3. Health providers should make key workers or champions aware of AYA patients with a high suspicion of cancer, and key workers or champions should meet all newly diagnosed AYA patients and their whānau within seven days of diagnosis.
4. Key workers and champions should be appropriately trained and skilled health providers, and should be responsible for:
 - a. co-ordinating a patient's medical and psychosocial care across the whole system and at all stages of the patient pathway, including as they move between care settings.
 - b. facilitating delivery of care that is based on evidence for the AYA age group.
 - c. ensuring the provision of a written care/treatment plan (after undertaking an initial needs assessment).
 - d. facilitating or providing practical and emotional support to the patient and their whānau.
 - e. facilitating the provision of information that is timely, is age appropriate, meets the needs of the whānau and is understood.
 - f. liaising with the multidisciplinary team.
 - g. working in partnership with Māori and Pacific health providers to effectively support Māori and Pacific AYA and their whānau.
5. Services should ensure that patient records clearly identify key workers' and champions' names and contact details.
6. In situations where a nominated key worker or champion is on leave or can no longer fulfil the role, providers should transfer responsibility for this role to another health provider and inform the patients and whānau.
7. Keyworkers or champions should provide the right level of case management and support to reflect the AYAs level of need.
8. Optimal care-coordination is difficult when AYA cancer patients are isolated by geography, when they receive care across DHB boundaries or when there are gaps in local AYA cancer service provision
Health providers should overcome this by:
 - a. ensuring there is a handover process for AYA patients requiring transfer between tertiary and regional areas/hospitals, and that patients have a key worker or champion in both centres.
 - b. creating communication networks between local health providers and the regional AYA cancer service, and encouraging the use of local and remote cancer services and youth health providers.
 - c. offering online resources and support for health professionals and AYA patients and their whānau (eg, a portal for AYA cancer-specific tools or peer support online).
9. Services should restrict the caseloads of key workers and champions to a size that enables them to provide quality care.



RATIONALE

Best practice for AYAs with cancer is delivered through a combination of specialised medical management and expert age appropriate psychosocial management.⁵⁷ Patients and whānau should have access to a range of multidisciplinary and multiagency expertise and services.¹²⁵ The complex range of services that AYA patients require access to often transcends both organisational and institutional boundaries.⁵⁷ For multidisciplinary/agency supportive care to be effective, providers need to overcome barriers to find innovative ways of working together.

Research shows that where multidisciplinary care co-ordination is achieved mainly through face-to-face meetings, the benefits include increased patient satisfaction with care, increased referrals and access to psychosocial care and information, increased perception by the patient that the team is managing their care, improved communication and familiarity with roles within the team, improved transition between paediatric and adult services, more equitable services, and better development of expertise and shared learning between members of the team.^{57,68}

STANDARD 15.2

All AYA cancer patients will have access to co-ordinated multidisciplinary and multiagency care.

GOOD PRACTICE POINTS

1. Multidisciplinary/multi-agency care for AYA patients and whānau should incorporate access to the following professionals/services: the cancer treatment team, psychology/psychiatry, education, palliative care, spiritual care advisors, youth providers, NGO providers, cultural support, physiotherapy, occupational therapy, social work, dieticians, government agencies, primary care services and community health and social teams.
2. Services should offer AYA patients a written resource identifying key members of their multidisciplinary team, including names, roles and contact details.
3. Services should ensure that, regardless of where a patient resides and receives treatment, they have equitable access to professionals and services
4. Services should develop good communication channels between cancer treatment teams, primary care providers, allied health workers, key workers, NGOs and community services/agencies
 - a. They should consider establishing a separate psychosocial MDT in addition to the treatment planning MDT, to provide a forum for holistic consideration of each patient and whānau that includes both medical and psychosocial aspects.
5. Services should make available a directory of local health services, youth/social support services and resources for AYAs with cancer and their whānau.
6. On entrance to an AYA cancer service, health providers should inform patients about the multidisciplinary team/multi-agency approach to care, and about how the wider team shares information. Services should develop a process by which they seek consent and determine limitations for information sharing for each AYA patient and their whānau.

SECTION 3 INSTITUTIONAL SUPPORT

If we want to improve survival and ensure equitable outcomes for AYA cancer patients, we need **high-quality services, strong regional clinical leadership and clear governance** that links with the national strategy for AYA cancer care. A sustainable and effective AYA cancer service requires **strong youth participation**, the development of a **trained AYA cancer work force**, **developmentally appropriate environments and effective performance monitoring**. The following five standards explore these key elements in detail.



GOVERNANCE & CLINICAL LEADERSHIP

STANDARD 16.1

There will be a governance structure with identified clinical leadership that provides direction and oversight for AYA cancer care.

RATIONALE

Internationally, health systems are beginning to recognise AYA cancer care as a distinct discipline, we need to recognise it as a distinct discipline here too.^{4,57,91,126} If we are to improve outcomes for AYA with cancer in New Zealand, we need to ensure that changes to existing models of care are co-ordinated, measurable and significant. To effect change and achieve broad sector engagement, we need cohesive and visible leadership and governance, at the regional and the national level, encompassing paediatric and adult health care professionals, and multiple agencies and organisations.

GOOD PRACTICE POINTS

1. Each AYA cancer service should have :

- a designated health professional or team providing clinical leadership for AYA cancer. This needs representation from both paediatric and adult services and smaller treatment centres.
- a clear interagency governance structure that reports on issues related to delivery of care and outcomes for patients.
- meaningful representation and/or participation of Māori and Pacific health advocates within the governance structure.
- a service delivery strategy that links to the national strategy for AYA cancer care and entails a plan to address existing inequalities.
- a process to identify how the service will measure service quality and patient outcomes, with reference to these Standards of Care.
- a process to seek feedback and evaluation.

“Probably 80-90% of these issues could be dealt with by **improving consistency** - putting in place **effective processes and structures**”

~ AYA Advisory Group member

RATIONALE

It is not uncommon for health professionals working with AYA patients to report a lack of skills to address both health and psychosocial needs of this particular age group.^{4,7,92}

The best care for AYA cancer patients is provided by health professionals who have been specifically trained to care for them. Currently, nursing and medical undergraduate training programmes do not include significant amounts of targeted AYA education.¹²⁷

We need to expand the provision of AYA cancer education. Key learning topics include effective confidential care, communication, psychosocial assessment, promotion of AYA's capacity for self-management and transition to adult services.^{4,100,128,129}

No formal evaluation has yet been completed on existing post-graduate AYA cancer training programmes. However, it has been shown that post-graduate training in youth health among clinicians in school health services in New Zealand is associated with fewer students reporting mental health difficulties and binge drinking.⁹² These findings support the value of specialised training in youth health for clinicians working with AYA patients.

Research has found that the AYA age group poses a number of challenges for health professionals.^{57,68} To ensure this age group receives the best possible care, organisations need to consider providing targeted support for their workforce, including clinical supervision.⁵⁷

STANDARD 17.1

Health care professionals and the supportive care workforce who work with AYA cancer patients will be trained to deliver developmentally appropriate care.

“Need to make sure this is a **whole service** - this is not just about the key worker role. They can't do everything so other staff need to be trained up”

~AYA Advisory Group member



GOOD PRACTICE POINTS

1. All providers who care for AYA patients on a regular basis should have access to basic youth health competency training. A number of New Zealand and international basic training packages are available online: the AYA Cancer Network Aotearoa can provide information on these.
2. Health providers in particular those in advanced AYA cancer care roles, such as key workers, cancer champions and lead clinicians, should have access to advanced AYA cancer care education (eg, a postgraduate AYA cancer course). Services should explore funding opportunities (eg, through NGO scholarships).
3. Each treatment centre should train their AYA cancer champions to the appropriate level.
4. Services should make available support to assist providers working in sole practitioner roles (eg, key workers should have access to individual clinical supervision and mentoring).
5. Services should ensure that informal and/or formal staff support (eg, through debriefing sessions) is available to all teams working with AYAs.
6. Services should encourage and consider funding members of the multidisciplinary team working with the AYA group to attend international AYA conferences.
7. Health services should explore multidisciplinary fellowship opportunities and the cross-training of cancer trainees through paediatric and adult cancer-based rotations.
8. Services should support the recruitment of Māori and Pacific health professionals and support providers.
9. Services should support culturally safe and responsive training for the AYA cancer workforce, with a particular focus on service provision to Māori and Pacific AYA patients and their whānau.



YOUTH PARTICIPATION

STANDARD 18.1

AYA cancer patients will be provided with the opportunity to actively participate in the development, implementation and evaluation of regional and national AYA cancer care programmes and services.

RATIONALE

Government and non-government agencies in New Zealand are increasingly involving consumers in policy and service development. As the 2009 Ministry of Youth Development document *Keepin' it Real* states, "by utilising youth participation principles in the development of youth services you are more likely to get it right the first time and avoid wasting time and money on services, programmes and resources that young people don't want to use".¹³⁰

GOOD PRACTICE POINTS

1. Services should familiarise themselves with and apply the guiding principles of the Health Quality and Safety Commission's *Engaging with Consumers: A Guide for DHBs* and *Keepin' it Real* (which guides organisations in involving young people in their policy development, programmes, services and organisations).¹³⁰
2. Services should have access to an identified youth advisory group that contributes to service development, research design and quality improvement in AYA cancer care. This may be achieved by working collaboratively with an advocacy group such as CanTeen. Advisory groups should represent the diversity of young people in New Zealand in terms of gender, age, ethnic background, life style interests and sexual orientation. Where youth participation is effective, consumers:
 - a. can review health information to make sure it is comprehensible and useful
 - b. are involved in the design of facilities, including the selection of furniture and equipment
 - c. are involved in developing and delivering staff training
 - d. are involved in staff recruitment procedures.

“She gave me the tools to **advocate for myself** and I live like that to this day. She was **life changing** for me.”

~AYA patient

AGE APPROPRIATE ENVIRONMENTS

RATIONALE

It is essential that we treat AYA patients in environments that provide developmentally appropriate care, and facilitate access to age-appropriate facilities and recreational resources.

Internationally, and particularly in the United Kingdom, considerable funding and resource has gone into developing specialised AYA cancer units. Evidence has shown that AYA patients prefer undergoing treatment in facilities with others of a similar age.^{53,131,132} Dedicated facilities are more likely to adequately address the educational, social and vocational needs of AYA patients and engage them in their treatment in a more positive manner.¹³¹ The co-location of AYA patients in one treatment setting also facilitates the development of expertise in AYA cancer care among treating teams.¹⁰⁶

Dedicated AYA cancer treatment areas may not be feasible in cancer services that treat low numbers of AYA cancer patients per annum. However, services can still achieve age-appropriate environments through simple measures such as co-locating AYA patients when possible, providing access to age-appropriate recreational resources and information, and providing some flexibility in the structure of care. This can increase AYA engagement, promote feelings of normality, reduce patients' sense of being in a hospital setting, provide enjoyment, assist with apathy and depression, promote social interaction and encourage patients to have higher expectations of their treatment period.^{57,106}

STANDARD 19.1

AYA cancer patients will be treated in a health care environment that is developmentally appropriate.

“Being on the adult ward was **terrible**. I made it very clear I was going to be staying with my son and they put him in a six bed room with five females. There was nowhere for me to sleep. Eventually they found a single room for us and gave me a La-Z-Boy to sleep in. But then they moved us out again. **I was in tears** trying to pack up all our stuff. They said I'd have to **sleep on a couch in the corridor**.”

~ Parent of an AYA patient



GOOD PRACTICE POINTS

1. Services should admit AYA cancer patients to age-appropriate facilities or dedicated spaces where they are available.
2. Adolescent and young adult dedicated facilities should have the following spaces: a recreation room offering age-appropriate recreational activities, a school or study room, a kitchen, laundry facilities and an interview room.
3. Where there is no dedicated AYA facility, health providers should co-locate patients with other patients of similar age group. The most appropriate place for an AYA patient if this cannot be achieved is a single room.
4. Physical facilities should support a whānau-based approach to care (eg, they should provide space for whānau to accompany patients to treatment).
5. Service providers should develop guidelines for prioritising AYA bed placement.
6. Services should offer age-appropriate recreational resources and décor to all AYA patients, including television, game consoles, wireless internet, DVDs and relevant reading material.
7. Services should ensure that all AYA patients have access to recreational therapists or youth workers. The role of such workers may include one-on-one support, provision of recreational resources; ward-based social activities and facilitation of peer support. Support workers within NGOs may take on such roles.
8. Health provider processes and ward culture should create an age-appropriate environment in the following ways.
 - a. Visiting hours should facilitate support from whānau and peers unless this is medically contraindicated.
 - b. Ward routines should be flexible (eg, they should accommodate later waking times and flexible meal times).
 - c. Wards should offer AYAs the option of having a support person to stay overnight on the ward but should balance this offer with AYA patients' need for independence.
 - d. Services should actively work to minimise and reduce patients' time in hospital or outpatient facilities (eg, through offering late discharge when treatment finishes in the evening or during the night).
 - e. Food is identified as a significant issue for AYA patients during inpatient admissions. Wards should offer access to food storage, preparation facilities and flexibility in menu choice.

“The kids from CanTeen would come and just hang out with him. **They made him laugh** - and boy did he need that! They'd do some really silly teenage things and the **nurses let them** - it was great!”

~Parent of an AYA patient

CLINICAL PERFORMANCE & MONITORING

RATIONALE

At present, there is no reliable and widely available system of data collection for AYAs (people aged 12-24 years) with cancer in New Zealand. This is a problem in many other countries too; internationally, researchers view current data collection as inadequate to support much-needed clinical research.^{4,61} The New Zealand Children's Cancer Registry (NZCCR) was established in 2000; it collects demographic and treatment information on all children receiving treatment in New Zealand paediatric oncology centres. The registry includes information on AYA patients who receive treatment at a children's cancer treatment centre, but does not include those treated in adult treatment centres.

The New Zealand Cancer Registry is a population-based register of all primary malignant diseases diagnosed in New Zealand. It contains limited clinical data on treatment and management approaches, recurrences, clinical trial participation, multidisciplinary care, palliative care, late effects and psychosocial support/outcomes.

Investigation as to the feasibility of a minimum national data set and/or an AYA cancer electronic database is a priority. Such a data set would need to link in with the New Zealand Cancer Health Information Strategy¹³³ and would support clinical case management, service planning, clinical performance monitoring and research.

STANDARD 20.1

A nationally agreed AYA cancer dataset will be collected within each DHB.

GOOD PRACTICE POINTS

1. Regional AYA cancer services should have a current system in place for case management and monitoring of AYA patients.
2. National data collection overseen by the AYA cancer network should include data on access to, timeliness of and quality of care; treatment and management approaches; recurrences; clinical trial participation; multidisciplinary care; palliative care; late effects; and psychosocial support/outcomes.
3. The AYA Cancer Network should report national AYA cancer incidence and survival data every three to five years.
4. Where services collect data, they should do so in accordance with the National Cancer Core Data Definition standards.¹³⁴
5. All AYA cancer services should have an equity-focused quality improvement plan in place which covers collecting, analysing and reporting ethnicity data at a minimum. Services should collect ethnicity data according to *Ethnicity Data Protocols for the Health and Disability Sector*.⁵⁰

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