



# Midland Adolescent and Young Adult Oncology Haematology Service Report

2008

Action Plan

2008 – 2010



This report has been produced by the Midland Cancer Network for Bay of Plenty, Lakes and Waikato DHBs.

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## Acknowledgements

*To the memory of those children for whom our knowledge was insufficient; to those children who have been cured but must approach adult life with the residual of treatment; and to the children of the future who will benefit from scientific advances that may limit treatment toxicity so as to truly approach a cure.*

Dedication from the book: Survivors of Childhood and Adolescent Cancer: A Multidisciplinary Approach

The Midland Cancer Network acknowledges the health professionals from Starship, Bay of Plenty, Lakes and Waikato DHBs and Midland community organizations who contributed their time and expertise. We look forward to their continued involvement and support as we implement the action plan for the Midland AYA OHS.

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Term, abbreviation or acronym	Definition or description
AYA OHS	Adolescent and Young Adult Oncology Haematology Service
LEAP	Late Effects Assessment Program
AYA	Adolescents and Young Adults
DHB	District Health Boards
MCN	Midland Cancer Network
NZCCS	New Zealand Cancer Control Strategy
NZCTWP	NZ Cancer Treatment Working Party
NZCCSG	NZ Cancer Control Steering Group
MDMs/MDTs	Multidisciplinary meetings/teams

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## **Executive Summary**

Although a relatively small group, adolescents and young adults (AYA) between 12-24 years with cancer have special needs that can be readily addressed. AYA cancer prevalence in the Midland region is highest in skin, leukaemia, testicular, Hodgkin's and brain cancer. Although less than a quarter will die from their cancers, Midland AYA currently experience variations and fragmentations to service delivery.

The national Adolescent and Young Adult Oncology Haematology Service (AYA OHS) service specifications (draft) outlines the model of care required for the Midland region. The Midland AYA OHS commenced in January 2008. In 2007-2008, the Midland Cancer Network initiated and led a project to support the development of the service. Development of an AYA OHS reflects a creative and innovative approach to meet the specific needs of adolescent and young adult cancer patients through the partnering of the paediatric (supraregional) and adult oncology (regional) tertiary services to maximise:

- the cure rate for AYA with cancer
- entry onto age-appropriate clinical trials
- the psychosocial care delivered to the patient and their family/whānau
- a youth development approach to care.

The project approach supported the key worker and stakeholders to develop the Midland AYA OHS model of care.

2007/2008 key achievements include:

- AYA OHS key worker employed that assists with coordination of care
- a MCN AYA work group established under the governance of MCN
- identification of four lead adult clinicians for the service
- directory of AYA services and providers within the Midland region
- training and education programme developed and implemented
- fertility framework developed and implemented.
- strengthened relationships with supraregional, secondary/tertiary services and community groups.

The Midland AYA OHS report and action plan 2008-2010 provides the AYA OHS work group with the direction to further develop the service. It has been agreed that MCN AYA work group will lead, facilitate and coordinate progress on the AYA action plan. Key attention areas are as follows:

1. Support and develop the role of the AYA OHS lead clinicians.
2. Support further research and clinical audit to understand the reasons for poorer AYA Māori outcomes.
3. Waikato DHB to appoint a paediatric oncology shared care nurse as soon as possible.
4. A framework with agreement on roles and responsibilities of Waikato shared care nurse and AYA key worker is defined, ensuring cover for leave.
5. Clarify if psychologist assessment is an essential service component of the national LEAP for the Midland late effects follow-up clinic. Scope regional LEAP as per national service specifications.
6. Implement national supportive care guidelines for AYA once finalised. Scope options within allocated resources implemented for links/access to psychology services for AYA. This links with the MCN identified need for a psycho-oncology service model of care.
7. Lead paediatrician, shared care nurse and AYA key worker to work with Starship to develop the supraregional MDM framework.
8. AYA key worker and lead adult clinician(s) to attend local MDMs for AYA.
9. Lead adult clinician(s) to consider and refer where appropriate AYA entry into clinical trials.
10. Continue to implement education and training programmes. Monitor and evaluate effectiveness after one year.
11. Formalise that the AYA key worker patient contacts (ie FSA, follow-up) are captured within the contract framework, to assist with service planning.
12. Continue to develop youth friendly facilities throughout the region.
13. Formalise a referral process for AYA OHS to have AYA key worker input as early as possible.
14. Share and support cross-fertilisation of AYA models of care between Starship and Midland adult oncology services for AYA in both treatment and follow-up including surveillance for late effects of treatment.
15. Evaluation of AYA key worker position and plan by June 2010.

## 1. Introduction

The purpose of this paper is to report on the progress of implementing a Midland Adolescent and Young Adult Oncology Haematology Service (AYA OHS). A project approach was used for the development of a new service in the Midland region and has resulted in a regional AYA OHS model of care and action plan for future development of the service. The structure of the paper summarises:

- strategic background
- the AYA cancer burden for in the Midland region
- the AYA OHS project methodology
- the AYA model of care, key findings and achievements
- recommended action plan for the future development of the service.

The Midland region comprises Lakes, Bay of Plenty and Waikato District Health Boards (DHBs) with Waikato as the lead DHB. The Midland AYA OHS commenced in January 2008, under the umbrella of the Midland Cancer Network (MCN) with the aim to optimise treatment for adolescence and young adults by partnering paediatric and adult oncology services. AYA are defined as between the ages of 12–24 years.

## 2. Strategic Background

This section describes how the AYA OHS project and service aligns with national, regional and local strategies.

The New Zealand Cancer Control Strategy (NZCCS)<sup>1</sup> and associate Action Plan 2005–2010<sup>2</sup> (Action Plan) provide a national framework for reducing the incidence and impact of cancer as well as reducing inequalities with respect to cancer across the cancer control continuum. The Action Plan identifies priorities for action and outlines in detail how the strategy objectives can be achieved. Relevant Action Plan AYA goals and objectives are:

**Goal 3:** Ensure effective diagnosis and treatment of cancer to reduce morbidity and mortality.

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<sup>1</sup> Ministry of Health (2003)

<sup>2</sup> Ministry of Health (2005)

Objective 4: Improve the quality care delivered to adolescents with cancer and their family and whanāu.

**Goal 4:** Improve the quality of life for those with cancer, their family and whanāu through support, rehabilitation and palliative care.

Objective 3: Ensure all survivors of childhood and adolescent cancer receive timely and ongoing support and rehabilitation, including the early identification of, and intervention in, late effects.

Working towards achieving the NZCCS, the adolescent sub-group of the New Zealand Cancer Treatment Working Party (NZCTWP) developed draft AYA OHS service specifications (2008) that are going through a sign off process. The service specifications support introduction of an AYA OHS key worker and an integrated service model of care. The model of care is flexible to any proposed amendments to the service specifications. The Ministry of Health have supported introduction of the service specifications with AYA OHS implementation funding to lead DHBs.

The MCN, one of four regional cancer networks in New Zealand, was set up to work with DHBs and the wider cancer control community to achieve the goals of:

- reducing the incidence and impact of cancer and
- reducing inequalities with respect to cancer
- and improving the patient journey through the continuum of care.

Development of a Midland AYA OHS aligns with the Midland DHBs Cancer Control Action Plan 2006-2010<sup>3</sup> and the MCN work programme.

Waikato DHB as the lead is funded through a crown funding agreement variation. Funding was used to employ an AYA OHS key worker and a project officer to support development of the service.

### **3. Midland AYA burden of cancer**

A high level overview of the cancer burden for the AYA population in the Midland region identifies that there were 319 new cancer registrations and 70 cancer deaths between 1994 and 2004 for AYA between the ages of 15–24 years (table 1).

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<sup>3</sup> Waikato DHB, Bay of Plenty DHB, Lakes DHB Cancer Control Action Plan 2007-2010.

<b>Table 1. New Cases and Deaths for Youth Aged 15-24 years between 1994 and 2004 for New Zealand and specifically for Midland which includes, Waikato, Lakes and Bay of Plenty District Health Boards.</b>						
<b>Diagnostic Group and Subgroup</b>	<b>NZ New Cases</b>	<b>NZ Deaths</b>	<b>Midland New Cases</b>	<b>Midland % against NZ New Cases</b>	<b>Midland Deaths</b>	<b>Midland % against NZ Deaths</b>
i. Other Malignant Epithelial						
a. Malignant Melanoma	428	19	74	17%	8	4%
b. Thyroid	97	1	13	13%	0	6%
ii. Germ Cell						
a. Testicular	187	10	25	13%	0	0%
iii. Lymphoma						
a. Hodgkin's	142	10	13	1%	3	3%
b. Non-Hodgkin's	62	16	11	18%	1	1%
iv. Leukaemia						
a. Lymphoid	79	47	18	23%	10	21%
b. Myeloid	77	21	13	17%	3	14%
v. Central Nervous System						
a. Brain non-specific	100	49	13	13%	5	10%
vi. Connective & Soft Tissue	62	31	11	18%	4	13%
vii. Malignant Bone						
a. Osteosarcoma	65	29	9	14%	8	28%
viii. Stomach	18	11	11	61%	5	45%
Sub total	1317	244	211	16%	47	19%
Other Cancers	444	119	108	24%	23	19%
<b>Total</b>	<b>1761</b>	<b>363</b>	<b>319</b>	<b>18%</b>	<b>70</b>	<b>19%</b>
<b>Average per year</b>	<b>161</b>	<b>33</b>	<b>29</b>	<b>18%</b>	<b>6.4</b>	<b>19%</b>

Table 1 indicates that on average there were 29 new cancer cases diagnosed per annum, with an average of 6 deaths per annum for the Midland region between the years 1994-2004. The Midland average number of AYA registrations and deaths is lower than the national average. Of the predicted 29 new cases per annum, on average, just over 50% go to paediatric oncology and the rest are referred and managed via adult oncology.

Melanoma of the skin incidence volumes account for the highest number of new cases at 24%. Melanoma is the most common of AYA cancers for non-Māori in the region. Leukaemias, the second most common group of AYA cancers, constituted 10% regionally. Testicular and lymphomas followed closely at approximately 8% each (appendix one).

In regards to mortality, AYA diagnosed with bone cancer were most likely to die from their cancer. In addition to bone cancer, leukaemia's and stomach cancers (high Māori incidence/mortality) accounted for the greatest numbers of deaths at 37% for this age group. There are limitations with the data to enable identification of reasons for higher mortality rates.



Of the 319 new registrations 1994-2004, 61 or 19% were Māori. Of those 70 cases that died between 1994–2004 26 (37%) were identified as Māori. The Māori population is 23% of the total Midland population<sup>4</sup>.

### **3.1 Health Inequalities**

The data in regards to health inequalities is statistically insignificant due to the low case volume. Although the data does not indicate why inequalities are occurring, there are key themes that need consideration for the AYA population group.

There is evidence of inequalities for AYA people with cancer including socio-economic, ethnic, and people living in different geographical regions (appendix one).

The cancer burden in New Zealand is unequally distributed according to socio-economic status with Māori and Pacific people's disparity significantly worse in the Midland region overall.

For Māori AYA, cancer is a leading cause of morbidity and mortality and there are disparities between Māori and non-Māori in relation to incidence and mortality rates. An analysis of the morbidity and mortality data for 1994-2004 showed that Māori adolescents and young adults had a higher mortality rate for myeloid leukaemia, lymphoid leukaemia, stomach, brain and connective and soft tissue cancers compared to non-Māori.

Finally, there are diverse challenges in service delivery and additional barriers to accessing health services for Midland AYA travelling from remote rural locations. The Midland region catchment area covers 56,738 km<sup>2</sup>, and comprises 21.2% of New Zealand's land area. The Midland rural population is estimated at 43%<sup>5</sup>.

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<sup>4</sup> Statistics New Zealand. (2006). PHI Offline 2007. Public Health Intelligence, Wellington.

<sup>5</sup> Statistics NZ (2006). PHI Offline 2007. Public Health Intelligence. In this instance, the Midland reflects Lakes, BOP, Waikato, Tairāwhiti and Taranaki DHBs.

#### **4. The Midland AYA OHS Project Methodology**

Previously, AYA OHS key workers had been established in the paediatric oncology centres at Auckland, Capital Coast and Canterbury DHBs. In 2007-08 the Ministry of Health funded Waikato DHB to commence development of a Midland AYA OHS with the employment of a key worker<sup>6</sup>. A project approach was used to initiate the development of the AYA cancer service. The national AYA OHS service specifications (draft) outlined the model of care required for the Midland region. Development of an AYA OHS reflects an innovative approach to meet the specific needs of adolescent and young adult cancer patients through the partnering of the paediatric (supraregional) and adult oncology (regional) tertiary services to maximise:

- the cure rate for AYA with cancer
- entry onto age-appropriate clinical trials
- the psychosocial care delivered to the patient and their family/whānau
- a youth development approach to care.

The project approach supported the key worker and stakeholders to develop the Midland AYA OHS model of care. The service officially commenced January 2008.

The Midland AYA OHS project objectives included:

1. establish and develop a Midland AYA OHS work group
2. develop as part of the Midland Cancer Control Strategy Plan a section on the Midland AYA OHS. The plan includes the following:
  - a. stocktake of existing services against national AYA OHS service specifications
  - b. stocktake of AYA OHS services and providers
  - c. stocktake of paediatric and adolescent oncology workforce
  - d. training programme for those identified working with the AYA OHS
  - e. systems and processes including a MDT framework including supraregional MDT
  - f. framework to promote AYA participation in age appropriate clinical trials
  - g. framework to promote AYA participation in fertility services
  - h. implementation plan to transition AYA with cancer and their family and whānau onto the local Late Effects Assessment Program (LEAP)
  - i. youth model of care
3. assist and support development of AYA OHS service with all stakeholders.

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<sup>6</sup> Key worker commenced September 2007

## 5. Midland AYA OHS Model of Care

This section summarises:

- prior to implementation of a Midland AYA OHS how services were delivered and the gaps when compared to the national AYA OHS service specifications model of care
- key achievements over the last year against the project objectives
- area's for further development in the future.

This section also highlights the views and experiences through the eyes of adolescents and young adults along the cancer continuum. These experiences were drawn from AYA cancer patient focus groups facilitated by CanTeen (2001).

The aim of developing the AYA OHS model of care is to develop and integrate the two service pathways and to ensure that the adult oncology pathway for AYA is the same level as the AYA component of the paediatric shared care model. Prior to 2007-08 services to AYA cancer patients was provided by two separate services and was dependant on age. The two services are:

AYA, depending on age, were referred to either of two services.

1. Adolescents 15 years and below were referred to Starship, Auckland DHB and followed up by the Waikato DHB paediatricians and the Midland paediatricians and shared care nurses, an existing supraregional service/collaboration.
2. Those aged 15 years and above were referred to the Regional Cancer Centre adult oncology at Waikato Hospital.

Those between 15-18 years could be sent to either service.

The term “supraregional” is relatively new for cancer in New Zealand and is referred to throughout this document. It relates to the existing partnering of tertiary and secondary oncology services throughout New Zealand. Waikato is partnered with Starship Auckland. Other supraregional centres exist in Wellington partnered with Palmerston North and Christchurch partnered with Dunedin.

The Paediatric Oncology Steering Group (POSG) is the umbrella for the 3 tertiary paediatric oncology services and provides some of the consistency which exists for

paediatrics across the country. It is also responsible for the follow-up program called the LEAP.

The following discusses the systems and processes of the essential AYA OHS service components, highlights achievements to date and areas that require further action.

## **5.1        Supraregional links**

An important component of the AYA model of care is strengthened relationships between the secondary and tertiary paediatric centres and developing the relationship between the two key AYA supraregional and regional services.

The Midland AYA OHS key worker works closely with:

- the Auckland based supraregional AYA OHS key worker
- the shared care nurse for Starship
- the LEAP Clinical Nurse Specialist (national LEAP)
- the paediatric oncologists and paediatricians.

The shared care nurse, key workers and LEAP CNS utilise phone, email and telepaeds to share information between centres. Families can be introduced to the Midland AYA key worker through telepaeds to assure a streamlined transition back to the region. Starship also provides a written handover for each AYA transferred back to the region.

The full extent of the strengthened links will be realised with the development of the lead adult clinician(s) role that will work in partnership with the Midland AYA key worker and Starship lead clinician.

A national approach to service development is also being endorsed through fortnightly telepaeds videoconferences with all AYA OHS key workers. Telepaeds is located in the Waikato hospital children's clinic and connects the supraregional with regional child health centres. Current topics include role development, a standardised care pathway for AYA with cancer, educational resources, training, and branding of the service.

The AYA key workers from New Zealand attended an international adolescent and young adult with cancer conference in June 2008 in the United Kingdom. The key worker from Midland visited several youth cancer facilities and shadowed international colleagues. Learning's from the conference are being realised throughout the ongoing development of the service.

## **5.2 Midland Regional links**

Waikato, Lakes and Bay of Plenty DHBs have a paediatric oncology shared care model that is working well with Starship. The current vacant Waikato shared care nurse position, compounded by the Waikato lead paediatrician on leave has resulted in service delivery issues.

The Midland AYA OHS key worker, a 1 fte clinical nurse specialist, provides care coordination, advocacy, education and support to AYA with cancer and their family/whānau along the cancer continuum. As of September 2008, the service had 35 patients enrolled and up to 5 active at any one time. The low volume of AYA allows for consideration of amendment to responsibilities for the key worker. The key worker has relied on education and relationship building to engage health professionals. The key worker is the link between paediatric and adult oncology services as well as between Midland DHBs for adult oncology AYA.

The AYA OHS key worker is employed by the regional cancer centre and works closely with:

- Waikato, BOP and Lakes paediatric oncology shared care team
- AYA under adult oncology services that includes the lead clinicians, cancer care co-ordinators within the Midland region and other team members.

The MCN has established a care coordination work group that covers community, primary, secondary and tertiary representation and a continuity of care framework. The AYA OHS key worker participates in the forum and links with these organisations.

The MCN and the Midland AYA OHS completed a stocktake (appendix two) and developed a stakeholder database which identifies all AYA services and providers along the cancer continuum.

### **5.3 Midland Cancer Network AYA OHS Work Group**

In March 2008, the establishment of the MCN AYA OHS work group was utilised initially as a consultative process with key stakeholders to develop the model of care for the service. Once the consultative process finished, the group was mandated, as agreed in the terms of reference (appendix three), to:

- take a proactive clinical leadership approach to AYA with cancer
- support and advise the AYA key worker
- oversee the implementation of the regional AYA action plan
- advise on possible initiatives to reduce inequalities across the cancer continuum and the impact cancer has on AYA and their families/whānau.

The work group links at local, regional and national levels (appendix four).

A key requirement of this Midland group was the identification of a lead adult clinician. In November 2008 the Clinical Director of the MCN identified four lead adult clinicians reflective of the type and incidence of Midland AYA cancers:

- medical oncologist
- radiation oncologist
- haematologist
- neurosurgeon

Clinical lead roles are new and flexibility is required as they get established. The role is integral to drive the clinical components of the service specifications such as clinical trials and the supraregional MDT.

### **5.4 AYA OHS Facilities**

The national AYA OHS service specification (draft) recommended dedicated age appropriate cancer facilities. There is no dedicated AYA facility within the Midland region.

The value of a physical unit for AYA with cancer is not warranted in the Midland region due to low AYA incidence of cancer per annum. Rather, AYA depending on age and patient choice will be referred to specialist services. The AYA OHS is working towards youth friendly spaces in paediatrics and oncology (appendix five).

To date, discussion around youth friendly spaces have occurred in Waikato paediatrics and adult oncology with input by CanTeen.

Foundation 2020, an independent fundraising body set up in 2005, began working with the Midland region public, community groups, businesses and health professionals to raise funds for a proposed child/youth focussed care facility by the year 2020 located at Waikato hospital. It is unclear at this point in time how this initiative will advance.

***The service through patients' eyes:***

*"Like the old people, you have to be really quiet or they'll get annoyed at you and it makes you feel like there's no place for you".*

*"Yeah and if I stay with all the little kids they cry too much and they go beep beep with the buzzer and you can't sleep!"*

*"And I think that with a lot of the older people they are terminal like they're getting near the end of their life and their's quiet a lot of death, really, which is quite hard to be around"*

*"I think a communal thing would be cool cos you know if there was a youth space for when they were feeling well, there could be stuff to do"*

*Source: O'Connell, A. (2001). Where do all the middle ones go?*

## **5.5 Referrals**

There are two referral pathways for AYA OHS, paediatric oncology or adult oncology. There are no formal referral guidelines. Typically, 15 years and under are referred to paediatric oncology and 15 years and above to adult oncology. For the 15-18 year subset, referrals to either service are determined by the clinician who must take into consideration patient and family choice, stage of development in addition to the ability to enrol into clinical trials when referring to either of the two services.

Paediatric referrals are received via the Waikato Referral Coordination Centre from primary services for Waikato DHB. Waikato paediatrics then refers onto Starship utilising the Waikato shared care team. Typically, Lakes and BOP DHBs refer directly to Starship.

AYA OHS adult oncology referrals to the Regional Cancer Centre are received at the Waikato Referral Coordination Centre from primary and secondary services.

Referrals then can be directly actioned under the adult oncology service or as required referred onto Starship for those 15 years and under. Refer to appendix six for details of the referral processes.

When the AYA key worker commenced there was no referral pathway for the AYA key worker to receive referrals from either paediatric or adult oncology services. Currently referrals are received on an ad hoc basis from stakeholders. The key worker in the first year has focused on building rapport with key stakeholders, in particular Starship, tertiary and community services. Referrals are received via email or direct phone contact with the key worker. There is the aim to involve the AYA key worker as early as possible. This model will be extended to engage with professionals at the primary level as well as in the areas of surgery and plastics.

Starship AYA key worker refers AYA patients back to the Midland AYA key worker. The Starship shared care nurse specialist refers to the regional shared care nurses. A current key issue at Waikato is the vacancy of the shared care nurse (0.6 fte) compounded by the lead paediatrician on leave. There is no clear agreement of the role and functions between the Waikato shared care nurse and AYA key worker. The majority of referrals to the AYA key worker are going to come from adult oncology (i.e. less than 15 new cases per annum). The above issues need to be clarified to justify a full time AYA key worker.

## **5.6 Care Coordination**

Care coordination is a comprehensive approach to achieving continuity of care for patients and their family/whānau. The care coordination approach aims to ensure that care is delivered in a logical, connected and timely manner so that the health and personal needs of patients are met<sup>7</sup>. The introduction of the AYA OHS key worker is one strategy that assists with care coordination. All members of the multidisciplinary team have a responsibility in coordinating care. The Midland AYA continuum of care is described in appendix seven.

Each DHB has a shared care framework supported by a shared care nurse that links and coordinates care for paediatric oncology. Each DHB has a number of

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<sup>7</sup> Galetakis, S.(2006). Care Co-ordination – *Striving to make the difference in Victoria*. Retrieved September 10, 2007 from <http://health.vic.gov.au/cancer>.



community, primary and secondary/tertiary nurse care coordinators within adult oncology. The AYA key worker is employed within the regional cancer centre along with other cancer care coordinators to enable and build working relationships to improve care coordination with specialist adult care coordinators. One key area for development is between the Waikato paediatric shared care nurse and the AYA key worker. It was agreed by Women and Children's Clinical Director that the roles be complementary, including cover for leave.

*The service through patients' eyes*

*"They'll have you on a list (for tests), but they've got the wrong time or whatever, and you need to come back and come back..."*

*"They are quite slack, for want of a better way of putting it, you know, the results should be back at 'yay' time, and they come back the next day...sometimes, the next week!"*

*Source: O'Connell, A. (2001). Where do all the middle ones go?*

## **5.7 Multidisciplinary Care**

Multidisciplinary care is not a new concept, but increased emphasis is being placed on the benefits of supporting multidisciplinary care. The rationale for multidisciplinary team (MDT) working is to improve decision making and coordination of care, thereby reducing errors and improving quality of care. It is well documented and accepted that multidisciplinary care represents best practice in terms of treatment planning and care for cancer patients.

The AYA OHS service specifications (draft) support multidisciplinary care at the regional as well as the supraregional level.

At a supraregional level there is no MDM involving the regional team. The AYA OHS service specifications (draft) recommend that there is a supraregional MDM established, this has yet to occur between Starship and the Midland region.

Regionally, due to a low volume of cases via the adult oncology service, a separate multidisciplinary meeting (MDM) is not warranted. The MCN has completed a stocktake of MDMs (refer to the Midland non-surgical cancer treatment service plan). The MCN along with the regional cancer centre and other stakeholders are further developing and enhancing MDMs. The Midland AYA OHS lead clinician, supported by the AYA key worker, can link into the appropriate tumour stream MDM for AYA

under the adult oncology service. At the supraregional level, the key worker has established communication pathways for AYA between the two services. This will be further developed as the lead clinician roles are embedded. Appendix eight details the Midland AYA OHS MDT framework.

To support development of MDMs Waikato DHB has employed a multidisciplinary team meeting co-ordinator for the regional cancer centre. This role will assist improving clinical multidisciplinary review meetings and implementing systems and processes. The MCN is also developing a multidisciplinary care framework for the Midland region.

***The service through patients' eyes:***

*"A registrar....was telling me about an operation....and he kinda went 'oh its probably a good idea if we go over there, where it's more private', and afterwards I thought it was a good idea...it could've happened in front of other people otherwise..."*

Source: O'Connell, A. (2001). *Where do all the middle ones go?*

## **5.8 Education and Training**

Midland health professionals with specialist interest in adolescent and young adult cancer include the AYA OHS key worker, lead paediatrician, shared care nurses and staff within Rainbow Place and True Colours.

Training and education is an integral component to the AYA OHS model of care. An AYA OHS training and education framework has been developed and implemented to support the needs of health professionals in the Midland region. This framework can be found in appendix nine.

The framework provides several modules including three one day sessions comprising strategies clinicians can utilize in their practice that may assist in obtaining best health outcomes. The strategies are based on cognitive behavioural therapy, motivational interviewing and a youth focussed CHEADss assessment tool.

***The service through patients' eyes:***

*"then my dad started having a fight with them to get me out cos I was really really sore and they were pushing me 'just one more minute' and I was so sore...they were really pushy"*

*"Some talked to you and have a chat, but others are just like oh, you're getting in the way"*

Source: O'Connell, A. (2001). *Where do all the middle ones go?*

## **5.9 Supportive Care**

The service specifications require linkages between service providers with supportive care services in the Midland region. A stocktake of AYA OHS supportive care services along the cancer continuum is detailed in appendix seven under support and rehabilitation.

Identified gaps in supportive care included LEAP, that has a component of supportive care. This is discussed later under the LEAP section.

The MCN has already identified supportive care gaps and inequalities related to the level of providers and limited access to psycho-oncology services compared to the rest of New Zealand. Midland does not have a psycho-oncology service. The MCN is reviewing psycho-oncology models to address this gap in psychological services for Midland.

In addition, the Guidance for Improving Supportive and Rehabilitative Care for Adults with Cancer in New Zealand (2008, draft), out for consultation, will address gaps in service for the total population. The aim of the guidelines is to develop equitable and appropriate supportive care.

The project identified a key gap for AYA under adult oncology services which have less access to community based psychological support compared to those under the care of paediatric oncology.

The Cancer Society will provide up to six sessions by a community counsellor chosen by the AYA patient. If psychological needs are beyond the scope of the counselling sessions, a referral for assessment can be made to mental health services. Each region<sup>8</sup> has separate criteria for accessing services depending on diagnosis. In comparison, supportive care services for AYA 18 years and below and their family/ whānau are provided by True Colours and Rainbow Place throughout the cancer continuum.

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<sup>8</sup>Waikato DHB Children and Adolescent and Adult Mental Health service provide services for only the top 3-5% of mental health diagnosis.

Supportive care extends to home support services which is required at different points along the cancer continuum. As cancer falls under the personal health continuum, ongoing home help or respite care is only accessible during terminal stages for both children and adult oncology services.

The AYA key worker coordinates the supportive care needs of AYA patients under adult oncology. In addition the AYA key worker has picked up coordinating supportive care needs of AYA paediatric patients once transferred back from Starship, due to current shared care nurse vacancy at Waikato. The key worker attends multi service organisations meetings to discuss any 12-18 years AYA with cancer.

## **5.10 Clinical Trials**

Enrolment in clinical trials is associated with improved outcomes for adolescents and young adults. There are several scenarios to account for reduced enrolment in the Midland region including:

- AYA not being offered clinical trials
- AYA not meeting criteria to enrol in clinical trials
- AYA experience barriers to enrolling or maintaining clinical trials.

Key gaps in access to clinical trials include:

- 15–17 years under the adult oncology service do not meet the criteria to enrol in most clinical trials. In response to this issue, consensus was gained that a lead adult oncology clinician should consider the AYA person within this age group, when appropriate to be referred for treatment at Starship enabling access to approved COG clinical trials.
- in comparison to the paediatric services, AYA in the adult oncology service are less likely to be enrolled in clinical trials. The major barrier is the economies of scale due to the small number of AYA patients in regards to open trials. There are several other barriers such as domicile of the AYA person, financial aspects for the AYA person to travel to Waikato to participate in a clinical trial, limited research resources, compliance and support to maintain the person on the trial. The AYA key worker has met with the clinical trials coordinator to acknowledge these barriers and plan to work collaboratively on these barriers.

The Midland AYA OHS clinical trials framework is detailed in appendix ten.

### **5.11 Fertility**

There is one fertility service for the Midland region, Fertility Associates, based in Hamilton. For Midland AYA, males can access sperm banking to preserve fertility. Females have access to fertility services, although they may experience barriers in regards to time and effectiveness of services including:

- partner required at time of diagnosis to benefit from the current contract
- delays to commencing of chemo/radiotherapy to ensure removal of eggs
- females without a partner must pay for alternative services such as egg or ovarian tissue freezing.

An AYA fertility framework has been developed to enhance access for females to fertility services (appendix eleven).

### **5.12 Late Effects Assessment Program (LEAP)**

The AYA OHS service specifications state that following completion of planned therapy, the regional AYA MDT should ensure that the adolescent and young adults with cancer and his/her family/whanau transitions to the local late effects assessment program

LEAP is the name of a guideline tool developed by the POSG to assist tertiary paediatric clinicians with oncology follow-up for patients following treatment in the paediatric program. Follow-up has always occurred for this age group but the LEAP tool provides formality to this process. LEAP is resourced at New Zealand supraregional centres, Starship Auckland, Wellington and Christchurch. Ministry funding was allocated to LEAP to employ additional resources for this follow-up, particularly nursing and psychologist services.

In regards to Midland AYA with cancer, Starship Auckland provides follow-up for those AYA who have received treatment at the supraregional centre. This follow-up

occurs at a monthly outreach clinic organised by the Starship shared care and LEAP CNSs in conjunction with Waikato staff and is provided by paediatric oncologists Scott Macfarlane and Jane Skeen. The Midland AYA key worker attends the clinics based at Waikato Hospital. Typically, patients will meet with the paediatric oncologist, Midland oncology shared care paediatrician, shared care nurse and AYA clinical nurse specialist where they undergo assessment, receive a health passport and referral to other services based on needs, including referral for psychologist assessment at Starship.

The difference between follow-up for AYA residing in Auckland and the Midland region receiving services through Starship is on site availability of psychologist assessment.

For AYA 18-24 years there is no coordinated late effects follow-up, regionally or nationally, unless they have been followed through the paediatric oncology program. As well, there is no coordinated late effects follow-up for 15-17 years treated under adult oncology services. It is unclear where and how late effects follow-up should occur for the 18-24 age subset, as age and developmental stage are different in comparison to paediatric cancers. Follow-up for this age subset can happen independently to paediatric services but adult services may choose to adopt the LEAP tool as a convenient and appropriate way to deliver that service. The MCN sent a letter to the Ministry of Health cancer team highlighting the gap in the late effects/AYA service requesting direction.

There is a national draft document Guidance for Improving Supportive and Rehabilitative Care for Adults with Cancer in New Zealand (draft, 2008), which will go some way to supporting the 18-24 year AYA with late effects.

## **6. Conclusion**

In summary, there is agreement that improving care to AYA through the integration of paediatric and adult oncology services is warranted. The volume of AYA cancer incidence is small in the Midland region with approximately 29 new cases per annum, with over half of the cases, managed through paediatric oncology. There are inequalities with Māori mortality rate; however, information is limited as to the reasons.

The Midland region AYA OHS model of care focuses on building and enhancing existing services by developing the adult oncology pathway for AYA to the same level as the AYA component of the paediatric shared care model.

Key achievements over the last year include:

- AYA OHS key worker employed that assists with coordination of care
- a MCN AYA work group established under the governance of MCN
- identification of four lead adult clinicians for the service
- directory of AYA services and providers within the Midland region
- training and education programme developed and implemented
- fertility framework developed and implemented.
- strengthened relationships with supraregional, secondary/tertiary services and community groups.

There is an opportunity to build on the key achievements to enhance AYA service delivery and patient experience and outcomes. The area's that require further action are summarised in the action plan section.

## **7. Action Plan**

The Midland AYA OHS action plan 2008-2010 provides the AYA OHS work group with the direction to further develop the service. It has been agreed that MCN AYA work group will lead, facilitate and coordinate progress on the AYA action plan. Key attention areas are as follows:

1. Support and develop the role of the AYA OHS lead clinicians.
2. Support further research and clinical audit to understand the reasons for poorer AYA Māori outcomes.
3. Waikato DHB to appoint a paediatric oncology shared care nurse as soon as possible.
4. A framework with agreement on roles and responsibilities of Waikato shared care nurse and AYA key worker is defined, ensuring cover for leave.
5. Clarify if psychologist assessment is an essential service component of the national LEAP for the Midland late effects follow-up clinic. Scope regional LEAP as per national service specifications.
6. Implement national supportive care guidelines for AYA once finalised. Scope options within allocated resources implemented for links/access to psychology services for AYA. This links with the MCN identified need for a psycho-oncology service model of care.
7. Lead paediatrician, shared care nurse and AYA key worker to work with Starship to develop the supraregional MDM framework.
8. AYA key worker and lead adult clinician to attend local MDMs for AYA.
9. Lead adult clinician to consider and refer where appropriate AYA entry into clinical trials.
10. Continue to implement education and training programmes. Monitor and evaluate effectiveness after one year.
11. Formalise that the AYA key worker patient contacts (ie FSA, follow-up) are captured within the contract framework, to assist with service planning.
12. Continue to develop youth friendly facilities throughout the region.
13. Formalise a referral process for AYA OHS to have AYA key worker input as early as possible.
14. Share and support cross-fertilisation of AYA models of care between Starship and Midland adult oncology services for AYA in both treatment and follow-up including surveillance for late effects of treatment.
15. Evaluation of AYA key worker position and plan by June 2010.



## Appendix One Midland AYA OHS burden of cancer

### Introduction

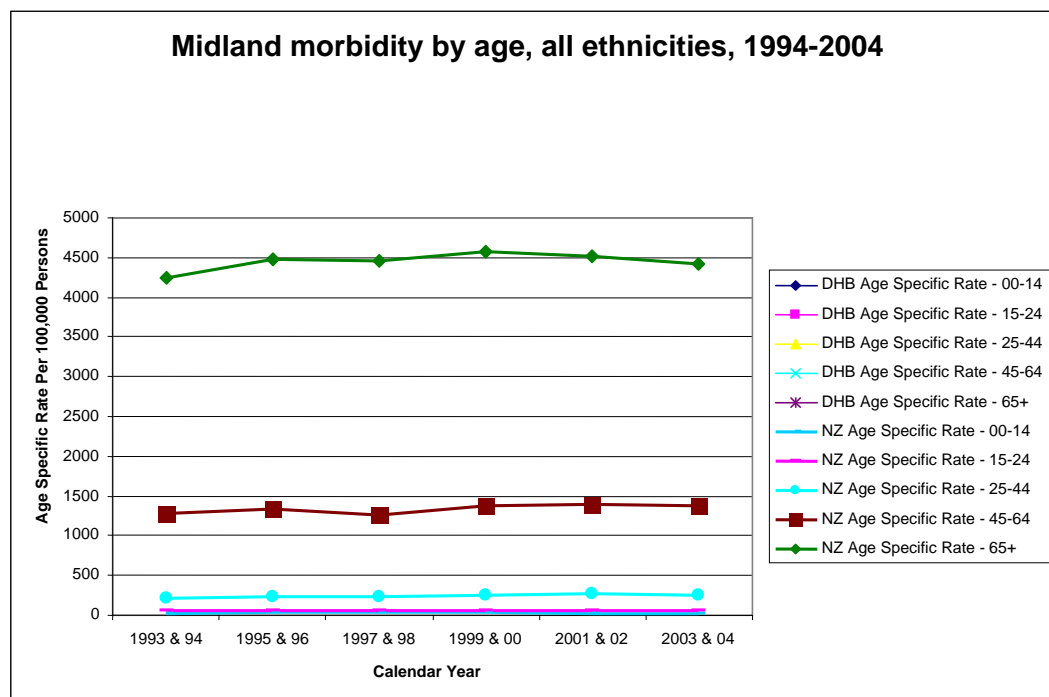
The following describes morbidity and mortality incidence and health inequalities in relation to cancer for AYA with cancer in the Midland region. The cancer burden for AYA in the Midland region has evidence of inequalities in health between age groups, socio-economic groups, ethnic groups, and people living in different geographical regions.

Limitation of data includes:

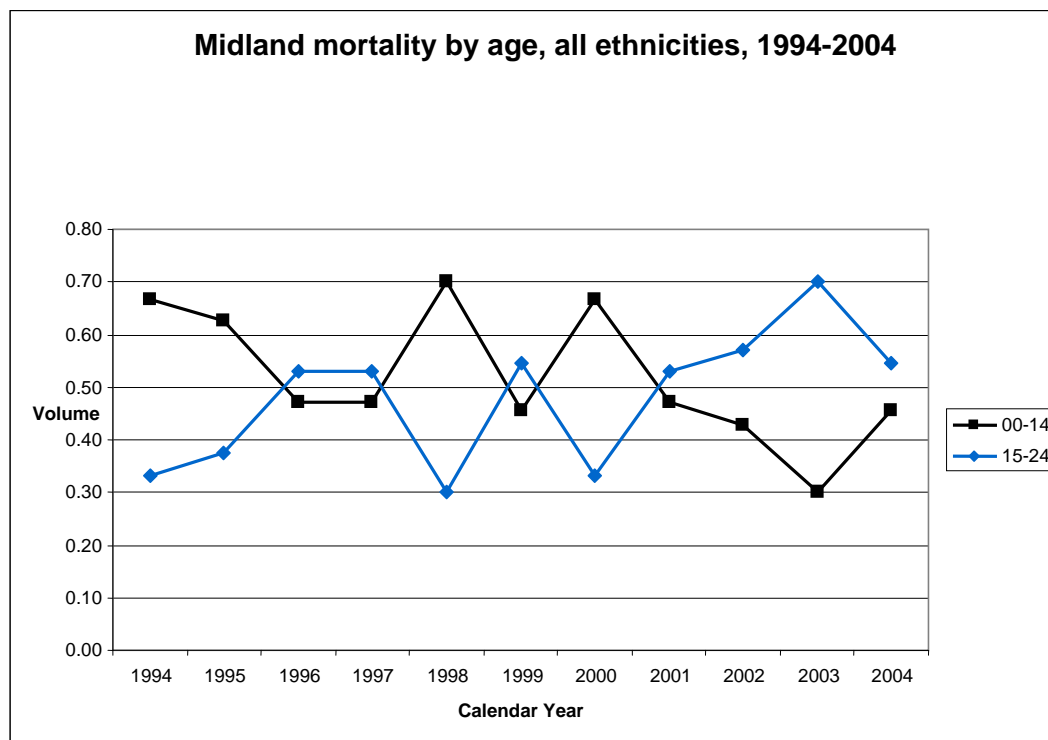
- AYA between 15-24 years, not 12-24 years as specified in the national AYA OHS service specifications
- data for gender and deprivation is expressed for all ages within New Zealand.
- data volume for Pacific is too low to analyse.

**Age:** Overall, in comparison with older age groups, cancer occurs rarely among Midland AYA, and most AYA who develop cancer will survive their illness.

**Chart 1:** Midland morbidity by age, all ethnicities, 1994-2004

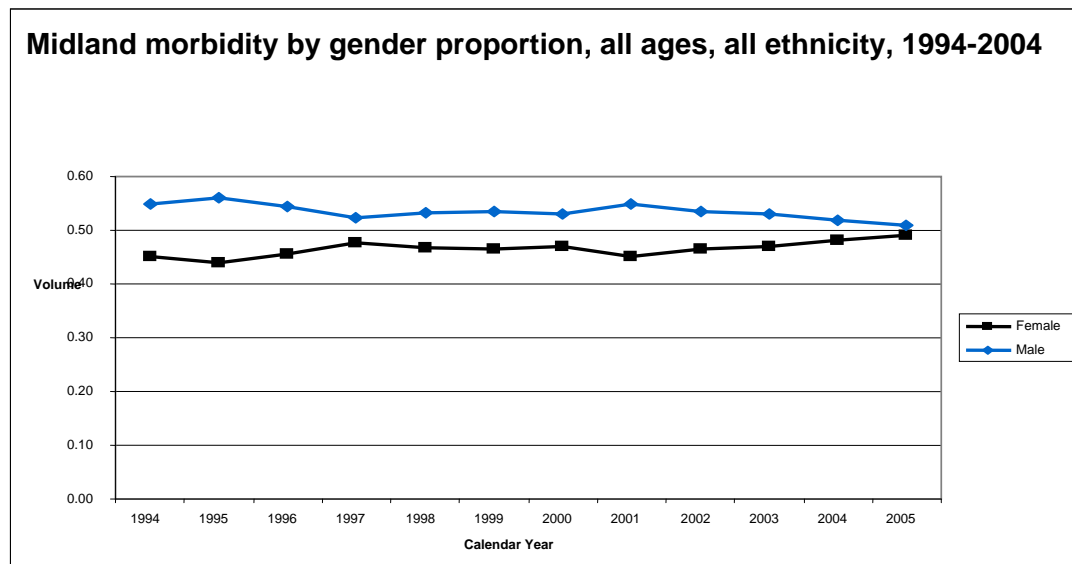


**Chart 2:** Midland mortality by age, all ethnicities, 1994-2004

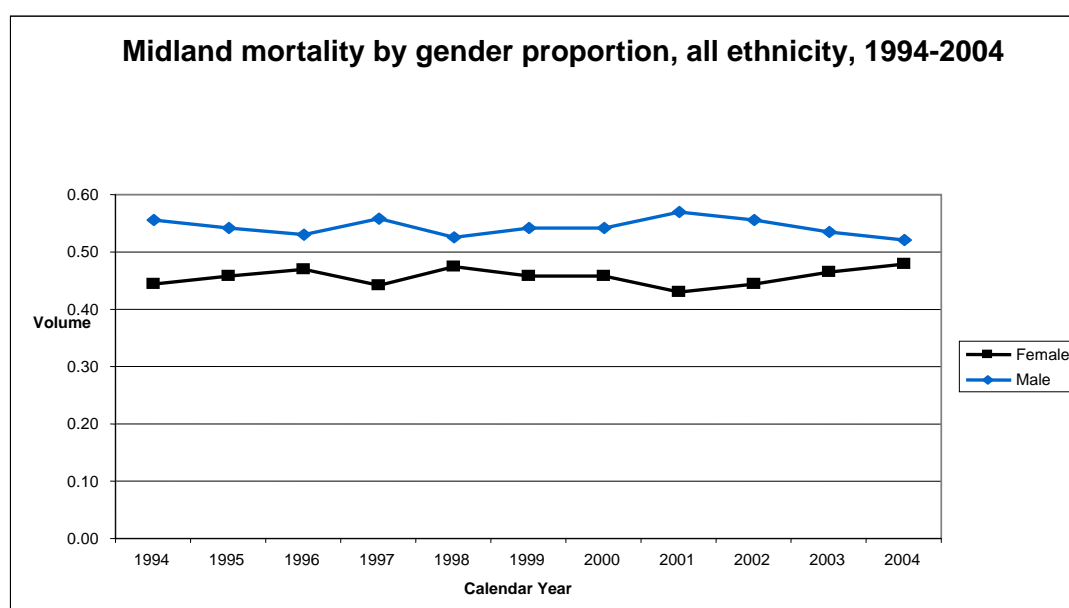


*Gender:* There is no significant difference between male and female morbidity and mortality. Females are slightly more likely to be diagnosed with cancer; 51% female to 49% male, whereas males are slightly more likely to die from cancer at 52%.

**Chart 3:** Midland morbidity by gender proportion, all ages, all ethnicity, 1994-2004



**Chart 4:** Midland mortality by gender proportion, all ages, all ethnicity, 1994-2004



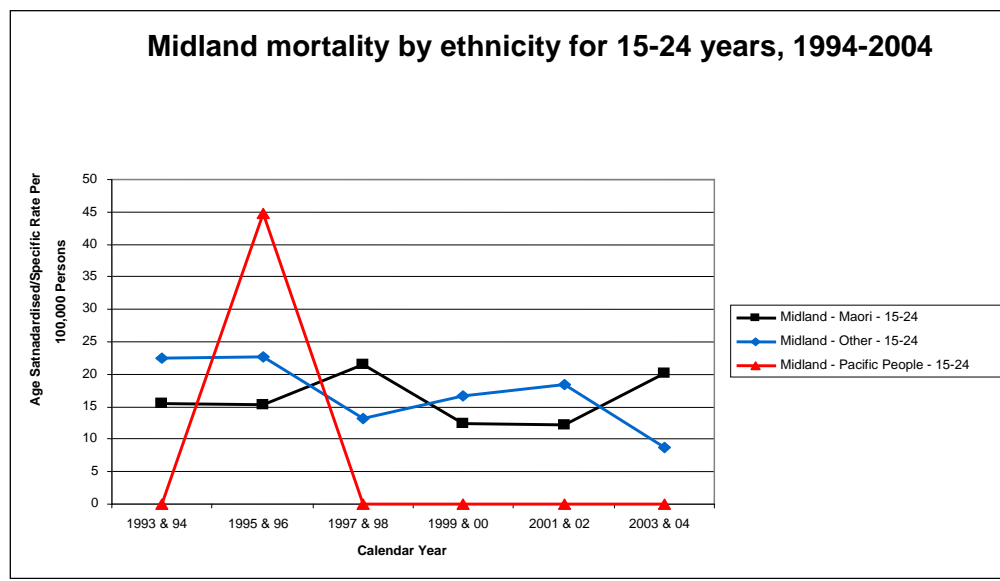
## Analysis by Ethnic Group

**Table 1:** Midland morbidity and mortality by top 16 cancers and ethnicity for 15-24 Years, 1994-2004

	ICD-10	Cancer	Morbidity	Māori	Other	Pacific	Mortality	Māori	Other	Pacific
1	C43	Skin	74		73	1	8		8	
2	C62	Testis	25	12	11	2	1	1		
3	C81	Hodgkin's	13	6	7		3	1	2	
4	C92	Myeloid Leukaemia	13	6	7		3	3		
5	C91	Lymphoid Leukaemia	18	6	11	1	10	5	5	
6	C73	Thyroid Gland	13	2	11	1				
7	C71	Brain	13	2	11		5	2	3	
8	C56	Ovary	11	3	7	1	2	1	1	
9	C49	Connective and Soft Tissue	11	4	7		4	3	1	
10	C40	Osteo-sarcoma	9	2	7		8	3	5	
11	C16	Stomach	11	10	1		5	5		
12	C83	Non-Hodgkin's	11	3	8		1		1	
13	C18	Colon	6	1	5		3	1	2	
14	C53	Cervix	4	1	3					
15	C50	Breast	4	2	2		1	1	1	
16	C64	Kidney	1	1			1		1	
Total			237	61	171	6	54	26	30	

Table 1 lists morbidity and mortality by diagnosis and ethnicity. The table was used to inform the analysis below in regards to ethnicity.

**Chart 5: Midland mortality by ethnicity for 15-24 years, 1994-2004**



#### Pacific:

- There is not enough data or volume to discern inequalities in comparison to other ethnic groups and cancer for Pacific.

#### Māori:

- One quarter of all AYA OHS cancer diagnosis was Māori. Approx 50% were diagnosed with testicular, myeloid leukaemia and connective and soft tissue malignancies. Approx 90% of stomach malignancy were Māori.
  - In discussions with the AYA OHS Work Group, it was thought that a particular Māori family in the Bay of Plenty were diagnosed with the majority of stomach cancers diagnosed in this period. Further research is required.
- Māori are also more likely to die from their cancers (48%). 100% mortality was found for stomach cancer as well as myeloid leukaemia. Māori face an approximate 50% chance or more of mortality for lymphoid leukaemia, brain and connective and soft tissue malignancy.
- Māori had no diagnosis for skin cancer and a low diagnosis for thyroid gland and brain cancers.

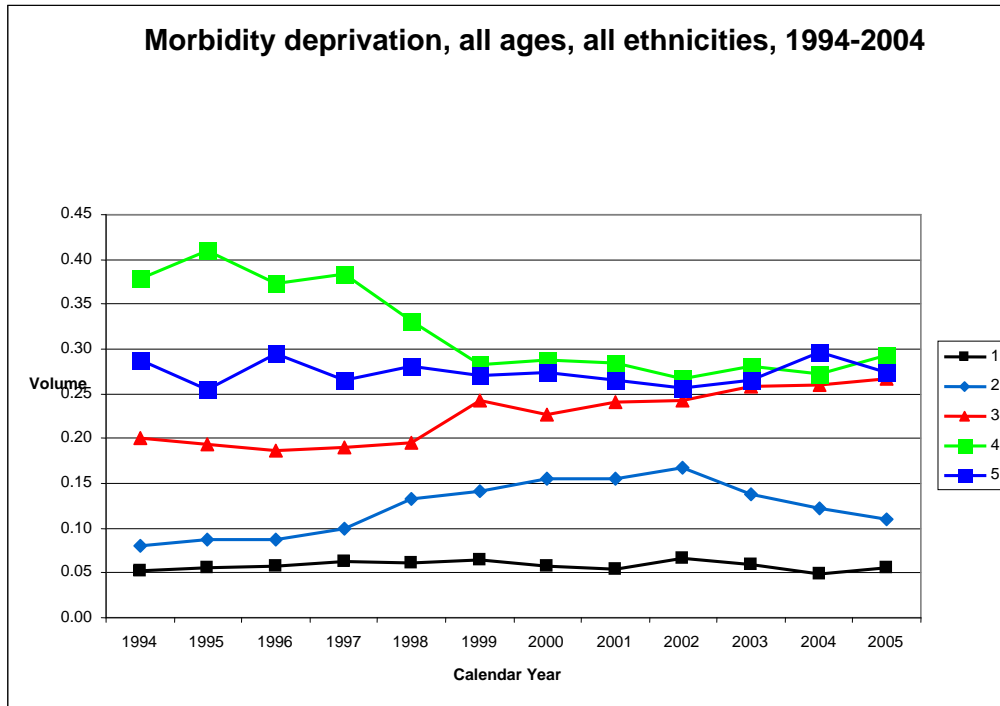
#### Other: Comprises of NZ European, Asian and all others.

- Skin cancer accounted for the highest number of malignancies and was the top morbidity for this group with 100% diagnosis and approx 11% mortality.
- In regards to mortality, Others had a 72% chance of mortality from osteosarcoma with an approx 50% chance of mortality from Leukaemia and brain cancers.

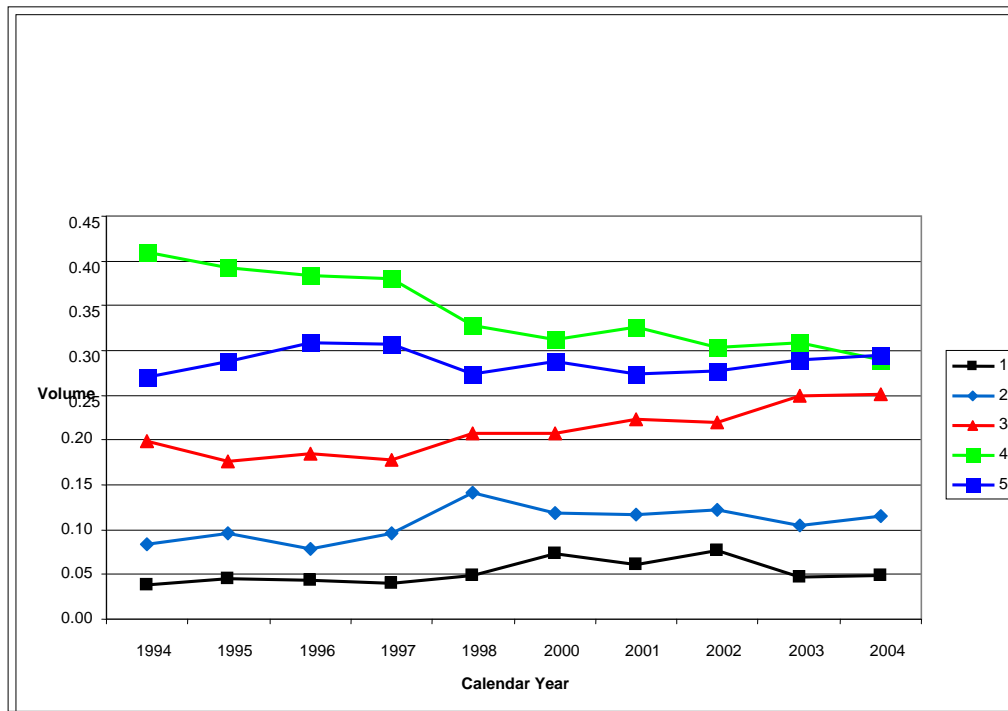
*Socio-Economic Status:*

- For all ethnicities, deprivation and malignancy have trended upwards
- Māori, overall, are becoming poorer

**Chart 6:** Morbidity deprivation, all ages, all ethnicities, 1994-2004



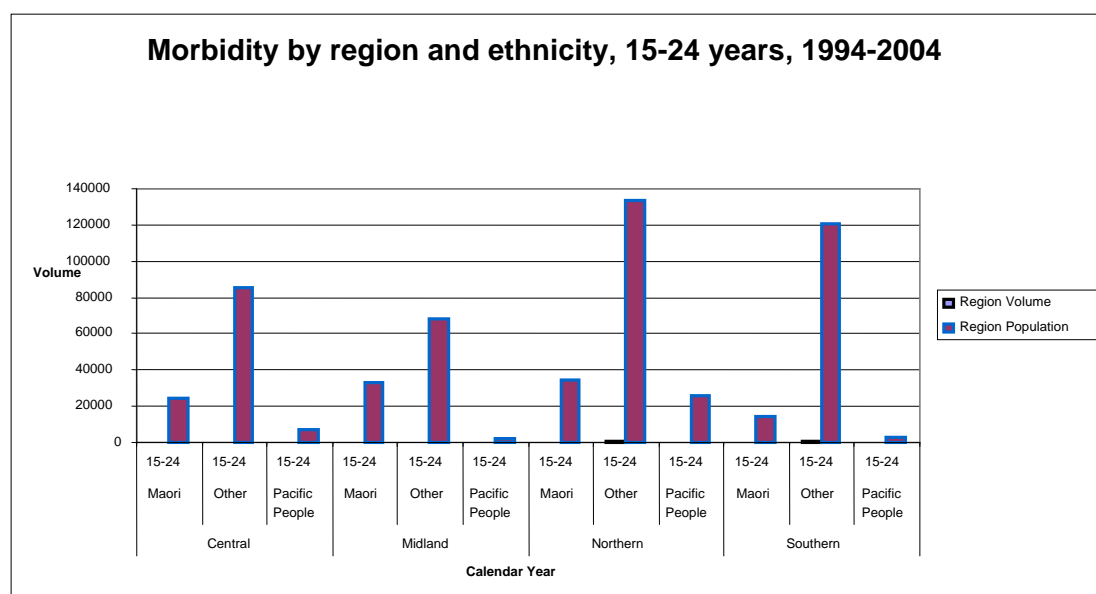
**Chart 7:** Mortality deprivation, all ages, all ethnicities, 1994-2004



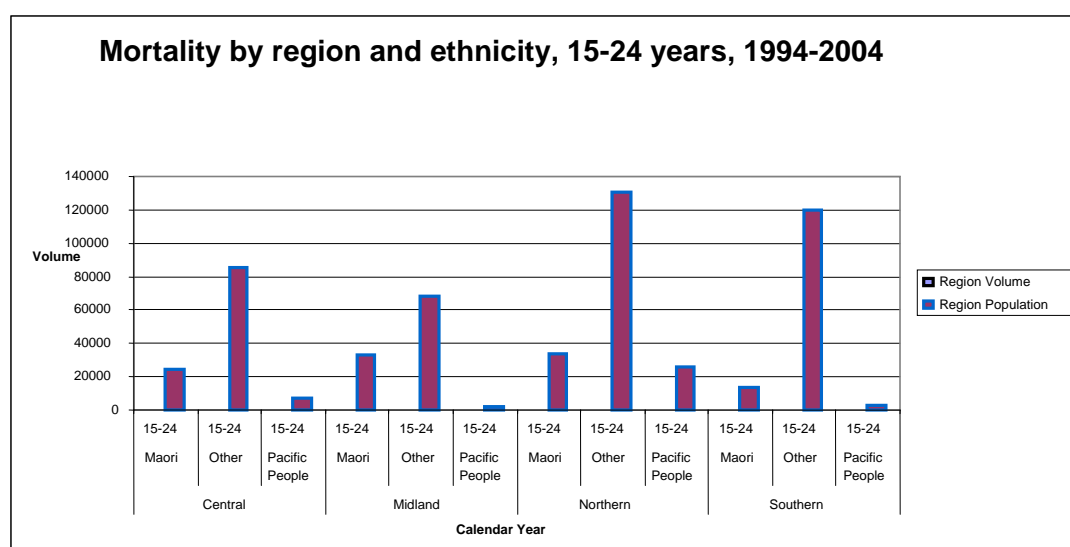
**Geography:** The Midland region includes the Waikato, Lakes and Bay of Plenty District Health Boards. The Midland area covers 56,738 km<sup>2</sup>, and comprises 21.2% of New Zealand's land area. The total Midland region population estimate is 812,265 for 2007, of which Waikato DHB, the largest, comprises 43.5% at 353, 460<sup>9</sup>.

The Māori population accounts for 23% of the Midland population or 137,000 persons. The region covers a large rural area as well as having a major metropolitan city. There are noted diverse challenges in service delivery and additional barriers to accessing health services for people travelling from remote rural. The Midland rural population is estimated at 43%<sup>10</sup>. Chart 8 and 9 describe the morbidity and mortality by ethnicity in the Midland region amongst other regions in New Zealand.

**Chart 8:** Morbidity by region and ethnicity, 15-24 years, 1994-2004



**Chart 9:** Mortality by region and ethnicity, 15-24 years, 1994-2004



<sup>9</sup> Statistics NZ (2007). Population Estimates prepared for MoH.

<sup>10</sup> PHI Offline 2007. Public Health Intelligence. In this instance, the Midland reflects Lakes, BOP, Waikato, Tairāwhiti and Taranaki DHBs.

## Appendix Two MCN Directory of AYA OHS services and providers

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
<b><u>Primary Health Organizations</u></b>					
Waikato PHO	Primary consultation, referral on to secondary services	All ages	Waikato – liaison with other DHBs and PHO's	Self	Jade Chase Clinical Project Manager 07 839 2888 <a href="mailto:Jade.chase@waikatopho.org.nz">Jade.chase@waikatopho.org.nz</a>
Hauraki PHO	Primary consultation, referral on to secondary services	All ages	Thames	Self	Hugh Kininmonth, CEO <a href="mailto:hugh@korowai.co.nz">hugh@korowai.co.nz</a> 07 868 5375
North Waikato PHO	Primary consultation, referral on to secondary services	All ages	North Waikato	Self	Wayne McClean, CEO <a href="mailto:Wayne.mcclean@rauakura.com">Wayne.mcclean@rauakura.com</a>
Māori PHO	Primary consultation, referral on to secondary services	All ages	Waikato	Self	Tureiti and Kiri Moxon, Representatives <a href="mailto:kiri@maoripho.co.nz">kiri@maoripho.co.nz</a>
<b><u>Provider Arms</u></b>					
<b>Waikato Health</b>					
• Waikato Hospital		All ages	Waikato, Lakes, BOP		
○ Intensive Care	Manage Intensive Care patients	All ages		Medical specialists	Matt Hughes, CNL <a href="mailto:hughesm@waikatodhb.govt.nz">hughesm@waikatodhb.govt.nz</a>
○ Surgical Services	Manage Surgical Problems	All ages		Medical specialists	Paul Taumanu Manager <a href="mailto:taumanup@waikatodhb.govt.nz">taumanup@waikatodhb.govt.nz</a>
▪ General	Manage general surgical patients	All ages		Medical Specialists	Lynley Gardner & David Bryden, Surgical Operations Managers <a href="mailto:gardnerl@waikatodhb.govt.nz">gardnerl@waikatodhb.govt.nz</a> <a href="mailto:Brydend@waikatodhb.govt.nz">Brydend@waikatodhb.govt.nz</a> Anne Ellis & Vin Kaur, CNL

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
					<a href="mailto:ellisa@waikatodhb.govt.nz">ellisa@waikatodhb.govt.nz</a> <a href="mailto:kaurv@waikatodhb.govt.nz">kaurv@waikatodhb.govt.nz</a>
▪ Paediatric	Neonatal, urology, general	0-14		Medical Specialists	Dr Udaya Samarakkody, Director <a href="mailto:samaraku@waikatodhb.govt.nz">samaraku@waikatodhb.govt.nz</a> Tracey Jackson, Acting CNE <a href="mailto:jacksont@waikatodhb.govt.nz">jacksont@waikatodhb.govt.nz</a>
▪ Orthopaedics	Musculoskeletal tumours, osteosarcoma, bones	All ages		Medical Specialists	Stu Hardy, Musculoskeletal Specialist <a href="mailto:hardys@waikatodhb.govt.nz">hardys@waikatodhb.govt.nz</a> Cynthia Ronaldson <a href="mailto:ronaldsc@waikatodhb.govt.nz">ronaldsc@waikatodhb.govt.nz</a>
▪ ENT	Ears, Nose & Throat, Head & Neck	All ages		Medical Specialists	Jacqueline Wynne Jones, CNL <a href="mailto:Wynne-jo@waikatodhb.govt.nz">Wynne-jo@waikatodhb.govt.nz</a>
▪ Plastics		All ages		Medical Specialists	Lynne Walker, CNL <a href="mailto:walkerl@waikatodhb.govt.nz">walkerl@waikatodhb.govt.nz</a>
▪ Neurosurgery	Brain and spinal cord tumours	15+		Medical Specialists	Alaina Campbell, CNL <a href="mailto:Campbela@waikatodhb.govt.nz">Campbela@waikatodhb.govt.nz</a> Dr. Balakrishnan, Director <a href="mailto:balakriv@waikatodhb.govt.nz">balakriv@waikatodhb.govt.nz</a>
○ Radiology	Nuclear medicine, Ultrasound, General, Vascular and Interventional Radiology, CT Scanning	All ages		Self, Medical Specialists	Mike Webb, Manager <a href="mailto:webbm@waikatodhb.govt.nz">webbm@waikatodhb.govt.nz</a> Sabaratna Muthukumaraswamy Clinical Director <a href="mailto:muthukuc@waikatodhb.govt.nz">muthukuc@waikatodhb.govt.nz</a>
○ Pathology/Laboratory	Blood/specimen collection and results Immunology, Haematology	All ages		Self, medical pathologists	Dr. Fred Mayall, Histopathology Chairman <a href="mailto:mayallf@waikatodhb.govt.nz">mayallf@waikatodhb.govt.nz</a>
○ Women's and Child Health	Assessment, diagnosis and treatment	0-16, + if deemed develop. appropriate		GP's, medical specialists, Health care professionals	Suzanne Lawes, Service Manager <a href="mailto:lawess@waikatodhb.govt.nz">lawess@waikatodhb.govt.nz</a> Deepika Singh, Paediatrician



Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
					<a href="mailto:singhde@waikatodhb.govt.nz">singhde@waikatodhb.govt.nz</a>
<ul style="list-style-type: none"> <li>Paediatric Community Resource Nurses</li> </ul>	Case Management, Coordination of care for children with complex illnesses	1-16	Waikato DHB	Children under Specialist care	Renee Streatfield <a href="mailto:streatfr@waikatodhb.govt.nz">streatfr@waikatodhb.govt.nz</a> Helen Haakma <a href="mailto:haakamah@waikatodhb.govt.nz">haakamah@waikatodhb.govt.nz</a>
<ul style="list-style-type: none"> <li>Children's Clinic</li> </ul>	Monthly Oncology Outreach Clinics with visiting Paediatric Oncologist Starship.	0-15	Waikato DHB	Referral Central Centre – GP, Public Health, Plunket, other DHBs	Deearne Campbell <a href="mailto:campbeld@waikatodhb.govt.nz">campbeld@waikatodhb.govt.nz</a> Rae Richmond <a href="mailto:richmonr@waikatodhb.govt.nz">richmonr@waikatodhb.govt.nz</a>
<ul style="list-style-type: none"> <li>Health Waikato Community Services</li> </ul>	Community nursing and allied health care (including collaborative model with Waikato Community Hospice)  Public Health Nurses also link with all pre-schools and schools across the Waikato DHB area.	0-15	Waikato	GP's, medical specialists, health care professionals	
<ul style="list-style-type: none"> <li>General Medical</li> </ul>	Assessment, diagnosis and treatment	All ages		GP's	Neil McKelvie, Service Manager <a href="mailto:mckelvin@waikatodhb.govt.nz">mckelvin@waikatodhb.govt.nz</a> Dr. Paul Reeve, Clinical Director <a href="mailto:reevepa@waikatodhb.govt.nz">reevepa@waikatodhb.govt.nz</a>
<ul style="list-style-type: none"> <li>Respiratory Service</li> </ul>	Assessment, diagnosis and treatment	All ages		GP's, medical specialists, Health care professionals	Julie Scanlon Lung Cancer Co-ordinator <a href="mailto:scanlonj@waikatodhb.govt.nz">scanlonj@waikatodhb.govt.nz</a>
<ul style="list-style-type: none"> <li>Gastroenterology</li> </ul>	Inpatient, day patient and outpatient assessment and management – uppergastroscopy, ERCP, small bowel investigation, flexible sigmoidoscopy, and colonoscopy	All ages		GP's, medical specialists, Health care professionals	Ann Currie, CNE <a href="mailto:curriea@waikatodhb.govt.nz">curriea@waikatodhb.govt.nz</a>
<ul style="list-style-type: none"> <li>Dermatology</li> </ul>	Assess, treatment & review	All ages		GP, Other Departments/Hosp, internal and	Amanda Oakley Director of Dermatology <a href="mailto:oakleya@waikatodhb.govt.nz">oakleya@waikatodhb.govt.nz</a>

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
				external, Private Practises	David McEwen CNM - Outpatients: Plastics & Dermatology <a href="mailto:mcewen@waikatodhb.govt.nz">mcewen@waikatodhb.govt.nz</a>
○ Plastics	Assess, treatment & review	All ages		GP, Other Departments/Hosp, Private Practises	Chris McEwan Unit Director for Plastics <a href="mailto:mcewenc@waikatodhb.govt.nz">mcewenc@waikatodhb.govt.nz</a> David McEwen CNM - Outpatients: Plastics & Dermatology <a href="mailto:mcewen@waikatodhb.govt.nz">mcewen@waikatodhb.govt.nz</a>
○ Pharmacy	Drug information, therapeutic drug monitoring	All ages		GP, medical specialists, Health care professionals	Jan Goddard, Manager <a href="mailto:goddardj@waikatodhb.govt.nz">goddardj@waikatodhb.govt.nz</a>
○ Te Puna Oranga	Māori Health Service – service provision (cultural support/advocacy)	All ages		Self, other health professionals	Erena Kara Project Manager <a href="mailto:karae@waikatodhb.govt.nz">karae@waikatodhb.govt.nz</a>
• Pacific Health Services					
○ Pacific Health Development and Support Unit	Work under CEO – specific projects relating to pacific action plans and health in general i.e HEHA		Waikato Region		Robbie Atatoa Pacific Health Project Manager Development & Support Unit Waikato District Health Board Phone: 07 834 3635 ext 7963 <a href="mailto:AtatoaR@waikatodhb.govt.nz">AtatoaR@waikatodhb.govt.nz</a>
○ South Waikato Pacific Island Health Inc			Tokoroa/Putaruru		Akarere Henry 07 886 0010
○ Te Rapakau Health	Health promotion, strong community links				Grace Mitchell, Manager
○ K'aute Pasificka					Peta Karalus, Manager 07 846 2280
• Māori Health Services					

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
○ Raukawa Trust Board	Family Start, Housing, Education, Environmental, health promotion, Registered Nurses, public, personal and mental health.	All ages	Raukawa Iwi region	Self, other health professionals	Tangaroa Whitiara Health Services Manager Ph: 07) 885 0260 <a href="mailto:tangaroa.whitiara@rauakawa.org.nz">tangaroa.whitiara@rauakawa.org.nz</a>
○ Raukura Hauora o Tainui	5 Clinics Waikato region, DSM, Community, Tamariki Ora, Primary care, Whānau Ora.	All ages, 17 and under free.	Frankton	Self, other health professionals	Wayne McLean, CEO 07 846 1389 <a href="mailto:wayne.mclean@rauakura.com">wayne.mclean@rauakura.com</a>
○ Taumarunui Community Kokiri Trust	Health & Disability, Social Workers, Rest home, Kohanga, GP service.	All ages	Taumarunui	Self, other health professionals	Christine Brears, CEO Ph: 07 895 5919 <a href="mailto:christine.brears@xtra.co.nz">christine.brears@xtra.co.nz</a>
○ Te Kohao Health	GP Service, DSM Nurse Kaumatua / Kuia Programme Health Education & Promotion Auahi Kore / Smoking Cessation Tamariki Ora Mobile Nurse Dental Therapist Home Based Support Service	All ages	Hamilton, Cambridge, Ngaruawahia	Self, Internal and external agencies	Tureiti Moxon, CEO Ph: 07 856 5479 <a href="mailto:tureitim@tekohaohealth.co.nz">tureitim@tekohaohealth.co.nz</a>
○ Te Korowai Hauora o Hauraki	Nurse, GP, Free 0 – 25yrs, frees sexual checkups until 25yr. \$15 if not on care-plus, if on \$5. 65yrs Counselling services, Mental Health, Smoking Cessation, Tattoo removal, dental care - \$10/checkup.	All ages	Thames	Self, other health professionals	Hugh Kininmonth, CEO Ph: 07 868 5375 <a href="mailto:hugh@korowai.co.nz">hugh@korowai.co.nz</a>
○ Te Rohe Pōtae o Rereahu	Te Pou Ora - GP service Te Pou Awhina – Mental Health service	Across Life Span	Te Kuiti - Maniapoto	Self, other practitioners, whānau, community Mental health	Gale Pihama, CEO Ph: 07 878 8082 <a href="mailto:terohepotae@xtra.co.nz">terohepotae@xtra.co.nz</a>
○ Raukura Waikato Social Services Trust	Youth Justice services – court and charged with offence 16-19yrs depending on needs, (intervention/prevention), Respite care – contract with CFPYS.	0 – 16yrs	Hamilton	Self, various stakeholders – CYFS, Police and various community	Jenny Riini, Manager Ph: 07 848 1047 <a href="mailto:whangai@wave.co.nz">whangai@wave.co.nz</a>

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
	Health Services – advocacy, counselling and therapy, low level intellectual disability residential service, whānau development and restoration services – DV programmes and alternative programmes for women, support programmes for their children. Specialist services – pre-employment programme. Tikanga Māori programme. ALT services via Fairfield and Huntly.			services.	
○ Hauora Waikato	Te Aka Kura Services – assessment opportunities and individualised management of Child & adolescent mental health needs. Te Aka Toro – provides specialist care for young people experiencing psychosis.	0-20	Hamilton/ Waikato Region	Self, parent/care giver, Educational Staff, other Community or Health Agencies.	Rei Wirihihana, CEO Ph: 07 839 9916 <a href="mailto:rei.wirihihana@hauorawaikato.org.nz">rei.wirihihana@hauorawaikato.org.nz</a>
○ Northern King Country Drug & Alcohol Co Te Ngaru o Maniapoto	A&D under supervision, Behavioural work, Dual diagnosis.	5–17 years	Te Kuiti	Self, GP, Courts, Teachers	Nettie-Anne Ball, Manager Ph: 07 878 8885 <a href="mailto:Te-Ngaru@xtra.co.nz">Te-Ngaru@xtra.co.nz</a>
○ Te Runanga o Kirikiriroa Trust	Mental Health 1. Youth assessment 2. Rongotea – youth residential –A&D. Also provides community education.	13-7yrs	Midlands	Whānau, CYFS, self and any community services	Mere Balzer, CEO Ph: 07 846 1042 <a href="mailto:Te.runanga@clear.net.nz">Te.runanga@clear.net.nz</a>
○ Marae Pact Trust	Disability services, home care services, Rangatahi services – social services. Education Services – young people that get stood down. Whānau Ora – education. Kaumatua Services.	All ages	Te Kuiti	Self, whānau, GP or other community services.	Dennis Astle, General Manager Ph: 07 878 0028 <a href="mailto:ngati@maniapoto.org.nz">ngati@maniapoto.org.nz</a>
○ Te Awhi Whānau	Supportive accommodation for people with Mental Illness	18 – 30yrs	Hamilton	GP, Social Workers,	Edward Beattie, Director Ph: 07 852 5413

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
				Nurses, WDHB.	<a href="mailto:taitok@ihug.co.nz">taitok@ihug.co.nz</a>
○ Ngā Miro Health Clinic	Intervention & Prevention and Health Promotion	All ages	Ngaruawahia	Self, GP.	Glenda Raumati, Manager Ph: 07 824 5129 <a href="mailto:ngamiro@wave.co.nz">ngamiro@wave.co.nz</a>
○ Te Hauora o Ngāti Hauā			Waharoa		Darren Haimona, CEO <a href="mailto:josie@tehauora.co.nz">josie@tehauora.co.nz</a>
○ Pai Ake Solutions	Dual diagnosis. Offer programmes/interventions.	10yr and upwards	Hamilton area and outer regions	Self, or referred via other agencies	Mihaka Hohua Ph: 07 889 1123 <a href="mailto:paiake@paradise.net.nz">paiake@paradise.net.nz</a>
○ Tuhikaramea Medical Centre	GP services	All ages	Hamilton - Dinsdale	Self	Tiwini Hemi, GP Ph: 07 846 0082 <a href="mailto:tuhi@ihug.co.nz">tuhi@ihug.co.nz</a>
○ Te Ahurei a Rangatahi	Sexual health, D&A, youth issues work. Run 2 Youth Groups – Synergy (leadership programme) Phat Pak – work with youth to promote health messages, and events. Run in schools. 2 Free counsellors (male and female) once / week (M-T) Run camps, dance parties etc	12 – 24 yrs However can work with younger	Hamilton, another office in Huntly & Morrinsville Initiatives with D&A	Self, other networks refer to them – Whai Marama, High Schools, Alternative Learning Centres.	Eugene Davis, Manager Ph: 07 838 3013 <a href="mailto:e.davis@xtra.co.nz">e.davis@xtra.co.nz</a>
○ Waahi Whanui Trust	Counselling services – D&A and counselling Have a male & female counsellor available. GP service	14yr+	Huntly	Self, GP, Probation Clients	Sue Fielding, Manager Ph: 07 828 9695 <a href="mailto:trust@whanui.org.nz">trust@whanui.org.nz</a>
○ Piako Community W Whānau Charitable Trust	Alternative Education for Matamata, Morrinsville and Te Aroha Colleges, Wahine Toa Programme for Young Mums and their babies.	13yr – 24 yrs	Morrinsville	Referral from Schools for Alt Ed and Work and Income and open referrals	Anaru Hawkins, Manager Ph: 07 889 5136
• Child Development Centre	Support with an acquired disability as a result of either their cancer, or treatment for it	0-15yrs	Waikato	Health, education and welfare and	Maureen Anderson Team Leader <a href="mailto:andersoM@waikatodhb.govt.nz">andersoM@waikatodhb.govt.nz</a>

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
				social agencies	
<ul style="list-style-type: none"> <li>Child &amp; Adolescent Services (Mental Health)</li> </ul>	Assessment and treatment for moderate to severe psychiatric disorders and severe emotional or behavioural problems	Up to 17yrs, 20yrs if appropriate	Waikato	GP's, medical specialists, school guidance counsellors, CYFS and community groups	Marie Connelly Team Leader Infant, Child & Adolescent Mental Health Service <a href="mailto:connellm@waikatodhb.govt.nz">connellm@waikatodhb.govt.nz</a>
<ul style="list-style-type: none"> <li>Mental Health and Addiction Services</li> </ul>	Adult Mental Health, Forensic and Rehabilitation Services, Specialty & Rural Services	18+	Waikato, Lakes, BOP, Taranaki	GP's, medical specialists, school guidance counsellors, CYFS and community groups	Rajiv Singh, Clinical Director <a href="mailto:singhr@waikatodhb.govt.nz">singhr@waikatodhb.govt.nz</a> TBA, General Manager
<ul style="list-style-type: none"> <li>Health Waikato Community Services</li> </ul>	Community nursing and allied health care (including collaborative model with Waikato Community Hospice)	All ages	Waikato	GP's, medical specialists, health care professionals	Clinical Nurse Leader Adult 021 531 082
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Child and Youth Health Co-ordinator</li> </ul> </li> </ul>	Acute home support Strengthening the secondary-primary links with projects and initiatives supporting the continuum of care	0-18	Waikato	GP's, medical specialists, health care professionals	Jenny Ballantyne, <a href="mailto:ballanje@waikatodhb.govt.nz">ballanje@waikatodhb.govt.nz</a> Nurse co-ordinator Andrea Mockford <a href="mailto:mockforda@waikatodhb.govt.nz">mockforda@waikatodhb.govt.nz</a> 021359580
<ul style="list-style-type: none"> <li>Sexual Health</li> </ul>	Free & Confidential – sexual health screen, skin conditions, free condoms, people experiencing pain during intercourse. ECP and small amount of contraception and HIV testing.	12 & older	Waikato Region	Self, GP	Kitty Flannery 07 839 8732 <a href="mailto:flannerk@waikatodhb.govt.nz">flannerk@waikatodhb.govt.nz</a>
<ul style="list-style-type: none"> <li>Population Health Services</li> </ul>	Smoking cessation	All ages	Waikato Region	Self, GP, health care professional	Kate Dallas Smokefree Hospital Coordinator <a href="mailto:dallsk@waikatodhb.govt.nz">dallsk@waikatodhb.govt.nz</a>

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
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•					
<i>Clinical Support Services</i>		All ages			
• Social Work services	Women's and Children, Adult psycho-social assessments and referral service		Waikato	Self, health care professionals	Cara Thomas Clinical Leader <a href="mailto:thomasc@waikatodhb.govt.nz">thomasc@waikatodhb.govt.nz</a>
• Allied Health	Physiotherapy, Occupational therapy, Speech-Language therapy, Dietician	All ages	Waikato	Health care professionals	Melinda Ch'ng, Manager <a href="mailto:Ch'ngm@waikatodhb.govt.nz">Ch'ngm@waikatodhb.govt.nz</a>
• <b>Regional Cancer Centre</b>					Dr Jeremy Long, Clinical Director <a href="mailto:longj@waikatodhb.govt.nz">longj@waikatodhb.govt.nz</a> Neil McKelvie, Service Manager Kim Holt, Operations Manager <a href="mailto:holtk@waikatodhb.govt.nz">holtk@waikatodhb.govt.nz</a>
○ Oncology	Diagnosis and treatment	16yrs and older	Waikato, Lakes, Bay of Plenty	PHO's, GP's, surgical and medical services	Chris Baker, CNM, Ward 25 <a href="mailto:bakerch@waikatodhb.govt.nz">bakerch@waikatodhb.govt.nz</a> Bronwyn Ward, CNM Oncology Outpatients <a href="mailto:wardb@waikatodhb.govt.nz">wardb@waikatodhb.govt.nz</a>
▪ Radiation	Manage radiation treatment	13 and older (depending on Dr)	Waikato, Lakes, Bay of Plenty.	Oncologists	Dr Leanne Tyrie, Clinical Director. <a href="mailto:tyriel@waikatodhb.govt.nz">tyriel@waikatodhb.govt.nz</a> Shelley Donnell, Charge Radiation Therapist <a href="mailto:donnells@waikatodhb.govt.nz">donnells@waikatodhb.govt.nz</a> George Coalter, Chief Medical Physicist <a href="mailto:coalterg@waikatodhb.govt.nz">coalterg@waikatodhb.govt.nz</a>
▪ Medical	Manage chemotherapy treatment				Dr Jeremy Long, Clinical Director Chris Baker, CNM - inpatients Bronwyn Ward, CNL Outpatients <a href="mailto:wardb@waikatodhb.govt.nz">wardb@waikatodhb.govt.nz</a>
○ Haematology	Management of Haematological Disorders	All ages	Waikato, Lakes, Bay of Plenty	Medical, Dental and Midwives	Dr. Gillian Corbett <a href="mailto:corbettg@waikatodhb.govt.nz">corbettg@waikatodhb.govt.nz</a> Robyn Segedin, CNS -

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
					Haematology <a href="mailto:segedinr@waikatodhb.govt.nz">segedinr@waikatodhb.govt.nz</a>
<ul style="list-style-type: none"> <li>○ Palliative Care</li> </ul>	<p>Specialist Palliative Care Unit – inpatient care, specialist consultation service outpatient clinics, outreach services, home visits (limited)</p> <p>Other specialist services – inpatient and outpatient</p>	16 years and older	Waikato	GP's, surgical and medical services, hospice, district nursing	<p>Margaret Stevenson, Co-ordinator <a href="mailto:stevensm@waikatodhb.govt.nz">stevensm@waikatodhb.govt.nz</a></p> <p>Sandi Haggar Clinical Nurse Specialist <a href="mailto:haggars@waikatodhb.govt.nz">haggars@waikatodhb.govt.nz</a></p>
<ul style="list-style-type: none"> <li>○ Clinical Trials <ul style="list-style-type: none"> <li>▪ Children's Oncology Group</li> </ul> </li> </ul>	Placement in international trials	All ages	Waikato, Lakes, BOP	Oncology Specialists	<p>Dr Jeremy Long Clinical Director Adult Oncology <a href="mailto:longj@waikatodhb.govt.nz">longj@waikatodhb.govt.nz</a></p> <p>Wendy Thomas, CNM Oncology Clinical Trials <a href="mailto:thomasw@waikatodhb.govt.nz">thomasw@waikatodhb.govt.nz</a></p>
<ul style="list-style-type: none"> <li>○ Breast Screen Midland Regional Cancer Centre, WDHB</li> </ul>		All ages	Waikato		<p>Rachael Collier Breast – Clinical Nurse Specialist Ph: 021 762 978 <a href="mailto:collier@waikatodhb.govt.nz">collier@waikatodhb.govt.nz</a></p>
		All ages	Waikato		<p>Lyn Little Clinical Nurse Specialist <a href="mailto:littlel@waikatodhb.govt.nz">littlel@waikatodhb.govt.nz</a></p>
		All ages	Waikato		<p>Suzanne Ryder Clinical Nurse Educator Outreach Ph: 021 763 592 <a href="mailto:ryders@waikatodhb.govt.nz">ryders@waikatodhb.govt.nz</a></p>
<ul style="list-style-type: none"> <li>○ Adolescent/Young Adult Oncology/Haematology Service (MCN)</li> </ul>	Support coordination of AYA OHS. Education, advocacy, training.	12-24yrs	Waikato/Lakes /BOP	Self, GP, Nurses, Medical Specialists	<p>Ellyn Proffit Clinical Nurse Specialist Ph: 07 839 9988 ext: 6958 <a href="mailto:proffite@waikatodhb.govt.nz">proffite@waikatodhb.govt.nz</a></p>
<b>Starship</b>	Cancer treatment, psycho oncology input	Up to 16 years; up to	Auckland, Waikato,	Medical specialists	Heidi McClintock AYA OHS Care Coordinator



Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
		mid-twenties	Lakes, BOP, Taranaki, Tairāwhiti		<a href="mailto:heidimc@adhb.govt.nz">heidimc@adhb.govt.nz</a>
<b>Thames Hospital</b>	Palliative Care specialist visiting service. Clinics 3/7 (Tues -Thur), 8:00 – 4:30. Acute admissions via A&E – admitted after consultation with WDHB Onc/Haem Team.	12+	Thames, Coromandel – Waihi Area	Waikato Oncologists & Haematologists.	Lauris Yule 1/6 Chemo Out/pt nurses. 07 8686550
<b>Tokoroa Hospital</b>	Palliative Care specialist visiting service – Hospice (partly DHB funded) – support person and equipment Monthly medical specialist (clinic and education)	All ages	Tokoroa	Self, GP, Nurses, Medical Specialists	Margaret Stevenson, Co-ordinator <a href="mailto:stevensm@waikatodhb.govt.nz">stevensm@waikatodhb.govt.nz</a> Sandra Haggar Clinical Nurse Specialist <a href="mailto:haggars@waikatodhb.govt.nz">haggars@waikatodhb.govt.nz</a>
<b>Te Kuiti Hospital</b>	Palliative Care specialist visiting service – Collaborative Care w/ DN, equipment, Monthly medical specialist (clinic and education)	All ages	Te Kuiti	Self, GP, Nurses, Medical Specialists	Margaret Stevenson, Co-ordinator <a href="mailto:stevensm@waikatodhb.govt.nz">stevensm@waikatodhb.govt.nz</a> Sandra Haggar Clinical Nurse Specialist <a href="mailto:haggars@waikatodhb.govt.nz">haggars@waikatodhb.govt.nz</a>
<b>Taumarunui Hospital</b>	Palliative Care specialist visiting service – Collaborative Care w/ DN, equipment, Bi-monthly medical specialist (clinic and education – alternate month Nurse specialist will go – clinic and education)	All ages	Taumarunui	Self, GP, Nurses, Medical Specialists	Margaret Stevenson, Co-ordinator <a href="mailto:stevensm@waikatodhb.govt.nz">stevensm@waikatodhb.govt.nz</a> Sandra Haggar Clinical Nurse Specialist <a href="mailto:haggars@waikatodhb.govt.nz">haggars@waikatodhb.govt.nz</a>
<b>Bay of Plenty DHB</b>					
○ Bay of Plenty DHB		All ages	Bay of Plenty		Lorraine Hammersley Clinical Nurse Co-Ordinator Cancer Care 021 223 2751 <a href="mailto:Lorraine.hammersley@bopdhb.govt.nz">Lorraine.hammersley@bopdhb.govt.nz</a>
○ Breast Care – BOP		All ages	Bay of Plenty		Julie Bailey Clinical Nurse Specialist Breast care 07 579 800 ext 5027/021

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
					795 388 <a href="mailto:Julie.bailey@bopdhb.govt.nz">Julie.bailey@bopdhb.govt.nz</a>
• <b>Tauranga Hospital</b>		All ages	Bay of Plenty		
○ Kaimahi Ngaio Tangā Hauroa Whānau	Cancer Support Nurse (MCN)	All ages	Tauranga	Self, GP, Nurses, Medical Specialists	Rose McEwen, Nurse Manager Kaitiaki Services 07 571 0144 <a href="mailto:rose@kaitiakiservices.co.nz">rose@kaitiakiservices.co.nz</a>
○ Satellite Chemotherapy Clinic	Mon-Friday chemo day case basis Transfusion support F/u assessment of oncology patients Outreach f/u clinics by Waikato based oncologists for chemo and radiotherapy	All ages	Western Bay	Medical Specialists	Rosemary Davies CNS Oncology Treatment (new appt. Nov 07)
○ On site Oncologist	Expected Jan 2008	All ages	Eastern & Western Bay	TBA	
○ Radiology	x-ray, CT, ultrasound, fluoroscopy	All ages		GP, Medical Specialists	Jill Wright Radiology Manager <a href="mailto:Jillian.Wright@bopdhb.govt.nz">Jillian.Wright@bopdhb.govt.nz</a> Ext. 8117
○ Mental Health and Addiction Services	Child and adolescent, community alcohol and drug services	All ages		Self, GP, Nurses, Medical Specialists	Margie Robinson, Clinical Co- Ordinator, CAMS ext. 8899 <a href="mailto:Margaret.Robinson@bopdhb.govt.nz">Margaret.Robinson@bopdhb.govt.nz</a>
○ Surgical Services	Orthopaedics, general/vascular, plastics	All ages		GP, Medical Specialists	<a href="mailto:Bronwyn.anstis@bopdhb.govt.nz">Bronwyn.anstis@bopdhb.govt.nz</a> Ext. 8375
○ Women, Children and Family	Paediatrics	0-16,18		GP, Medical Specialists	Cathy Taylor WCF Business Leader <a href="mailto:Cathy.taylor@bopdhb.govt.nz">Cathy.taylor@bopdhb.govt.nz</a> Ext. 8564
○ Māori Health	Kaitiaki Service – Māori support nurses to support clients and whānau affected by cancer			Self & other health professionals	Clint Lovett Manager Te Puna Hauora <a href="mailto:Clint.lovett@bopdhb.govt.nz">Clint.lovett@bopdhb.govt.nz</a> Ext. 8564 <a href="mailto:info@kaitiakiservices.co.nz">info@kaitiakiservices.co.nz</a>
○ Palliative Care	Inpatient, community and some hospital	All ages		Medical, self,	Waipuna Hospice

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
	palliative care, GP support no palliative care consultant			other Health care professionals	Director of Nursing, TBA Oct. 07 07 552 4380
○ Allied Health				Self, Medical, other Health care professionals	Dorothy Gilliland Allied Health Leader ext 4728
• <b>Whakatane Hospital</b>		All ages	Whakatane		
○ Satellite Chemotherapy clinics	3 days per week chemo day cases basis and limited treatments (no overnight treatments or 5 day treatments at present) Transfusion support F/u assessment of oncology patients Outreach clinics by Waikato based oncologists			Medical Specialists	Rosemary Davies CNS Oncology Treatment (new appt. Nov 07)
○ Palliative Care	Community service in close liaison with DN service – no specialist cover or inpatient beds			Self, medical and other health care professionals	Andrea Davis Palliative Care Coordinator <a href="mailto:Palliative.referral@hospicebop.org.nz">Palliative.referral@hospicebop.org.nz</a> 07 307 2244
○ Radiology	x-ray, CT, ultrasound, fluoroscopy			GP, Medical Specialists	Jill Wright Radiology Manager <a href="mailto:Jillian.Wright@bopdhb.govt.nz">Jillian.Wright@bopdhb.govt.nz</a> Ext. 8117
○ Laboratory	Diagnostic testing			GP, Medical Specialists	Kerri Freeman Clinical Support Services Manager Ext. 4770 <a href="mailto:Kerrie.freeman@bopdhb.govt.nz">Kerrie.freeman@bopdhb.govt.nz</a>
○ Māori Health				GP, Medical Specialists, Health Professionals	Amohaere Tangitu, Manager Ext. 4963 <a href="mailto:Amohaere.tangitu@bopdhb.govt.nz">Amohaere.tangitu@bopdhb.govt.nz</a>

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
<ul style="list-style-type: none"> <li><b>Lakes</b> Rotorua/Taupo Hospital</li> </ul>			Lakes		
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Oncology/ Haematology</li> </ul> </li> </ul>	Chemotherapy services, blood transfusions, visiting specialist.	All ages	Taupo, Rotorua	GP, Medical Specialists	David Boles Cancer Nurse Specialist Ph: 027 328 3112 <a href="mailto:David.boles@lakesdhb.govt.nz">David.boles@lakesdhb.govt.nz</a> Cath Mott Children's Shared Care Nurse Ph. 0274 788 320 <a href="mailto:Cath.mott@lakesdhb.govt.nz">Cath.mott@lakesdhb.govt.nz</a>
<ul style="list-style-type: none"> <li>Palliative Care</li> </ul>	Community Hospice Service Community Hospice Service	All ages All ages	Rotorua Taupo/Turangi	GP, Medical Specialists	Janet Whiteside 027 274 6997 Suzy Kuper 027 226 6778
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Radiology</li> </ul> </li> </ul>	MRI, CT	All ages	Rotorua/Taupo	GP, Medical Specialists	Greg Hunt ex 8903 <a href="mailto:Greg.Hunt@lakesdhb.govt.nz">Greg.Hunt@lakesdhb.govt.nz</a>
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Surgical Services</li> </ul> </li> </ul>	Orthopaedics, General	All ages		GP, Medical Specialists	Greg Vandergoot Manager <a href="mailto:Greg.Vandergoot@lakesdhb.govt.nz">Greg.Vandergoot@lakesdhb.govt.nz</a>
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Woman, Child and Family Service</li> </ul> </li> </ul>	Assessment, diagnosis and treatment	0-15, + if deemed develop. appropriate	Rotorua/Taupo	GP, Medical Specialists	CNL Ilona Weekley ex 8730 <a href="mailto:Ilona.Weekley@lakesdhb.govt.nz">Ilona.Weekley@lakesdhb.govt.nz</a> Head of Department Stephen Bradley ex 7884 <a href="mailto:Stephen.Bradley@lakesdhb.govt.nz">Stephen.Bradley@lakesdhb.govt.nz</a>
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Children's Outreach Nursing Service</li> </ul> </li> </ul>	Case Management, Coordination of care for children with complex illnesses	0-15	Lakes DHB	Children under Specialist Care	Cath Mott <a href="mailto:Cath.mott@lakesdhb.govt.nz">Cath.mott@lakesdhb.govt.nz</a>
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>Children's Clinic</li> </ul> </li> </ul>	Outreach Clinics every 3-4 months with visiting Paediatric Oncologist from Starship	0-15	Lakes DHB	Specialists and other DHBs	Bev Winters 07 349 7932 <a href="mailto:Beverley.Winters@lakesdhb.govt.nz">Beverley.Winters@lakesdhb.govt.nz</a>
<ul style="list-style-type: none"> <li> <ul style="list-style-type: none"> <li>General Internal</li> </ul> </li> </ul>	Medicine ICU/CCU/Radiology	All ages	Rotorua/Taupo	GP, Medical Specialists	Manager Kevin Harris ex 8946 <a href="mailto:Kevin.Harris@lakesdhb.govt.nz">Kevin.Harris@lakesdhb.govt.nz</a>

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
○ Pathology/Laboratory	Blood/Specimen, collection and results Immunology, Haematology	All ages		Medical Specialists	
○ Pharmacy	Drug Information, therapeutic drug monitoring	All ages	Rotorua/Taupo	GP, Health Professionals, Specialists	Kevin Stanley-Clarke Ext 8769 <a href="mailto:Kevin.Stanley-Clarke@lakesdhb.govt.nz">Kevin.Stanley-Clarke@lakesdhb.govt.nz</a>
○ Allied Health	Physiotherapy, Occupational therapy, Dietician	All ages	Lakes DHB	Health Care Professionals	Kevin Harris – Manager Extn 8946 <a href="mailto:Kevin.Harris@lakesdhb.govt.nz">Kevin.Harris@lakesdhb.govt.nz</a>
○ Social Work Services	Women and Child Health, Adult Service	All ages	Lakes KHB	Self, Health Care Professionals	Shelley Kirk Professional Advisor for Social Work <a href="mailto:Shelley.Kirk@lakesdhb.govt.nz">Shelley.Kirk@lakesdhb.govt.nz</a>
○ Mental Health/CAFÉ Team		All ages	Rotorua/Taupo	Medical Specialists, GP	John Turner Extn 5010 <a href="mailto:John.Turner@lakesdhb.govt.nz">John.Turner@lakesdhb.govt.nz</a>
○ Māori Health	Hunga Manaaki Te Oranga	All ages	Rotorua/Taupo	Self, Specialists and other Health Professionals	General manager Phyllis Tangitu ex7857 Te Whakaruruhau Ngaroma Grant 7825
<b><u>Non Governmental Organizations</u></b>					
<b>Hospice</b>					
Waikato District Community Hospice Trust	Collaborative care (with Health Waikato Community Services) Children and family focused service 4 beds (sub contract) Day Hospice	18+	Waikato – Hamilton, Cambridge, Ngaruawahia & shared care w/ DN, BOP	self/families, GP's, staff and district nurses, social workers,	Raewynn Jarvis-Hall Clinical Nurse Manager <a href="mailto:raewynn@hospicewaikato.org">raewynn@hospicewaikato.org</a> 07 858 6811 Waipuna Hospice, BOP 07 552 4380
Rainbow Place	2 respite beds in new hospice unit Specialised children's nursing Counselling, bereavement support Play, art and family therapy Workshops and a teenage group Resource library and community	0-19 years	Waikato DHB	self/families, friends, health care professionals, schools, social services	Penny Parsons, Manager Children and Young people service of Hospice Waikato <a href="mailto:penny@hospicewaikato.org.nz">penny@hospicewaikato.org.nz</a> 07 839 4194

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
	education				
Tokoroa District & Community Hospice Trust	Family Volunteer Support, Equipment. Patient advocacy	All ages	Tokoroa District	Hospital, District Nurses, GP and Family/Self Referral.	Vicky Ray Service Co-Coordinator <a href="mailto:tokhosp@xtra.co.nz">tokhosp@xtra.co.nz</a> 07 886 5014
<b>Community Support</b>					
Fertility Associates	Assist with the preservation of fertility prior to treatment	All ages, Males 16yrs & older, females 18 or 20yrs & older.	New Zealand	Self, health care professionals	Andrea Coxhead, Waikato branch <a href="mailto:acoxhead@fertilityassociates.co.nz">acoxhead@fertilityassociates.co.nz</a> www.fertilityassociates.co.nz
True Colours	Nurse consultation, crisis intervention, bereavement support, counselling, creative therapies, family therapy, workshops, presentations and support groups	0-18 years	Waikato, King Country, Thames Valley	Self/families, health care professionals, community services	Cynthia Ward, Manager <a href="mailto:Cynthia@truecolors.org.nz">Cynthia@truecolors.org.nz</a>
CanTeen	Social activities, workshops, peer support, financial and hardship support.	13-24	Waikato/BOP/Lakes Division of a National Body	Self/families, Health care professionals, community services	Patient support coordinator <a href="mailto:pscwaikato@canteen.org.nz">pscwaikato@canteen.org.nz</a> 07 839 1130
Cancer Society of New Zealand	Liaison nurse, financial support, advocacy, accommodation, support groups, education	All ages	Waikato/BOP	Self/families, friends, health care professionals, community services	Diana Bowen <a href="mailto:dianabowen@cancersociety.org.nz">dianabowen@cancersociety.org.nz</a> 07 838 2027
Child Cancer Foundation	Family support, education	0-13	Waikato/BOP/Lakes	Self/families, friends, health care professionals,	Heather Oatway, Waikato <a href="mailto:oatway@xtra.co.nz">oatway@xtra.co.nz</a> 07 825 2020

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
				community services	
Leukaemia and Blood Foundation	Support, education, research	All ages	Waikato/BOP/Lakes	Self/families, friends, health care professionals, community services	Aimee Munroe Auckland & Upper Nth Is Support 09 638 3556 Toll Free: 0800 15 10 15
Ronald McDonald House	Accommodation, mobile dental care	0-18yr, after this done by case by case	Starship	Self/families, friends, health care professionals, community services	09 303 1365
Camp Quality	High quality recreational services	5-16	Waikato/Lakes/BOP	Self/families, friends, health care professionals, community services	Jan Barnett (Secretary) <a href="mailto:info@campqualitynz.org.nz">info@campqualitynz.org.nz</a>
Koru Care	Make children's dreams come true through yearly trips to Disneyland and the Gold Coast	7-14	Waikato/Lakes/BOP	Self/families, friends, health care professionals, community services	Koru Care Charitable Trust <a href="mailto:korucare@xtra.co.nz">korucare@xtra.co.nz</a>
Make-A-Wish Foundation	Grant wishes to children	3-18	Waikato/Lakes/BOP	Self/families, friends, health care professionals, community services	Make-A-Wish <a href="mailto:nationaloffice@makeawish.org.nz">nationaloffice@makeawish.org.nz</a>
Royal New Zealand Foundation	Comprehensive range of services	Children's	Hamilton	Self-referral	07 839 2266

Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
for the Blind	available to its blind, deaf blind and vision-impaired members. These include rehabilitation services for independent living. Others: Counselling, Children's services, Deaf blind services, Māori and Pacific Island services, communication & computer services.	Services – 0-18 years Adult services – 18yrs+	Region		F: 07 839 558
Family Planning Association	Provides sexual and reproductive health information, clinical services, education, training, and research -contraception, STI checks, educational resources, PMS, adolescent sexuality, pregnancy, youth sexuality cancer program Youth clinic Fridays 4:30-7:30 pm	All ages			Louise Were
○ Health Educator	Free for under 22's, \$3 for a box of condoms, Over 22, \$5				Julia Drury 07 834-1433 027 294 4385
○ Youth Development Co-ordinator					Maeroa Nikora
Hau Ora Takatapui – New Zealand AIDS Foundation	Health Promotion, one on one counselling, SW support, HIV education	All ages	Midland	Self, Healthcare Professionals	Geoff Ruaine <a href="mailto:Geoff.ruaine@nzaf.org.nz">Geoff.ruaine@nzaf.org.nz</a>
<b>Community Development Support</b>					
Whai Marama	Youth counselling, alcohol and drug counselling, youth groups, youth transition service (vocational), internet café for vocational purposes	12-24	Waikato	self	Ruth Choudharey, Youth Liaison Waikato Hospital/Whai Marama Youth Connex <a href="mailto:ChoudaR@waikatodhb.govt.nz">ChoudaR@waikatodhb.govt.nz</a>
Te Ahurei a Rangatahi	Support and empower rangatahi and whānau towards positive and informed choices. (education, resources, participation/leadership, promoting	12 – 24 yrs However can work with	Hamilton & outlying areas	Self, other networks refer to them – Whai Marama, High	<a href="mailto:teahurei@xtra.co.nz">teahurei@xtra.co.nz</a>



Provider	Types of Service	Age Range	Catchment Area	Referral Process	Key Contact
	health)	younger		Schools, and Alternative Learning Centres.	
Central King Country Youth Link Trust	Youth Development Organisation in Taumarunui	10 – 25 yrs	Central/King Country/ Taumarunui		Penny Neil Youth Link Trustee Waikato 07 895 4620/ 021 356 879
NZ Ass. of Adolescent Health and Development	Young people and people working with young people	12 – 24 yrs	New Zealand	Clarke Koopu Health Promoter, WDHB	Sarah Helm National Executive Officer 04 382 9944 <a href="mailto:sarah@nzaahd.org.nz">sarah@nzaahd.org.nz</a>
Waikato Youth Collective	For youth workers – people working with young people. Professional development, raising awareness of work. Support.	Any age of people working with youth.	Waikato, Hauraki and King Country.	Self	Megan Bell, Chairperson <a href="mailto:megan@whaimarama.co.nz">megan@whaimarama.co.nz</a> Maraea Nikora, Social Services <a href="mailto:maraea@ssw.org.nz">maraea@ssw.org.nz</a>
Hamilton City Council Youth Development	Co-Ord. with the youth council, meet Feb-Nov. Aim: young people a voice within local govt processes to voice their concern. Effectively to give young people a voice in the city. 15 youth councillors	15-25 yrs	Hamilton City	Nominated or referred by teacher/parent/c aregivers or self.	Mahuru Robinson Youth Development Advisor <a href="mailto:Mahuru.robinson@hcc.govt.nz">Mahuru.robinson@hcc.govt.nz</a> 07 838 6699 then ask for ext.
Work and Income New Zealand	Hospital Liaison for benefits and financial queries	18+	Waikato Hospital only	Self/families, Social Workers, Nurses, Ward Clerks	Ginny Thrush <a href="mailto:Ginny.thrush001@msd.govt.nz">Ginny.thrush001@msd.govt.nz</a>
Housing New Zealand	Hospital liaison for housing assistance	18+	Waikato Hospital Only	Self, Social Workers	Sharon Fosser Hospital Liaison F: 07 878 7810
National Travel Assistance	Transportation and accommodation support	All ages	Waikato/BOP/ Lakes	Self, Hospital Staff.	To be named

<b>Provider</b>	<b>Types of Service</b>	<b>Age Range</b>	<b>Catchment Area</b>	<b>Referral Process</b>	<b>Key Contact</b>
Department of Child, Youth & Family	To protect children, manage young offenders, ensure that children in need are secure and cared for, help families maintain and strengthen their child-rearing role.	0-17y	Nationally	Self, Family, other professionals i.e Education/Health/ Police	Geoff Williams/Don Horsfield (acting) Regional Director of Midlands CYPFs 0508 family
Healthcare NZ – medically fragile children	Helping with domestic tasks and personal care in own home, specialised nursing services for more complex health needs, residential facilities and other community support options for people with disabilities	All ages, for Medically Fragile – up to 14yrs	Nationally	Disability Support Link, DN from WDHB, Private referrals	Home Support Services Hamilton 07 839 9012 <a href="mailto:hamilton.office@healthcarenz.co.nz">hamilton.office@healthcarenz.co.nz</a>
<b>LEAP</b>					
Late Effects Assessment Programme	Coordination of long-term follow-up clinics, database maintenance and oversight of treatment summaries	0-18	North of Taranaki	Medical Specialists	Kathy Yallop Nurse Specialist/LEAP <a href="mailto:yallopk@adhb.govt.nz">yallopk@adhb.govt.nz</a>

## **Appendix Three    MCN AYA OHS Work Group Terms of Reference**



### **Adolescent and Young Adult Oncology Haematology (AYA OHS) Work Group Terms of Reference**

#### **Background**

The Midland Cancer Network (MCN) is responsible for supporting and advising the DHBs and constituent organisations about the issues, activities and priorities related to the implementation of the New Zealand Cancer Control Strategy Plan Action Plan (Action Plan, MOH, 2005) and the New Zealand Palliative Care Strategy (MOH, 2001).

In 2007-2008, the MCN led a project to assist with the development of the AYA OHS for the Midland region. The project produced a Midland AYA OHS action plan to optimise care for AYA with cancer.

#### **Purpose**

The AYA OHS Work Group will take a proactive leadership approach to reduce the inequalities, incidence and impact of AYA with cancer across the cancer continuum for the Midland region.

The group will be responsible for the prioritisation of the regional action plan into a work programme and is accountable to the Network Executive Group for the delivery of the agreed work programme.

#### **Roles and responsibilities**

To contribute to the development of the Midland Cancer Control Strategy Plan

To prepare for the Midland Cancer Network an annual report on progress

To support and develop the AYA key worker role

To support and develop AYA multi-disciplinary teams (MDTs) and associated meetings at both a regional and supraregional level.

To oversee and coordinate service improvement work

To develop and agree local / regional / supraregional AYA clinical guidelines

To disseminate and share the above guidelines in order to seek agreement with other colleagues, and to ensure acceptance and adherence to the agreed guidelines

To develop and agree appropriate network wide clinical audit as appropriate

To develop and agree a minimum dataset(s) for the collection of data for AYA services for monitoring the quality of services, patient outcomes and facilitating clinical audit (within allocated resources)

To act as a forum for discussion of new treatments/services, including their efficacy, effectiveness and resource implications, and advise the Midland Cancer Network accordingly

To act as a forum for research and development in the field AYA oncology / haematology, including access to age appropriate clinical trials

Provide expert advice relating to AYA with cancer as and when required

Identify opportunities for improved collaboration across the care continuum in the delivery of local / regional /surpraregional cancer services.

## Membership

<b>Clinical Leader (s) (Chair)</b>	
<b>Haematology</b>	<b>Hugh Goodman, Haematologist</b>
<b>Medical Oncology</b>	<b>Ian Kennedy, Medical Oncologist</b>
<b>Radiation Oncology</b>	<b>Herman Van de Vyver Radiation Oncologist</b>
<b>Neurosurgery</b>	<b>Thirayan Muthu, Neurosurgeon</b>
AYA Care Co-ordinator	Ellyn Proffit, CNS
Deputy Clinical Leader representing Lakes DHBs	David Boles, Cancer Care Coordinator
Deputy Clinical Leader representing BOP DHB	Lorraine Hammersley, Cancer Coordinator
Regional Cancer Centre & MCN	Dr Charles De Groot, Clinical Director
Midland Cancer Network	Jan Hewitt, Manager
Haematology	Robyn Segedin, CNS
Oncology	Kim Holt, Operations Manager
Paediatric Oncologist	Dr Deepika Singh
Paediatric Shared Care Link	Denise Bregman, CNL Ward 52
Oncology / Haematology / Palliative Care Inpatient Nursing	Chris Baker, CNL Ward 25
Hospice Waikato - Rainbow Place	Penny Parsons, Manager
True Colours	Cynthia Ward, Manager
CanTeen/ Consumer Advocate	Ankia Kleinsmith
Allied Health	Ruth Choudharey Youth Social Worker / Advisor
Primary Care representation	PHO or GP Liaison TBD
Te Puna Oranga	Erena Kara
Cancer Society Waikato / BOP Division	Helen Smathers
Starship supraregional representation	Heidi McClintock
Planning & Funding	Rachael Poanaki, Portfolio Manager

Decisions will be made by consensus. If it is not possible to reach consensus then areas of disagreement will be identified and reported to the Network Executive Group.

Members are expected to declare conflicts of interest should they arise. Any conflicts will be dealt with on a case-by-case basis.

### **Chair and Administration Function**

Administrative and analytical support will be provided by the Network Management team through the Network Manager.

Chair: Clinical Leader  
Administration: Midland Cancer Network secretariat

#### **Meeting Schedule**

Frequency: Quarterly  
Venue: Bryant Education Centre on Waikato Hospital campus (with telephone conference link)  
Teleconference: Phone: 083033, Pin – 772256#

### **Minutes and Agenda**

Minutes are circulated to members within seven days of the meeting via email.

Agenda items are sought ten days preceding each meeting.

The agenda is circulated one week prior to the meeting including all briefing/background papers to be discussed. If there is a significant briefing paper then two weeks will be allowed for members to adequately review the document. If a decision is required a recommendation will be clearly stated at the end of the paper.

Minutes will be available to other MCN groups as requested once these are signed off.

### **Reporting and Communication**

The MCN AYA OHS Group Chair reports to the MCN Executive Group.

An annual progress report and annual work programme is developed and submitted to the MCN Executive Group for endorsement

Minutes will be made available to other staff within the MCN as requested.

The process for managing any correspondence from the MCN AYA Oncology Haematology Group will be directed by the Chair.

Any matters related to DHB HNA, DSP, DAP and / or prioritisation process will be processed through the Midland Region General Manager Planning and Funding Group via the MCN Executive Group.

## Appendix Four Midland AYA OHS governance links

Governance	Objectives	Links	Reports to:	Lead
<b>NATIONAL</b>				
NZ Cancer Control Steering Group (NZCCSG)	Achieve the NZCCS Action Plan	NZ National Advisory Group Midland Cancer Network	Joint MoH/DHB initiative	
NZ Cancer Treatment Working Party (NZCTWP)	Draft and review service specifications	New Zealand Ministry of Health; New Zealand Cancer Networks - Northland, Midland, Midland and Southern; Supraregional AYA OHS.	NZCCSG	TBD
NZ AYA OHS Advisory Group	Supports development of the national AYA OHS	New Zealand Ministry of Health; New Zealand Cancer Networks - Northland, Midland, Midland and Southern; Supraregional AYA OHS.	NZCTWP	
<b>SUPRAREGIONAL</b>				
The Midland Supraregional AYA OHS	Partner Paediatric and Adult Oncology Services MDTs	NZ AYA OHS Advisory Group (2 key workers are members); NZ Cancer Networks; Midland AYA OHS Work (Management) Group; Auckland, Wellington, Palmerston North, Christchurch and Dunedin's Management Groups	NZ Cancer Control Steering Group; NZ Advisory Group	An AYA OHS key worker and Lead Clinician for each supregion
<b>REGIONAL</b>				
Midland Cancer Network (MCN)	Governance, Support and Liaison	New Zealand Ministry of Health; NZ Cancer Networks DHBs; CCC; DHBs	Midland DHBs	Manager, MCN
Midland AYA OHS Work Group	Implementation of the Midland AYA OHS Action Plan 2008-2010	New Zealand AYA OHS Advisory group Supraregional AYA OHS	MCN	Key Worker Lead Clinician

## Appendix Five      Midland AYA OHS place of treatment

AYA OHS service specifications (draft) please refer:

### 4.8      *Place of Treatment*

*Care for adolescents and young adults should be delivered in age –appropriate  
Haematology/ Cancer facilities in order to achieve the best possible health outcomes*

The service specifications recommend a physical place of treatment for the AYA OHS. Regionally, there is no physical facility to deliver care to AYA. Rather, service is provided through standard primary, secondary and tertiary facilities as outlined in the existing services section. In April 2004, Waikato DHB announced that it would undertake a \$252 million Service and Campus Redevelopment (SCR) project. There are two streams of the project to be completed by 2013: (1) better patient journey experience and (2) new buildings/refurbishments. The SCR project manager, youth facilities and/or enhancements are not being considered in this redevelopment.

In 2005, Foundation 2020, an independent fundraising body set up in 2005, began working with the Midland region public, community groups, businesses and health professionals to raise funds for a proposed child/youth focussed care facility by the year 2020 located at Waikato Hospital. Kids' Place Hospital aims to be a three levelled structure, comprising of 66 beds, specifically for those aged 0-18 years. The status of this project is unclear at the time of this report.

Supraregionally, Starship Auckland, who provide a child specific facility for children and youth up to 18 years recently allocated four beds for AYA which are set to open in early 2009.

“Like the old people, you have to be really quiet or they’ll get annoyed at you and it makes you feel like their’s no place for you”.

“Yeah and if I stay with all the little kids they cry too much and they go beep beep with the buzzer and you can’t sleep!”

“And I think that with a lot of the older people they are terminal like they’re getting near the end of their life and their’s quiet a lot of death, really, which is quite hard to be around”

“I think a communal thing would be cool cos you know if there was a youth space for when they were feeling well, there could be stuff to do”

For the Midland region, a specific unit should be considered for 2020, if not for the value to AYA with cancer, but for all children and youth medical needs throughout the region. Although the volume of patients for the AYA OHS is low, hospital admissions for children and youth from the Midland region are significant. Between the years 2000 and 2005, 18,056 adolescents aged 12-18 years were admitted to inpatient settings at Waikato hospital. International evidence suggests that young people generally make up 5-7% of general hospital admissions, which is similar to that of children. This percentage is considered enough to justify the provision of children’s services, and, in the United Kingdom, Australia and USA, the provision of Adolescent Units<sup>11</sup>.

<sup>11</sup> O’Connell, Anne (2003). Where do all the middle ones go? Snapshot Report prepared for CanTeen.

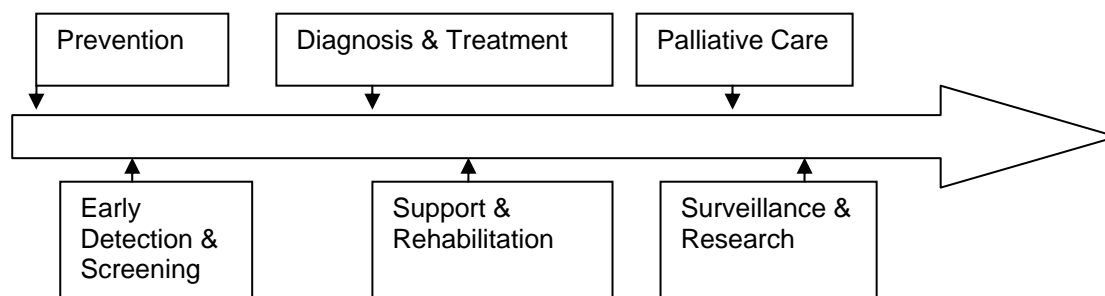
## Appendix Six

## Regional and supraregional referral practices

Provider	Referral Process	Midland AYA OHS Link
<p><u>Primary care:</u> Assessment, minimal relevant investigation, and rapid onward referral of any case of suspected malignancy to secondary/tertiary level provider.</p>	<p>Waikato DHB: Patients seen by GP and can be referred on to secondary or tertiary through the Waikato Referral Coordination Centre</p> <p>Regional: Patients seen by GP and referred to regional hospitals through their own designated referral centres. Referral can be sent to Waikato Referral Coordination Centre if referred to Waikato Hospital.</p>	<p>Midland AYA OHS interface w/ primary care:</p> <ul style="list-style-type: none"> <li>Links established through PHO's and GP liaison</li> <li>Strengthening of stakeholder relationships</li> <li>Key worker communication via letter/phone call with GP once a patient returns to the community</li> </ul>
<p><u>Secondary level provider:</u> assessment of the referred patient, further minimal investigation where necessary to establish the likelihood of malignancy, stabilisation of any immediately life threatening problem, discussion with the tertiary centre and onward referral at the earliest practical time.</p>	<p>Primary to secondary referral:</p> <ul style="list-style-type: none"> <li>Waikato DHB: Referral to regional hospitals via Waikato Referral Coordination Centre</li> <li>Bay of Plenty DHB: Own designated referral processes to regional hospital at Tauranga or Whakatane</li> <li>Lakes DHB: Own designated referral processes to regional hospitals at Taupo or Rotorua.</li> </ul>	<p>Midland AYA OHS interface w/ Secondary:</p> <ul style="list-style-type: none"> <li>Links established at hospitals</li> </ul>
<p><u>Tertiary level provider:</u> diagnostic and staging investigations, assignment and initiation of management strategy, coordination of care within AYA multidisciplinary meetings (MDM)</p>	<p>Primary and/or Secondary referral to Tertiary:</p> <ul style="list-style-type: none"> <li>Starship (not via Waikato Hospital) for &lt;15: Consultant on call takes the patient under his/her care;</li> <li>Waikato Hospital: Emergency department including transfer from secondary emergency departments <ul style="list-style-type: none"> <li>Referral on to Starship as necessary</li> </ul> </li> <li>Waikato Hospital Radiology/specialist services for outpatient appointment (2-6 weeks) <ul style="list-style-type: none"> <li>Referral on to Starship and/or medical/surgical services for further diagnosis and treatment.</li> <li>For 15 &gt; Referral to the Regional Cancer Centre is through the Waikato Referral Coordination Centre after surgical/medical assessment, diagnosis and/or treatment</li> </ul> </li> <li>Inpatient chemotherapy at Tauranga Hospital</li> </ul>	<p>Midland AYA OHS interface at the Tertiary level:</p> <ul style="list-style-type: none"> <li>Partnering paediatric and adult oncology services</li> <li>Supraregional MDT</li> <li>Midland AYA OHS work group</li> <li>Midland MDMs</li> </ul>



## Appendix Seven Midland AYA OHS continuum of care



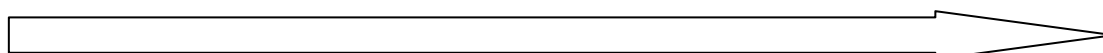
The New Zealand Cancer Control Strategy Action Plan 2005 – 2010 states:

**Goal 3:** Ensure effective diagnosis and treatment of cancer to reduce morbidity and mortality.  
Objective 3 Ensure patient centred and integrated care for those with cancer, their family and whānau.

This objective acknowledges that the cancer journey is complex and challenging and it is not uncommon for patients to be seen by many health professionals within and across multiple health services. Navigating the complex system is difficult for AYA and their family/whānau particularly while having to make huge decisions regarding treatment and care.

Coordinated care is an important part of management for AYA OHS who require transition from paediatric to adult cancer services and/or a variety of treatments and care, particularly when care is provided over time and between settings. AYA and their families/whānau should perceive that providers involved in their care have a broad knowledge of their journey and experiences so far and be operating within a commonly understood continuum of care. The need for improved care coordination is in response to service provision at times being varied and fragmented in the journey of an AYA with cancer.

### *Prevention and Early Detection & Screening*



AYA begin their journey, pre-diagnosis, by accessing primary care health services within their regions. Primary Health Organisation (PHO) enrolments, reduced costs, and health promoters are current mechanisms to increase and enhance access for AYA and their family/whānau to providers at the primary level.

If further assessment of the patient is required, the primary provider will then refer on to secondary or tertiary level services via the Referral Coordination Centre at Waikato Hospital. There are some variations to this if the patient is acutely unwell, the patient may enter via the Emergency Department or transfer to the ward (Haematology) or directly to Starship after phone consultation with the respective consultant/ward. Referral practices are further detailed in appendix six for supraregional and regional services at the primary, secondary and tertiary levels.

### Diagnosis and Treatment



In the case of suspected malignancy not confirmed at the primary level, AYA OHS are referred by their primary provider for further consultation, opinion and initiation of

appropriate specialist investigations/interventions at secondary/tertiary services. AYA usually enter through paediatric or adult specialty clinics.

For 15 years and below, AYA who come to the paediatric clinic are seen by a paediatrician, if cancer is suspected, then it is the paediatric oncologist liaison and shared care nurse who links with Starship and assists with the coordination of care between the two services. The shared care nurse also links with other Midland shared care nurses located at the Lakes and Bay of Plenty's secondary hospitals. At present, there is not a shared care nurse for paediatrics although the position (.6 fte) is expected to be advertised late this year.

For 15 years and older, AYA may enter through the adult specialty clinics. After tumour-specific surgery they are then referred on to the Regional Cancer Centre via the Referral Coordination Centre. Tertiary services use a standard referral sheet with patient details, diagnosis, and request for review by the service. Again, AYA acutely unwell may be directly transferred to or within tertiary services. Due to the large numbers of cancer patients that pass through the Regional Cancer Centre care coordination is unlikely but may be provided by clinical nurse specialists. This varies from tumour stream to tumour stream and is dependent on the CNS' individual interpretation of their scope of practice. Cancer coordinators have been established in the Lakes and Bay of Plenty but again scope of practice varies.

#### Determination of Treatment

This part of the cancer journey, based on best cancer practice, would involve multidisciplinary meetings (MDMs) and multidisciplinary teams (MDTs) to determine tumour-specific surgery, radiation and chemotherapy treatments, consent, enrolment in clinical trials, and access to fertility services within the region. For the Midland AYA OHS, per the service specifications, there are required multidisciplinary roles at both a regional and supraregional level.

At a supraregional level, Starship uses a multidisciplinary model of care. Regionally, for adult oncology, multidisciplinary discussions, processes and/or agreements between GPs, surgeons and/or oncologist specialists do not occur for AYA. There are tumour specific MDTs where AYA may be discussed.

An essential component when determining treatment is consent. Refer Midland AYA OHS service specifications (draft);

#### **4.13 Consent**

*Patients less than 16 years of age are formally regarded as minors by New Zealand law. However, unless compromised by clinical condition or cognitive state, such adolescents must provide, along with their caregivers, informed consent for participation in clinical trials. Adolescents between 16-18 years of age may receive treatment for which they refuse consent if:*

*They are deemed unable to provide an informed opinion, and  
The view of their care-givers differs from theirs.*

Consent from the patient and/or family/whānau is typically gained for Midland AYA OHS at the commencement of treatment.

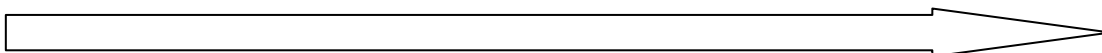
#### Treatment

At this point, AYA with cancer and their family/whānau should understand the diagnosis, have agreed to the treatment plan, enrolled into a clinical trial by choice and

be an integral component to the MDM process and the surgeons and/or consultants involved in their care. AYA have access to and link with a range of specialist services including:

<b>Linked Providers</b>	<b>Nature of Linkage</b>	<b>Accountabilities associated with linkages</b>
Specialist nursing service including but not limited to: primary healthcare nurses, specialist haematology/ oncology/paediatric oncology nursing, community nursing services	Refer to relevant Hospital services as appropriate	Work with other relevant professionals whenever there are concerns relating to a particular adolescent/young adult
Hospital services providing adolescent/young adult cancer services, including (but not limited to): paediatric oncology medical oncology haematology medical specialities surgical specialities mental health services radiation oncology pathology laboratory services diagnostic radiology services intensive care social work services physiotherapy, occupational therapy, speech-Language therapy, dietetic services.	Refer to relevant hospital services as appropriate	Work with other relevant professionals whenever there are concerns relating to a particular adolescent/young adult
Palliative care services within DHBs and those contracted to supply services in the community	Refer or liaise re individual adolescent/young adult as appropriate	Work with other relevant professionals whenever there are concerns relating to a particular adolescent/young adult

## Support and Rehabilitation



### *Follow-up Care*

Follow-up care is dependant on each tumour stream, medical or radiation oncologist or haematologist. There are no specific protocols and frequency and duration is mostly determined on a case by case basis. Some AYA OHS continue on with follow-up care for a significant period at the tertiary level. Others are referred back to the GP or surgeon to provide follow-up care. At discharge from the service, the GP receives a discharge summary for each patient.

After the follow-up period, patients return to the care of their GP. Within two years post treatment, patients can be transitioned onto the Late Effects Assessment Program for education and follow-up clinics if treated under the paediatric program.

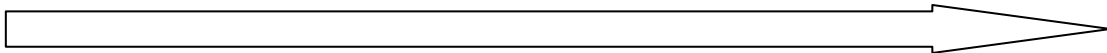
## *Supportive Care*

Although described under support and rehabilitation, supportive care is required by AYA and their family/whānau throughout the cancer continuum. Supportive care can range from practical supports namely accommodation and travel during the determination and treatment phases of cancer journey. Initially, AYA with cancer and their family/whānau may meet with the social worker to ascertain practical and psycho social supports. Referral onwards and inpatient support are then determined.

During the treatment phase, AYA with cancer 18 years and below and their family/whānau have access to psycho social services through Starship and programs, such as, CanTeen and True Colours as well as Rainbow Place. In addition, there are also culturally sensitive programs like the Kaitiaki service that can refer onwards to support Māori in the community. Geographical limitations to these services become prevalent when the patient is not receiving treatment at the tertiary hospital. Most regional patients are able to access similar or same services in their areas including the Cancer Society and CanTeen but on a limited basis. A monthly meeting is held comprising CanTeen, True Colours, Rainbow Place and the Child Cancer Foundation which the Midland key worker attends to discuss and best coordinate the ongoing psycho social needs of AYA and their family/whānau.

If AYA reach a palliative stage, they can continue to be supported by these services at home or in the hospital. For those aged 18 and above, Hospice, a service that supports quality of life during the last six months of life is available to AYA and their family/whānau. Supports can range from home visits to counselling for family/whānau. Again, geographical limitations apply for this service as well.

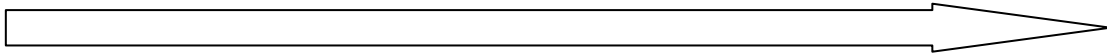
## *Palliative Care*



AYA OHS who require end of life care will be referred to the palliative care services available within the Midland region provided both in the hospital and community setting. The Liverpool Care pathway is a pathway for care of the dying patient, whether in hospital or community. Close liaison occurs between district nurses, GPs, Hospice and palliative care.

Patients within a certain geographical area around Waikato Hospital have access to a comprehensive palliative care service (Liverpool Pathway) for patients wishing to return home. Although there is a geographical boundary for the full service, patients outside of the area can still access collaborative care through their GP, district nurses and Hospice with consultative support from palliative care at Waikato hospital. Additional psycho social support is provided by Hospice/ Rainbow Place, and True Colours as able. AYA with cancer 18 years and above are psycho socially supported by Hospice. In Lakes and Bay of Plenty DHBs, AYA with cancer are known to the cancer care coordinators who link to provide support to the shared care nurses. The shared care nurse can utilize and liaise with palliative care specialists at the Regional Cancer Centre. The shared care nurse works in collaboration with the GP and district nurse. Bay of Plenty is looking at workforce need and/or development of an oncology district nursing team.

## *Surveillance and Research*



## *Determination of plans and treatment for recurrence*

Surveillance occurs for most AYA 18 years and under through the Midland late effects follow-up clinic. If there is symptom recurrence patients will re-enter the cancer pathway and depending on symptoms/diagnosis receive treatment with their original specialist, age permitting. Placement and age criteria for patients who experience recurrence are determined on a case by case basis.

For AYA aged 18 and above, there is no co-ordinated surveillance program but patients will continue to be seen as needed by the oncologist or their primary physician.

### Survivorship

Survivorship is an ongoing personal state for those who live with, through and beyond cancer. Cancer survivors are not only people who have been diagnosed with cancer but those affected by the diagnosis as well, such as family/whānau, friends, and caregivers. For Midland AYA, survivorship will mean either returning to or commencing work, relationships outside of the cancer community, school or vocational studies, or an overseas experience. Usually, if an AYA has returned to school, they may be no longer under late effects services. In the Midland region, there are no support services that assist AYA with this ongoing state of being and no data has been collected to ascertain the ongoing needs of these AYA with cancer.

## **Appendix Eight     Midland AYA OHS Multidisciplinary Care Framework**

### **Introduction**

The purpose of this framework is to define multidisciplinary care for AYA with cancer, identify existing practices and ways to enhance multidisciplinary care for AYA in the Midland region.

### **Background**

The NZ Cancer Control Strategy aims to ensure patients have access to a multidisciplinary team (MDT) approach. To achieve this District Health Boards (DHBs) and Cancer Treatment Providers are required to have documented procedures for a multidisciplinary approach, hold regular multidisciplinary case conferences and produce evidence that a multidisciplinary team approach is established.

From February 2006, \$3.14 million per annum sustainable funding was devolved to DHBs to develop a number of initiatives including supporting multidisciplinary teams. All DHBs have identified the establishment of multidisciplinary teams and meetings as an action in their cancer plans but since 2006 there has been variable progress across the DHBs on the action.

Regional Cancer Networks established in 2007, are committed to improving the journey for cancer patients, their carers and whānau. It is envisaged that they will become the engine room for achieving the goals of the Cancer Control Strategy. The networks are collaborating on the development of a consistent regional cancer network framework, which includes the development of a Multidisciplinary Meetings (MDM) Framework for cancer services.

The service specifications support the development of multidisciplinary care at regional and supraregional level. Refer AYA OHS service specifications;

#### **4.5 Multidisciplinary Teams**

*Roles of the Supraregional(SR) and Regional(R) AYA MDTs:*

- *assess eligibility of patient for treatment within the Service (R)*
- *determine optimal place of treatment i.e. within adult or paediatric services (SR)*
- *establish the diagnosis (R, SR)*
- *allocate age-appropriate treatment by entry onto clinical trial or treatment according to recommended therapy protocol (SR)*
- *evaluation of progress through treatment (R, SR)*
- *Provide a comprehensive youth health assessment that identified psychosocial needs (R, SR).*
- *coordinate age-appropriate psychosocial care for the patient and their family/ whānau (R).*
- *ensure access to youth development activities (R).*
- *construct end-of-treatment plan with particular reference to cancer surveillance and toxicity evaluation (R).*
- *coordinate transition to the national Late Effects Assessment Program (R)*
- *facilitate the involvement of community based and palliative care services as needed (R)*

### **Existing Midland multidisciplinary care practices**

In the Midland region, there are a number of facility-specific differences to models of care and multidisciplinary care for cancer patients in general. There are variations in

the coverage and quality of the provision of multi-disciplinary care, the types of cases and at what points in the care pathway patients are discussed. There are no existing multidisciplinary care practices specifically for AYA in the Midland region.

The table below identifies a range of existing multidisciplinary care practices at the supraregional, regional and local level in which an AYA case may be discussed. Per fortnight at Waikato hospital alone there are more than 56 meetings. There are main multidisciplinary meetings such as breast and colorectal which reflect National Policy and Quality Standards. The majority of multidisciplinary meetings are hospital-organised meetings, not reflective of National Policy and Quality Standards, but aim to discuss ongoing treatment issues at the tertiary level. Attendance is intermittent by consultants and other medical staff as well as allied health members.

<b>Tumour Stream/Service</b>	<b>Place and type of meeting</b>
Supraregional	Starship Hospital – hospital organised, not site specific, facilitated by the AYA OHS key worker
Paediatric Oncology	Waikato Hospital - hospital organised, not site specific, facilitated by the AYA OHS key worker
Adult Oncology	Waikato Hospital – hospital organised, not site specific, facilitated by the AYA OHS key worker
Haematology	Waikato Hospital – hospital organised, attended by a range of tertiary hospital professionals
AYA OHS supportive services	Community – Attended by Canteen, Child Cancer Foundation, Rainbow Place and True Colours
Oncology Outpatient	No current meeting
<b>Site Specific</b>	
Breast (Midland)	BreastScreen, hospital organised meetings
Colorectal	Waikato Hospital
Lung	Waikato Hospital
Bay of Plenty DHB	Breast Cancer and Colorectal MDTs, no specific AYA OHS focus
Lakes DHB	Information not obtained

## **Midland AYA OHS Framework**

Regionally, due to a low volume of cases, a separate MDM is not warranted but protocols need to be developed and agreed by the work group to discuss the degree of multidisciplinary input required for individual patients. The Midland key worker has been linking with existing multidisciplinary care practices on the wards and enhancing communication links with the cancer co-ordinators in the region. At the supraregional level, the key worker has established communication pathways for AYA between the two services. Without clinical leadership, there will be no realisation of a supraregional MDM.

Waikato DHB has commenced the process to implement a multidisciplinary team meeting co-ordinator for cancer care. This role will assist improving clinical multidisciplinary review meetings and implementing systems and processes to meet national standards. The MCN is also working on adopting and adapting a national multidisciplinary care framework for the Midland region.

Additionally, the AYA OHS MDM practices, even once informed by the upcoming frameworks, will require ongoing development over the next few years but is identified as a priority for adding value to the patient's journey along the cancer continuum.

## **Appendix Nine      Midland AYA OHS Education and Training Framework**

### **Introduction**

This framework provides education and training modules for health professionals to access throughout the Midland region to optimise their skills when working with AYA with cancer.

### **Background**

The New Zealand Cancer Control Strategy (NZCCS) provides a framework for reducing the incidence and impact of cancer in New Zealand along the whole cancer control continuum of prevention, early detection, effective diagnosis and treatment, rehabilitation, support and palliative care. The Midland Cancer Network (MCN) is committed to effective planning, coordination and integration of resources and activities, and monitoring and evaluation of cancer services across the cancer continuum.

The NZCCS: Action Plan 2005-2010 identifies priorities for action and outlines in detail how the strategy objectives can be achieved. Refer to:

Goal 3: Ensure effective diagnosis and treatment of cancer to reduce morbidity and mortality.

Objective 4: Improve the quality of care delivered to adolescents with cancer and their family and whānau.

Goal 5: Improve the delivery of services across the continuum of cancer control, through effective planning, coordination and integration of resources and activity, monitoring and evaluation.

Objective 1: Develop a coordinated national cancer workforce strategy

### **Midland AYA OHS education and training framework, a guide to optimal training for staff**

Although a relatively small group, AYA with cancer have special needs that can be readily addressed. Service provision needs to incorporate the medical and developmental aspects of this age group in addition to other prevalent health issues such as physical, social and emotional health; sexual orientation; health-comprising behaviours; substance use; unprotected heterosexual intercourse; same-sex relationships; emotional difficulties and abuse<sup>12</sup>. This training framework is best provided in conjunction with other youth training frameworks throughout the region in order to maximize workforce development for all AYA throughout the region.

This framework will aim to:

- Create a base line of generic workforce skills
- Reduce variations among practice settings
- Increase comfort among health workers for dealing with complex psychosocial issues of young people
- Provide health workers with a “tool kit” for screening, interviewing and working with youth in the health sector
- Provide an overview of the youth/cancer model of care integrated with evidence based best practices of cancer services

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<sup>12</sup> Blum, R., Beurhing, T., Wunderlich, & Resnick. M., (1996). Don't Ask, They Won't Tell: The Quality of Adolescent Health Screenings in Five Practice Settings. American Journal of Public Health. 86; 1767-1772.



## Education and training framework

<b>Training:</b> “Tool Kit” for working with youth – Yearly training <b>Who should attend:</b> All oncology/haematology professionals working with youth <b>Venue:</b> Bryant Education Centre, Waikato Hospital	
<b>Module 1</b>	<b>Sessions per year \ hours</b>
<b>1. CHEADss tool</b> CHEADss (Culture, Home environment, Education/employment, Eating, peer-related Activities, Drugs, sexuality, suicide/depression) is a supplemental adolescent assessment tool for clinicians working with youth in health. The tool will aid clinicians to proceed naturally from expected and less threatening questions to more personal and intrusive questions <sup>13</sup> . It is associated with strength based and best practice models along with improved health outcomes <sup>14</sup> .	1/8
<b>2. Motivational Interviewing</b> Motivational Interviewing is a client-centred, directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence. This technique will aid clinicians to ensure the success and sustainability of bio-psycho-social interventions for AYA along the cancer continuum.	1/8
<b>3. Panel - Youth in the health sector</b> Panel - Youth in the health sector. A facilitated question and answer session on diagnosis and youth development factors such as high risk, like alcohol and drug users. The panel will aim to look at trends across the Midland region in regards to the admission and treatment of youth, and compare treatment to international best practices which will improve the clinician's ability to acknowledge and best treat co-morbidities.	1/1
<b>4. Youth and their family/ whānau – culture, grief and loss</b> Health, youth and their family/ whānau will look at communication strategies to best work with youth and their families/ whānau. The culture, grief and loss component will provide health professionals with the tools and techniques to best manage and support and interact with AYA and their family/ whānau.	1/2
<b>5. Panel - Late Effects</b> Late Effects Panel will provide health professionals with the effects of treatment in the short and long term for AYA. The panel will include Medical, Radiation and Pharmacy Oncology representatives who will do case presentations, followed by a Q & A session.	1/1
<b>6. Clinical Trials and Consent</b> Clinical Trials and Consent will provide health professionals with an overview of the successes, challenges and barriers of youth enrolment in clinical trials nationally and internationally.	1/1
<b>7. Multidisciplinary Care – Best Practices for Youth Health/ Current Thinking in Youth Health and Youth Development</b> Best Practices for youth through Multidisciplinary Care /Current thinking in Youth Health and Youth Development will introduce the benefits of multidisciplinary care in regards to AYA OHS along with community projects promoting youth health and the reduction of cancer diagnosis.	1/1
<b>Training:</b> Specialised Postgraduate Study in Youth Health <b>Who should attend:</b> Health professionals interested in specializing in Youth Health <b>Venue:</b> University of Auckland	
<b>Module 2</b>	<b>Sessions per year</b>
<b>Youth Health (Paeds 172)</b> Core Skills in Youth Health including: effective engagement, assessment and intervention skills for working with young people in a range of clinical or community settings.	Semester 1
<b>Youth Health 2 (PAEDS 720)</b> The aim of this course is to extend the participants knowledge of youth health and well-being and prepare participants for leadership roles in youth health. Students will expand their knowledge of the youth development theory and study examples of effective youth development programs	Semester 2

<sup>13</sup> Goldenring, J. M. & Rosen, D.S. (2004).

<sup>14</sup> Chase, J. (2006).

<b>POPHLTH732</b> The aim of this course is to prepare students for a role in youth health in a variety of locations and sectors. In doing this, students are exposed to current research and practice relating to population youth health and evidence based health-care. Students will learn the rationale, bases of need, means of assessment and evaluation of population programmes focusing on the health of youth. They will also learn how to translate ones professional orientation into population level applications, associated with the organization and provision of community based health activities. As well as study and discuss opportunities for improving the health of young people and families in the community.	Semester 2
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<b>Training:</b> Staff in-services/ Adolescent and Young Adults, Cancer and Bio-psycho-social topics <b>Who should attend:</b> All interested health professionals with access to telepaeds <b>Venue:</b> Wards 25 and/or 52 at Waikato Hospital	
<b>Module 3</b>	<b>Sessions per year/ hours</b>
Fertility	1/1
Dating/intimacy	1/1
Confidentiality	1/1
Peer relationships/activities	1/1
Te Whare Tapa Wha	1/1
Self-esteem	1/1
Cultural Communication	1/1
CanTeen	1/1
Family/ whānau	1/1
Other topics as indicated by stakeholders and consumers	3/1

## Training provision

CHEADDS Training and Motivational Interviewing will be presented by the Centre for Youth Health who specializes in education and training packages to providers and who work with young people.

The remainder of the courses will be provided/presented by internal and external AYA OHS stakeholders of the Midland region with representatives from Starship, Oncology, AYA OHS, Pharmacy, Clinical Trials, Population Health, MDT Care Coordinator, Rainbow Place, True Colours, CAMS, PHOs, Whai Marama, and Te Ahurei Rangitahi among others.

## Training coordination

The AYA OHS key worker will be responsible for liaising and organizing in addition to facilitating, as required, the “tool kit” and in-service trainings.

The AYA OHS training framework caters to clinicians and health professionals along the cancer continuum and across the region. With the limited number of AYA cancer diagnosis per year and the region wide identified need for workforce development in the area of AYA, it is logical and thus strategic to make it a generalised framework building in a specialised cancer component.

Marketing, flyers, facilitation, evaluations and certifications will be supported by the Learning and Development (Waikato District Health Board).

Modules 1 will take place at Waikato Hospital, Bryant Education Centre.  
Module 2 is provided through Auckland University and its associated campuses.  
Module 3 will take place on Ward 25, Adult Oncology during handover times.

## **Training fees**

The CHEADss tool and Motivational Interviewing cost \$50 per person per 8 hour session. A minimum of 20 persons is required to cover the direct costs of these sessions. These fees will aim to be reduced between years 3 to 5 in hopes that staff will be able to provide either of these sessions post training and implementation of the tools.

All other “tool kit” sessions as well as in-services will have no charge.

Specialised study will be coordinated through Auckland University School of Population Health and interested parties should consult their respective managers for appropriate funding streams.

Any other fees associated with the training e.g. food and materials; funding should be sought from a youth affiliated service like Paediatrics or the Regional Cancer Centre or a relevant community stakeholder such as CanTeen, Child Cancer Foundation or Cancer Society.

## **Regional links**

The day “tool kit” sessions will be advertised region wide for the Waikato District Health Board, via Learning and Development training calendar. Links have also been established with Bay of Plenty and Lakes Regional Learning and Development Equivalent Consultants. Regional quotas for each DHB can be determined as required by the training facilitator/convenor.

Linking with non-governmental organizations and/or AYA OHS stakeholders has no formalised process but a list of DHB contracted providers can be attained from respective Planning and Funding departments.

The specialised papers are provided through Auckland University and staff should contact their managers and Human Resources to arrange participation in these classes.

## **Evaluation and future development:**

Annual evaluation of the trainings will take place to ensure the framework is meeting the needs of the workforce.

A session evaluation will assure appropriateness and satisfaction of training content.

Evaluation data collected in regards to course content and effectiveness will be tabled and reviewed at one of the Midland AYA OHS Work Group meetings.

In the future, it is desired that Bay of Plenty and Lakes District Health Board also have access to the training via telepaeds.

## **2008/09 Plan**

Dates for CHEADss and Motivational Interviewing are confirmed for October 7<sup>th</sup>, 2008 and November 4<sup>th</sup>, 2008 as per existing youth health coordination on the Learning and Development Calendar (Waikato DHB). The 3<sup>rd</sup> day (youth cancer) will be organised for early 2009.

## **Appendix Ten      Midland AYA OHS Clinical Trials Framework**

### **Introduction**

The purpose of this framework is to identify existing enrolment practices onto clinical trials, barriers to enrolment and a pathway forward to promote enrolment and reduce barriers to clinical trials for AYA with cancer.

### **Background**

Part of the NZCCS Action Plan 2005–2010 identifies priorities for action and outlines in detail how the strategy objectives can be achieved in addition to the new AYA OHS service specifications (draft). Refer to;

Goal 3: Ensure effective diagnosis and treatment of cancer to reduce morbidity and mortality.

Refer AYA OHS service specifications;

#### *4.10 Clinical Trials*

*Whenever possible, patients should be treated on age-specific open clinical trials; if this is not possible, treatment should be delivered according to national/supraregional agreed treatment protocols. Adequate resourcing of Cancer Centres is essential, to permit maximal entry onto clinical trials.*

### **Midland AYA OHS clinical trials framework, a guide to optimal treatment outcomes for youth**

Consistent with international literature, treatment outcomes for under fifteen have improved in the Midland area between 1994-2004. Treatment outcomes for 15 and above have declined since 1994. A dearth of research indicates that overall, for youth worldwide, outcomes have improved the least out of all the age groups<sup>15</sup>. Conclusions of the study found that access to clinical trials is a contributing factor to enhanced survival rate. Further, recommendations report that AYA OHS specific consultants should oversee treatment and enrolment onto trials. Due to the low volume of AYA OHS cases, this is not advisable for the Midland area.

The framework will aim to:

- Reduce variations in referral practices for AYA OHS and Clinical Trials
- Increase access and enrolment on to Clinical Trials for AYA OHS
- Utilize and enhance supraregional and regional links and MDT/MDMs practices
- Support AYA OHS and their family/ whānau pre, during and post clinical trials

### **Existing framework**

#### *Starship*

AYA OHS, fifteen and younger who receive treatment at Starship are offered to enrol in open clinical trials. It is estimated that 40-45% of this group enrol onto trials supported by the Children's Oncology Group (COG)<sup>16</sup>. The majority of patients enrolled, will be followed by Starship until completion of their protocol and/or treatment. Starship has three Clinical Research Associate's (CRAs) to compile and record trial documentation. A fourth CRA is expected in 2008.

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<sup>15</sup> Shaw, P and Gorlick, R. New York City; December 2007, *Journal of Pediatric Hematology/Oncology*). 640 children, adolescents and young adults with cancer were treated at the Children's Hospital of Pittsburgh between July 2001 and June 2006 where only 36%. 38% of those under 15 participated in a clinical trial whereas only 27% of patients 15 and over participated in a clinical trial.

<sup>16</sup> Mark Winstanley, Paediatric Oncologist Starship, May 22<sup>nd</sup>, 2008.

The remainder of 15 years and under are offered standard arm treatments. No tracking/recording of these patients are undertaken. Barriers to entering clinical trials for 15 years and under have been identified as geography followed by funding to open paediatric trials at Starship.

#### *Regional Cancer Centre*

AYA OHS, eighteen and over, are offered to enrol in clinical trials at the Regional Cancer Centre. Per discussion with the clinical trials coordinator, a limited number are enrolled due to criteria of the trial, consultant resources, (CRAs) or patients'/ whānau ability to adhere to the regime of the trial. Time constraints and/or geography were the most noted constraints/barriers. If not on a trial, AYA 18 years and above receive standard arm treatments.

During the development phase of the Midland AYA OHS, a service gap was identified for 15-17 years, under the adult oncology service, who do not meet the age criteria for adult oncology clinical trials at the Regional Cancer Centre. It is estimated that this particular group would be 3-5 per annum. Of this number, some may be referred to Starship.

### **Midland AYA OHS clinical trials framework**

#### *Starship*

Existing Starship services meet service specification requirements. Promotion of this age group to increase enrolment into clinical trials can be supported by the Auckland and Midland key workers in regards to maintenance on clinical trials and coordination of care.

The identified enrolment barriers for 15-17 years under the adult oncology service onto clinical trials will best be facilitated by the supraregional MDTs. The Midland AYA lead clinician is integral to this process.

Discussion around the age barrier has taken place between Starship and the Regional Cancer Centre. Mark Winstanley, Paediatric Oncologist at Starship, and Dr Jeremy Long, previous Clinical Director of the Regional Cancer Centre discussed in light of international best practice research that AYA within this age group should be considered for treatment at Starship as they satisfy COG age requirements for open clinical trials. This process was agreed between the two services.

#### *Regional Cancer Centre*

The Regional Cancer Centre, on average, has 10-15 cases per annum of AYA with cancer. These patients are less likely to enter clinical trials than Starship. The clinical trials coordinator has met with the key worker to discuss consideration of a clinical trials coordinator to sit on the Work Group, to acknowledge barriers and to collaborate on reducing any barriers to enrolment and maintenance on clinical trials.

## Appendix Eleven Midland AYA OHS Fertility Framework

### Introduction

This framework describes the fertility service component of the Midland AYA OHS, existing processes, barriers to accessing services and a pathway forward for Midland AYA females with cancer.

### Background

The New Zealand Cancer Control Strategy (NZCCS) provides a framework for reducing the incidence and impact of cancer in New Zealand along the whole cancer control continuum of prevention, early detection, effective diagnosis and treatment, rehabilitation, support and palliative care.

The NZCCS: Action Plan 2005-2010 identifies priorities for action and outlines in detail how the strategy objectives can be achieved. Refer to:

Goal 3: Ensure effective diagnosis and treatment of cancer to reduce morbidity and mortality.

Objective 3: Develop defined standards for diagnosis, treatment and care for those with cancer.

Objective 4: Improve the quality of cancer delivered to adolescents with cancer and their family and whānau

Refer AYA OHS Service specifications;

#### 4.12 Fertility

*When fertility is likely to be threatened by anti-cancer therapy, semen or ovarian cryopreservation should be considered. In these situations the AYA with cancer (and if requested their family/ whānau) should be advised by a Fertility Specialist as soon as possible. The Fertility Specialist should preferably be a member of the AYA MDT.*

### Midland AYA OHS fertility framework, a guide to optimal access to fertility services for AYA

AYA with cancer in the Midland area can access fertility treatments through Fertility Associates (FA) based in Auckland and Hamilton. At the Regional Cancer Centre it is estimated that approximately 15 AYA will need fertility services and only 7 female AYA (50% of Regional Cancer Centre AYA cases) will experience barriers to services as the process for males to bank sperm is easily facilitated.

Due to the low volume of cases, it has been established that a fertility specialist will not be part of the Midland MDT, rather the AYA OHS key worker will liaise with AYA, fertility specialists and oncologists throughout the region.

During the development phase of this service, the following barriers to accessing fertility services were identified:

Males: There were no barriers found to accessing fertility services

Females:

1. Working relationships between Fertility Associates and the Regional Cancer Centre have lapsed.

2. Female AYA have barriers to accessing embryo freezing:
  - a. Must be in a partnership at the time of diagnosis/FA consultation
  - b. Time delays when seeking fertility services to oncology treatment
  - c. Dearth of research around the effectiveness of embryo freezing

Fertility awareness, in relation to a diagnosis with cancer, is a way to help young people understand their maturing bodies and how to protect their own reproductive health throughout treatment. As well as educating and referring them to services in a timely manner, discussing the physical and emotional changes and signs of fertility will help AYA become knowledgeable about how their bodies function and empower them to make appropriate decisions about sexual behaviour during and after oncology treatment.

This framework will aim to:

- Identify fertility funding available to male/female AYA in the Midland region
- Identify alternatives/latest technologies for female fertility services
- Address barriers for females to access fertility services
- Reduce variations among practice settings
- Provide health professionals with a foundation to be aware of and discuss fertility and the latest treatments during and after treatment.

<b>Ministry of Health funded services for Midland AYA OHS – contract with Fertility Associates NZ</b>	
<b>Males</b>	Receive sperm freezing and storage for 10 years. Fertility Associates have the ability to apply for a period extension in five year blocks through the Ethics Committee (unknown if this is publicly funded as there are no cases to date). Long-term storage of sperm is almost always possible before chemotherapy and irradiation therapy. Treatment deferment is not usually necessary.
<b>Females</b>	Receive a consultation, IVF for embryo freezing and treatment with storage of 10 years. This treatment is limited to women who at time of diagnosis have a partner and will then require 12 non cancer treatment days from start of menstrual cycle (subsequent treatment delay between 2-6 weeks depending on start of cycle). Good quality embryos can be frozen, and later thawed to give a chance of pregnancy. Freezing and thawing have to be done under special conditions; about 60-70% of embryos can survive the procedure. When embryos are to be thawed the woman's menstrual cycle is monitored with blood tests to make sure the embryos are replaced at the right time of the menstrual cycle.
<b>Alternatives for consideration and not currently funded:</b>	

<b>Egg Freezing</b>  Cost: approx NZ\$8,000 (not including the future treatment of thawing and Embryo replacement)  Plus annual storage charge	<p>The National Ethics Committee on Human Assisted Reproduction (NECAHR) has given Fertility Associates the go ahead to offer egg freezing to New Zealand women. Around 65 babies have been born worldwide following the freezing, thawing and subsequent fertilising of eggs so this is a new technology with limited long term data.</p> <p>The process around egg freezing involves the same ovarian stimulation regime as those used in IVF. The eggs are collected, as for any egg pick-up (OPU), under sedating drugs and then frozen. When the woman wishes to use the eggs, they are thawed, the sperm is injected inside the eggs (ICSI) and the resulting embryos are placed in the woman's uterus. If there are surplus embryos these are frozen. While the fertilisation rate per egg injected is poor in comparison to other instances of ICSI, the chances of a pregnancy are expected to be similar to that of a frozen and thawed embryo.</p>
<b>Ovarian Tissue Freezing</b>  Approx: NZ\$6,000  Plus annual storage charge	<p>At the moment Fertility Associates can freeze and store small pieces of the ovary. There has now been one report of a human pregnancy following the storage, thawing and replacement of ovarian tissue. Currently Fertility Associates clinic only has permission from the National Ethics Committee (NECAHR) to offer storage of frozen tissue. This tissue will not be thawed until techniques have been further developed and ethical approval obtained for its use. They are unsure when or if this will occur.</p> <p>Freezing of ovarian tissue is available to women aged 16 to 35 undergoing with a medical condition which has a significant chance of causing ovarian failure. The ovarian tissue is removed laparoscopically.</p>
<b>Temporary Ovarian Suppression</b>	<p>Ovarian suppression is used to describe stopping the ovaries from working, temporarily. Used by Fertility specialists as a possible way to preserve fertility, the use of Zoladex (Goserelin) decreases the production of the hormone estradiol (which may stimulate the growth of cancer cells) to levels similar to a postmenopausal state. When the medication is stopped, hormone levels return to normal. An option for AYA females, it is thought that using Zoladex alongside chemotherapy may protect the ovaries by stopping them from working temporarily so that the chemotherapy is less likely to damage them. Clinical trials are currently being carried out to establish if this treatment is effective in preserving fertility in women receiving chemotherapy.</p>

### Midland AYA OHS fertility framework

Increased communication, knowledge and understanding of fertility services between Regional Cancer Centre and Fertility Associates Specialists will be enhanced through a bi-annual presentation by Fertility Associates (Hamilton) to the Regional Cancer Centre Oncology Grand Round. Oncology Grand Rounds take place every Monday morning. The key worker will be responsible for organising the presentation with the clinic manager at Fertility Associates and the Oncology Round co-ordinator which is currently Leanne Tyrie. The presentation should cover:

1. Any alterations to funding between the Ministry of Health, Fertility Associates and the District Health Boards



## 2. Latest male and female fertility treatments

Learning from these presentations should be passed on by the specialists to the patients during the treatment planning phase. Inclusion of the key worker at this stage is valuable to ensure patients receive timely access and support through the fertility process.

### *Inequalities*

Further reduction of barriers will require AYA key workers to utilize the detailed analysis of the AYA cancer journey to address and/or support any ethnic, socio economic needs or time delays in the case where an AYA female pursues fertility treatment.

In regards to the effectiveness of current fertility treatments, the establishment of a process is necessary by the AYA OHS Work Group to consider and review alternative fertility treatments for females. These considerations should be made available to the Manager of the Midland Cancer Network to consider an appropriate funding advocacy pathway.

### *Education*

Education around fertility awareness should be built into the multidisciplinary care and care coordination frameworks for the AYA OHS. AYA key workers should draw on AYA OHS national processes/protocols in regards to standardised fertility information to be discussed/passed on to AYA. Youthnet's My Changing Body: Fertility Awareness of Young People is a good document for health professionals to best engage and cover sexual and reproductive health with their patients.

The relationship with the key worker and a representative for fertility associates is integral in regards to updating them on mortality and location of AYA as there is a limited time for which fertility specimens are stored.

A component around fertility should be built into the Late Effects follow-up care as AYA re-integrate into the community and commence or continue intimate relationships.

## **Supraregional and regional links**

Key workers should continue to build on existing relationships and care coordination processes to ensure that fertility needs and education is being met along the cancer continuum.

## **Evaluation and future development**

An evaluation component should be adopted for the Oncology Grand Round to provide feedback to the service and Fertility Associates about the value of the presentation and its appropriateness as a bi-annual event.

## **2008/2009 Plan**

A Fertility Associates presentation at the Oncology Grand Round took place in August 2008. The next presentation will need to be organised for 2010.

## **Appendix Twelve Late Effects Assessment Programme (LEAP)**

### **Introduction**

This framework explains the LEAP and local Midland late effects follow-up clinic. It addresses gaps in services and development work associated with addressing those gaps.

### **Background**

The NZCCS Action Plan 2005–2010 identifies priorities for action and outlines in detail how the strategy objectives can be achieved. Refer to;

Goal 4: Improve the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care.

Objective 3: Ensure all survivors of childhood and adolescent cancer receive timely and ongoing support and rehabilitation, including the early identification of, and intervention in, late effects.

Refer AYA OHS service specifications:

#### *4.1 Late Effects Assessment Program*

*Following completion of planned therapy, the regional AYA MDT should ensure that the adolescent/young adult with cancer and his/her family/whānau transitions to the local Late Effects Assessment Program (LEAP).*

### **LEAP Starship/Auckland**

LEAP is the name of a guideline tool developed by the POSG to assist tertiary paediatric clinicians with oncology follow-up for 0-18 years. Follow-up has always occurred for this age group but the LEAP tool provides formality to this process. LEAP is resourced at New Zealand supraregional centres, Starship Auckland, Wellington and Christchurch. Ministry funding was allocated to LEAP to employ additional resources to follow-up, particularly nursing and psychologist services.

Follow-up care is coordinated by Auckland DHBs' LEAP CNS based at Starship hospital for 0-18 year olds 6 months to two years post cancer treatment. Members are referred by cancer health professionals. The LEAP CNS position has been in place for over two years and organizes outreach follow-up clinics for the oncologists at Starship in the Midland, Northland, Midland and Central regions.

#### *Provision*

Prior to the clinics, patients are sent reminders including Quality of Life questionnaires to bring with them to the appointments. Patient's meet with a follow-up oncologist(s) who has a special interest in late effects and support services in Auckland. AYA cancer patients also meet with a psychologist and the LEAP CNS to discuss any surrounding quality of life matters. From there, referrals to health professionals, such as neuropsychology are made as required.

Patients, after follow-up, receive a copy of their treatment summary or 'Passport' to take with them for future use. They can also contact the LEAP CNS at any point with any further concerns. Criteria for transitioning out of follow-up include being independent with health needs, finished with school and studies and living independently. These factors are reviewed and decided amongst the patient, their whānau and the MDT.

## **Midland outreach late effects follow-up clinic**

In regards to Midland AYA, Starship Auckland provides follow-up for 12-18 years AYA who have received treatment at the supraregional centre. This follow-up occurs at a monthly outreach clinic organised by the LEAP CNS Starship and provided by paediatric oncologists Scott MacFarlane and Jane Skeen. The Midland AYA key worker attends the clinics based at Waikato Hospital. Typically, patients will meet with the paediatric oncologist, Midland paediatric oncology liaison, shared care nurse and AYA clinical nurse specialist where they undergo assessment, receive a health passport and referral to other services based on needs.

Referral onwards for further medical investigations, development, and/or social services happens at these clinics. Termination from the clinics is determined between the patient and oncologist after follow-up visits reach a yearly basis. Further to this, patients can be considered to re-join the follow-up clinics as needed. This is determined on a case by case basis. After each clinic, GPs are notified with a clinic letter in regards to any identified needs and/or referrals.

The difference between follow-up for AYA residing in Auckland and the Midland region who receive services through Starship is a psychologist assessment and referral on.

For AYA 18-24 years there is no late effects follow-up, regionally or nationally. As well, there is no late effects follow-up for 15-17 years treated under adult oncology services. It is unclear where and how late effects follow-up should occur for the 18-24 age subset, as age and developmental stage are different in comparison to paediatric cancers. Follow-up for this age subset can happen independently to paediatric services but adult services may choose to adopt the LEAP tools as a convenient and appropriate way to deliver that service.

The MCN sent a letter to the Ministry of Health cancer team highlighting the gap in the local late effects/AYA service provision:

- The existing supraregional LEAP and local Midland late effects follow-up clinic does not include the 18-24 yrs age group.
- The existing services exclude 15-18 year olds who do not receive treatment at Starship
- The existing Starship LEAP is over extended due to geographical variations in addition to volume

The discrepancies for the Midland region have been identified to the Ministry of Health and the service is awaiting feedback. In the interim, Midland AYA OHS has met with the visiting paediatric oncologist from Starship, Scott MacFarlane, to strengthen links between Midland and Starship. The role of the Midland shared care nurse to the local Midland late effects clinic was discussed. It was agreed that the Midland key worker and shared care nurse will work closely together to optimise care for AYA with cancer in the Midland region.

There is also a national draft document Guidance for Improving Supportive and Rehabilitative Care for Adults with Cancer in New Zealand (2008), which will go some way to supporting the 18-24 year AYA with late effects.