NATIONAL HEALTH BOARD
POARI HAUORA Ā-MOTU

MINISTRY OF HEALTH
MANATŪ HAUORA

National Plan for Child Cancer Services in New Zealand

Acknowledgements

The Ministry of Health and the National Health Board would like to thank the following organisations and groups for their input and feedback during the development of this national plan for child cancer services in New Zealand.

- Service providers of paediatric oncology at Auckland DHB, Capital and Coast DHB and Canterbury DHB
- The Paediatric Oncology Steering Group
- Paediatric oncology clinicians, paediatric clinicians and other health professionals working in child cancer services
- District Health Boards providing shared care child cancer services
- Cancer Control New Zealand
- Child Cancer Foundation
- Canteen
- Parent Focus Group at Capital and Coast DHB
- The Paediatric Society of New Zealand
- The Royal Australasian College of Physicians, Board of Paediatrics and Child Health.

Citation: Ministry of Health. 2010. *National Plan for Child Cancer Services in New Zealand*. Wellington: Ministry of Health.

Published in November 2010 (Revised December 2011)
by the Ministry of Health
PO Box 5013, Wellington 6145, New Zealand

ISBN: 978-0-478-37409-4 (Online)
HP 5269

This document is available on the Ministry of Health website:
http://www.moh.govt.nz

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Executive Summary

The *National Plan for Child Cancer Services in New Zealand* is the first national service plan to be developed by the Ministry of Health and the National Health Board in conjunction with District Health Boards (DHBs) and the Paediatric Oncology Steering Group.

Child cancer services encompass the full spectrum of services available to treat and support children diagnosed with cancer, and their families and whānau. Paediatric oncology is the medical subspecialty that provides specialist services within child cancer services.

National planning for the provision of child cancer services has been recommended in service reviews undertaken over previous decades. Increasing subspecialisation, complexity of treatment regimes, quality and safety concerns, and cost of care have resulted in consolidation of specialist paediatric oncology centres from five in 1995 to two today. Auckland and Canterbury DHBs currently provide the specialist component of paediatric oncology care to all children with cancer in New Zealand.

The provision of high-quality child cancer services nationwide presents challenges for New Zealand, given the wide geographic distribution of our small population. An average of 196 new cases of child cancer are diagnosed each year, with just over 320 children receiving active therapy at any one time. Services remain vulnerable, particularly because of the small paediatric oncologist workforce available internationally. This vulnerability was highlighted in 2009 with the unplanned closure of Capital & Coast DHB's specialist paediatric oncology service after the two paediatric oncologists resigned.

This national Child Cancer Services Plan has been developed with the aim of strengthening services by achieving national agreement on the service delivery model for child cancer services. The Plan needs to describe a model that will provide:

1. equitable access to the appropriate level of service required by individual children with cancer throughout New Zealand
2. certainty for parents, families and whānau of children with cancer regarding the patient pathways, location(s) of the children's treatment and resources available to support the families and whānau when they need to travel to another location
3. clarity for DHBs and other service providers as to the referral pathways for all children suspected of cancer
4. sustainable child cancer services in New Zealand into the future.

In the development of this Plan, the following issues informed the service delivery model options:

- New Zealand's child cancer services currently achieve the same outcomes for New Zealand children as the best services in the world. They also achieve the same outcomes regardless of a child's ethnicity, socioeconomic status and domicile.
- New Zealand clinicians have led the continued specialisation and centralisation of paediatric oncology, the implementation of expert multidisciplinary teams in child cancer, and the development of shared care models to support families and whānau. These developments reflect international best practice recommendations.
- There is a nationally standardised and agreed pathway of care for children with cancer regardless of their domicile. The shared care model varies across DHBs depending on a DHB's size and available clinical skills in each hospital.

- No significant change is predicted in the total number of New Zealand children requiring cancer services in the next six years. However, an increasing proportion of children with cancer will be in the north of New Zealand, where more children will live in the future, and an increasing proportion of these children will be of Māori or Pacific ethnicity.
- Over 44 percent of families and whānau of children with cancer travelled to receive specialist paediatric oncology care in New Zealand when Capital & Coast DHB was a specialist centre. Since Capital & Coast DHB reverted to shared care arrangements in 2009, this proportion has increased to 52 percent.

Analysis of these issues identified that consideration could be given to:

- providing a greater range and complexity of services from shared care providers to enable children to have as much treatment as close to home as possible within the bounds of effectiveness and safety
- strengthening the model through more formalised shared care arrangements between specialist centres and their network of agreed providers
- reviewing the level of supportive care available to families/whānau to ensure equitable access to support, regardless of the DHB of domicile.

Three options for a service delivery model have been evaluated against specific criteria. All options assume a strong shared care model and establishment of a national clinical network:

- Option one: one specialist centre at Auckland DHB
- Option two: two specialist centres, one at Auckland DHB and one at Canterbury DHB
- Option three: two specialist services delivered from three centres with one service at Auckland, and a second service across both Canterbury and Capital & Coast DHBs.

Evaluation of these options identified option two as the service delivery model receiving the highest grading against the evaluation criteria. This two-centre model, with shared care arrangements with other DHBs builds on the strengths of the current model and takes into consideration issues that have challenged the viability of previous service configurations. The preferred option achieves the best balance between the need for access for families and whānau, and the need for consolidation to support a scarce paediatric oncology workforce and best clinical practice.

The Plan includes actions to further enhance and support the implementation of this preferred service delivery model. These actions include:

- reviewing the current supportive care available to all families and whānau of children with cancer
- revising the *Paediatric Oncology Service Specification* to ensure that it supports the agreed model of care and service configuration
- formalising shared care agreements, with the two specialist centres to work with their shared care providers to formalise agreements in line with guidelines developed by a new national clinical network for child cancer services
- reviewing pricing for paediatric oncology to better reflect current costs
- establishing a national clinical network for child cancer services, building on the foundation of the existing Paediatric Oncology Steering Group.

Recommendations

The following recommendations are made regarding child cancer services in New Zealand.

1. That New Zealand have a two-centre model for the provision of specialist paediatric oncology care, with shared care arrangements with other DHBs; and that the two specialist centres be Starship Children's Hospital at Auckland DHB and Christchurch Hospital at Canterbury DHB.
2. That a national clinical network be established for child cancer services in New Zealand.
3. That the Implementation Action Plan be monitored six monthly by the Ministry of Health and the National Health Board.

1. Introduction

When a child is diagnosed with cancer, New Zealand's publicly funded health service should provide a safe and effective service that is focused on the child and their family or whānau. This Plan outlines options for a preferred model of care and service configuration for child cancer services in New Zealand that will give families and whānau in New Zealand confidence in the services that will be delivered, regardless of where they live. It also recommends a preferred model of care and a service delivery configuration that is most likely to provide safe, high-quality care and achieve equitable health outcomes for children and young people with cancer. This introductory section outlines:

- the purpose of the national Child Cancer Services Plan
- principles that have guided the development of the Plan
- the strategic context for the delivery of child cancer services
- an introduction to national service planning.

Child cancer services encompass the full spectrum of services available to treat and support children diagnosed with cancer, and their families and whānau. Paediatric oncology is the medical subspecialty that provides specialist services within the child cancer service.

1.1 Purpose of the Plan

The purpose of developing this Plan is to achieve national agreement on the service delivery model for child cancer services in New Zealand that will provide:

1. equitable access to the appropriate level of service required by individual children with cancer throughout New Zealand
2. certainty for parents, families and whānau of children with cancer regarding the patient pathways, location(s) of their children's treatment and resources available to support the families and whānau when they need to travel to another location
3. clarity for District Health Boards (DHBs) and other service providers as to the referral pathways for all children suspected of cancer
4. sustainable child cancer services in New Zealand into the future.

The provision of high-quality child cancer services presents challenges for New Zealand given the wide geographic distribution of our small population. An average of 196 new cases of child cancer are diagnosed each year, with just over 320 children receiving active therapy at any one time. Paediatric oncology is becoming increasingly specialised, and there is evidence of improved outcomes where services are centralised and co-located with paediatric and other subspecialty services. The care provided to each child with cancer is increasingly complex including a significant number of planned interventions across a number of treatment modalities. Effectively managing the continuum of care requires co-ordination of services in a manner that balances the need for highly specialised care with the desirability of providing appropriate therapies as close as possible to the child's home.

This Plan does not specifically address the issue of service provision for adolescents and young adults. These age groups are increasingly managed by paediatric and adult services working co-operatively with care provided in age-appropriate facilities in order to achieve the best health outcomes.[1]

In addition, this Plan does not address specific service issues related to paediatric palliative care, which are being considered separately through the review of paediatric subspecialty services (Ministry of Health 2010). This review identifies that of the life-limiting conditions in childhood requiring palliative care, 35 percent are malignant and 65 percent non-malignant. Palliative care is a component of the care pathway for children with cancer and their families.

1.2 Guiding principles

The principles guiding the development of this Plan are those of the previous paediatric specialty services review and published in the report *Through the Eyes of a Child: A national review of paediatric speciality services* (Health Funding Authority and Paediatric Society 1998).

The overarching principle is that 'children and young people in New Zealand will have their needs treated as paramount'. More specifically the following eight principles have guided the development of the preferred model of care and service delivery model.

Child cancer services principles

Child cancer services will be:

- focused on the child and their family or whānau
- as close to home as possible within the bounds of quality and safety
- provided to achieve equity of outcome
- based on international best practice, research and education
- monitored and evaluated regularly
- integrated with other health services
- culturally safe
- fiscally responsible.

1.3 Strategic context for child cancer services

The strategic context for child cancer services is provided by The New Zealand Cancer Control Strategy (Ministry of Health 2003), the purpose of which is to reduce the incidence and impact of cancer, and reduce inequalities with respect to cancer.

1. The Service Specification *Co-ordination of Adolescent/Young Adult Cancer Service; Tier Level Three* was agreed with the sector in late 2009.

The Ministry of Health, DHBs and regional cancer networks are the key groups responsible for implementing the New Zealand Cancer Control Strategy and the Government's priorities for cancer. They fulfil this responsibility via the national cancer control programme, which integrates policy activity and national service development with the local leadership and service delivery responsibility of DHBs. There are four regional cancer networks that work across the cancer continuum at a regional level in support of DHBs and other providers including NGOs. Co-ordination of children's cancer services falls largely outside the activities of regional cancer networks because of the different model of care for children with cancer (see section 3.2).

The Paediatric Oncology Steering Group is the national group that provides advice to the Ministry of Health and DHBs on issues related to clinical paediatric oncology. Its membership includes representation from stakeholders involved in providing child cancer services, such as the Ministry, DHBs, clinicians, CanTeen and the Child Cancer Foundation.

The Paediatric Oncology Steering Group was established in 1999 to provide expert clinical and consumer advice on the implementation of the recommendations for paediatric oncology arising from the national paediatric specialty service review. At the time of establishment, its aim was to ensure the timely, efficient and safe configuration of services within the framework of a national child cancer service. Its role has now broadened to include: leading key child cancer projects; supporting the professional development of the workforce; and advising on the resolution of clinical and service issues.

Child cancer services also fit within the wider context of paediatric services, with paediatric oncology as one of New Zealand's paediatric subspecialty services. Paediatric subspecialty services are generally highly specialised, low volume services that rely on a small highly specialised workforce and infrastructure. This provides particular challenges ensuring sustainable and equitable access and outcomes for all children. Therefore, these services were prioritised for national service planning.

1.4 National service planning

This *National Plan for Child Cancer Services in New Zealand* is the first national plan to be developed by the Ministry of Health and National Health Board (NHB), in conjunction with DHBs and the Paediatric Oncology Steering Group. The development of a national plan for paediatric oncology has been recommended in service reviews conducted over the previous decade (see Appendix 1).

The most recent review was of Capital & Coast DHB's paediatric oncology service at Wellington Children's Hospital in 2007. The sudden resignation of one of its two resident paediatric oncologists led the DHB to cease providing specialist care. The review by an international paediatric oncology leader concluded that the configuration of services at Capital & Coast DHB was essentially managed and staffed as a shared care centre rather than a paediatric oncology centre.

The reviewer proposed that unless there be agreement to the creation of a single paediatric oncology service with a single management structure delivering services in both Wellington and a larger centre, Capital & Coast DHB should cease to manage new patients independently and continue its current status as a secondary shared care unit linked to both Auckland and Christchurch.

However, in 2008 Capital & Coast DHB recruited two paediatric oncologists and re-established its specialist centre. In 2009, this arrangement ceased when the replacement oncologists both resigned.

Government has recently determined the framework to be used to decide at which level of the health system (national, regional, district) services should be planned, funded and provided. The guiding principle is the size of the population best able to ensure the future clinical and financial viability of a safe, quality health and disability service.

Application of this principle will start with those services currently most vulnerable to service disruption due to, for example, lack of suitable permanent workforce of sufficient size, and take into account the need to:

- provide a unified service with effective service integration across all providers, especially community, primary and secondary
- make best use of workforce and capital, planning and funding capability, and minimise administrative and contracting overheads
- minimise risk and disruption and provide for longer-term service continuity
- be responsive to distinctive local needs.

Government is still to determine which services will be designated as National Services (to be planned and funded by the NHB). This new NHB role will begin in July 2011, and the move of planning and funding responsibility from the DHBs to the NHB for such services will be staged.

2. Overview of Child Cancer in New Zealand

Child cancer services are provided to children with an existing or previous diagnosis of cancer up to their 15th birthday. However, in keeping with international trends and evidence on cancer outcomes for adolescents, young people aged 15–18 years may be treated in paediatric units, where this is judged to be in the best interests of the young person and their family or whānau. New Zealand has recently developed a service specification that supports the delivery of cancer care for adolescents and young adults.[2]

The three main types of childhood cancer are: leukaemia and lymphomas; solid tumours; and brain tumours. Childhood cancers are generally unique to children but may, in rare circumstances, occur in people over 19 years of age. In these circumstances, paediatric oncologists will consult and support people in adult cancer services. Similarly, paediatric oncologists will seek assistance from adult services when dealing with children with cancers more commonly occurring in the adult population.

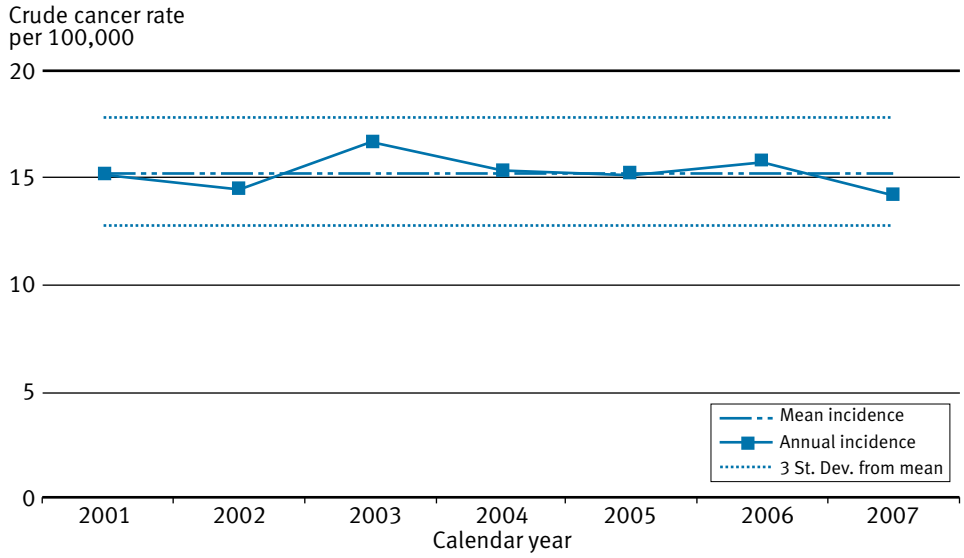
In planning child cancer services it is important to have an understanding of key issues that will significantly influence decision making in regard to service location and therefore service delivery models. This section presents the important considerations of the current and forecast incidence of childhood cancer, its geographic spread, and mortality and survival rates.

2.1 Incidence of childhood cancers

In New Zealand, the incidence of cancers in children and adolescents aged 0–19 years has not varied substantially in the last seven years, with a mean of 15 per 100,000 children aged 0–19 years (Figure 1).[3] This mean incidence equates to an average of 196 children diagnosed with cancer in any one year. Prior to 2001, data are less reliable but it is known that the incidence has not changed significantly. Likewise the incidence by region, district and ethnicity has not changed since 2001.

In 2005 the most common type of cancer for children under 15 years of age was leukaemia, followed by cancer of the brain. Child cancers account for 1.4 percent of all cancer registrations in New Zealand (Ministry of Health 2009a).

Figure 1: Cancer incidence rate in children (0–19 years) 2001–2007

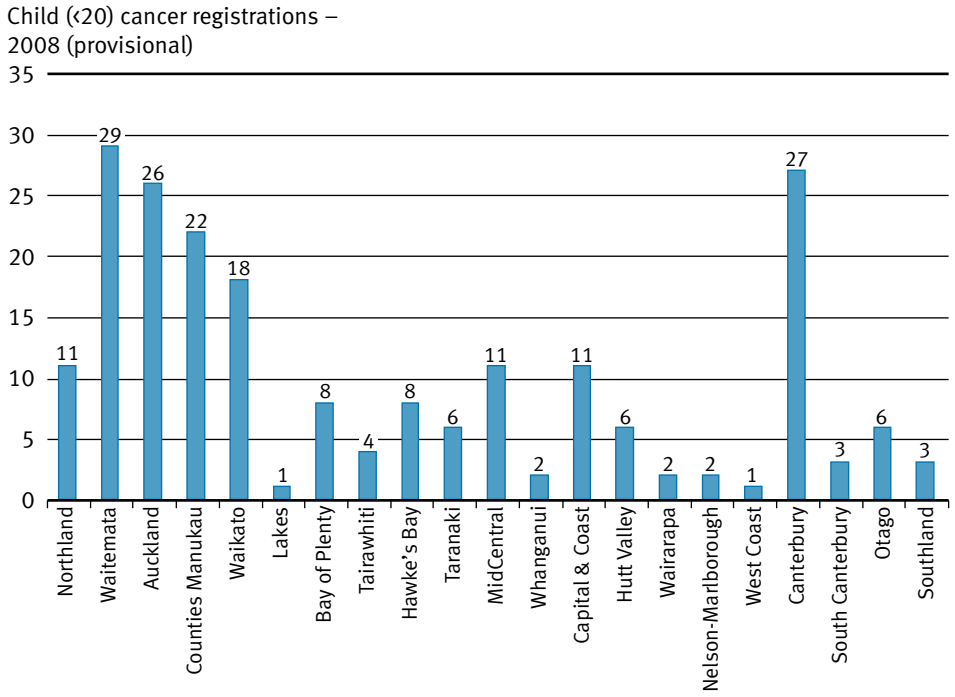


2 The *Tier Level Three: Service Specification: Coordination of the Adolescent/Young Adult Cancer Service* was launched by the Ministry of Health and CanTeen on 26 February 2010.

3 For the purpose of this report, all people aged 0–19 years will be referred to as children.

Figure 2 shows the number of cancer registrations in 2007 for children aged 0–19 years by DHB of domicile. Although these numbers will vary year by year, they are considered indicative of the trend over time (Figure 1).

Figure 2: Cancer registrations in children (0–19 years) 2008 by DHB of domicile



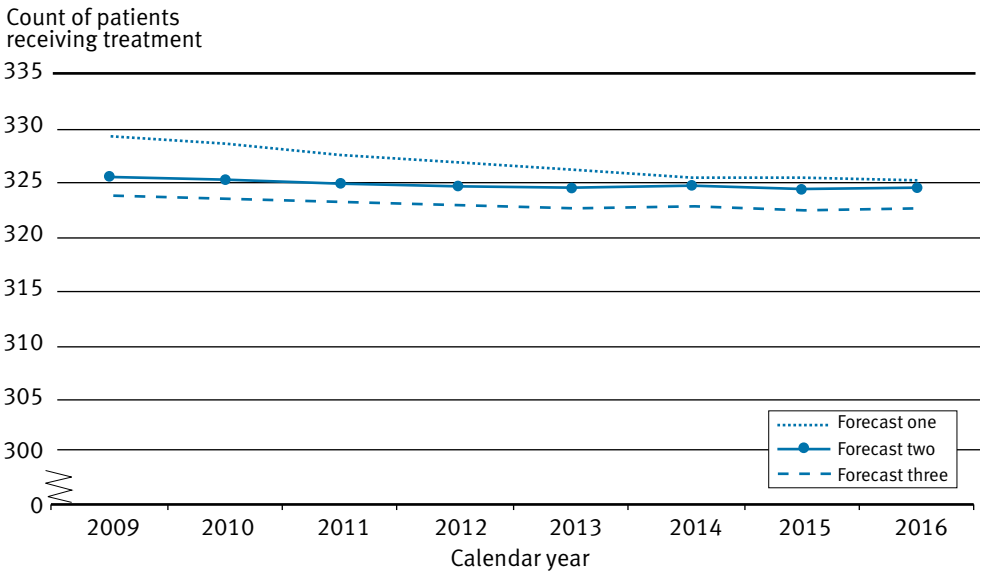
2.2 Projected child cancer rates

The number of children being treated for cancer is driven by the number of children in the population. The overall number of children in the general population aged 0–19 years is predicted to decline after 2010. It is therefore projected that there will be no significant change in the total number of New Zealand children requiring cancer services over the next seven years, with an expectation of a slight decline in numbers overall. This projection is consistent across three different modelling scenarios (Figure 3).[4]

4 The forecasting has been completed using three sets of assumptions:

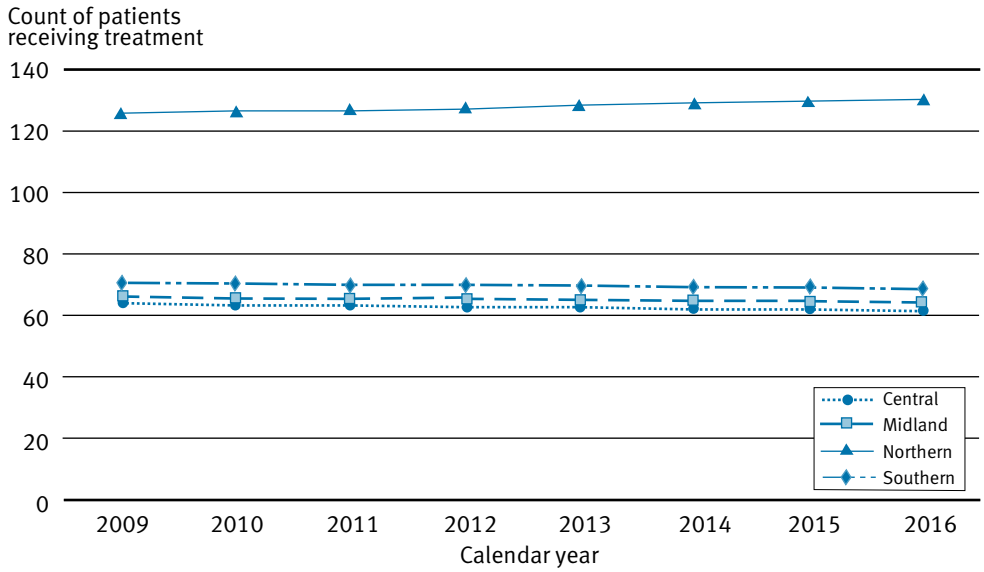
- Forecast one uses the calculated eight-year mean treatment rate for cancer for those aged 0–14 and those aged 15–19. This rate was then applied to the respective age group cohorts within the standard Statistics NZ 2006 population projections.
- Forecast two uses the calculated eight-year mean treatment rate for cancer for those aged 0–19. This rate was then applied to the 0–19 age group cohort within the standard Statistics NZ 2006 population projections.
- Forecast three uses the calculated seven-year mean treatment rate, where the treatment rates have been calculated as a two-year rolling average of both treatment and population, for those aged 0–19. This rate was then applied to the 0–19 age group cohort within the standard Statistics NZ 2006 population projections.

Figure 3: Forecast number of paediatric oncology patients in treatment, 2009–2016



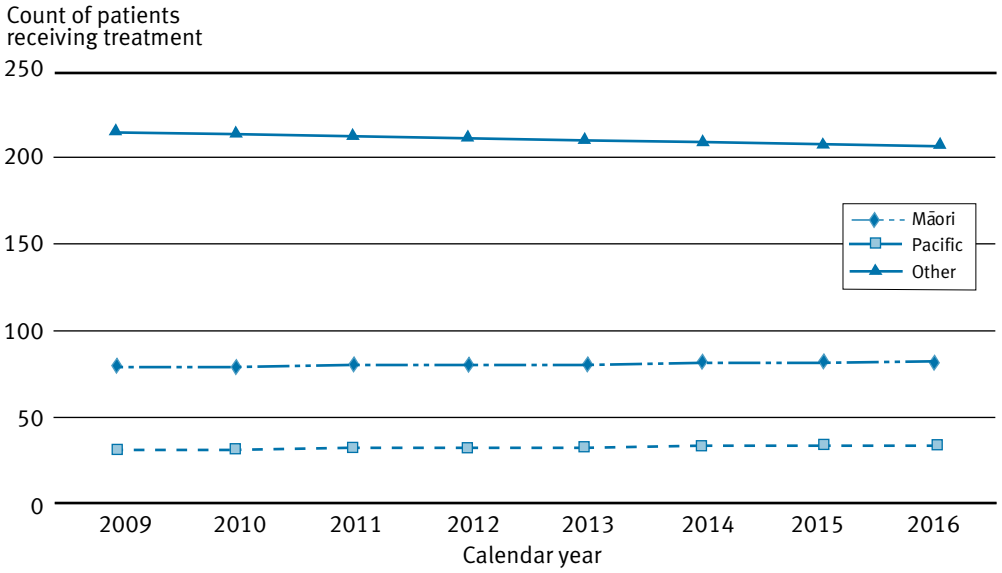
It should be noted, however, that the birth rate in the Northern region is higher than in other regions. As a result, in the future a greater proportion of the children requiring treatment will be living in the Northern region, compared with now (Figure 4).

Figure 4: Forecast number of paediatric oncology patients in treatment by region of domicile, 2009–2016



It is also expected that the proportion of Māori and Pacific children in the childhood population will increase; resulting in more Māori and Pacific children needing child cancer services (Figure 5). The impact of this increase needs to be considered in the context of whānau/fono centred care.

Figure 5: Forecast number of paediatric oncology patients in treatment by ethnicity, 2009–2016



2.3 Children receiving treatment by DHB of domicile

The number of children being treated for cancer from each DHB correlates directly to their paediatric population. Due to the length of treatment for many childhood cancers, the number of children with cancer in treatment at any one time is more than double the annual number of new childhood cancer registrations. Table 1 below illustrates the distribution of children in treatment for cancer in each DHB in 2008.

Table 1: Children with cancer in treatment by DHB of domicile, 2008

	Number	Total by region	
Northland	12		
Waitemata	36		
Auckland	29		
Counties Manukau	44		
		Northern	121
Waikato	32		
Bay of Plenty	11		
Taranaki	11		
Tairawhiti	4		
Lakes	9		
		Midland	67
Whanganui	3		
MidCentral	8		
Hawke's Bay	8		
Wairarapa	3		
Hutt Valley	10		
Capital & Coast	26		
		Central	58
Nelson-Marlborough	11		
Canterbury	44		
South Canterbury	3		
West Coast	3		
Otago*	17		
Southland*	5		
		South Island	83
Total children	**329**		

* Otago and Southland are now combined as Southern DHB.

Source: Inpatient treatment volumes were sourced from the National Minimum Dataset (NMDS). See Appendix 3.

2.4 Child cancer mortality and survival rates

In 2005, 65 children and young people aged less than 25 years died from cancer; and of these 23 were under the age of 15 years (8 male, 15 female). The most common cause of death in children under 15 years was leukaemia (10 deaths), followed by cancer of the brain (7 deaths) (Ministry of Health 2009a).

The survival rates for childhood cancers in New Zealand compare well internationally. A recent analysis of the New Zealand Child Cancer Registry (NZCCR) against death registrations for the five-year period 2000–2004 confirmed an initial analysis of NZCCR, which showed an overall five-year survival for children with cancer in New Zealand of 80 percent with no difference in outcome for any ethnic group including Māori (Ministry of Health 2009b). In England and Wales, the overall survival rate for 0–14 year olds in 2005 was 75 percent, although age-specific survival rates did vary (National Institute for Health and Clinical Excellence 2005b).

3. Current Child Cancer Services in New Zealand

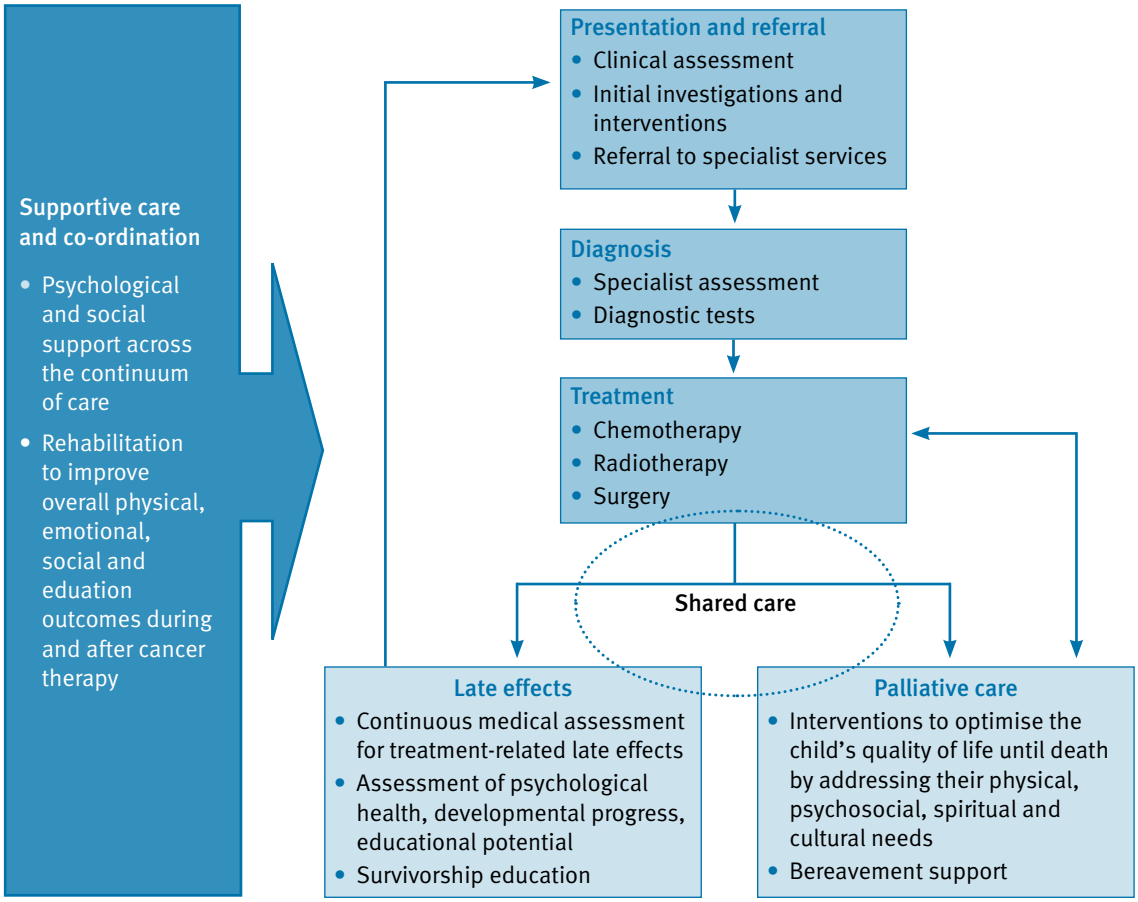
When a child is diagnosed with cancer, New Zealand's publicly funded health service should provide a safe and effective service focused on the child and their family or whānau. These children need to follow a carefully planned and co-ordinated pathway of care. This section outlines:

- the care pathway for children with cancer
- current models of care
- service delivery models
- current funding arrangements.

3.1 The care pathway

Central to the provision of child cancer services is the availability of the service components that provide a continuum of care for children with cancer and their families and whānau across a planned care pathway. Each child will follow a unique care pathway as determined by their individual diagnosis and treatment regime. Each step of the care pathway requires appropriate responses and effective interventions tailored to meet the individual needs of the child and their family or whānau. Figure 6 sets out the generic pathway of care.

Figure 6: Care pathway for children with cancer



3.2 Current model of care

The different components of the pathway outlined above may be delivered in different locations, depending on where the child and their family or whānau live, as well as their individual care requirements. The provision of care will also involve a range of health professionals.

The model of care for child cancer services describes how the various child cancer service providers relate to each other across a child's care pathway. It contains three key elements:

- provision of treatment from specialist centres
- shared care between providers
- multidisciplinary teams.

These elements are outlined below. For a more detailed explanation of responsibilities, see the *Paediatric Oncology Service Specification Tier Two* (Ministry of Health and DHBNZ 2004).

3.2.1 Provision of treatment from specialist centres

Central to the management of all children with cancer is the provision and co-ordination of treatment from a paediatric oncology specialist centre.

New Zealand's specialist services are currently provided by Auckland DHB through Starship Children's Hospital, Paediatric Oncology Unit, and by Canterbury DHB through Christchurch Hospital and the South Island Child Cancer Service. This two-centre arrangement has been in place since July 2009, at which time Wellington Child Cancer Service became a shared care service with the support of Canterbury DHB (see 'Shared care' below).

Both internationally and in New Zealand, specialist centres have contributed to improving survival rates for children with cancer. The following are key features of these specialist centres:

- There is a catchment population large enough to support a team of specialist medical and nursing staff who are available 24 hours a day, seven days a week. It is generally accepted that a service requires a minimum of three paediatric oncologists to enable 'reasonable rostering' and appropriate clinical cover for this round-the-clock service.
- The centre is able to provide complex therapies and adopt evidence-based changes in practice. This capacity extends to participating in paediatric oncology clinical trials conducted by large, international co-operative study groups (both Starship and Christchurch Hospital are members of the United States Children's Oncology Group).[5] In larger centres it also includes the ability for clinicians to subspecialise. It is critical that sufficient volumes of patients exist to support the provision of the high-level paediatric services that are generally provided in the one centre (ie, in Starship Children's Hospital).
- The centre is co-located with other paediatric specialist services both to support the provision of aspects of care and also to manage any complications experienced by children receiving treatment. The importance of this feature was highlighted in the 1998 report *Through the Eyes of Child* (Health Funding Authority and Paediatric Society 1998) and further reinforced by the 2008 United Kingdom report on specialised paediatric services (National Health Service 2008).

5 The United States Children's Oncology Group (COG), comprising over 240 member institutions in North America, Europe and Australasia, offers up-to-date clinical trials to manage children with cancer.

3.2.2 Shared care

'Shared care' is care provided with a DHB that is geographically distant from the lead paediatric oncology specialist service. A specialist paediatric oncology service is responsible for advising on and co-ordinating the initial diagnostic work-up, the provision of intensive therapy, and overall management of a child's care. However, once a child is stabilised, components of treatment can be provided closer to the child's home, where there are appropriately trained staff and adequate facilities to ensure quality and safety.

Many DHBs are able to provide some services for children with cancer through outreach clinics and shared care arrangements with the specialist centres. The level and type of services available from these shared care DHBs are determined primarily by the availability of suitably skilled clinical staff able to administer ongoing therapy and care as required, and to a lesser extent by the availability of other related subspecialty services.

The responsibilities of shared care DHBs are outlined in shared care agreements between the two specialist centre DHBs and their shared care DHBs. These agreements formally specify and define the shared care components of the clinical relationships for safe management of children with cancer. Variations in the level of shared care between DHBs may be required on occasions because of temporary changes in staffing and facility resources.

3.2.3 Multidisciplinary teams

The complexity of managing childhood cancer requires the collaborative interaction of a multidisciplinary team. In addition to specialist nurses and paediatric oncologists, the multidisciplinary team is a core element of the service model and critical to achieving the best treatment outcomes for each child. These team members need to have expertise in paediatric oncology, often within a broader field of specialist practice. The team will individually and collectively manage the care of each child and their family or whānau.

The multidisciplinary care involves a wide variety of specialist areas including:

- paediatric medical subspecialties
- ability to provide intensive care for paediatric patients
- paediatric pathology, including histopathology
- paediatric surgery
- neurosurgery
- orthopaedic cancer surgery
- radiation oncology
- clinical pharmacy
- dietetics
- social work
- clinical psychology
- genetics
- paediatric radiology
- play therapy
- palliative care
- occupational therapy
- physiotherapy.

The above list is not exclusive as the specialist team requires access to a wide range of expertise depending on the type and location of the tumour, for example, specialist head and neck surgery. For some rare conditions there may be a need for treatment overseas. In all cases however, the depth of expertise and effective co-ordination of this large team are essential to ensure high-quality outcomes for children.

3.3 The service delivery model: how services are configured

Specialist centres and shared care providers provide different levels of care. The *Paediatric Oncology Service Specifications Tier Two* (Ministry of Health and DHBNZ 2004), which describe in detail the responsibilities of specialist centres and shared care providers, should be employed to define the service configuration. Of critical importance is the skill of the paediatric shared care workforce, in particular, the shared care paediatrician and nursing staff. The availability of radiation oncology, laboratory and blood transfusion services may enhance the ability of the paediatric teams in those centres to provide a higher level of shared care than in centres without those services. The presence of an adult oncology service at a shared care DHB does not directly contribute to the management of paediatric patients, but it does mean that paediatric patients have access to other diagnostic and treatment resources such as linear accelerators.

In 2008 New Zealand developed a Role Delineation Model (RDM) to define the complexity levels of services provided by New Zealand's DHBs and to enable a consistent understanding of the difference in services provided by various DHBs. The principles from the RDM for paediatric oncology and haematology services (see Appendix 2, table 10 for details of the RDM for paediatric oncology and haematology services) have been used to establish an understanding of the key differences between the services provided by a specialist child cancer service and child cancer share care providers.

Table 2 shows the level of care that is provided by each of New Zealand's DHBs and their relationship to a specialist centre.

Table 2: Current Levels of Service Provided by DHBs

Specialist child cancer service provider+	Child cancer shared care provider^	No child cancer service
Auckland	Northland	Waitemata
	Bay of Plenty	Counties Manukau
	Waikato	
	Hawke's Bay	
	MidCentral*	
	Taranaki	
	Tairawhiti	
	Lakes	
	Whanganui*	
Canterbury	Capital & Coast*	Wairarapa*
	Nelson Marlborough	Hutt Valley*
	Southern	South Canterbury
		West Coast

Notes:

* The DHBs marked with an asterisk were linked to the Capital & Coast DHB service until July 2009 and have since been allocated between Auckland and Canterbury as shown.

\+ There are differences in some aspects of the range of care available from the specialist child cancer service providers, which relates to expertise in some rare cancer types, the provision of allogeneic stem cell transplants and the availability of specialised paediatric intensive care.

^ There are differences in the range of care available through shared care providers, which is determined by the availability of staffing expertise, diagnostic and treatment facilities.

The Paediatric Oncology Service Specifications and DHB shared care agreements describe the responsibilities of each of the providers. They also link together the providers in a practical sense ensuring the safety of children receiving cancer treatment.

3.4 Current funding model

The current funding model for paediatric oncology is the same as for all specialty services in New Zealand. The DHB of domicile is funded using the Population-Based Funding Formula (PBFF) and is allocated funding to pay for its population's use of child cancer services from a specialist centre at the nationally agreed inter-district flow (IDF) price.

The Ministry of Health pays a tertiary adjustor to Canterbury and Auckland DHBs (and previously Capital & Coast) for provision of paediatric oncology (and other such specialised services).

Additional services currently funded directly by the Ministry include the Late Effects Assessment Programme (LEAP) and a contribution to the Adolescent and Young Adults (AYA) co-ordination service.

The key features of the current funding model are:

- child cancer services are prioritised with other services funded by DHBs, rather than funding levels being nationally determined
- DHBs providing specialist paediatric oncology centre services make their own internal funding and investment decisions for child cancer services
- the current payment model can provide a fluctuating revenue stream, which challenges long-term planning by the specialist centres, and fluctuating costs for the DHBs of domicile. This can create financial risk.

The current approach has the advantage of relatively clear statutory accountabilities: DHBs of domicile are accountable for deciding what services to fund (and provide) to maximise the health of their population within their PBF share. DHBs can decide (after appropriate consultation and in accordance with the Operating Policy Framework requirements) whether to buy the service from another provider or to provide it themselves.

4. Issues and Challenges for Service Planning

The issues and challenges that need to be addressed in finalising a national service plan for paediatric oncology include:

- the number of specialist centres, where they should be and their catchment areas
- clinical leadership and governance
- support for the families and whānau of children with cancer
- the levels of service that shared care providers should provide
- availability of appropriate facilities
- adequacy and best use of funding
- workforce roles, availability, recruitment and retention
- provision of services for adolescents and young adults
- access to the Late Effects Assessment Programme
- access to information on child cancer outcomes.

This section examines each of these issues in turn.

4.1 The number of specialist centres, where they should be and their catchment areas

There are two significant issues when considering the number of specialist child cancer services: the co-location of child cancer services with other specialist services; and the number of children being treated to provide sufficient work to support subspecialisation.

For specialist paediatric oncology services, the critical relationships are with those services where the interests of children are best served by co-location. It is in this regard that the presence of other specialties impacts on the safety and quality of services for children with cancer. The principles from the RDM clarify the need for co-location of specialist paediatric oncology services with other paediatric services.

New Zealand has only one Paediatric Intensive Care Unit (equivalent to paediatric critical care in Table 3), meaning that Starship Children's Hospital can provide a complete range of other services to support the provision of paediatric oncology services. It may be appropriate that there is only one Paediatric Intensive Care Unit; this possibility will be examined in the future in the context of the review of paediatric subspecialty services (Ministry of Health 2010). In addition, paediatric oncology should be provided in association with the management of non-malignant childhood blood disorders (for example, haemophilia and bone marrow failure syndromes). Currently New Zealand's only specialist paediatric haematologists are based at Starship Children's Hospital. This is another issue that will be considered in the review of paediatric subspecialty services.

Capital & Coast DHB, although now operating a shared care model for paediatric oncology with Canterbury DHB, still has a range of subspeciality capacity for treating children with cancer. Effective use of these subspeciality services through shared care supports more care at Wellington Hospital for children in its catchment, although they are still required to travel to Christchurch for the more intensive components of their care. Furthermore, these subspecialties are also necessary components of other paediatric care.

Table 3 is provided as an example of how services are identified as critical for specialist paediatric oncology services in the United Kingdom, where co-location has been analysed in depth (Department of Health 2008). The 'critical' and 'important' co-locations listed in Table 3 are the most significant.

Table 3: Paediatric oncology specialty co-locations in the United Kingdom

Critical co-locations	Important co-locations	Preferred co-locations
Paediatric Critical Care	Respiratory Medicine	Bone Marrow Transplant
Paediatric General Surgery	Neurology	Infectious Diseases
Paediatric Anaesthesia	Neurosurgery	Cardiology
Clinical Haematology	Nephrology	Cardiac Surgery
	Gastroenterology	Urology
		Major Trauma
		Specialist Orthopaedics/Spinal
		Endocrinology
		ENT (Airway management)

As well as being appropriately co-located with other services, a paediatric oncology specialist centre has to have a catchment population that provides sufficient numbers of children to ensure the centre and its staff can sustain clinical competency and safe practice. The previous New Zealand paediatric oncology service reviews did not critically consider the number of new and ongoing cases that a paediatric oncologist or a specialist centre needs to manage to be able to sustain clinical competency and safe practice.

In the United Kingdom, the East Midlands Children's Integrated Cancer Centre has one clinical team across two organisations treating about 110 patients annually (University Hospitals of Leicester Children's Cancer Centre 2009).

Table 4 describes the number of cases managed by each specialist centre in New Zealand over the last eight years. Capital & Coast DHB had a caseload significantly below those examples noted above, reflecting referral decisions by clinicians in other DHBs.

Table 4: Numbers of children with cancer being treated by the three specialist centres 2001–2008

Year	Auckland	Canterbury	Capital & Coast	Total
2001	173	81	57	311
2002	177	79	44	300
2003	210	63	41	314
2004	178	71	44	293
2005	189	71	39	299
2006	189	75	43	307
2007	189	76	40	305
2008	199	78	37	314

4.2 Clinical leadership and governance

The Paediatric Oncology Steering Group provides advice on the development of child cancer services. However this group is not formally linked into either the national cancer control programme or the regional cancer networks. The future role of this group needs to be considered, particularly within the evolving role and structure of clinical networks and the development and implementation of this national Child Cancer Service Plan.

4.3 Family and whānau support

The impact of cancer on a child and their family and whānau is profound. Treatment is intensive and requires a significant number of attendances and admissions at a specialist centre, in addition to care that may be provided either in a shared care facility or at home. There is an additional impact on those who do not live near a specialist centre, and those who cannot receive shared care at their local hospital.

Table 5 below shows the proportions of children with cancer who travelled for specialist treatment in 2006 and an extrapolation of the proportions to demonstrate the impact of a change on the service.

The figures for children with cancer receiving treatment in 2006 are considered indicative of the distribution of services for all years when Capital & Coast DHB was a specialist centre.

The data indicates that the travel demands are compounded if Capital and Coast DHB becomes a shared care centre only. Specifically the change observed is:

- with three specialist centres (2006), approximately 135 children and their families and whānau (44 percent) who did not live near a specialist centre had to travel[6] to Wellington, Auckland or Christchurch for treatment
- if Capital & Coast is a shared care centre in 2009, approximately 159 children and their families and whānau (52 percent) would have to travel to receive specialist care at either Auckland or Christchurch.

Table 5: Impact on the proportion of children with cancer travelling for treatment

2006 Actual	Auckland	Christchurch	Wellington	Total	%
Did not travel	110	39	24	173	56
Required to travel	83	35	17	135	44
Total children	**193**	**74**	**41**	**308**	
Extrapolation with no Wellington centre	**Auckland**	**Christchurch**		**Total**	**%**
Did not travel	110	39		149	48
Required to travel	94	65		159	52
Total children	**204**	**104**		**308**	

Specialist centres, working with shared care providers, seek to minimise the impact on families by limiting the number of days per annum a child is an inpatient at the specialist centre and supporting shared care hospitals to provide components of the subsequent care.

Regardless of where families and whānau live, it is critical that they are able to access appropriate supportive care throughout the care continuum. As treatment can last several years, it can have a significant emotional, social and economic impact on these families and whānau.

The National Travel Assistance (NTA) scheme, administered locally by DHBs, provides financial support for children and their families and whānau to attend treatment away from their local DHB (Ministry of Health 2005c). This support includes meeting travel and accommodation expenses for the child, and two support people.[7] Although the NTA does provide support for family and whānau to be with their child during treatment, it is not intended to fully compensate for the wider economic burden on families that frequent travel entails, such as the loss of income, costs of additional support for children at home, and other incidentals associated with travel. DHBs can also differ in their application of the NTA policy.

Significant levels of support are provided by non-governmental organisations (NGOs) such as the Child Cancer Foundation, CanTeen, Ronald McDonald House and the Cancer Society.

6 Travelling families and whānau are those who live in DHBs regions beyond the metropolitan area served by the specialist centre. The impact of any form of travel beyond a metropolitan area is significantly influenced by socioeconomic status and exact geographic location. Due to the small number of identified families and whānau in this category, aggregated analysis was determined to be the most valid and consistent over time.

7 An average of $2,600 for travel and accommodation costs was spent per family/whānau per year for treatment during the fiscal years of 2007 and 2008 (end June). The range across DHBs is significant, from $950 per family/whānau per year in one DHB to $5,400 per family/whānau per year in another DHB. This variance reflects geographical location and the intensity of treatment. It does not take into account funding support from non-governmental organisations.

4.4 Determining the levels of service provided by shared care providers

Whenever safely possible, children with cancer should be able to receive treatment at a facility close to their home. In practice, the level of service available locally is significantly influenced by the absence or presence of paediatric specialist services.

Furthermore, the range and availability of subspecialty services that are co-located within a DHB to support paediatric oncology determines the shared care arrangements that can be accessed at the local hospital level. Access to a wider range of subspeciality services provides the opportunity for more treatment to be delivered in the locality of the child with cancer and their family and whānau. For example Capital & Coast DHB, although not now a specialist centre, still has a range of subspeciality services available where children can receive treatment through shared care arrangements with Christchurch-based specialists.

Two categories of shared care providers have been identified: those who are able to provide a wider range of services for local therapy and clinical interventions; and those who are able to provide a smaller range of services for ambulatory support.

From a national planning perspective, however, it is important to determine the number and location of all shared care providers. It is also important to formalise in detail each shared care arrangement between the specialist care centre and the shared care providers. Variations in these arrangements are required on occasions to allow for short-term staffing changes.

4.5 Paediatric oncology facilities

Specialist paediatric oncology centres require facilities that support the provision of complex therapy and that meet the specific needs of children with cancer and their families and whānau. Such facilities include inpatient accommodation that minimises infection risk to immuno-compromised children.

A change in referral patterns or an unexpected increase in the number of children in active treatment can place enormous pressure on existing facilities. It is therefore important that capital planning for paediatric oncology facilities aligns with national planning expectations including future cancer volume projections.

Starship Children's Hospital has recently completed renovations and can accommodate the increased number of patients from Whanganui and MidCentral DHBs. However, an increase in caseload above the current level would require further development.

Canterbury DHB requires significant upgrading of its paediatric facilities for its existing and future services. Such an upgrading represents an opportunity to develop additional accommodation to cater for the increased number of patients that has arisen from the 2009 service change at Capital & Coast DHB.

The current facilities of Capital & Coast DHB would also require renovation should a specialist child cancer service be re-established.

Where families and whānau are required to travel to a distant centre for their child's cancer care, accessible and appropriate accommodation facilities are extremely important. In Auckland and Christchurch these facilities are provided primarily through the local Ronald McDonald House

trusts, which operate with extensive community support. Changes in referral patterns or changes in patient volumes or treatment intensity will have a significant effect on the demand for this type of accommodation.

4.6 Adequacy of funding and appropriateness of the funding for paediatric oncology

At present the funding framework used for child cancer services is the same as that for all DHB-referred services. Current policy work is assessing which services should be designated as National Services and hence funded by the National Health Board rather than DHBs (see section 1.4). Once this assessment has been made, it will be important to consider the benefits and risks of adopting any new funding model for paediatric oncology.

Regardless of the funding model, it is essential that the level of funding available reflects the cost of providing the service.

There is some evidence that the current caseweights[8] that support paediatric oncology (and determine the current IDF prices) are not reflective of the true cost of child cancer services. A review of the current pricing of paediatric oncology is necessary to reach a conclusion on this issue.

4.7 Workforce roles, availability, recruitment and retention

As with other specialty services, paediatric oncology faces significant issues in relation to its specialist workforce. These include:

- recruiting and retaining a highly specialised clinical workforce with specific expertise in paediatric oncology
- having a sufficient number of paediatric oncologists to allow 'reasonable rostering' and appropriate clinical cover, 24 hours a day, seven days a week
- maintaining clinical competence, which requires sufficient numbers of presenting children, and access to training and ongoing education of the workforce (particularly for nurses)
- building strong multidisciplinary teams and shared clinical roles to strengthen the model of care
- supporting the professional development and training requirements for clinical staff from shared care providers to ensure they have the learning opportunities available through major centres, which may include clinical placements
- considering an expansion of roles for some of the workforce, for example, by developing the role of expert paediatric oncology nurses. The Nursing Council of New Zealand has a nurse practitioner scope of practice for the registration of expert nurses within a specific area of practice (Nursing Council of New Zealand 2008). These nurses also may choose to apply for prescribing rights. More than 65 nurse practitioners have registered in a wide range of speciality nursing areas since 2001; however none has as yet completed the competency requirements for paediatric oncology practice.

8 Caseweights are used to measure the value of treatments and interventions in health care, including paediatric oncology, relative to other treatments and interventions for all hospital health services. They are also the mechanism used to assess the costs and the distribution of the tertiary adjustor and determine IDF prices. Many DHBs also use them to fund their internal hospital specialty services. The accuracy of caseweights has an impact on the relative funding made available to paediatric oncology services. The Ministry of Health continuously reviews caseweights to assess their accuracy in reflecting costs.

4.8 Provision of services for adolescents and young adults

The provision of cancer services for adolescents and young adults raises special challenges as treatment and care involves partnership with the paediatric and adult oncology, and haematology specialist services. A service specification *Co-ordination of Adolescents and Young Adult (AYA) Cancer Service* was agreed with the sector in late 2009. Central to the AYA service are multidisciplinary teams, psychosocial services and the AYA key worker, all of whom link all the service components to provide a seamless journey for the young person and their family or whānau.

The Ministry of Health provides additional funding to support the co-ordination of care directed to the specific needs of adolescent and young adult cancer patients. As this funding is directed towards co-ordination of care and not the provision of a separate service, a significant proportion of adolescents and young adults with cancer will continue to be treated within the child cancer service. The AYA service specification provides the blueprint for the delivery of this service and it is important that it is fully implemented.

4.9 Late Effects Assessment Programme

The Late Effects Assessment Programme (LEAP) provides long-term assessment of the medical, psychological and educational needs of all young people who have completed cancer treatment and are at low risk of disease relapse. Treatment of cancer in children involves chemotherapy, radiotherapy and surgery, all of which when given at a young age are associated with long-term related effects on normal growth and development.

The Ministry of Health funds three providers for LEAP: Auckland, Canterbury and Capital & Coast DHBs. The programme is delivered primarily as an outpatient service as an extension to the routine follow-up of child cancer survivors provided through paediatric oncology clinics. Given that this service is provided at other DHBs through the shared care model, consideration could be given to reviewing whether LEAP should be provided from more DHBs with shared care arrangements.

4.10 Information management

The Paediatric Oncology Steering Group is responsible for overseeing the New Zealand Child Cancer Registry (NZCCR). This database holds, in a single place, verified information on all new child cancer patients since January 2000. It is important that this database can be linked into the health system's national information collections and that it is easily accessible to health planners, researchers and paediatric oncology specialists. As well as benefiting future health planning processes it is central to evaluating the health outcomes for children with cancer.

4.10.1 Future child cancer services in New Zealand

This section considers options for the future provision of child cancer services in New Zealand. Included in these considerations are:

- the existing preferred model of care
- a proposed service delivery model to support the model of care
- three options for service delivery.

After outlining each of these areas in turn, this section sets out five evidence-based evaluation criteria and uses them to appraise each of the service delivery options. It then evaluates this information and puts forward recommendations for service delivery and a national clinical network.

4.11 Preferred model of care

The preferred model of care for child cancer services is the current model as described in section 3.2. It consists of three key elements:

- the provision of treatment from specialist centres
- shared care between providers
- multidisciplinary teams.

This current model of care is well supported by an internationally established evidence base and New Zealand's paediatric oncology clinical leaders. It is not under review.

To enhance the current model, consideration could be given to:

- providing a greater range and complexity of services from some shared care providers, where clinically safe. This would maximise the treatment and care options available locally and minimise where possible the travel associated with treatment
- formalising shared care arrangements between specialist centre(s) and their network of agreed providers
- reviewing the level of supportive care available to families and whānau to ensure equitable access to support, regardless of the DHB of domicile.

4.12 Service delivery model

The service delivery model for supporting this model of care needs careful consideration as an inappropriate model has the potential to create the greatest risk. To be effective, the model must outline the number and location of specialist services and the number of shared care centres across New Zealand. The configuration arrived at is fundamentally a function of sufficient volume of children to support maintenance of a high-quality service with critical mass, and the location of services, and specifically their impact on geographic access to care for children and their families and whānau.

This *National Plan for Child Cancer Services in New Zealand* largely focuses on the preferred configuration of the specialist centres. Once the opportunities for shared care centres to provide a greater range of clinically safe services have been considered, it will be possible to confirm the configuration of shared care centres across New Zealand.

4.13 Options for service delivery

The service delivery model is optimised by the balance between the number of specialist centres and the extent to which the shared care model is implemented. The distribution of shared care centres is determined by the resources and expertise available within shared care DHBs and the prospective number of children needing cancer services.

The following options reflect the current providers of specialist paediatric oncology services in New Zealand, and the ongoing critical need for co-location with other paediatric specialist services to ensure the services provided are safe and of high quality.

Table 6 outlines the three options for service delivery.

Table 6: Service delivery options

Option	Service delivery	Description
Option One	One specialist centre Shared care arrangements in place with other DHBs	All specialist care would be provided by Starship Children's Hospital at Auckland DHB with shared care arrangements with other DHBs nationwide. Canterbury DHB and Capital & Coast DHB would be shared care providers.
Option Two	Two specialist centres Shared care arrangements with other DHBs	Specialist care would be provided by Auckland and Canterbury DHBs. Capital & Coast DHB would provide a significant level of care as part of a shared care arrangement with Canterbury DHB so that Wellington children with cancer are treated as close to home as possible. Shared care arrangements would be in place with other DHBs.
Option Three	Two specialist services provided across three centres Shared care arrangements with other DHBs	Specialist care would be provided by a centre at Auckland DHB and from a centre across both Canterbury and Capital & Coast DHBs. Families and whānau from three DHBs (eg, Hawke's Bay, Whanganui and MidCentral) would need to be redirected from Auckland DHB to Capital & Coast DHB so it had enough children to maintain a high-quality service. Shared care arrangements would be in place with other DHBs.

Option One is relatively straightforward, requiring no further elaboration.

Option Two builds on existing arrangements and relies on effective shared care arrangements between DHBs and the two specialist centres at Auckland and Canterbury DHBs.

Option Three is based on a proposal put forward by Professor Ross Pinkerton in his 2007 review of the paediatric oncology services at Wellington Children's Hospital. His suggestion was that, subject to a number of issues being resolved (including the urgent recruitment of a second paediatric oncologist), consideration could be given to a single virtual tertiary centre with a single management structure existing between Canterbury and Capital & Coast DHBs. Requirements of this option would include:

- both DHBs supporting a satisfactory management structure and agreeing on clinical governance issues
- a sufficient volume of patients to support the maintenance of on-site paediatric oncologists providing 24/7 care at both centres.

A fourth option involving three specialist centres across three DHBs was considered during the development of this Plan. However, it is not put forward here as one of the options for consideration. It was rejected by Professor Ross Pinkerton in his 2007 review and is not widely supported as an option.

4.14 Evaluation criteria

Criteria have been developed to evaluate each service delivery option, based on the evidence regarding effective models of care and the principles adopted to guide this Plan's development (Section 1.2). These criteria are important as they reflect the critical factors that will determine safe and sustainable specialist child cancer services. The preferred model in this Plan must support a long-term view, and minimise any risk of vulnerability due to reduced quality or temporary closure of service.

The five evaluation criteria are that the model:

- supports the viability of the specialist centre
- provides optimal access for children and their families and whānau
- optimises quality and safety
- allows for workforce development
- enables the best use of available funds (ie uses resources efficiently).

Table 7 describes how each of these criteria is applied to evaluate the service delivery options.

Table 7: Criteria for evaluating the service delivery options

Criterion	The preferred service delivery option is one that:
Supports viability of specialist centre	• supports continuing improvement in outcomes for children with cancer based on international best practice • has projected volumes per centre that indicate each centre will have sufficient numbers of children to support safe practice and to build a sustainable workforce • co-locates paediatric oncology with other key paediatric specialties (integrated with other health services) • utilises existing clinical infrastructure for oncology services effectively
Access for children and their families and whānau	• balances the need for specialisation in fewer centres with the need to provide as many services as possible close to home • gives confidence to families and whānau that, regardless of domicile, their child will receive the highest quality of care • enables parents, families and whānau to support their child while sustaining other commitments to their families and whānau
Quality and safety	• has sufficient volumes to support safe practice for specialist oncologists and the multidisciplinary team • is able to be monitored and evaluated regularly and is part of international research • considers the emotional and social needs of children and their families and whānau at all stages of the care pathway (child and family/whānau focused) • supports a service that is clinically safe and has the following attributes: – offers consistent and clear referral pathways with an identified clinical owner – provides equity of access to the care pathway for all families and whānau regardless of domicile – offers certainty for parents of children with cancer regarding the availability of support services – is culturally safe for all families and whānau
Workforce development	• supports workforce development and succession planning, in particular for paediatric oncologists • makes the best use of scarce expert specialist paediatric oncology skills including medical and multidisciplinary workforce • improves recruitment and retention of skilled staff • supports and enhances multidisciplinary teams who are specialists in child cancer services
Best use of available funds	• makes the best use of scarce health resources and is most likely to be affordable over time • enables DHBs to invest transparently in child cancer services at all levels

4.15 Options appraisal

Table 8 sets out the results of an appraisal of each of the three service delivery options (as described in Table 6) against the evaluation criteria (Table 7). The evaluation process draws on the evidence outlined in this Plan to identify the option most likely to achieve the criteria for safe and sustainable specialist child cancer services.

For each of the criteria, each option has been allocated a rating, from one, which indicates that the option will have a limited impact on the achievement of this criterion relative to the other options, to five, which indicates it will have a significant impact on the achievement of this criterion relative to the other options.

Table 8: Appraisal of the service delivery options

Criterion	Option One: One specialist centre	Option Two: Two specialist centres	Option Three: Two specialist services across three centres
Supports specialist centre viability	**Five** Consolidates all resources and enables significant specialisation in paediatric oncology	**Four** Co-locates appropriate paediatric subspecialties Supports an increase in volumes at Canterbury DHB improving its sustainability	**One** Lower levels of co-location with lower levels of paediatric subspecialisation at Capital & Coast DHB Loss of caseload volumes for Auckland's Starship Children's Hospital will decrease capacity in New Zealand to provide the high-level paediatric services only maintained in the one centre (eg, allogenic stem cell transplantations) Insufficient volumes to support viability of virtual service delivered across two low-volume sites at Capital & Coast DHB and Canterbury DHB

Access for children and their families and whānau	**One** Approximately 64% (n=198*) of families and whānau nationwide required to travel for specialist care some over long distances (an additional 63 families and whānau over the Option Three total) The percentage required to travel would reduce over time due to the projected growth of proportion of children in the Northern region	**Two** Approximately 52% (n=159*) of families and whānau nationwide required to travel for specialist care (an additional 24 families and whānau over the Option Three total) The percentage required to travel would reduce over time due to the projected growth of proportion of children in the Northern region Less distance travelled than Option One as centres in both North and South Islands	**Four** Approximately 44% (n=135*) of families and whānau required to travel for specialist care (135 families and whānau in total) Less distance travelled overall as the three centres would be spread across the country
Quality and safety	**Three** (with strong shared care) Greatest level of specialisation possible with likely benefits of increased clinical safety through improved clinical practice Some risk for families and whānau with increase in travel requirements nationally	**Four** (with strong shared care) Supported clinically as achieves a more effective balance between centralisation and shared care, maximising benefits for safe clinical practice and access for families and whānau	**Two** (with strong shared care) Substantial clinical concerns that volumes of patients across virtual service would not be sufficient to support specialisation and safe practice in all three centres Levels of access for families and whānau same as current levels
Workforce development	**One** Consolidation of scarce workforce could prevent the use of existing multidisciplinary workforce in other centres Loss of specialist workforce or failure to utilise expertise in related paediatric services in other centres	**Four** Existing paediatric oncology specialist workforce utilised and consolidated Supports development of specialist multidisciplinary teams	**Two** Sustains current recruitment risks for Canterbury and Capital and Coast DHBs and increases risk for Auckland DHB Would utilise existing expertise in related paediatric services in Capital & Coast DHB

Best use of available funds	**Two** Once existing pricing issues are resolved, the service may be more affordable in the longer term but would require: • increased investment in shared care services • increased investment in travel support • some capital investment at Starship to develop additional capacity	**Three** Once existing pricing issues are resolved, the service is likely to be more efficient with consolidation at two sites but would require: • increased investment in shared care services • increased investment in travel support • capital investment to create sufficient capacity at Canterbury DHB	**Two** Overhead costs in operating a virtual centre across two sites unknown Capital investment still required for upgrade of current facilities at Canterbury and Capital & Coast DHBs

Note:

* These numbers represent the children under treatment for cancer, and their families and whānau who would be required to travel to a specialist centre for treatment, as shown in Table 5.

4.16 Evaluation

The above options appraisal indicates that the service delivery option receiving the highest grading against the evaluation criteria is Option Two, involving two specialist centres that would have shared care arrangements with other DHBs. The two specialist centres proposed are Starship Children's Hospital at Auckland DHB and Christchurch Hospital at Canterbury DHB.

This two-centre model builds on the strengths of the current model and takes into consideration issues that have challenged the viability of previous service configurations. The preferred option achieves the best balance between the need for access for families and whānau, and the need for centralisation to support a scarce paediatric oncology workforce and best clinical practice.

It also builds on: the existing strong core of clinical expertise in paediatric oncology; the high-quality care already provided by these two specialist centres; and the opportunity for more formal shared care arrangements to make the best use of available resources in regional DHBs. These strengths will help to address issues around workforce retention, recruitment and succession planning for paediatric oncology; and will continue to improve the already world-class outcomes for childhood cancer in New Zealand of an overall five-year survival rate of 80 percent.

This option is supported by the Paediatric Oncology Steering Group. In May 2009, in response to a request for advice to the Ministry and the Minister of Health when Capital & Coast DHB indicated it may need to withdraw from specialist service provision, the Paediatric Oncology Steering Group advised:

> That Paediatric Oncology services for New Zealand should be based on a national service provision model with tertiary services offered from two sustainable appropriately resourced sites operating a shared care model with paediatric services in most of the country's DHBs.

Furthermore, there was clinical agreement in principle on the direction of referral of patients from the Wellington Hospital catchment area. Such referral would be determined on a fairly strict geographical basis: children who currently receive care in Hawke's Bay, Whanganui or MidCentral DHB areas would be referred north to Auckland, and children in the Wairarapa, Hutt and Capital & Coast DHB areas would be referred south to Christchurch.

Centralisation of specialist centres will continue to require families and whānau of children with cancer living outside Auckland and Christchurch to travel for the specialist component of their care. The sudden closure of the Capital & Coast DHB specialist centre in 2007, and again in 2009, had a significant impact on families and whānau. One of the key purposes of this national Plan is to provide parents, families and whānau of children with cancer with certainty regarding the future patient referral pathways, location of treatment and support resources available when they need to travel.

It will be particularly important that implementation of this service configuration takes into account a specialist centre's ability to formally agree on a shared care arrangement that takes advantage, as much as possible, of existing staff and services at a shared care centre. As Stevens (1999, p 37) notes:

> The aim of shared care is to deliver safe, effective and appropriate treatment closer to the patient's home. The needs of the patient will be best served by a unified and co-ordinated approach, and it is necessary to define formally the expectations between the tertiary centre and the shared care centre in terms of responsibility for the delivery of care. This will largely depend on the level of staffing and the skill and experience of staff in the shared care centre. However, this is a two way process and staff in the tertiary centre must commit themselves to providing necessary skills training, regular updating of staff, provision of detailed written guidelines and protocols, easy access to advice and, when possible, the provision of outreach clinics.

The other actions recommended in Section 7 of this Plan enhance and support the implementation of a two-centre model that supports families, whānau and clinicians in achieving the best outcomes for our children.

Recommendation: That New Zealand have a two-centre model for the provision of specialist paediatric oncology care, with shared care arrangements with other DHBs; and that the two specialist centres be Starship Children's Hospital at Auckland DHB and Christchurch Hospital at Canterbury DHB.

4.17 Child Cancer Services National Clinical Network

Whichever of the above options is adopted, it is important to develop the Paediatric Oncology Steering Group further into a clinical network for child cancer services. This group has fulfilled an essential role in the development of specialist paediatric oncology services since its establishment but has been limited in its role and mandate.

Government policy is for clinical networks in the future to be responsible for providing advice to the appropriate decision-making body (whether at national, regional or district level) on matters relating to:

- service planning and funding
- improving equity of access
- defining and strengthening clinical pathways
- the continuum of care from prevention through treatment and rehabilitation

- workforce planning and development
- development and maintenance of standards
- increasing service efficiency
- improving quality and safety.

A clinical network for child cancer services could provide oversight of service delivery and link with multiple provider organisations. It could be established at a national level to provide consistent clinical governance including appointment of a network clinical leader; and movement toward consistent quality assurance activities, guidelines for shared care agreements, prioritisation rules, clinical pathways, referral guidelines and treatment protocols, and associated service audit.

This network would make recommendations to the National Health Board and the host provider DHBs, as appropriate, and undertake an annual agreed work programme. This Plan therefore recommends that the Ministry of Health and the NHB work with the Paediatric Oncology Steering Group to establish a national clinical network.

Recommendation: That a national clinical network be established for child cancer services in New Zealand.

5. Way Forward

The development of this *National Plan for Child Cancer Services in New Zealand*, creates an opportunity to not only consider the way in which services are configured but also to identify related issues that need resolution. This section outlines:

- a proposed implementation action plan for the preferred service configuration
- areas for further work to support implementation and to address related issues.

5.1 Implementation Action Plan

This Plan outlines a proposed service configuration that, in effect, is similar to the way services are currently being delivered. However, to ensure this service configuration is implemented in a sustainable way, the actions set out below will be undertaken.

Table 9: Actions to support the implementation of the proposed service configuration

	Action required	Responsibility	Time frame
a.	**National clinical network** Review the existing role of the Paediatric Oncology Steering Group, its alignment with the national cancer programme, and work currently being undertaken on clinical networks in relation to paediatric services; and establish a national clinical network.	*Cancer Team/ NHB with the Paediatric Oncology Steering Group*	Establish clinical network by December 2010
b.	**Review of service costing and pricing** The National Pricing Programme will review the current prices plus adjusters for paediatric oncology. In the short term Auckland and Canterbury DHBs will need to work with the National Health Board on a process for managing existing cost pressures.	*NHB*	**Urgent:** Review service costs by 31 December 2010 **Longer term:** Adjust IDFs and caseweights (as appropriate)
c.	**Review of Tier Two service specification** Review Paediatric Oncology Service Specification to ensure it supports the agreed model of care and service configuration.	*Cancer Team with the clinical network*	Review to commence in 2010 once configuration confirmed
d.	**Review of shared care agreements** Specialist centres should work with their shared care provider DHBs to formalise shared care agreements. Guidelines developed by the clinical network will inform the content of these shared care agreements.	*DHBs*	During 2010/11

e.	**Family/whānau support** Review the current supportive care available to all families. Guidance should be provided to DHBs to ensure consistent interpretation of policies such as the National Travel Assistance scheme.	*Cancer Team/ NHB with the clinical network*	During 2010/11
f.	**Facility planning** Canterbury DHB will progress a solution for accommodating additional caseload of children.	*Canterbury DHB*	Planning to be undertaken in context of wider DHB capital planning

5.2 Areas for further work

Section 4 has identified a number of issues additional to those noted above. It would be timely for these issues to be addressed or progressed alongside the areas for action noted in Table 9. These related issues have been identified as follows.

a. **Adolescent and Young Adult services:** The AYA service specification provides the blueprint for the delivery of adolescent and young adults' services. Full implementation of this service specification needs to continue.

b. **Late Effects Assessment Programme:** There should be a review of the way LEAP is provided to determine how this programme is best delivered to shared care providers with the support of specialist centres. Incorporating LEAP into the Paediatric Oncology Service Specification should also be considered.

c. **Information management**: Consideration should be given to how the New Zealand Child Cancer Registry interfaces with the health sector's national collections and how it can support the evaluation of outcomes for children with cancer.

d. **Funding of national services**: The NHB is developing a process for the management and funding of national services. Options for a future funding model for paediatric oncology services will be considered following a decision on the service configuration and decisions by the NHB on funding models.

6. Conclusions

Child cancer services in New Zealand achieve survival rates for children equal to the best rates elsewhere in the world. As a result of the continued specialisation of this service accompanied by a shared care model, all children with cancer in New Zealand are able to access the same quality of clinical care regardless of location, ethnicity or socioeconomic status. This is an outstanding achievement for any service in New Zealand and in many ways sets a gold standard for service development in New Zealand.

This achievement has largely been a consequence of the clinical leadership in the service across many years. This national leadership has worked to a best practice framework that has resulted in specialisation in a few centres. There remains strong clinical support for further consolidation in two centres, particularly to ensure that the specialist centres are able to attract and retain a skilled workforce and continue to improve on outcomes for the children of New Zealand.

This Plan has focused on achieving the optimal outcome for all children in New Zealand and balancing clinical needs with those of family and whānau.

This Plan has identified a number of further actions to support its implementation. It is recommended that the implementation of these actions be monitored by the Ministry of Health and the NHB on a six-monthly basis.

Recommendation: That the Implementation Action Plan be monitored six-monthly by the Ministry of Health and the National Health Board.

7. Recommendations

This *National Plan for Child Cancer Services in New Zealand* makes the following recommendations:

1. That New Zealand have a two-centre model for the provision of specialist paediatric oncology care, with shared care arrangements with other DHBs; and that the two specialist centres be Starship Children's Hospital at Auckland DHB and Christchurch Hospital at Canterbury DHB.
2. That a national clinical network be established for child cancer services in New Zealand.
3. That the Implementation Action Plan be monitored six-monthly by the Ministry of Health and the National Health Board.

Appendix 1: Development of Child Cancer Services

Background

The development of specialist care for children with cancer has evolved over time from services provided by general paediatricians throughout the country to care provided by specialist paediatric oncologists in only a few centres. Services were initially based in the academic paediatric departments with five specialist child cancer services provided in Auckland, Waikato, Wellington, Christchurch and Dunedin. These were consolidated to four centres in 1995 when Waikato merged with the Auckland service and then to three centres in 1999/2000 when the Dunedin service merged with Christchurch.

Child cancer services were becoming increasingly specialised with children and their families and whānau requiring complex and co-ordinated care that frequently required them to travel to another centre for treatment. Services had no formal linkages or guidelines that were accepted nationally, and there were ongoing concerns with service sustainability. In response to these issues, there have been a number of reviews since 1998. The outcomes of each of these reviews are summarised below.

Review 1: Through the Eyes of a Child – National Review of Paediatric Specialty Services

In 1997, the Health Funding Authority (HFA) launched a national review of paediatric speciality services, published as the report *Through the Eyes of a Child* (Health Funding Authority and Paediatric Society 1998) in conjunction with the development of the national Child Health Strategy (Minister of Health 2005a). The review's recommendation for paediatric oncology was for a single nationwide service whose role included: oversight of the New Zealand Child Cancer Registry; the development of guidelines for diagnosis and treatments; and the development of supportive services including outreach and shared care across the country and that co-ordinated involvement in agreed clinical trials. It also made the following recommendations in regard to the type of specialty relationships required for a specialist unit:

- Children with cancer benefit from a multi-disciplinary team of paediatric oncologists, nurses and allied health professionals (including physiotherapists, occupational therapists, psychologists and counsellors, pharmacists, dieticians, social workers, play therapists) along with links to pathology, haematology and laboratory staff, radiotherapists, paediatric surgeons and neurosurgeons and radiologists.
- The child cancer centre(s) should have access to:
  - paediatric surgeons and some types of specialist surgery, for example, orthopaedics or radiation oncologists with expertise and appropriate facilities to treat children
  - tertiary level pathology and radiology personnel
  - anaesthetic, infectious diseases, cardiology, respiratory, renal, neurology and intensive care services and bone marrow transplantation services (Health Funding Authority and Paediatric Society 1998, p 88).

The report also recommended that improvements to paediatric palliative care and adolescent oncology be considered as part of paediatric oncology.

Review 2: Provision of Children's Cancer Services in New Zealand (1999)

In 1999 the HFA commissioned a report specifically on the provision of children's cancer services nationwide, from Professor Mike Stevens, to make specific recommendations for the optimal configuration of services for children with cancer (Stevens 1999).

Stevens' report recommended that paediatric oncology services be provided from only three of the then four centres. Dunedin ceased to provide these services shortly thereafter. It recommended that Wellington should remain as a tertiary centre **only** if it was possible to achieve adequate senior staffing support as it was supported by a sole paediatric oncologist and had experienced difficulties attracting and retaining a senior clinician.

This report also strongly highlighted the need for minimum standards for specialist centres and for formal shared care agreements in the non-specialist centres. Professor Stevens identified four levels of shared care as well as specialist centres. These four levels were:

- Level 1: Management of outpatient chemotherapy
- Level 2: Management of inpatient chemotherapy
- Level 3: Management of febrile neutropenia
- Level 4: Induction of chemotherapy for acute lymphoblastic leukaemia (Stevens 1999, p 38).

Review 3: Capital & Coast DHB Review of Tertiary Paediatric Oncology Services

In 2007, Capital & Coast DHB commissioned a review of the paediatric oncology services at Wellington Children's Hospital (Pinkerton and James 2007).

This review was undertaken by Professor Ross Pinkerton, the Director of Cancer Services for the Royal Children's and Mater Hospitals in Brisbane. Its purpose was to provide advice on the shortfalls in the Wellington service provision (identified in the Stevens report) that would need to be addressed in order to continue as a tertiary centre. In addition, there was the unexpected resignation of one resident paediatric oncologist.

This review made a number of recommendations and concluded that the service provided was essentially managed and staffed as a shared care centre and the appointment of a second paediatric oncologist was critical. It also proposed that unless there was agreement on the creation of a single virtual tertiary centre with a single management structure with the Christchurch centre, the Wellington centre should cease to manage new patients independently and continue as a secondary shared care unit.

Appendix 2: Role Delineation Model Levels of Service

In 2008 New Zealand developed a Role Delineation Model (RDM) to differentiate between the levels of complexity of services provided by New Zealand's DHBs and enable DHB services to be described consistently. The RDM for paediatric oncology and haematology services is outlined in the table below[9]. It highlights the importance of clustering relevant services.

- Shared care providers are those providing services at Levels 3 and 4.
- Specialist centres are those providing services at Levels 5 and 6.

Table 10: Role Delineation Model for paediatric oncology and haematology services

Level	Description
1	• No service.
2	• No service.
3	As for Level 3 paediatric medicine* plus: • general paediatrician with an interest in paediatric oncology in normal business hours; specialist paediatrician available 24 hours • nursing staff with experience in child cancer care • supports some outpatient paediatric chemotherapy • participates in disease surveillance and late effects monitoring for children and adolescents.
4	As for Level 3 plus: • adult oncology service on site with enhanced laboratory and blood transfusion services and presence of radiation oncology capacity for use in selected situations.
5	As for Level 4 plus: • paediatric subspecialty services available on site, including neurology, endocrinology, gastroenterology, anaesthetics, infectious diseases, respiratory • supports all forms of cancer treatment for children/adolescents including autologous haemopoeitic stem cell transplantation (excluding allogeneic transplantation) • dedicated child/adolescent cancer unit • specialist paediatric oncologists and haematologists providing 24-hour cover.
6	As for Level 5 plus: • provides allogeneic haemopoeitic stem cell transplantation • has dedicated child/adolescent palliative care • has Paediatric Intensive Care Unit on site.

Table 11 shows the RDM level of care that is provided by each of New Zealand's DHBs and their relationship to a specialist centre.

9 The New Zealand RDM for paediatric oncology was developed from the NHS interdependencies framework for safe and sustainable specialised paediatric oncology services (National Health Service 2008).

Table 11: Current levels of service provided by DHBs

Specialist child cancer service provider+	Child cancer shared care provider ^		No child cancer service
Levels 5 and 6	Level 4	Level 3	Levels 1 and 2
Auckland	Waikato	Northland	Waitemata
	MidCentral*	Bay of Plenty	Counties Manukau
		Hawke's Bay	
		Taranaki	
		Tairawhiti	
		Lakes	
		Whanganui*	
Canterbury	Capital & Coast*	Nelson Marlborough	Wairarapa*
	Southern		Hutt Valley*
			South Canterbury
			West Coast

Notes:

* The DHBs marked with an asterisk were linked to the Capital & Coast DHB service until July 2009 and have since been allocated between Auckland and Canterbury as shown.

+ There are differences in some aspects the range of care available from the specialist child cancer service providers that relates to expertise in some rare cancer types, the provision of allogeneic stem cell transplants and the availability of specialised paediatric intensive care.

^ There are differences in the range of care available through shared care providers that is determined by the availability of staffing expertise, diagnostic and treatment facilities.

Role delineation model for paediatric medicine and medical subspecialties

Table 12: Paediatric Medicine and Medical Subspecialties

Level	Service description checklist
1	• Primary and emergency care to children, which may include stabilisation for children before moving to appropriate higher level of service. • Provided by rostered general practitioners or medical officers.
2	As for Level 1 plus: • paediatrician specialist outpatient consultation in normal business hours; may be visiting And/or • inpatients may be in a general ward under the care of a general physician • formal consultative links with Level 3 paediatric medical service.
3	As for Level 2 plus: • inpatient and outpatient specialist paediatric medical care for all children • specialist paediatricians on site, normal business hours • medical officer rostered on site 24 hours.
4	As for Level 4 plus: • designated paediatric inpatient unit • specialist paediatricians rostered on call 24 hours • provides integrated hospital inpatient, ambulatory family and child health services, and community health services for most child health needs.
5	As for Level 4 plus: • on-site access to paediatric general surgical service • paediatric registrar on site 24 hours.
6	As for Level 5 plus: • paediatric medical and surgical subspecialties available on site provided by paediatric trained specialists – This will include anaesthetics, cardiology and cardiac surgery, oncology and haematology, neurology and neurosurgery, orthopaedics and ORL • clinical and diagnostic services provided by appropriately trained paediatric specialists.

Appendix 3:
Data Sources and Methodology

Data sources

The primary data sources for this plan are the New Zealand Cancer Registry (NZCR) and the National Minimum Dataset (NMDS). Although the NZCCR has been collecting diagnosis, treatment and outcome information on children with cancer since the year 2000, the full NZCCR dataset was not able to be validated in time to inform this plan. However, an extract of diagnoses by NHI was matched to the New Zealand Cancer Registry data to identify differences in recording methodologies. This process resulted in a match rate of 97.43 percent where the diagnosis was a primary malignancy. This gives confidence that the data could be used for the purposes of understanding the extent of child cancer services for that group of patients.

NZCCR and NZCR are highly concordant for the registration of cancer in children 0–14 years when classified according to international cancer registry criteria (ICD). However this does not include all diagnoses in children when classified according to the International Children's Cancer Classification system (ICCC). The NZCCR records all cases by both ICD and ICCC. ICCC codes juvenile pilocytic astrocytoma, a common brain tumour as a low-grade glioma but these cases are not registered by ICD. Some other cases are not registered in NZCR, including diffuse pontine glioma, as these tumours are diagnosed by radiology only and a pathological diagnosis is rarely made. Further, the histiocytic disorders including Langerhans histiocytosis are not considered malignant by ICD but are coded by ICCC.

Hence, registrations to the NZCCR are a more true reflection of clinical workload across New Zealand and provide the best data set for international comparison.

Methodology

Cancer incidence methodology

Cancer incidence figures have been calculated using the NZCR in conjunction with Statistics New Zealand population projections.

Treatment profiling (treatment variation: those serviced locally vs those travelling for service, Spoke Model)

The data used in this analysis have been sourced from the National Minimum Dataset (NMDS) as at 8 November 2009. The analysis includes all hospital events where paediatric or oncology Purchase Units have been recorded for the event and where the patient was 19 years or younger on the last day of their inpatient stay. The Purchase Units used are set out below.

Purchase Unit	Purchase Unit Description
M10.05	Specialist Paediatric Cardiac – Inpatient Services (DRGs)
M34.01	Specialist Paediatric Haematology – Inpatient Services (DRGs)
M49.01	Specialist Paediatric Neurology Inpatient Services (DRGs)
M50.01	Oncology – Inpatient Services (DRGs)
M54.01	Specialist Paediatric Oncology – Inpatient Services (DRGs)
M55.01	Paediatric Medical – Inpatient Services (DRGs)
S55.01	Paediatric Surgical Services (DRGs)

Whether the service was local or not was determined by applying the following matrix against the patient's DHB of domicile.

Serviced locally	Travelling for service	
Auckland	Northland	MidCentral
Counties Manukau	Waikato	Whanganui
Waitemata	Bay of Plenty	Nelson Marlborough
Capital & Coast	Lakes	West Coast
Hutt Valley	Taranaki	South Canterbury
Wairarapa	Tairawhiti	Otago
Canterbury	Hawke's Bay	Southland

Volume forecasting methodology

Volume forecasting combined two datasets for the forecast: inpatient treatment volumes and New Zealand population estimates. Outpatient data have not been used as this captures data at the Purchase Unit level rather than the procedure level.

Inpatient treatment volumes have been sourced from the NMDS as at 8 November 2009. The analysis includes all inpatient hospital events where paediatric or oncology Purchase Units have been recorded for the event and where the patient was 19 years or younger on the last day of their inpatient stay.

New Zealand population estimates were sourced from Statistics New Zealand's population estimates, which are based on the 2006 census and assume average population growth.

The volume forecasts use an eight-year average treatment rate for those aged 0–19 years, which are extrapolated into out years using the projected New Zealand population.

Glossary of Terms

Access	The ability of people to reach or use health services
Chemotherapy	The use of drugs that kill cancer cells, or prevent or slow their growth
Child cancer service	Health and disability service for children with cancer, and their family and whānau to assist in meeting their total needs
District Health Board (DHB)	A DHB is responsible for providing, or funding the provision of, health and disability services in its district. There are 20 DHBs in New Zealand, established when the New Zealand Public Health and Disability Act 2000 came into force on 1 January 2001
Evidence-based practice	Practice that is based on scientific evidence that demonstrates its effectiveness
Incidence	Number of new cancer cases
Inter-district flow (IDF)	The flow of funding between districts where services are provided in another DHB. The Ministry of Health manages the transfer of funding associated with the flow of patients between DHB districts
Multidisciplinary	Describes a treatment planning approach or team that includes a number of doctors and other health care professionals who are experts in different specialties (disciplines). In cancer treatment, the primary disciplines are medical oncology (treatment with drugs), surgical oncology (treatment with surgery) and radiation oncology (treatment with radiation)
National Pricing Programme	The joint National Pricing Programme between DHBs, DHBNZ and the Ministry collects DHB provider arms' cost and volume annually to develop national prices (via inter-district-flow or IDF prices). IDF prices are used for IDF payments between DHBs when patients receive health care outside their DHB of domicile. The data is also used for setting the tertiary adjuster pool and updating the New Zealand caseweight system
New Zealand Cancer Registry	The New Zealand Cancer Registry is a population-based register of all primary malignant diseases diagnosed in New Zealand, excluding squamous cell and basal cell skin cancers. Incidence counts and rates are based on the number of primary tumours rather than the number of individuals with cancer. The New Zealand Cancer Registry database records multiple primary cancers in the same person, of which only some are counted for incidence purposes, according to the rules of the International Agency for Research on Cancer and the International Association of Cancer Registries
Nurse practitioner	A registered nurse educated and authorised to function autonomously and collaboratively in an advanced and extended clinical role in a specific area of practice. The nurse practitioner role can include prescribing medicines and ordering diagnostic tests
Paediatric	Refers to children, including neonates, infants, children and young people up to the age of 19 years

Paediatric oncologist	A medical specialist dealing in the treatment of children and young people with cancer
Paediatric Oncology	The study, diagnosis, treatment and management of malignant disease in children and young people
Paediatrician	A medical physician who specialises in the development and care of infants, children and young people, and treatment of their diseases
Palliative care	Care of people with a life-threatening illness
Principle	A fundamental basis for action
Protocol	An agreed policy that defines appropriate action
Radiotherapy	The use of radiation, usually X-rays or gamma rays, to kill cancer cells and treat tumours
Rate	In epidemiology, the frequency with which a particular type of health event (eg, cancer) occurs in a defined population
Regional cancer networks	Regional cancer networks are complex organisational and service delivery structures that work across organisational boundaries. They bring together key stakeholders to plan and deliver a set of comprehensive and integrated cancer services, that are co-ordinated across patient care pathways through a multidisciplinary team approach, for a given population area (region). These networks can increase access to comprehensive cancer services by promoting a collaborative approach to care planning and delivery. There are four regional cancer networks in New Zealand
Specialist service	A service for a specific medical scope of practice that includes a range of inpatient and outpatient medical and surgical services
Subspecialty service	A service that is the next level of specialisation from general specialist services such as general paediatrics
Supportive care	Care that helps the patient and their family or whānau and carers to cope with cancer and its treatment throughout the cancer journey
Whānau	Extended family, including kaumātua, pakeke, rangitahi and tamariki. The whānau is recognised as the foundation of Māori society

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