



A Vision of Care and Roadmap to Guide the  
Paediatric Integrated Cancer Service (PICS)

*'The best care in the best facility as close to home as possible'*

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## Acknowledgements

This document outlines the plan to achieve an integrated cancer service for children with cancer and their families in Victoria. It uses the seven broad key target areas identified by the Victorian Department of Human Services to frame the work to be undertaken.

This vision is based on the philosophy of assessing the needs, requirements and standards of service as determined by the child and family. It is child and family focused and centres on the need for team delivery of care within a co-ordinated and standardised system within each site and between the PICS partnership.

Gaining consensus on the vision has created challenges for many groups, both professional and for hospitals within the State. We thank the many medical, nursing and allied health professionals who have embraced the concept of PICS and have worked with us on creating the vision.



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## 1. Introduction

*'The best care in the best facility as close to home as possible'*

The Paediatric Integrated Cancer Service (PICS) is a partnership between the Royal Children's Hospital (RCH), Southern Health (SH, Monash Medical Centre-MMC), and the Peter MacCallum Cancer Centre (Peter Mac).

PICS was established in 2004 as part of the Victorian State Government's Caring for Children Package. PICS is also part of the Department of Human Services' (DHS) broader cancer reform strategy through which three metropolitan and five regional integrated cancer services have been established to strengthen high quality, consistent and integrated cancer care for all Victorians. As a specialist service supporting a relatively small number of children with cancer and their families across Victoria, PICS is the only state-wide Integrated Cancer Service.

While the majority of children with cancer are now successfully treated, the diagnosis and subsequent treatment can be very demanding over a long period of time. The short-term and long-term impact on children and their families can be profound. This impact is compounded if access to high quality, well-coordinated clinical treatment and care is constrained by geography, variations in medical management, poor access to clinical trials and poor communication and fragmentation across services and sectors.

Over the four years of the PICS Program (2004-08)<sup>1</sup> the goal of PICS is to improve outcomes for children with cancer and their families through achieving consistent medical, nursing, allied health and psychosocial services across the PICS partnership and drawing regional services into the partnerships as appropriate.

Children must wherever possible have access to equivalent services, by credentialed staff in a safe and trusting environment. The child and family must be able to move within the PICS site and between sites as appropriate, depending on the phase of their treatment, with full confidence in the staff, clinical work practices and the standard of care.

To achieve this, the PICS Coordinating Group (PICS-CG) together with the DHS have set the following seven key target areas for achievement by 2008:

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<sup>1</sup> Since the commencement of this document in 2005, ongoing funding for PICS has been assured by DHS.

Number	Key target area
1	To improve the delivery of state-wide specialist paediatric cancer services through the establishment of a state-wide PICS.
2	To ensure safe, low risk, best practice, efficient and high quality services to all PICS sites.
3	To enable quality improvement, consistent clinical practice and maintenance of professional expertise across the PICS partnership.
4	To improve coordination and sharing of expertise across all three paediatric cancer sites.
5	To create the capacity to improve state-wide trials, coordination and associated data management within the state-wide PICS.
6	To develop a multidisciplinary/multi campus approach to the provision of psychosocial support services.
7	To provide support for regional and community cancer services.

Following the establishment of PICS the development of this Vision of Care was a priority recommendation in the first key target area. The document therefore outlines this Vision of Care and details the core components of this Vision. As such it provides guidance for services for the future.

From this Vision the recommendations under each of the above target areas were developed and are listed in Appendix 1. This is the 'roadmap' to achieve the PICS Vision of Care.

However, this Vision remains '*a work in progress*' and will be the focus of ongoing discussion and debate. While the Vision will guide service improvement, it will need to evolve as PICS builds on its achievements and identifies new opportunities and challenges. It will also evolve as PICS responds to the changing needs of children and families, the changing workforce needs and other challenges within the health service and community environment.

This document first provides a brief overview of the context of paediatric cancer care in Victoria and the challenges to improving cancer care in the future.

It then provides a Vision for the future and articulates the components for turning this Vision of care into a reality.<sup>2</sup>

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<sup>2</sup> It should be noted that this document has developed over a twelve month period. During this time, certain initiatives or policy directions at a DHS or service level have also evolved. Where appropriate this document reflects these new policy or service directions.

## 2. Background

### 2.1 The policy context

Two major Victorian Government policies with complementary perspectives and recommendations, have been instrumental in the development of PICS.

Firstly, the Children's First Policy focuses on ensuring all children and their families, and in particular vulnerable children, gain access to a range of health and community services that optimises the child's developmental growth and family support. Key recommendations focus on strengthening integrated services, and establishing better links and transitions between services and sectors.

Secondly, the Victorian Cancer Service Framework aims to strengthen access to high quality cancer services for all Victorians, with the Integrated Cancer Service (ICS) initiative being a major platform for this service reform. There are three Metropolitan ICS (MICS) and five Regional ICS (RICS). Each ICS cover a defined geographic region and a number of health services. The key foci guiding this service reform include improving access to evidence-based clinical management and multidisciplinary care, improving access to high quality psychosocial care and enhancing continuity of care within and across services and sectors.

While it is a state-wide program, the PICS partners also sit within the Western and Central Metropolitan ICS (WCMICS) and the Southern Metropolitan ICS (SMICS) and will have to develop relationships with the regional ICS.

Finally, during 2005 a further DHS initiative, the Victorian Paediatric Rehabilitation Program was developed to strengthen Victorian children and families' access to quality rehabilitation services. This initiative of which both RCH and MMC are a part, has relevance for those children whose cancers and / or treatment result in short or long-term functional loss or disabilities.

### 2.2 The profile of children with cancer

In 2005, 159 children were diagnosed with cancer at one of the two major Victorian treatment services (RCH and MMC)<sup>3</sup>. Of these children:

- Over 75% (n =120) occurred in children under the age of 13 years
- 45% (n=71) were aged 5 years and under
- 31% (n=49) were aged 6-12 years
- 25% (n=39) were adolescents aged over 13 years.

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<sup>3</sup> All children under the age of 15 years were diagnosed within the two major treating services. At least a proportion of older adolescents may be diagnosed and managed within adult services. This data is based on data from RCH and MMC.

Of all the different cancers diagnosed:

- 51.5% were leukaemias or lymphomas,
- 27% were solid tumours such as Wilm's tumours and bone cancers
- 21.3% were brain tumours or other tumours of the central nervous system (CNS).

In 2005, approximately 70 children received radiotherapy at the Peter MacCallum Cancer Centre.

The following table summarises the profiles of newly diagnosed children in 2005 by service site.

**Table 1: Profiles of newly diagnosed children by site, age and disease category in 2005**

		Service					
		RCH		MMC		Peter Mac <sup>4</sup>	
Category		n	%	n	%	n	%
Age	0-5	55	41%	16	67%	21	30%
	6-12	43	30%	6	25%	26	38%
	13 +	37	27%	2	8%	21	31%
	<b>Total</b>	<b>135</b>	<b>100%</b>	<b>24</b>	<b>100%</b>	<b>68</b>	<b>100%</b>
Disease category	Liquid tumours	71	52.5%	11	44%	16	23%
	Brain tumours	29	21.5%	5	21%	28	41%
	Solid tumours	35	26%	8	32%	24	35%
	<b>Total</b>	<b>135</b>	<b>100%</b>	<b>24</b>	<b>100%</b>	<b>68<sup>5</sup></b>	<b>100%</b>

Forty two percent of the children diagnosed in 2005 lived more than 40 kms from the Melbourne Central Business District (CBD) with 17% of children and families living greater than 200 kms from the CBD.

<sup>5</sup> This data was initially provided as part of the PICS Psychosocial Services Review Project in early 2006. Updated data accessed from Peter Mac in June 2006 indicated a total of 71 children or adolescents were treated in 2005 for a total of 82 separate treatment courses. We only have the age or disease breakdown on the original 68 children identified.

Finally while the numbers of children newly diagnosed in Victoria each year are expected to remain stable, the increasing treatment success rates results in the absolute numbers of survivors of childhood cancer continuing to grow.

### **2.3 The current service delivery context**

In Victoria, care of children with cancer is offered and coordinated at two centres with radiotherapy provided at a third.

The **Royal Children's Hospital (RCH)** is a specialist paediatric hospital and provides a full range of clinical services, tertiary care and health promotion and prevention programs for children and adolescents. The hospital is the major specialist paediatric hospital in Victoria, and also cares for children from Tasmania, southern New South Wales and other states around Australia and overseas. It is positioned close to the CBD.

As the major paediatric hospital in Victoria, the RCH provides clinical, academic and advocacy services for children and young people throughout Victoria. It is internationally recognised as a leading centre for research and education. The Murdoch Children's Research Institute (MCRI) is based at the RCH providing a bench to bedside process.

The RCH Children's Cancer Centre is the major provider of paediatric oncology services and provides the full range of treatment for all conditions (with the exception of radiotherapy) and provides the most complex care including bone marrow transplantation.

**Monash Medical Centre (MMC)** was formed in 1987 as a result of the amalgamation of three hospitals. It underwent further expansion in 1995 when it joined with other hospitals to form the Southern Health (SH). SH cares for people of all ages and most illnesses. It is also a teaching hospital and a centre for research.

MMC has two campuses at Clayton and Moorabbin. It provides major cancer services for adult Victorians and hosts the Peter Mac radiotherapy satellite centre at its Moorabbin campus.

With respect to paediatric cancer services at its Clayton campus, MMC offers day oncology services for chemotherapy and an in-patient service within its general paediatric units. MMC provides care to a smaller number of children that tend to be younger in age group than those seen at RCH (see Table 1) and does not treat children with acute myeloid leukaemia or others who require bone marrow transplantation.

The **Peter MacCallum Cancer Centre (Peter Mac)** in East Melbourne is the only site in Victoria offering radiotherapy to children under the age of 16 years, and is the largest paediatric radiation centre in Australia. It is a public hospital solely

dedicated to cancer research, treatment and care. Peter Mac has 150 beds and provides outpatient services to approximately 51,000 patients per annum.

Paediatric cases are a small percentage of this overall figure. Each year the paediatric unit receives referrals from 50 to 60 new patients and treats about 70-80 patients. A very small number of children (1-2 per month) are admitted to Peter Mac usually for total body irradiation in preparation for bone marrow transplantation. They are then transferred back to the RCH for the rest of the treatment.

In addition to its paediatric service Peter Mac hosts the OnTrac@PeterMac program. Funded by Telstra, this is an adolescent and young adults program. It is a state-wide and only service specifically designed to support teenagers or young adults with cancer in Victoria wherever they are treated. One of the drivers of this program was the evidence that adolescents and young adults with cancer treated in diverse settings have not experienced the treatment benefits in terms of increased survival and improved morbidity seen within the younger paediatric population.

The morbidity and mortality outcomes of onTrac@PeterMac adolescents and similarly grouped adolescents at the RCH, MMC and adult based centres have not been compared or evaluated.

While these three PICS service sites provide the majority of care for Victorian children, a level of shared care with regional services has developed over the years on an ad hoc basis. This shared care has been predominantly for the provision of local care for central venous access devices and the early management of febrile neutropaenia.

Finally the **Victorian Paediatric Palliative Care Program** (VPPCP - consisting of RCH, MMC and Very Special Kids) provides a consultation-liaison team responsible for the facilitation of the care of children with palliative care needs and their families, including children with cancer.

## **2.4 Factors influencing the development of the PICS Vision of Care**

A major challenge for the development of the PICS vision and guidance for future directions has been that the scope of service enhancement and the amount of material and evidence for review is vast. PICS therefore has focused on those aspects of the service that are likely to have a significant impact on health outcomes for children and families and / or are priorities as identified by the PICS Coordinating Group or the Children's Cancer Centre Parent Advisory Group (CCCPAG).

A number of other factors also provide significant challenges and opportunities for enhancing quality service delivery for Victorian children and their families. These have implications for the PICS partnership, the development of new partnerships with regional services and for DHS policy and funding directions.

### **2.4.1 Children's age and differing needs**

Very different issues arise depending on the age and maturity of the individuals whose needs are being addressed. Childhood and adolescence is a time of enormous change, physically, psychologically and socially, and this influences the different patterns of malignancy seen, their pathological behaviour, response to treatment and eventual outcomes.

The truism that outcomes encompass more than improved health, in terms of survival, mortality and morbidity, is even more of a reality for children, whose outcomes need to include the ability to mature successfully into adulthood. The late effects of treatment are particularly relevant in this context.

This PICS Vision and guidance therefore needs to cover children of all ages, from birth to young people in their late teens presenting with cancer, and the whole range of services required to meet their needs. The guidance has not used a specific upper age limit in the recommendations, recognising that any such limit is arbitrary and that services should be provided to individual needs.

We also need to recognise that providing a service within one facility that can be tailored to the differing social and developmental needs of all young children and adolescents and their families, is a significant challenge.

Finally we strongly recognise the challenges of providing optimal care to adolescents and young adults. PICS together with the Regional Integrated Cancer Services and OnTrac@PeterMac program will need to work together to achieve financial recognition within the Cancer Services Framework for adolescents and young adults with cancer.

### **2.4.2 Families**

The dependence of children and young people on their families and the profound effect severe ill health and/or death of a child or young person has on other family members are additional important factors that need to be considered in service planning and delivery.

A significant proportion of families live more than 40 kms away from the treating service. Travel costs and dislocation from their home and community supports impact on children and families and may have a particular impact for the care of siblings. This is further compounded for regional and interstate children with cancer and their siblings and families when extended stays are required within Melbourne.

The needs of the family need to be included in the PICS Vision of Care.

### **2.4.3 Service Organisation**

Equitable access to services is a key issue.

Many services have evolved over time and have been influenced by a range of constraints including geographical location, the availability of expertise and level of funding. These constraints remain real, but the implementation of PICS is an effort to minimise the variations in access and service provision.

While much of the PICS service development will focus on the initial treatment phases, the increasing long-term survival of the majority of children presents additional challenges to service organisation. At least a proportion of children will experience significant short-term and longer term physical and psychosocial consequences of their disease and treatment.

Service organisation and enhancement must consider the implications of providing long term follow-up, referral between RCH and MMC and the need to develop strong partnerships with regional centres to manage the increase in future service demand.

Finally the need for additional funding to facilitate equitable care across the continuum is recognised and PICS, together with DHS will seek to address these issues as part of achieving the vision.

## **2.5 Principles guiding the Vision of Care**

The following principles were adopted in forming the recommendations for the PICS Vision of Care.

- The aim is for safe, effective and high quality services as locally as possible, not local services as safely as possible
- An integrated, practicable and achievable whole systems approach to services is essential.
- There needs to be a sustainable balance between centralisation, decentralisation and integration. Some services will be better delivered as one central site, others will require decentralisation with separate service provision and others will benefit from integration.
- Consumer involvement is essential and should be included wherever appropriate and feasible.
- The recommendations are based on agreed best or optimum practice without consideration of funding, organisational hazards or restrictions. However, it is acknowledged these limitations will influence the ability to achieve some of the recommendations.

*The aim is for safe, effective and high quality services as locally as possible, not local services as safely as possible.*

### 3. The PICS Vision of Care

*The Vision of Care*

*'The best care in the best facility as close to home as possible'*



The PICS Vision of Care and subsequent service model must go across the whole care pathway from diagnosis to long-term survival or death, and through the many developmental stages of the child or adolescent's life.

The PICS Vision of Care includes both the clinical management and psychosocial care of the child and the psychosocial support of the family.

The **goal** for PICS is as follows:

All Victorian children and adolescents with cancer and their families have access to high quality, safe and effective clinical and psychosocial care that is well coordinated and provided in environments that are conducive to healing and coping, as close as to home as possible. This will:

- optimise long-term survival
- maximise the quality of life in the short and longer-term for the child or adolescent and their family
- maximise the child's / adolescent's achievement of developmental and academic milestones and facilitates their successful transition into adulthood.

Regardless of where care is provided within specialist or generalist services, in metropolitan Melbourne or regional Victoria, it will be informed by shared **core values** and **principles** (See Box)<sup>6</sup>.

A significant challenge to achieving this vision and goal, is the rarity of childhood cancer overall, and within this, the extreme rarity and complexity of some specific tumours. Within this context to achieve *'the best care in the best facility as close as home as possible'* may mean that the child and family have no choice but to be treated within a major tertiary service with limited options for any local care. Many families are accepting of this in order that their child does receive the best care possible.

For other families, at least some care may be provided more locally through agreed shared care arrangements.

To meet these challenges and to achieve the PICS vision and goal, an enhanced **system of service delivery** is needed across Victoria. This service delivery model includes:

- A framework that will guide the delivery of children's cancer services across Victoria through both specialist and generalist providers. This framework will include the required infrastructure, support services and staffing requirements for the different levels of service.
- Clear and consistent pathways of care across the disease trajectory. This includes clinical pathways, psychosocial support, rehabilitation and long-term follow-up, and end-of-life care.
- Agreed models of care that will inform how care is delivered including access to multidisciplinary care, continuity of care and access to clinical trials.

The remainder of this document details the key elements of the proposed service delivery model.

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<sup>6</sup> It should be noted that these PICS Core Values and Principles have been modified from those developed with consumers and service providers as part of the 2006 PICS Psychosocial Services Project. Further work may need to be undertaken to ensure that these values and principles reflect the broader work of PICS and its stakeholders

## PICS Core Values and Principles

The **core values** of PICS and its partners are to work as an effective **team** together to provide optimal **family-centred care**.

In line with these values, the following **principles** will guide practice:

- We accept that the provision of high quality clinical **and** psychosocial care is the core business of all PICS sites and agreed regional services.
- We will provide family-centred care with the child and family as the unit of care.
- We will provide optimal clinical care in line with evidence-based clinical practice and agreed standards of care.
- We will support and facilitate the child / family's access to appropriate clinical trials.
- We will actively participate in or contribute to a range of laboratory, clinical or psychosocial research activities that aim to improve outcomes for children and families in the future.
- We work in partnership with the family to ensure informed decision-making and to provide care for the child that meets their emotional, social, and developmental needs.
- We will proactively identify and meet the needs of the individual child and family.
- We recognise that our families are highly stressed and distressed. We will take a preventative and early intervention approach, aimed at building children and families' resilience, and develop systems and processes that will reduce and not exacerbate distress wherever possible.
- Our services and care will be age and developmentally appropriate.
- We recognise that families come from diverse backgrounds with differing capacities and skills. We will not make assumptions about the capacity of the family to cope practically and emotionally.
- We will take a whole of system approach to respond to the needs of children and families.
- We will work cooperatively recognising and respecting the skills of all disciplines and facilitating collaboration and communication between providers within and across services and sectors to optimise outcomes for children and families.
- We are committed to strengthening a family's resilience and on helping families to build a network of support (peer or community).
- We will work collaboratively with community providers and consumers to optimise services for the care of children and families.
- Our service takes a proactive approach to strategic planning and quality improvement to enhance care for children and families.
- We recognise and support our staff to gain the skills and support they need to facilitate optimal clinical and psychosocial care for children and families.

## 4. The recommended service framework

*'The best care in the best facility as close to home as possible'*

The recommended service framework describes five levels of cancer treatment centres or services needed to achieve the vision. This framework provides a draft of definitions and responsibilities of each level of cancer service site.

Given the rarity of children's cancer, the major elements of treatment, particularly initial diagnostic work-up and management planning by a multidisciplinary team (MDT) will take place within the higher service levels (Level 1 or Level 2). However throughout the cancer journey, various components of care may be delivered at a number of locations, ranging from the community to tertiary settings.

Given the proportion of families living greater than 40kms from the CBD, there needs to be an established process for Level 1 and 2 cancer service sites to work in conjunction with regional paediatricians and services to develop agreed shared care arrangements.

Irrespective of the level of cancer service site, care should:

- be delivered by appropriately trained, experienced and credentialed staff
- be responsive to tumour type and stage
- reflect the age related needs of patients and families
- include explicit arrangements for unexpected admissions
- be co-ordinated to ensure consistency of service delivery, timely intervention and accurate following of clinical protocols.

The evaluation of all service levels need to take into account local expertise, staffing levels, facilities and the ability of each site to address the recommendations made regarding provision of care within this Vision of Care.

***Hospitals and centres delivering care to children with cancer need to be assessed and credentialed within the agreed descriptions.***

Table 2 provides an overview of the key components of care for each service level.

Each service level is then described in more detail.

**Table 2: A summary of the levels of cancer treatment centres**

Level of care	Key service features
Level 1	<ul style="list-style-type: none"> <li>• Major centre dedicated to paediatrics with &gt;100 diagnoses per year.</li> <li>• Access to full range of paediatric specialist medical services including ICU and Emergency (24 x 7)</li> <li>• Access to the full range of paediatric qualified and experienced allied health and psychosocial services.</li> <li>• Must have 4 FTE paediatric oncology consultants.</li> <li>• Links to palliative and community based care must be in place.</li> </ul>
Level 2	<ul style="list-style-type: none"> <li>• Moderate sized paediatric service within a larger facility with &gt;20 diagnoses per year</li> <li>• Access to full range of paediatric specialist medical services including ICU and Emergency (24 x 7) and the full range of paediatric qualified and experienced allied health and psychosocial services.</li> <li>• Full-time cover of paediatric oncology consultants including after hours care.</li> </ul>
Level 3	<ul style="list-style-type: none"> <li>• Primarily a chemotherapy centre with access to in-patient paediatric beds (minimum 2)</li> <li>• Access to paediatric experienced medical, nursing, allied health staff and psychosocial support.</li> <li>• Regional centres in partnership as shared care providers would normally fit within this level of service.</li> </ul>
Level 4	<ul style="list-style-type: none"> <li>• Generally based in regional Victoria, a level 4 service will have a paediatrician credentialed to manage paediatric oncology case.</li> <li>• A smaller team will be available to support the service but may not necessarily be trained in paediatrics.</li> <li>• May join with PICS as regional shared care providers</li> </ul>
Level 5	<ul style="list-style-type: none"> <li>• Regional Victoria in remote areas.</li> <li>• Access only to GP who will assist to manage the child for specific treatment and triage in partnership with a higher level site.</li> <li>• May require specialised monitoring and support from medical and nursing staff to share care.</li> <li>• Usually coopted due to a child diagnosed under the GP care</li> </ul>

While inter-related, the five levels of cancer service sites will be considered under two categories:

- those services or '*Children's Cancer Centres*' that provide a range of specialist paediatric oncology diagnostic and treatment services for a **population of children**
- those services that provide more generalist paediatric or community services that have the capacity to provide shared care for **individual children** and their families in association with a Level 1 or 2 cancer service site.

## 4.1 Specialist Paediatric Cancer Services

These include Level 1 and 2 Cancer Service Sites or '*Children's Cancer Centres*'.

### 4.1.1 Level 1 cancer service site

The Level 1 Cancer Service Site is a designated major *Children's Cancer Centre* that provides expertise and experience in the management of all types of children's cancers.

Level 1 Cancer Service Sites would normally serve a population of over 100 new diagnoses per year. New patients may be referred from primary care providers, Level 2-5 Cancer Service Providers or internally within their own broader hospital service.

Level 1 Cancer Service Sites require 24-hour specialist paediatric medical and nursing staff cover, expertise in a wide range of cancers and be able to meet defined minimum levels of staffing and expertise as outlined in Table 3.

Level 1 Cancer Service Sites will be strongly affiliated with research facilities and have access to clinical trials.

Associated services required include access to family and child off-site accommodation, video conferencing facilities and bereavement services.

#### **Level 1 services: action to address impact of access issues**

While access to facilities should be with the least inconvenience to patients and families, the rarity of paediatric cancer overall and some specific tumour groups means that treatment may always require a Level 1 Service. This involves considerable travel for families, even if there is a more local Level 2 cancer facility. While generally accepted by patients and families, this does impose additional burdens on them.

**In order for PICS to influence Government funding and prioritise operational programs to assist families, consideration should be made to quantify the economic cost to families of children who have cancer.**

### 4.1.2 Level 2 cancer service site

A Level 2 cancer service site is a *Children's Cancer Centre* that operates essentially as 'smaller' or 'scaled down' Level 1 site and manages a smaller population of children (greater than 20 new diagnoses a year).

For some children and adolescents referral will be directly to a Level 2 site from the hospital emergency or outpatient services or from primary care providers. For other children the diagnosis may be made at a Level 1 cancer service site with referral to a Level 2 service site for ongoing management.

A Level 2 site should be able to enrol children on clinical trials and to undertake all aspects of low complexity treatment (except bone marrow transplant, stem cell harvest and radiotherapy).

Table 3 outlines the agreed core components for a Level 2 Cancer Service Site.

### **Level 1 and 2 cancer service sites – key points**

Within Victoria, the definitive investigation of children and young people with a suspected diagnosis of cancer should only take place at a Level 1 site and for some diagnosis at a Level 2 site.

All newly diagnosed patients must be managed in a Level 1 or Level 2 site. Once the diagnosis is made, a treatment plan will be formulated and appropriate shared care arrangements negotiated including transition to Level 2 or regional sites or services (Levels 3-5).

PICS will facilitate discussions between Level 1 and Level 2 sites to establish guidelines which outline the range of diagnoses and treatments to be offered at the respective sites.

Written guidelines for referral, admission, communication at discharge and follow-up should be in place and agreed across PICS.

Level 1 and 2 services will have defined clinical procedures and clear policies for transition to age appropriate environments and specialist teams.

In the event that specialist clinical services such as haematology, paediatric orthopaedic or neurosurgery were to be reduced or removed from a Level 1 or 2 site, the range of diagnoses able to be fully managed at that site will need to be reviewed and clearly defined.

## **4.2 Generalist services providing shared care services**

These services include both 'cancer service sites' and individual service providers that work with Level 1 or 2 Cancer Service Sites to provide agreed levels of care within the child's regional area or local community.

### **4.2.1 Level 3 cancer service site**

Level 3 cancer service sites provide care that is generally limited to the provision of chemotherapy that may be provided within an adult chemotherapy setting.

Level 3 cancer sites should ideally have a minimum of two dedicated paediatric beds with nurses and after hours staff credentialed to care for children. After hours emergency facilities are mandatory.

Clinical information relating to children attending Level 3 sites for chemotherapy who are on clinical trials must be accessible to the Level 1 or Level 2 cancer service site managing the child.

As with all sites, nursing, pharmacy and allied health members involved in the provision of paediatric oncology treatment or chemotherapy care will need to participate in initial and ongoing Continuous Professional Development programs.

#### **4.2.2 Level 4 cancer service**

The Level 4 cancer service will most likely exist in regional Victoria.

It will have a paediatrician credentialed to manage the child's treatment in a shared care arrangement with the Level 1 and Level 2 site. The paediatrician will be located within a regional base hospital and have access to hospital-based clinicians, nursing and allied health staff.

#### **4.2.3 Level 5 cancer service**

A Level 5 cancer service is identified as occurring in small regional towns where GP access is available but little or no other medical facilities or paediatricians credentialed to manage children with cancer are available. Distance to formal shared care centres or family circumstances make local care, wherever possible, preferable. The Level 5 Cancer service is a unique relationship established to manage and care for a particular child and/or family.

Across Victoria on average a GP will see a child under 15 with cancer every 10-20 years. Within the context of a Level 5 Cancer Service, a 'one-off' training and education program/session for the GP may be required on the diagnosis of a child from within this community in order to assess the GP's and community's individual needs and requirements. This will also provide the referring service with additional understanding of the child and family circumstances as well as an understanding other support services that may be available locally.

Technological assistance such as video conferencing should be considered to support the GP, the child and family and ongoing monitoring and professional support with the Level 1 or 2 centres would be required.

### **4.3 Peter MacCallum Cancer Centre**

As a specialist service providing radiotherapy to children and adolescents with cancer, usually over a relatively short period of time, it is more difficult to fit its service into this service delivery framework.

While the majority of radiotherapy is undertaken in the ambulatory setting, one in-patient bed is required for children receiving total body irradiation and should be suitable for children and families with facilities for a parent to stay. Wherever

possible, outpatient facilities should be oriented towards the child and family and in-patient and outpatient equipment and facilities be safe for paediatric care.

The Radiation Oncologist treating the child at Peter Mac should also be a member of the multidisciplinary team at both Level 1 and Level 2 sites. Adequate back up and on call arrangements for paediatric radiation oncology must be assured and in place.

As Peter Mac establishes satellite sites for radiotherapy for the adult population, consideration should be given to decentralising paediatric radiation to the sites whilst maintaining an integrated service. The principle of assisting children to have appropriate and agreed elements of their care close to home underpins this proposal.

#### **4.4 Tasmanian services**

The relationship between Tasmania and Victoria requires exploration and development.

Preliminary discussions indicate the service in Hobart is separate from the RCH Children's Cancer Centre but will be supported by the Children's Cancer Centre. Medical oncologists will support the local clinicians by attending agreed clinics in Hobart.

Training opportunities for Royal Hobart Hospital medical, nursing, allied health and psychological support will be facilitated by PICS and the RCH and MMC Children's Cancer Centre staff. It will be necessary to have a formalised agreement with Tasmania.

**Table 3 : Core service components by service level**

Core service components	Service Level				
	1	2	3	4	5
<b>Personnel – Clinical Services</b>					
<ul style="list-style-type: none"> <li>• Designated lead clinician (Director)</li> <li>• Paediatric clinical oncologist</li> <li>• Paediatric clinical haematologist</li> <li>• Radiation oncologist with expertise in paediatric radiotherapy (available to team)</li> <li>• Paediatrician</li> <li>• GP</li> </ul>	√	√	√	√	
	Min 2	Min 1			
	Min 2	Min 1			
	Min 2	Min 1			
			√	√	
					√
<b>Junior and middle grade cover</b>					
<ul style="list-style-type: none"> <li>• Fellow</li> <li>• Registrar</li> <li>• Resident</li> </ul>	2-3	1			
	1	1			
	2	1			
<b>Other specialist services necessary on site (24 hours)</b>					
<ul style="list-style-type: none"> <li>• Paediatric anaesthetist</li> <li>• Paediatric surgical service (general, orthopaedic, neurosurgical)</li> <li>• Paediatric medical imaging service</li> <li>• Paediatric pathology</li> <li>• Paediatric In-patient ward</li> <li>• Transition service</li> <li>• Designated paediatric oncology pharmacist</li> <li>• Designated lead psychological service</li> <li>• Designated lead psychiatric service</li> <li>• Pharmacist</li> <li>• Rehabilitation team/services</li> </ul>	√	√			
	√	√			
	√	√			
	√	√			
	28	8	2		
	√	√			
	√	√			
	√	√			
	√	referral			
				√	
	√				
<b>Nursing establishment</b>					
<ul style="list-style-type: none"> <li>• Paediatric Oncology Unit Manager</li> <li>• Identified lead paediatric nurse</li> <li>• Specialist trained nurses for ward and day care</li> <li>• Paediatric oncology clinical nurse co-ordinator</li> </ul>	√				
	√	√	√	√	
	√	√	√		
	√	√			
<b>Core paediatric allied health professional service (oncology specific) available to team)</b>					
<ul style="list-style-type: none"> <li>• Art/music therapy</li> <li>• Interim prosthetic service (recommended)</li> <li>• Dietetics and Nutrition</li> <li>• Physiotherapist</li> <li>• Educational Play specialist</li> <li>• Social work</li> </ul>	√				
	√				
	√	√	√		
	√	√	√		
	√	√			
	√	√	√		

• Speech Pathology	√	√			
• Occupational therapist	√	√			
• Audiology	√	√			
• Education – school outreach program	√	√			

**Table 3 (continued) : Core service components by service level**

Core service components	Service level				
	1	2	3	4	5
<b>Research support and capacity</b>					
• Laboratory	√				
• Public health	√				
• Clinical research	√	√			
• Clinical education nurse	√	√			
• Affiliated with research facility	√	√			
• Access to Data Manager support	√	√			
<b>Immediate access (24 hours) to:</b>					
• Intensive care unit with paediatric beds	6 beds	3 beds			
• Paediatric consultant emergency service (with on site junior medical staff)	24 hrs	24 hrs	24hrs		
• Paediatric consultant neurosurgical services	24 hrs	24 hrs			
• Other tertiary paediatric services (cardiology, renal, endocrinology, other specialised surgical services)	√	√			
• Pain management team and/or service	√	√	√		
<b>Mandatory multidisciplinary clinics; documented and held regularly</b>					
• Tumour group specific	√	General			
• Long Term Follow-up	√	√			
• Transition	√	√			
<b>Allied/Associated Services</b>					
• Access to offsite hostel/family accommodation	√	√	√		
• Video conference facilities	√	√	√		
• Bereavement service	√	√			
• Dental services	√	√			
• Palliative Care Services	√	√			
• Education	√	√	√		
• Formal continuing education program					
<b>Documentation</b>					
• Written guidelines to support agreed levels of care	√	√	√	√	
• Identified shared care agreement	√	√	√		
• Clear protocols to guide practice	√	√	√	√	
• Identified key contacts	√	√	√	√	

## 5. The pathway of care

*'The **best care** in the best facility as close to home as possible'*

Whether children receive their care within one service or through a range of shared care agreements, there must be an agreed pathway of care. The ability for a service to provide care within a shared-care agreement will be dependent on their capacity to provide the range of services required at the relevant points within the pathway.

There are a range of components that make up the pathway of care and include:

- the clinical aspects of care at the different points in the care pathway
- the components of psychosocial care required to support the child throughout the treatment and their long-term recovery
- end-of-life.

While in practice all or some of these pathway components are clearly integrated for the effective care of children and families, for ease of reading, the next three sections detail the elements that make up each of the identified components of the pathway.

## 6. The pathway of care – clinical and supportive care services

This includes consideration of the requirements at key points in the diagnostic and treatment pathway as well as the clinical services needed to support the child through active treatment.

### 6.1 Presentation and referral for diagnosis

A prompt diagnosis and referral of patients with suspected cancer to Level 1 or 2 cancer sites is essential.

As indicated PICS should facilitate discussion to ensure that:

- there are agreed guidelines for referral of children and young people with suspected cancer from the community and hospitals to Level 1 or 2 Cancer Service Sites.
- there is clear agreement regarding the diagnoses to be managed at Level 1 and 2 cancer sites.

These arrangements should be well publicised to health professionals within Victoria and should reflect the different types of cancer which may occur, and age-related needs. Information should include the availability of telephone

advice, named specialists, web page information and via a program of organised training and education for general and medical specialists.

## 6.2 Diagnosis

Establishing an accurate diagnosis is essential for the management of cancer in children and young people. In almost all cases, a histopathologically or cytologically confirmed diagnosis from a needle or open surgical biopsy or bone marrow aspirate is required. Diagnosis also requires access to cytogenetics, molecular genetics and immunophenotyping.

### 6.2.1 Pathology services

Histopathological diagnosis of paediatric tumours can be difficult due to their relative rarity, the overlapping morphological phenotypes, the increasing use of small core biopsies for primary diagnosis and the different interpretation of pathological features in the context of paediatric as opposed to adult cases.

Haematologists are responsible for the morphological diagnosis of leukaemia and for the reporting of bone marrow aspirates and trephine biopsies from patients with solid tumours. The spectrum of leukaemia in childhood is different from that in adults, and so diagnosis and the ongoing assessment of response to chemotherapy is best provided by a specialist paediatric haematologist.

#### Key point

Many leukaemias and solid tumours are unique to children and thus pathology and histopathology services for children should be provided by specialist paediatric haematologists and pathologists.

Level 1 and Level 2 cancer service sites must have access to:

- specialist paediatric histopathologists for the pathological diagnosis of solid tumours in children
- specialist techniques, such as immunohistochemistry, cytogenetics
- molecular genetics, molecular diagnosis or spinal fluid cytology for paediatric tumour samples.
- facilities for tissue/cells/DNA storage.
- paediatric haematologists for the laboratory and clinical management of children with leukaemia and hemopoietic stem cell transplantation (HSCT)
- paediatric anatomical pathology facilities for undertaking autopsies.

### 6.2.2 Diagnostic imaging

Timely access to appropriately skilled paediatric diagnostic imaging specialists, including nuclear medicine physicians, is essential in evaluating children and young people with possible or confirmed malignant disease. There are particular difficulties in imaging younger children and infants, which mean that these procedures need to be carried out in centres with the appropriate expertise.

Magnetic Resonance Imaging (MRI) is essential for the accurate diagnosis of CNS tumours and for many other solid tumours of childhood. However, there are difficulties with access in many centres in Victoria due to the child's need for general anaesthesia.

For some patients, imaging-guided needle biopsy may be the most appropriate method to obtain tissue for diagnosis. Although this may prevent the need for an open surgical biopsy, it requires particular expertise not only for the procedure itself, but also in the handling of the resulting tissue sample. Level 1 and Level 2 cancer sites must have the services of an experienced Medical Imaging expert in paediatric interventional radiology.

The role of Positron Emission Tomography (PET) scanning in managing paediatric patients requires clarification, however it is established that PET has a role in evaluating patients with malignant lymphoma, which constitutes a significant proportion of paediatric patients. As PET becomes more widely available, its application to the paediatric setting will be clarified. If appropriate, a paediatric PET should be considered at the Level 1 site (RCH).

Following diagnosis, children and young adults with malignancy often require serial imaging for the assessment of disease response and recurrent CT scanning may expose them to significant amounts of radiation. CT scanners with specialised paediatric features including dose reduction should be available.

#### Key points

- Timely access to appropriately skilled paediatric diagnostic imaging specialists, including nuclear medicine physicians, is essential in evaluating children and young people with possible or confirmed malignant disease.
- Wherever possible a cumulative record of radiation dose from medical imaging procedures should be available and may be needed by the long term follow-up team.

### 6.2.3 Surgical diagnosis

Paediatric surgical expertise is required from specialist paediatric surgeons for children and young people with suspected malignancy. The majority of children with solid tumours require surgery, either a biopsy to establish a diagnosis or

surgical resection before or after chemotherapy as part of the definitive treatment.

See 7.3.2 for additional information of surgical management.

### **6.3 Treatment**

Treatment describes those therapeutic interventions used directly for the management of the malignant condition. The medical treatment of childhood and adolescent cancers comprises three main modalities; surgery, chemotherapy and radiotherapy. Other modalities are also used e.g. stem cell transplantation.

The relative use of each modality depends on the underlying diagnosis and, to some extent, the age of the patient. For instance, radiotherapy is avoided whenever possible in young children, given the greater long-term effects.

#### **6.3.1 Chemotherapy**

Chemotherapy is the primary modality of treatment for haematological malignancies. For solid tumours it is usually used in combination with surgery, with or without radiotherapy.

The use of chemotherapy in the treatment of central nervous system tumours has also increased over recent years.

Regimens of varying intensity, employing different routes of administration and patterns of delivery, are used. Many are becoming increasingly complex and intensive and can be associated with significant immediate and late side effects and morbidity. The delivery of chemotherapy to children, particularly small children, is more complex with a greater potential for errors than in adults.

There are a number of reasons why there are particular risks of error in giving chemotherapy to children:

- all doses have to be carefully calculated and prepared and fluid volume has to be tailored to the size of the child. Standard or upper dose limits are less relevant in children and there is a wide range of dosage e.g. methotrexate
- weight loss or gain can significantly alter the correct dosage, requiring close patient observation
- many drugs are not licensed for use in children, in particular the very young. Many are not routinely prescribed and treatment protocols are often very complex
- oral preparations may not be palatable or available to children and adherence may be difficult
- tablets may not be available in sufficiently small sizes, requiring portions of the tablets to be given or necessitating metronomic prescribing.

### **Key points**

- Chemotherapy should be delivered by properly trained staff in approved centres.
- These sites should work together to achieve agreed standards of service, with agreed written protocols for administration and recording of chemotherapy.

Most children and young people receive treatment administered in hospital under the direct supervision of health professionals, however, some treatment regimens can be administered safely at home, either by children's community nurses, other health professionals or families. Where this is possible, home-based care should be developed and supported.

Some patients receive prolonged outpatient based oral maintenance chemotherapy. However, there is some evidence to suggest that children's adherence with taking oral chemotherapy could be improved. Adherence may be worse in teenagers, those with a poor understanding of their illness, those with greater levels of denial, those with lower literacy levels and perhaps those where English is a second language.

New methods of improving and assessing adherence should be explored and encouraged.

A standardised chemotherapy and drug instruction chart should be developed across PICS sites for use by all pharmacies for all children especially for those not on clinical trial.

Consideration should be given to developing a standardised 'drug' package and instruction kit common to all PICS drug-dispensing units which uses 'plain' English and ideally be available in alternative languages.

### **Pharmacy services**

- All chemotherapy should be prepared and monitored by pharmacists trained to national standards.
- There should be adequate provision of facilities for the aseptic reconstitution of cytotoxic agents.
- A designated paediatric pharmacist should be part of the multidisciplinary team in Level 1 and 2 sites with a senior credentialed pharmacist at Level 3 site.
- In the interest of patient safety and consistency of distribution, consideration be given to the development of state-wide agreed methods of distribution and documentation.

### **6.3.2 Surgical management**

There is growing expertise in paediatric surgical oncology with surgery being undertaken with both diagnostic (see 7.2.3 ) or therapeutic intent. Many patients also need surgery for other reasons, such as establishing and maintaining central venous access or the insertion of a gastrostomy to aid nutrition.

As some patients present as emergencies or develop complications requiring urgent surgery, it is important that there is appropriate access to emergency operating theatre sessions within and outside normal working hours.

Surgery for retinoblastoma, bone tumours and liver tumours requires very specialist expertise and for this reason, should be treated only at a Level 1 Cancer Service Site, preferably by a core team of paediatric surgeons who will develop oncology expertise.

The concept of creating the role of a specialist paediatric surgical oncologist and surgical planning team at the Level 1 cancer service site is supported by PICS and the RCH.

### **6.3.3 Neurosurgery**

Skilled neurosurgery is perhaps one of the most important determinants of outcome in many CNS malignancies. The presenting symptoms are such that referral is often made directly to a neurosurgical centre. Immediate referral to paediatric oncology is required if the child has presented initially at a neurosurgical/neurology clinic.

Referral mechanisms to facilitate timely referral to paediatric oncology should be developed.

### **6.3.4 Radiotherapy**

Radiotherapy is an important part of the management of many children and young people with cancer and in Victoria is provided through Peter Mac.

As curative radiotherapy commonly requires daily treatment for up to 5 weeks, it is essential that all available techniques including play therapy and distraction are used to promote the comfort of the child and potentially reduce the need for a general anaesthetic. Where general anaesthesia is needed for planning or treatment anaesthetic staff across PICS sites should work together to achieve consistent medical practice and procedures.

Nursing care must be provided to in-patient and outpatient children by nurses credentialed in paediatric care.

Therapy radiographers, with training in the planning and management of children with cancer are needed to provide safe and efficient care during radiotherapy. These specialists have detailed knowledge in the planning, delivery and anticipated side effects of radiotherapy and are required to maintain continuity of care during the planning and treatment period for the child and family.

The referral process and transition between services should be seamless. Clinical information needed including the referral, copies of diagnostic reports and images and pathology results should be available electronically for the referral process.

#### **Key points**

- The referral and treatment pathway for the child should be clearly documented and agreed.
- Referral could be enhanced by the inclusion of a multidisciplinary new patient clinic at the referring service site (Level 1 or 2).

#### **6.3.5 Clinical trials**

The inclusion of children in clinical trials has been the most important factor, among others, that has led to the improved cure rates in childhood cancers over the past 25 years.

It is vital that the maximum number of eligible patients participate in clinical trials, as this allows the consideration of identified prognostic factors, such as age, stage of disease and certain biological characteristics. Without high levels of participation, randomised clinical trials cannot be undertaken successfully and the potential for improvements in survival are lost.

#### **Key point**

- Both Level 1 and 2 cancer service sites should have access to clinical trial participation.

#### **6.4 Supportive care services**

Supportive care is the term for interventions used to support the patient through the anticancer treatment period. Outcomes in cancer are dependent not only on the safe and effective delivery of treatment, but also on the timely and effective management of the acute and longer-term side effects.

The management of issues such as pain and fatigue is vital for children and young people with cancer. When input is provided at the right time, it can facilitate home discharge and benefit the health and wellbeing of parents/carers, as well as the patient. Improvements in supportive care have played a key role in increased survival.

#### **6.4.1 Anaesthetic services**

Skilled paediatric anaesthetists and support staff (anaesthetic nurses/ technicians) are essential to the provision of safe care to children both for diagnostic and therapeutic interventions (see) and for the management of other diagnostic and therapeutic procedures (see below) .

Equipment for the provision of sedation, anaesthetics and recovery must meet standards required for paediatrics in all PICS sites.

Multidisciplinary protocols, which are consistent across the PICS, should be in place to support the safe and effective use of analgesia and these should be available in all care settings. Information provided to children and families should be consistent across the PICS.

#### **6.4.2 Procedural pain management**

A particular issue in the treatment of children with cancer is a need for regular painful procedures such as lumbar puncture and bone marrow biopsy. Often as a result of inadequate pain management, children experience distress associated with procedures. This may manifest itself in symptoms such as marked anticipatory anxiety including sleep disturbance, vomiting, feeling ill prior to arrival, withdrawal, lowered mood or even refusal of treatment.

Many younger children require general anaesthesia for these procedures. However play and the use of techniques, such as distraction or the use of cognitive behaviour therapies to enhance coping skills, can prepare children and young people for these procedures negating the need for a general anaesthetic.

Play specialist and recreational therapists are essential members of the pain management team and should be available within Level 1 and 2 services and ensure techniques used effectively with a child in one setting should be available across PICS and relevant regional shared-care programs.

### **Key points**

- A combination of psychological behavioural and pharmacological programs should be considered as part of a wider project to implement a standardised pain management program for the PICS.
- PICS should work with sites in establishing a procedural pain management model which is consistent and to which a child attending any site can expect to access .

### **6.4.3 Central venous access**

Children and young adults requiring venous access for chemotherapy and supportive treatment for cancer often need central venous access devices because:

- peripheral veins are more difficult to find and maintain in children
- the treatment regimens are complex and require multiple peripheral venous access
- the physical and emotional distress associated with the repeated peripheral venous access is an unacceptable burden for a child.

However, central venous catheters (CVCs) are associated with significant morbidity and, sometimes, mortality. Therefore, attention to detail in choice of device, method and timing of insertion, post-insertion care, maintenance and removal is essential.

General anaesthesia for insertion is necessary for children and may be necessary for many in the older age group. For Level 1 and 2 cancer service sites this will mean at least one weekly dedicated operating list.

Removal of CVCs should only be managed by trained personnel in an appropriate setting. Provision of sedation and/or anaesthesia as described above is usually necessary for some of these procedures.

### **Key points**

- There should be written guidance on the management of central venous access devices, including expert advice and consensus on the standard vascular devices available and imaging equipment which is consistent across PICS.
- All healthcare professionals involved in caring for patients with these devices should be trained to ensure competency.

#### 6.4.4 Fever and febrile neutropenia

Episodes of febrile neutropenia should be managed with caution and most patients are admitted for intravenous antibiotics.

Any treating unit should ensure it has sufficient capacity to allow admission to a bed with:

- appropriate facilities to permit isolation and protection for the sick child
- staff, both medical and nursing, trained and credentialed in the management of febrile neutropenia and its complications.

Patients and parents/carers should have consistent education and written information on the importance of seeking appropriate medical attention in a timely fashion and that care can be accessed readily.

There should also be an agreed open access policy with limited wait in Emergency Department. Methods to fast track emergency attendance should be considered (e.g. letter, passport, electronic stick).

#### Key points

- Protocols for the management of febrile neutropenia need to be consistent across PICS sites. When care is shared across treatment sites, this protocol should be agreed between Level 1, 2 and 3 cancer service sites and should include urgent transfer of sick patients when required.
- The protocol should be available in all relevant clinical areas, including wards and emergency departments.
- Copies of up-to-date protocols should be included in all shared care packs and be available on the hospital intranet.

#### 6.4.5 Blood product support

Children and young people who receive intensive or prolonged chemotherapy for cancer, develop pancytopenia (anaemia, neutropenia and thrombocytopenia from bone marrow suppression) and will require support with red cell and platelet transfusion.

Some children may develop abnormal blood clotting needing correction with fresh frozen plasma, and others may require regular intravenous immunoglobulin during periods of immunosuppression.

### **Key points**

- Blood products should be available 24 hours a day at Level 1 and 2 Cancer Service Sites and the same day at Level 3.
- Written protocols for the management of blood product support, agreed between the Level 1, 2 and 3 Cancer Service Sites should be available.

#### **6.4.6 Management of nausea, vomiting and bowel disturbance**

Nausea, vomiting and change in bowel habits are among the most distressing side effects of cytotoxic chemotherapy and radiation. Nausea and vomiting vary with the emetogenic potential of the drugs and individual susceptibility. Diarrhoea is a side effect of many drugs and also occurs as a result of immunosuppression. Constipation is also a common symptom.

Advances in the management of these symptoms have occurred with the use of improved drugs and evidence based multidisciplinary protocols.

Non pharmacological approaches to the management of nausea and vomiting are also available. Children and young people can be helped in the management of anticipatory nausea and vomiting through play and the use of techniques such as distraction, or the use of cognitive behaviour therapies such as relaxation and guided imagery to enhance coping skills.

### **Key points**

- There should be a written protocol across PICS for the management of chemotherapy and radiation induced nausea and vomiting.
- The protocol should also be available in all relevant clinical areas and in shared care packages.

#### **6.4.7 Nutrition**

Children differ metabolically from adults and continued growth and development is essential throughout treatment. Nutritional support in childhood cancer is an important part of supportive care and as treatment has become more intensive this has become even more essential. Nutritional depletion, secondary to prolonged anorexia, nausea, vomiting, mucositis and significant infectious complications, can be severe.

Other common side effects such as taste abnormalities, dry mouth, constipation, renal impairment and food aversion also affect nutritional intake. Children who experience swallowing difficulties should be referred to Speech Pathology.

Nutritional support, enteral or parenteral, should be designed to provide adequate protein, calories, vitamins and minerals for all children and young people, taking into account their age, condition and treatment.

Level 1 and 2 Cancer Service Sites must have dedicated trained paediatric dieticians.

The dietician and speech pathologist should attend relevant multidisciplinary meetings and meet with families at least once during admission and as referred by the multidisciplinary team.

**Note**

- Training in the general field of paediatrics is available for dieticians via the RCH certificate training program.
- Access to this course should be facilitated by PICS for all PICS sites including regional partners.

#### **6.4.8 Oral and dental care**

Cancer treatment results in acute oral cavity problems, such as mucositis and infection, as well as affecting developing teeth with an increased incidence of structural dental anomalies.

PICS should review oral care practice between centres with regard to preventative therapies and dental check-ups.

Consideration should be given to develop base guidelines for oral care for children and young people being treated for cancer, which includes an initial review at diagnosis, and information generation to the family preferred dentist. In addition, professional dental services should be identified at the treatment centres and referral mechanisms established.

**Key Point:**

Consistent information on the effects of cancer treatment to the mouth should be provided to all patients and their parents/carers in the initial information pack and via the shared care package.

#### **6.4.9 Immunisation**

Advice to families regarding immunisation is not consistent between medical staff across the PICS.

**Key Point:**

Policy and information should be reviewed and included in the new diagnosis information pack for children and parents and GP packs.

## 7 The pathway of care – supporting the child and family

*'The best care in the best facility as close to home as possible'*

The impact of a cancer diagnosis and treatment can have a profound impact on children and their families, both in the short and longer term. These impacts may include cognitive impairment, functional loss, emotional distress, loss of connection with peers and significant disruption in schooling. Disruption to the family can cause family and sibling distress both during and following treatment.

A range of approaches are required to support children and their families both during treatment, rehabilitation and long-term follow-up

### 7.1 Psychosocial care

The diagnosis of cancer in a child or young person often throws a family into crisis. The patient faces the challenge of the disease, its symptoms and the side effects of treatment. Children and young people may experience significant problems with body image, anxiety, mood changes, relationships with peers and potential partners, difficulties with schooling and other education, or with employment.

The family experiences the shock and grief of a child faced with a life threatening illness and they too will have significant psychosocial needs. Evidence is clear that the majority of children with cancer and their families face the experience with competence and resilience and do well on the psychosocial level in the short and long-term. It should however be remembered that paediatric cancer treatment is traumatic and that however well they manage, it will have an impact on family life which may be long-lasting.

For a significant minority of patients and their families, ongoing distress and disturbance will be exhibited. For example, very high levels of anxiety in parents on diagnosis are predictive of ongoing levels of distress five years post-diagnosis.

Particular populations that require attention regarding needs and services also include:

- adolescents
- siblings
- infants
- families from culturally and linguistically diverse (CALD) backgrounds

- bereaved families

Psychosocial services need therefore to encourage and support resiliency in the majority of the population in an appropriate manner while targeting and addressing risk factors and distress in the minority.

There are also many practical issues for families to face during the treatment, such as difficulties with work, increased costs due to travel and hospital parking, living away from home, increased family stress, caring for other siblings, anxiety and depression in other members of the family. Consistent information on these issues and appropriate interventions targeting these issues, should be available to all patients at diagnosis and throughout treatment.

Psychosocial support needs are highly individual and will change as individuals and families move through the different stages of the treatment pathway as well as different child and family developmental stages (e.g. transitions to school, adolescence, birth of a new child).

Support services have an important role to play at all stages, including after completion of treatment and transitions into adult life, palliative care and family care after bereavement.

Some key principles guiding psychosocial services are summarised below.

**Key principles for the provision of the psychosocial service include:**

- Psychosocial services to children with cancer should be family-centred, child-focused and be provided within a developmental framework.
- Psychosocial resources should be fully integrated into multidisciplinary care teams and not be regarded as an adjunctive service.
- Psychosocial services should relate to and work in close collaboration with other psychosocial service providers, within and across cancer service sites and regional and the community sector.
- Development of mental health and psychosocial services should include the capacity for research and evaluation to allow the development of evidence based services.
- Psychosocial services should be available when and where the child/family needs them (location, in hours/after hours and by a range of disciplines).

It is essential that the roles and responsibilities of the team members delivering psychosocial care are clearly articulated and that there is avoidance of unnecessary service duplication.

There should be access to expert onsite psychological support with clear routes of referral at Level 1 and Level 2 cancer service sites. This should include

identified psychologists or other members of psychological services with expertise in the care of children and young people with cancer and their families.

Patients, siblings and family support groups are a valuable resource and should be managed centrally with a joint committee for access by all PICS sites.

The provision of appropriate psychosocial support to children, young people and their families is complex and multidimensional. The provision of support from psychosocial care professionals currently relies heavily on philanthropic sector funding. This funding should be quantified across the PICS sites with the view of achieving a sustainable service with government funding.

Psychosocial services between the PICS is varied in access, delivery and professional groups. Previous reviews of psychosocial services have concentrated on service site-specific issues and have not had a state-wide perspective.

In order to establish the needs across the PICS, PICS should undertake a review of psychosocial services (see Box)

#### **Key aspects of a proposed psychosocial review**

- a literature review and summary of National and International sites of “expertise”
- minimum levels of service (in hours and after hours).
- definitions of “best practice”
- recommendation for credentials of professional staff required to deliver the service.
- a model and structure of psychosocial services across PICS.

## **7.2 Neuropsychology services**

Access to neuropsychological services for cognitive assessment should be available, as appropriate, for all patients, particularly those with CNS tumours. Referral mechanisms should be established with the aim of providing a baseline assessment and yearly follow-up.

Due to the highly specialised nature of this discipline, discussion regarding centralisation of this service should be held.

## **7.3 Communication with children, young people and families**

Open communication between professionals, children/young adults and their families is a prerequisite for success. It is essential the patients and their families understand their cancer, their treatment and choices they may have. All patients and families are able to contribute to the management of their condition.

Information can be provided in different ways, including verbal, written, electronic and audiovisual. Different age groups will have different needs, as will parents, families and carers, and ensuring information is provided in an accessible way is a challenge.

Information provided should be consistent across PICS sites and managed centrally in an organised manner.

PICS should review information available to children and families at key points in the pathway with the intention of developing uniform, consistent documentation, which will be available to all sites in written and electronic (web) formats. Patients, families and service provider input should be requested when designing new information resources.

Consideration should be given to the development of communication by electronic and telecommunication. For example:

- text messages for adolescents or families to remind them of medical appointments or to take medications as needed
- email updates for routine communication of up and coming events, sibling days and perhaps even for reminders of appointments etc.

Whilst maintaining the probable need for hard copy correspondence, consumer involvement in establishing the extent of electronic communication should be investigated.

All healthcare professionals caring for children and young people with cancer should have appropriate training in communication skills. They should be trained to communicate sensitively and effectively with children and their families and allow sufficient time to do so.

Psychosocial services can play a key role in supporting this aspect of care. PICS will develop a suitable communications skills training program as part of its training model.

Consideration should be given to expanding the RCH consumer advisory group to include MMC families and if not suitable, a formal parents advisory group should be commenced at MMC. Consumer input should be facilitated and welcomed at all cancer service sites.

#### **7.4 Education services**

Children may be absent from school for considerable periods of time throughout their treatment, both when treated as in-patients and outpatients. It is important they maintain contact with their school teacher and class whilst an in-patient or unable to attend school.

For children unable to maintain levels of education due to frequent school absence flexible programs should be in place to permit access to the following:

- middle and senior school teachers available to adolescents admitted to the ward.
- school based and home based tutors.
- pre-school level education during in-patient stays.
- education programs to link the child with school.
- regular review and assessment of individual children on referral or recommendation from the clinical team.

## 7.5 Rehabilitation

The key characteristics of a Rehabilitation Service is that it offers combined and co-ordinated multidisciplinary care to those with functional loss through a goal-oriented, time-specific process.

Rehabilitation comprises the combination and co-ordination of interventions used to improve physical, emotional, social and educational outcomes as a result of functional loss during and after cancer therapy.

The requirements for rehabilitation fluctuate and can be urgent, particularly where prevention of further functional loss is required. Children in particular need for rehabilitation services include those following limb amputation, head and neck surgery or neurological surgery, when there may be a need for intensive and prolonged rehabilitation.

Rehabilitation uses a combination of approaches and interventions by a variety of different professional groups at different stages in the patient's pathway including speech pathology, physiotherapy, occupational therapy, prosthetics and orthotics, rehabilitation medicine, social work, neurology, endocrinology and psychology and neuropsychology.

Rehabilitation services should be available at Level 1 and Level 2 cancer service sites for both in-patient and ambulatory care.

### Key points

PICS together with Level 1 and Level 2 cancer service sites should ensure that:

- documented referral policies to guide referral for rehabilitation between the PICS sites and externally to regional and community providers are available
- adequately staffed rehabilitation teams are available to support children and young people and their families in hospital and the community
- an equipment hire/loan distribution centre is accessible from Level 1 and Level 2 cancer service sites.
- occupational therapists and other allied health team members are available to review the child and family in the home and school as part of the discharge plan.
- assessment and teaching of family and care givers in their own physical care and protection in caring for the child should be part of the discharge process and plan.

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PICS should work with the newly developing Victorian Paediatric Rehabilitation Service to ensure integrated paediatric cancer services are aligned with this service.

## **7.6 Long-term sequelae - late effects**

With increasing survival of children treated for cancer, the physical, emotional and social sequelae which may impair the quality of life in the long term, become more important.

Although many of those cured of cancer during childhood or young adulthood will return to good health, others will experience significant late sequelae. These include problems such as:

- impairment of endocrine function (including infertility, abnormal growth and development or bone mineral accretion),
- cardiac and neurological impairment,
- cognitive decline (e.g. following treatment for CNS tumours)
- psychological effects
- increased risk of developing a second cancer.

On average, four percent of childhood cancer survivors develop a second primary malignancy within 25 years of diagnosis although for certain diagnoses this figure is higher. Radiotherapy is a particular risk factor.

Depending on age at the time of therapy and the anticipated late effects, most patients enter long-term follow-up at five years after finishing active treatment.

It is estimated that in excess of 130 Victorian survivors of childhood cancer become eligible for long term follow-up each year. The number of patients needing access to a long-term follow-up service will steadily rise with improvement in survival rates.

Particular challenges in providing a long-term follow-up service are the wide range of services needed and the need for care to be sustained over many years for those patients experiencing or at risk of significant long-term effects.

Some patients with little or no morbidity may also need to be able to contact the treatment centre or follow-up service to receive relevant new information, emotional support or help with insurance and employment issues.

Continuity of care and transition to adult and community services is important in the treatment and follow-up of the original disorder, its sequelae or relapse, as well as in the provision of palliative care. While care may be provided throughout the journey by various medical clinicians (original consultant, long-

term effects consultant etc), the important aspect is that the approach to late effects preparation and management should be consistent.

### Key points

- Due to this increasing survivorship of children with cancer and the need for an ongoing relationship with medical, psychosocial and allied health staff in many cases into adulthood, there is a need to develop a comprehensive long-term follow-up program for Victoria.
- The program for managing the long term follow-up including transition to it requires discussion, agreement and implementation across the PICS.

## 8 The pathway of care - end of life care

*'The best care in the best facility as close to home as possible'*

Cancer remains a significant cause of death for children and young people. When cure is no longer possible, care should be tailored to the choices of the patient and family and take into account variations in local service provision.

End of life care involves care of the patient from the time when therapy is no longer given with curative intent. It is an active and total approach to care, embracing physical, emotional, social and spiritual elements. Dietetics, occupational therapy, play therapy and physiotherapy are an integral part of paediatric palliative care. Professionals from psychosocial services are integral in helping to support children, young people and their families, as well as being a resource to professionals. Palliative care may also appropriately involve active treatment with chemotherapy, including Phase I and II research studies, surgery or radiotherapy.

Most parents choose for their child to die at home. For some, particularly those with brain tumours, the palliative phase of their illness can be protracted and they may require complex symptom management during this time. It is important that appropriate medication and specialist equipment is always easily available.

The Victorian Paediatric Palliative Care Program (VPPCP) was established by the DHS to provide an important link between hospital services and community based palliative care.

PICS will work with VPPCP to ensure there is equitable and enhanced access to paediatric palliative care which includes:

- a sound community children's nursing infrastructure
- multidisciplinary teams
- coordination and continuity of care through a system of named key workers

- skilled medical support from general paediatricians with an interest and some training in paediatric palliative care
- appropriate links with voluntary services.

Teenagers and young adults with palliative care needs require special provision, which will often entail the development of partnerships between children and adult services. These patients require individual packages of care, which:

- recognise teenagers and young adults as a distinct group with special needs
- give full involvement in all aspects of decision making provided by multidisciplinary, multi-agency services
- provide coordinated joint working or transitional care with adult services
- address specific staff training needs regarding both palliative care and the management of young people.

### **8.1 Bereavement Services**

Although the family of a child or young person with cancer may experience a sense of grief from the time of diagnosis, this section deals only with bereavement after the death. Death usually occurs at home, following a period of palliative and terminal care, but may also occur in hospital. Less commonly, death may occur during treatment, either in hospital or at home. Bereavement support frequently begins during terminal care.

All families should have access to the support of psychosocial practitioners such as social workers and mental health practitioners that have expertise in bereavement care. In general, most patients and families benefit from the ongoing support of practitioners that they have formed a relationship with over the active treatment phase. In some instances, it is appropriate to introduce a new psychosocial practitioner who may be part of a local palliative care program or a local bereavement service.

Specific issues to be considered prior to and following death include:

- acute grief reactions from family members
- if death occurs in hospital, coordination of care of the family and transfer home
- ongoing needs of the family and transition to community based bereavement services if needed.
- post mortem, consent and tissue retention (including sperm storage)
- registration of the child's death by which practitioner.

## 9 Approaches to care, service systems and workforce development

*'The best care in the best facility as close to home as possible'*

A range of approaches will assist in providing optimal care to children and their families. These include the ways which service providers work together, streamlining of systems and processes to facilitate service consistency, continuity and efficiency, research and quality improvement and workforce development.

### 8.1 Approaches to care

Key approaches to care include the role of multidisciplinary teams, coordination and continuity of care and clinical information collection and sharing.

#### 9.1.1 Multidisciplinary teams

A complex range of services is required for children and young people with cancer, involving many disciplines and professional groups, and crossing organisational and institutional boundaries.

#### Key point

These multidisciplinary teams are many and varied, the composition of which, at any one point in a patient's journey, will differ and should reflect the patient's needs, both disease and age related.

Table 4 below gives the essential members of the multidisciplinary team in relation to particular needs. Other health care professionals may be involved in some or all of these meetings. The constitution and organisation of teams and meetings should also reflect the specific clinical activity/profile of individual treatment settings.

**Table 4: Suggested attendance of MDT members at Level 1 and Level 2 cancer sites during the care pathway**

Discipline	Diagnosis	Treatment	Psychosocial Support	End of Life Care/Supporting Care	Radiotherapy/Transition MDT	Long Term Follow-up
Paed.Oncologist	√	√	√	√	√	√
Fellow	√	√	√			
CNC	√	√	√	√	(Lvl 1 or 2/CNC PeterMac)	√
Social Worker	√	√	√	√	Lvl 1 or 2 and SW PeterMac)	
Nurse (ward/IP/OP)		√	√			
Data Manager		√				√
Pharmacist		√		√		
Dietician		√		√		√
Allied Health Professionals		√	√	√		√
Rehab Team		√		√		√
Play Specialist		√	√			
Mental Health	√	√	√	√		√
Teacher/Education Advisor		√	√			√
Medical Physician				√		√
Radiation Onc					√	
Endocrinologist						√
GP/Paediatrician						√
Palliative Care/ Psychosocial				√		√

### 9.1.2 Continuity of Care

There is a need to ensure integration and coordination of care within and between primary, secondary and tertiary care settings and across statutory and voluntary sectors.

Continuity of care will be enhanced by a range of processes including multidisciplinary care, clear routes of communication, consistent information and standardised treatment and referral protocols between different care/treatment settings within PICS. However, given the complexity of paediatric cancer care within and across services, a clinical nurse coordinator (CNC) should be identified for each child or young person and their family to coordinate services and assess the child's and family's needs.

#### Key point

- The CNC is seen as the pivotal or centralised professional coordinating the care and treatment of the child with cancer.

Because of the important role of the CNC, consistency of service and role definition, training and succession planning is essential across PICS sites.

To ensure the CNC has up-to-date knowledge of the services and skills available within the multidisciplinary team, a orientation program for new CNC staff should be developed and provided by allied health and psychosocial professionals.

Each child or young person and their family should have a written care/treatment plan, which draws together the provision of all components of care. Where appropriate, voluntary and community agencies can be recognised as integral to this care plan.

The written care/treatment plan can be updated regularly to include the individual arrangements for transition to end-of-treatment services. This plan should be documented by the CNC with sign-off from the appropriate clinician and other multidisciplinary team members. It should be available electronically to facilitate access by any member of the clinical team, including from remote sites.

## 8.2 Service systems

This includes outpatient and in-patient services, clinical information sharing and research and quality improvement.

### 9.2.1 Outpatient services

It is important that children attending PICS sites for outpatient medical care or day chemotherapy, experience similar environments and procedures.

When reviewing outpatient services, consideration should be given to establishing similar and consistent structures and operations across PICS sites and may include:

- consistent bookings/ appointments structure

- streamlined access to pathology/radiology results with access available across the PICS
- similar pharmacy prescription and record keeping
- consistent billing and privatised clinic structure
- video conferencing between clinics
- minimum standards of consultant attendance to review patients under their care.
- electronic linking of pathology, imaging and other support services
- balanced relationship between commitment and patient service for research-orientated clinicians and those oncologists working mainly in clinical care .
- consistent approach to communication to GPs and community staff.

### 9.2.2 In-patient services

In order to ensure high standards of nursing care, maximum medical consultation opportunities and access to dedicated oncology equipment and facilities, in patient care should be centralised in a paediatric focused cancer ward.

In-patient ward rounds should be held daily between medical, nursing and allied health staff. One large multi-disciplinary ward round open to any interested discipline should be held weekly at a predetermined and fixed time. A consultant rostered to care for a child throughout the journey should expect to maintain contact with the child at agreed levels of care, which are consistent throughout the cancer service.

This agreed levels of contact and managing the patient expectations including the expectation of privately admitted patients requires exploration across the PICS.

In-patient wards must have the following facilities:

- paediatric safe bed and equipment including resuscitation equipment
- play therapists/recreational therapists/music therapists
- play/ art room appropriate for children and young people
- sound proofed treatment/procedure room
- parent sleep-over facilities
- parent retreat/parent and family room
- access to interview rooms for staff to conduct private and confidential discussions with patients and families.

#### Key points

- Level 1 and Level 2 Cancer Service Sites should have appropriate isolation facilities for the most heavily immuno-suppressed patients.
- Level 3 Cancer Service Sites without suitable facilities and where the child requires isolation, should transfer children to the Level 1 or 2 sites.

PICS should consider if a procedure is required to assist Level 3 sites without isolation facilities to document the trigger points for transfer.

### 9.2.3 Patient information collection and sharing

Clinical information about the patient collected at all PICS sites including radiotherapy should be available at any of the sites including regional partners via electronic technology.

## 9.2.4 Research and quality improvement

Level 1 cancer service sites should be affiliated with a research centre and encourage joint appointments for medical staff across the clinical and research precincts. The balance should be considered of the number of clinical sessions versus research time for hospital employees. The required number of sessions to provide required outpatient and in-patient service, research, administration and back-up for leave should be established.

In order to effectively measure the services provided within the partnership, a set of agreed indicators and acceptable standards should be developed and measured annually.

Examples of appropriate indicators are:

- clinical trial accrual
- number of children receiving multidisciplinary assessment
- frequency of consultant review during in-patient stay
- documentation of pain assessment
- discharge of summary completion rate (% with 3 days)
- % of discharge plan provision
- % of letters sent to GPs on new diagnosis
- correspondence turnaround rate
- patient / parent satisfaction
- adverse events
- number of complaints
- rural family satisfaction
- febrile neutropenia rate
- ICU admissions
- central line infection rate
- bone marrow transplant infection rate
- Cost (\$) per patient (compare this with cost per non-clinical trial patient)

### Key points

- Level 1 Cancer Service should be affiliated with research facilities.
- A set of measurable performance indicators should be agreed to for application across Level 1 and 2 sites.

## 8.3 PICS workforce development,

This includes both regional workforce development to support Level 3-5 services, as well as workforce issues across all service levels.

### 9.3.1 Facilitating shared care with regional services

As part of the discussions relating to services needed in the regional areas to achieve this Vision of Care, each hospital should be assessed with the intention of credentialing the staff for paediatric oncology competency, ability to support treatment protocols and procedures, facilities and equipment.

Recent consultation with the RICS and a survey of regional paediatricians have identified major areas of service and support required to achieve the PICS vision. These areas include professional education and access to information and include:

- education/continuing education delivered locally
- scholarship/attendance at Level 1 Cancer Service Sites for on-the-job training.
- diagnostic and pathology training.
- developing a network of information.
- Provision of a program of short courses, which can be made available to metropolitan and regional centres.
- An updated RCH Children's Cancer Centre
- Development of consistent printed information to GPs, paediatricians and regional centres.
- clarification of transition and shared care arrangements and consistency of approach is required across PICS.

### 9.3.2 Workforce development, credentialing and staff support

Services can only be sustained and developed if there are adequate numbers of appropriately trained staff. Providing care for children and young people with cancer and their families is emotionally demanding and recruitment of many varied professions is often difficult.

There are particular issues around the recruitment and retention of the following:

- paediatric radiologists, pathologists, medical and radiation oncologists
- laboratory staff, scientists and paediatric radiation technologists
- paediatric allied health professionals and nurses
- clinical psychologists and other members of the psychological team
- specialist hospital pharmacists

PICS, together with the professional disciplines should establish the recommended credentials and skill base required for the professionals working in the various levels of cancer service sites including regional centres.

Significant rates of stress and burnout is experienced by health care professionals caring for oncology patients, which impacts on staff retention. This emotional stress necessitates the need for a PICS wide staff support program developed with staff.

#### Key points

- PICS, together with identified regional centres should develop a formalised regional outreach and shared care program. The program should include access to clinical information across sites, sharing of expertise and up skilling of regional partners.
- Recommended credentials for all professional disciplines working in children's cancer services should be identified and documented.
- A staff support program for professionals working in children's cancer services should be established

## Attachment 1: PICS Roadmap to achieving the Vision

### Introduction

In the initial development of PICS, a series of seven key target areas were identified to guide the development of an integrated service system for children with cancer and their families.

They are as follows:

Number	Key target area
1	To improve the delivery of state-wide specialist paediatric cancer services through the establishment of a state-wide PICS.
2	To ensure safe, low risk, best practice, efficient and high quality services to all PICS sites.
3	To enable quality improvement, consistent clinical practice and maintenance of professional expertise across the PICS partnership.
4	To improve coordination and sharing of expertise across all three paediatric cancer sites.
5	To create the capacity to improve state-wide trials, coordination and associated data management within the state-wide PICS.
6	To develop a multidisciplinary/multi campus approach to the provision of psychosocial support services.
7	To provide support for regional and community cancer services.

The following grid identifies each key target area and the key recommendations required to facilitate their achievement. Within each key target area, the recommendations are numbered e.g. 1.3, 4.2.

In the grid, comments and / or links have been made between key target areas and their recommendations with key sections within the Vision of Care. However further work is needed to confirm those recommendations that are less clearly articulated in the Vision of Care.

It is also important to note, that the key target areas have overlapping elements and recommendations. In the future development of a specific strategy, it will be necessary to draw on the relevant recommendations across key target areas.

For example, a communication / information strategy for children and families would include the following recommendations:

**Key target area 1:** recommendation 1.4.vii: consistent information across the pathway

**Key target area 2:** recommendation 2.8: electronic and telecommunication approaches to communication / information provision

recommendation 2.9: consistent, informative consumer information resources in electronic and hard-copy

**As with the Vision of Care, this RoadMap is a 'work in progress' and will be reviewed as part of regular strategic planning.**

**Key target area 1:** To improve the delivery of state-wide specialist paediatric cancer services through the establishment of a state-wide PICS.

Number	Recommendation	Comments /link with Vision of Care
1.1	<p><b>An organisational structure to support the PICS initiative which includes:</b></p> <ul style="list-style-type: none"> <li>i) documenting the relationship structure between service providers, PICS and DHS.</li> <li>ii) development of an organisational structure for the PICS in order to provide an agreed future direction for planning of clinical.</li> </ul>	Required prior to development of this Vision.
1.2	<p><b>A model of care for Victorian will be developed which will have wide circulation for comment and discussion.</b></p>	Section 3: Background Section 3.5: Principles guiding the Vision
1.3	<p><b>PICS will undertake a service mapping exercise which provides an audit or 'snap-shot' of services provided by PICS sites as of 1 July 2005.</b></p>	Section 3: Background
1.4	<p><b>PICS will work to ensure that for services provided to children and young people within the PICS partnership:</b></p> <ul style="list-style-type: none"> <li>i) there is clear identification of cancer services that are credentialed for levels of service, based on infrastructure and support services and available facilities.</li> <li>ii) that all aspects of care for children and young people with cancer should be undertaken by appropriately trained and credentialed staff.</li> <li>iii) that all sites delivering cancer therapy should be subject to peer review.</li> <li>iv) that access is available to an agreed range of psychosocial services.</li> <li>v) there is an agreed range of pain management tools and services commensurate with the grading of the cancer site.</li> <li>vi) there are formalised and approved clinical protocols for treatment and care, minimum standards and defined areas of responsibility.</li> <li>vii) there is consistent information on diagnosis and equal access to ongoing information throughout the journey irrespective of where the child lives in Victoria</li> <li>viii) there is formalised shared care arrangements with regional centres</li> <li>ix) there are developed clinical pathways enabling children to attend facilities close to home for agreed components of care.</li> <li>x) that research underpins the work of the childrens cancer service across Victoria</li> </ul>	<p>Section 5: The recommended service framework</p> <p>Section 10.2.4: Research and quality improvement (<i>not specifically articulated</i>)</p> <p>Section 8.1: Psychosocial care</p> <p>Section 7.4.2: Procedural pain management</p> <p>Sections 7-10: Pathway of care and approaches to care.</p> <p>Section 8.3: Information and communication</p> <p>Section 5: The recommended service framework</p> <p>Section 10.3.1 Shared care with regional services</p>

Number	Recommendation	Comments /link with Vision of Care
1.5	PICS will ensure that a patient satisfaction survey common to all PICS sites will be developed and undertaken annually for three years.	Section 10.2.4: Research and quality improvement.

**Key target area 2:** To ensure safe, low risk, best practice, efficient and high quality services including increasing the supporting capacity of Monash Medical Centre

Number	Recommendation	Comments / link with Vision of Care
2.1	<p><b>Within the PICS partnership, the two Children’s Cancer Centres based at the Royal Children’s Hospital and Southern Health, Clayton Campus (MMC) should work towards :</b></p> <ul style="list-style-type: none"> <li>i) Uniform department policies and procedures.</li> <li>ii) Equivalent employment terms and conditions for those working across and between sites.</li> <li>iii) Uniform and consistent organisation and management of fee for service, outpatient clinic including billing, private practice arrangements booking procedures and medical attendance.</li> <li>iv) Similar “look and feel” to encourage patient movement between the sites as appropriate.</li> <li>v) Equivalent access to psychosocial, allied health, education and outpatient services between the sites.</li> <li>vi) Consumables used across PICS will be compared for purchase price and economics of bulk purchases and savings investigated.</li> </ul>	<p>Section 5: The recommended service framework. <i>(some of these recommendations are not specifically articulated)</i></p> <p>Section 10.2: Service systems</p>
2.2	<p><b>PICS will, in conjunction with the partnership work to ensure that children and young people have access to all elements of appropriate cancer services within the PICS sites.</b></p>	<p>Sections 5-10.</p>
2.3	<p><b>Transition between the Children’s Cancer Centres (MMC and RCH) and between these hospitals and the Peter MacCallum Cancer Centre should be reviewed with emphasis on minimising barriers to the child and family.</b></p>	<p>Section 5.1: Specialist paediatric cancer services Section 7.3.4: Radiotherapy Section 10.1: Approaches to care</p>
2.4	<p><b>A long term follow-up program including transition to be developed for PICS sites including protocols for transition .</b></p>	<p>Section 8.6: Long-term sequelae</p>
2.5	<p><b>The transition to palliative care requires consideration and discussion with the goal of achieving agreement on the process.</b></p>	<p>Section 9: End of life care</p>
2.6	<p><b>Clinical information at service sites, relating to the patient, should be held centrally and available at each site.</b></p>	<p>Section 10.2.3: Patient information collection and sharing</p>

Number	Recommendation	Comments / link with Vision of Care
2.7	A review of equipment in the paediatric wards, recovery, anaesthetic and treatment areas across PICS will be undertaken to ensure the best quality paediatric standards are met.	Section 7.1: Anaesthetic services Section 7.3.4: Radiotherapy Section 10.2: Service system
2.8	PICS will work to develop consistent, informative consumer information resources (electronic, web based and hard copy) for patients, families and shared-care partners.	
2.9	Electronic and tele-communication with individual children, adolescents and families should be considered.	Section 8.3: Information and communication
2.10	A combined PICS Parents Advisory Committee should be considered.	Section 8.3: Information and communication
2.11	PICS sites to recommend that children have chemotherapy only at centres credentialed to do so. A credentialing process to be established.	Section 5: The recommended service framework Section 7.3.1: Chemotherapy
2.12	There should be a consistent and standardised method of recording drug provision (chemotherapy agents) at the point of distribution across PICS sites.	Section 7.3.1: Chemotherapy
2.13	Children/families should receive drugs in an agreed method across the PICS sites, which includes alternative languages and consistent plain English instructions.	Section 7.3.1: Chemotherapy Section 8.3: Information and communication
2.14	General anaesthetic provision for children should be considered as part of a wider pain management and control program, which is common across all PICS sites.	Section 7.4.1 Anaesthetic services Section 7.4.2: Procedural pain management
2.15	Obtain consensus for CVA devices across PICS sites.	Section 7.4.3: Central venous access
2.16	Central line access should have consistent written information across the PICS.	Section 7.4.3: Central venous access Section 8.3: Information and communication
2.17	Methods to fast track admissions for neutropenia to Emergency Wards should be considered.	Section 7.4.6: Febrile neutropaenia
2.18	Appointment of a dedicated surgical oncology consultant to be investigated.	Section 7.3.2: Surgery

Number	Recommendation	Comments / link with Vision of Care
2.19	Access to dental services should be reviewed to document the referral process and to ensure consistent services are provided across the sites.	Section 7.4.8: Oral and dental care

**Key target area 3:** To enable quality improvement, consistent clinical practice and maintenance of professional expertise across the PICS partnership.

Number	Recommendation	Comments / link with Vision of Care
3.1	Consensus must be achieved between the PICS partnership and regional centres regarding the definition of cancer sites (Level,1, 2, 3, etc).	Section 5: The recommended service framework
3.2	A common quality assurance tool which meets EQUIP requirements should be developed for use in the Children's Cancer Centres across the PICS partnership.	Section 10.2.4: Research and quality improvement <i>(not specifically articulated)</i>
3.3	A set of key indicators should be developed and agreed across the partnership. The indicators should include clinical, administrative, outcome and qualitative items.	Section 10.2.4: Research and quality improvement
3.4	Clinical pathways (roadmaps) should be reviewed to obtain consensus and should be used throughout the Level 1 and Level 2 sites (and Level 3 where relevant).	Sections 6-10
3.5	The vision of PICS is to have medical, nursing and other positions as appropriate employed across PICS.	
3.6	A credentialing process for all clinicians and support staff should be undertaken with clear recommendations for staff development.	Section 5: The recommended service framework Section 10.3.2: Workforce development
3.7	Standards should be agreed across PICS for nurses working with childhood cancer.	
3.8	Guidelines for the model of care for consultant involvement in day-to-day and outpatient attendances should be formulated in order for children attending multiple sites to be able to expect similar arrangements. This should include the frequency and schedule of "on site" ward rounds and the method of allocation of children to consultants on diagnosis.	Section 10.2.2: In-patient services Section 10.2.4: Research and quality improvement
3.9	Continuing education programs should be reviewed, developed and integrated between the sites for all professional groups to have access.	Section 10.3.2: Workforce development <i>(not specifically articulated)</i>
3.10	Allied Health specialities across Level 1 and Level 2 sites should attend appropriate and agreed continuing professional development for managing children with cancer.	Section 8.5: Rehabilitation <i>(not specifically articulated)</i>
3.11	A staff support program should be established and made available across the PICS.	Section 10.3.2: Workforce development <i>(not specifically articulated)</i>

Number	Recommendation	Comments / link with Vision of Care
3.12	Philanthropic funding of core hospital activities should be quantified and a business plan prepared to seek funding support at government level.	

**Key target area 4:** To improve coordination and sharing of expertise across all three paediatric cancer sites.

Number	Recommendation	Comments / link with Vision of Care
4.1	Joint appointments (medical, nursing and allied health), wherever possible, should be pursued for staffing appointments across the partnership. Equivalent terms and conditions should be ensured.	Links with Key target area recommendation 3.5 ( <i>no clear articulation within Vision</i> )
4.2	Consideration should be given to the joint appointment of a Manager to the Children's Cancer Centres (RCH & MMC).	
4.3	To facilitate co-ordination and consistency between the Level 1 and Level 2 cancer site, an organisational and relationship structure should be considered which demonstrates an integrated approach to cancer.	Links with Key target area recommendations 1.1.ii 2.1
4.4	Formal avenues for communication between the sites and professionals should be established. Methods should include combined clinical meetings, multi-disciplinary forums, quarterly planning/executive meetings in conjunction with electronic and written means. Establishment of professional groups (medical, nursing and allied health) for clinical leadership as a state resource is encouraged.	
4.5	A review of expertise of staff and the frequency of need should be considered in order to ascertain how best to share expertise across the partnership e.g. where the requirement for specific expertise is rare, the specialist should remain centrally with a mechanism for sharing the expertise to the child and family.	
4.6	There should be a continuing improvement process.	Section 10.2.4: Research and quality improvement.
4.7	Across the PICS, an agreed position on immunisation and school attendance should be established and included in the patient information pack.	Section 7.4.9: Immunisation
4.8	Each newly employed CNC should attend an orientation program offered by allied health and psychosocial services in order to ensure the CNC is up to date with current available services and skills of the professionals working with childhood cancer.	Section 10.1.2: Continuity of care

**Key target area 5:** To create the capacity to improve state-wide trials, coordination and associated data management within the PICS.

Number	Recommendation	Comments / link with Vision of Care
5.1	All children and young people with cancer should be offered entry to any clinical research trial for which they are eligible. If there is no currently open relevant trial, children and young people with cancer should be treated according to agreed treatment and care protocols based on expert advice, and resources provided to monitor and evaluate outcomes.	Section 7.3.5: Clinical trials
5.2	An appropriately detailed costing is required to establish the real cost of providing clinical trials. The balance of funded and non funded trials require balancing with philanthropy and DHS approached to fund the non-funded trials.	Section 7.3.5: Clinical trials <i>(not specifically articulated)</i>
5.3	Consideration should be given to specifying the relationship of research to clinical care within the integrated cancer service including the balance of consultant time allocated to research within hospital sessions.	Section 10.2.4: Research and quality improvement
5.4	Benchmarking exercise should be undertaken to quantify the number of children on trials at other leading paediatric facilities.	Section 7.3.5: Clinical trials <i>(not specifically articulated)</i>

**Key target area 6:** To develop a multidisciplinary-multi-campus approach to the provision of psychosocial support services

Number	Recommendation	Comment / link with Vision of Care
6.1	As part of the review of psychosocial services clear recommendations are required regarding the need and aim of education play therapy, recreational therapy and education services for the child, the adolescent and young adults.	Section 8.1: Psychosocial care Section 10.2.2: In-patient services
6.2	Psychosocial needs will be reviewed and quantified by the development of a model of care for a co-ordinated approach to service provision across the PICS.	Section 8.1: Psychosocial care
6.3	<p>Pain management and control must form the basis of a collaborative project between the sites.</p> <p>The vision being a consistent approach to pain management, distraction and self directed care across all sites thus permitting children to move between sites with confidence and assurance. The preferred techniques will be available and acknowledged.</p>	Section 7.4.2: Procedural pain
6.4	A review of paediatric skilled/trained medical, allied health and psychosocial services on call and after hours service is required with the aim of best practice (e.g.. Physiotherapy, social work, medical specialists, mental health services).	Section 8.1: Psychosocial care
6.5	Standards for best practice bereavement care should be integrated into PICS standard.	Section 9.1: Bereavement

**Key target area 7: To provide support for regional and community cancer services**

Number	Recommendation	Comments /link with Vision of Care
7.1	<b>The Regional Outreach Program must include the needs as determined by the regional centres.</b> i) A regional survey should be conducted to ascertain the needs. ii) The regions will require access to agreed clinical protocols and procedures.	Section 5.2: Generalist services providing shared care Section 10.3.1: Facilitating shared care
7.2	<b>To establish quality of care delivered in regional sites a credentialing process will be necessary.</b>	Section 5.2: Generalist services providing shared care
7.3	<b>PICS will develop, in conjunction with the community and regional centres an education and training program tailored to the professional groups caring for children with cancer</b>	
7.4	<b>Children and families in the regions should where appropriate be able to access consultation via video conferencing.</b>	Section 5.2: Generalist services providing shared care ( <i>not specifically articulated</i> ) Section 10.3.1: Facilitating shared care ( <i>not specifically articulated</i> )
7.5	<b>PICS will establish regional “partners” which will have established contacts, referral mechanisms and access to CCC protocols and procedures.</b>	Section 5.2: Generalist services providing shared care
7.6	<b>PICS will establish key paediatricians identified as lead clinicians and centres in regional Victoria.</b>	Section 5.2: Generalist services providing shared care
7.7	<b>Formalised arrangements for referral of children with suspected cancer from the community and regional areas is required.</b>	Section 5: The recommended service framework
7.8	<b>Formalised transition and shared care for children returning to regional centres throughout the treatment pathway.</b>	Section 5.2: Generalist services providing shared care
7.9	<b>A training package will be developed for Level 5 cancer services which includes relevant “upskilling” for the local GP.</b>	Section 5.2.3: Level 5 cancer service
7.10	<b>The relationship with Tasmania requires consultation and consensus between PICS, DHS (Victoria &amp; Tasmania).</b>	Section 5.4: Tasmanian services
7.11	<b>An agreed model of shared care is required between PICS and Tasmania.</b>	Section 5.4: Tasmanian services



## Paediatric Integrated Cancer Service

A statewide cancer service for children

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