



Paediatric Integrated Cancer Service

A statewide cancer service for children

Art, music and play therapy

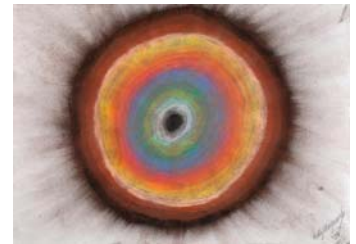
A service model for the future

Summary Report

Original report completed August 2007 by



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Executive summary

The Paediatric Integrated Cancer Service (PICS) was established in 2004 as a partnership between the Children's Cancer Centres at the Royal Children's Hospital and Monash Medical Centre and with Peter MacCallum Cancer Centre. The aim of PICS is to improve the quality of and access to cancer care for children and adolescents with cancer and their families across Victoria.

Art, music and play (AMP) therapy play an important role in creating a normal environment for children and adolescents with cancer and reducing the impact of the disease and treatment on both them and their families. However, the lack of sustainable funding has constrained service access and consistency of services for AMP therapy services.

A proactive approach is being adopted by PICS to develop stronger partnerships with specific Children's Cancer Charities to gain a more sustainable funding approach. This is underpinned by the development of an innovative AMP service model for the future across PICS service sites and related services.

Current AMP providers across sites have worked together to share experiences and knowledge to develop a **best practice model**. The more limited high level research evidence on the benefits of AMP service and the best way to deliver these services also provides an important opportunity to trial and evaluate new approaches to service provision.

The service model articulates **the vision for the future** being that all children and adolescents and their families will have access to developmentally appropriate experiences based on assessed need that will:

- Facilitate the child's normal growth, learning and development
- Reduce the impact of the illness and treatment on the child and family

A series of developed principles will also guide AMP practice in the future.

Key features of the service model are:

- A tiered approach based on need
- A focus on promotion, assessment, referral and care planning
- Strengthening service coordination and continuity of care
- Managing transitions as the child moves between services and sectors.

The service model is underpinned by enhanced professional development and a strong focus on quality improvement, service evaluation and the facilitation of research.

Achieving this service model presents an ambitious agenda for the future and requires significant investment of resources. Implementation also requires an investment by AMP and other stakeholders across PICS sites to work closely together to effectively trial and evaluate the proposed service model in a way that informs further service development.

Finally, the service model provides an opportunity to significantly strengthen Victorian children's and adolescents' access to high quality AMP services. It also provides an opportunity to set a benchmark for children's cancer services across Australia as well as services for other children facing significant life-threatening illnesses.

1 Introduction

The Paediatric Integrated Cancer Service (PICS) was established in 2004 as a partnership between the Children's Cancer Centres at the Royal Children's Hospital and Monash Medical Centre and with Peter MacCallum Cancer Centre. The aim of PICS is to improve the quality of and access to cancer care for children and adolescents with cancer and their families across Victoria.

Art, music and play (AMP) therapy play an important role in creating a normal environment for children and adolescents with cancer and reducing the impact of the disease and treatment on both them and their families.

The 2006 PICS Psychosocial Services Review identified some variations of and service gaps in access to AMP therapy services across service sites. This current variability in AMP access across PICS and the challenge of accessing sustainable funding has provided drivers to developing a high quality and consistent AMP service model across PICS sites and associated services.

This report firstly outlines the Project purpose and approach and the service context for current AMP services. It then provides an overview of the evidence for the role of art, music and play therapy for children and adolescents with cancer and summarises current AMP practices and service challenges within PICS. This then informs the development of the agreed service model for the future and the resources required to achieve this model.

Box 1 provides definitions for art, music and play therapy.

Box 1: Definitions for art, music and play therapy

Art therapy: The use of art expression and imagery with individuals who are physically ill, experiencing trauma to the body or who are undergoing aggressive medical treatment such as surgery or chemotherapy.¹

Music therapy: a systematic process of intervention in which the therapist uses music in the context of a relationship between the therapist and the patient to promote well-being in the patient.²

Play therapy: the systematic use of a theoretical model to establish an interpersonal process wherein trained play therapists use the therapeutic powers of play to help clients prevent or resolve psychosocial difficulties and achieve optimal growth and development.³

These definitions were identified through the literature review and have used differently terminology for 'patients / clients'. In the context of this PICS project, these are children and adolescents with cancer and their families.

¹ Malchiodi CA. 2000. The art and science of art therapy. In Malchiodi CA (ed) *Handbook of Art Therapy*. New York: The Guildford Press.

² Edwards J. 2005. A reflection on the music therapist's role in developing a program in a Children's Hospital. *Music Therapy Perspectives*. 23 (1): 36-45.

³ Association of Play Therapists 2001. As cited in Reddy LA, Files-Hall TM & Schaefer CE. 2005. *Empirically based play intervention for children*. Washington. American Psychological Association.

2 Project purpose

The purpose of the Project is to develop:

- An agreed, consistent and integrated service delivery model for art, music and play therapy services across PICS linking with regional and community based services.
- A strategic plan and business case to facilitate the achievement of the service model through the acquisition of more sustainable funding for the future.

3 Project approach

The key activities for the development of an agreed AMP service model were as follows:

Literature review: this review examined the evidence for the role and benefits of art, music and play therapy for children and adolescents with cancer and their families.⁴

This literature review built on that previously undertaken as part of the 2006 PICS Psychosocial Services Project. Evidence has also been drawn from a parallel literature search on the long-term effects of childhood cancer.

The proposed service model also draws on supportive (psychosocial) care policy and service frameworks currently being used to guide adult and paediatric cancer services^{5,6,7}. These frameworks focus on a tiered approach to services, whereby services are tailored to meet the differing needs of the specific population.

Stakeholder consultation: This included individual stakeholder consultations and two workshops with art, music and play therapists employed across the three PICS sites and other associated service providers including social workers, nurse unit managers, and related service managers.

Prior to each workshop, service providers completed a range of tasks which included:

- Identification of current services, referral processes, service gaps and challenges, and their vision for the future
- Analysis of current levels of practice based on differing needs.
- Case-studies to demonstrate current practices.

This data was then collated and presented back to the service providers for clarification and further discussion. Further work was undertaken with the relevant service managers to finalise the service model and resource requirements.

4 The service context

As indicated PICS is a partnership between three major services which provide diagnostic, treatment and ongoing services to all Victorian children and families with cancer.

4.1 The patient profile across PICS

Approximately 160 children in Victoria are newly diagnosed with childhood cancer each year, a small number of whom are from interstate or overseas. The five year survival (and potentially cure) rate across all childhood cancers is estimated to be 70%⁸ and increasing.

The following summarises the profile of the children diagnosed in 2005 (see Table 1).

⁴ The literature review is available as a separate document.

⁵ Department of Human Services. Supportive care needs of people with cancer and their families. A model for supportive care provision in Victoria. www.health.vic.gov.au/cancer. Accessed June 2007.

⁶ Fitch M. 2000. Supportive care for cancer patients. *Hospital Quarterly*. 3 (4): 39-46.

⁷ Kazak, A, Cant MC, Jensen MM et al. 2003. Identifying psychosocial risk indicative of subsequent resource use in families of newly diagnosed paediatric oncology patients. *J Clin Oncology*. 3220-5.

⁸ Wallace W, Blacklay A, Eiser C, Davies H, Hawkins M et al. Developing strategies for long-term follow up of survivors of childhood cancer. *British Medical Journal*. 323:271-274.

- Just over half (51%) of all new diagnoses are for 'liquid' tumours (e.g. leukaemias)
 - 21% of new cases are children with brain tumours
 - 27% of new cases are children with 'solid' tumours (e.g. Wilms tumour, osteogenic sarcoma)
- 44% of children are aged 5 years and under at time of diagnosis
 - 31% are aged 6-12 years
 - 26% of children are aged 13 plus at diagnosis.

Table 1 provides the profile of children by PICS service site.

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

		Service					
		RCH		MMC		Peter Mac ⁹	
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%
	Total	135	100%	24	100%	68	100%
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%
	Total	135	100%	24	100%	68	100%

4.2 The service profile

The following summarises the key elements of each service with additional information about AMP services being provided in 6.3.

The **RCH Children's Cancer Centre** is the largest paediatric oncology service in Australia treating between 75-85% of all Victorian children across all diagnostic categories, complexity and age groups. It also provides services to children and families from Tasmania, interstate and through international referrals.

The purpose built Children's Cancer Centre has a 28 bed in-patient facility and co-located day oncology service that treats 15-35 children per day. Children with brain tumours are located on the RCH neurological ward, at least on initial diagnosis. The outpatient area is geographically located as part of the Children's Cancer Centre floor but separate from the in-patient and day oncology services. Six outpatient clinics are held each week. In addition, two general anaesthetic procedures clinics are held in the RCH Day Centre per week for between 12-14 children per clinic.

The RCH Children's Cancer Centre AMP service provide services across all areas on either a group or individual basis including support for the *Comfort First Program*, the current pilot program for enhancing the management of procedural pain (see 5.5.1 for more detail).

⁹ Note: Children attending Peter Mac will be predominantly having their primary diagnosis and / or treatment at RCH or MMC and are not a different cohort of children.

The **MMC Children's Cancer Centre** is situated within a large general hospital, as part of a general paediatric service. It provides care to approximately 25-30 new cancer patients per annum. Children with acute myeloid leukaemia and others needing bone marrow transplant are referred to RCH. MMC tends to see a higher proportion of younger children, as reflected in the 2005 figures in which 67% of children were aged 5 years and younger.

The MMC Children's Cancer Centre is a purpose built ambulatory care setting providing outpatient clinics, day oncology services and a general anaesthetic procedure service within the same environment. In-patient care is provided on the two general paediatric wards, depending on the child's age.

The MMC Children's Cancer Centre AMP service provides care to children in the ambulatory and in-patient settings. This includes support for the *Comfort First* trial at MMC. The staff also provide care to some children with non-malignant haematological conditions who are also seen at the Centre.

Peter Mac, as a specialist adult cancer service, is responsible for providing radiotherapy for children and adolescents. In 2005 just under 70 new patients were referred from RCH or MMC, primarily for curative treatment. Almost all of this care is undertaken in the ambulatory setting, with only a small number of children being admitted if they need total body irradiation.

Peter Mac also provides specific services to adolescents (>16 years) and young adults through its On Trac program.

In 2005, just over 40% of children received radiotherapy for brain tumours. Approximately 20% of radiotherapy was given with palliative intent. Just under 40% of children treated in 2005 were aged 6-12 years with approximately 30% being aged under 6 years and 30% over 12 years.

Given that most children and adolescents will receive between 5-6 weeks of treatment, it is estimated that an average of 5-6 children may be treated per week. However, the numbers of children treated at any one time is variable.

A weekly children's outpatient clinic is held. One radiotherapy machine has also been identified as the preferred machine for children with an associated 'child friendly' environment. All children requiring a general anaesthetic for radiotherapy are treated first thing in the morning. While it is preferred that other children and adolescents are treated first thing in the morning to reduce unnecessary waits, there is flexibility in appointments to accommodate children and family needs.

In addition to treatment, an increasing number of children are being seen for PET scans. In 2006 a total of 125 children had PET scans, a 73% increase on the previous year. In 2007 it is predicted that 200 children (an additional 60%) will have a PET scan. Some but not all of these children may then go on to have radiotherapy at Peter Mac.

Music therapy has been offered intermittently as the only AMP service at Peter Mac and its benefits have been reflected in a recent publication¹⁰.

Regional services: currently PICS is developing a Regional Outreach and Shared Care Program with a number of services in regional Victoria. Additional training and skills development is being undertaken to support regional service providers to provide some local care for the child and family.

¹⁰ O'Callaghan C, Sexton M & Wheeler G. 2007. Music therapy as a non-pharmacological anxiolytic for paediatric radiotherapy patients. *Australasian Radiology*. 51 159-162.

5 Art, music and play therapy

This section firstly considers the evidence about AMP therapy and then those factors identified by stakeholders as influencing the child and family's needs for AMP therapy services. Current AMP therapy services across PICS sites are then discussed along with the identified issues and opportunities.

5.1 The evidence

The literature review explored the following key questions about:

- the role of AMP in normal childhood development
- the benefits of AMP for the hospitalised child
- the use and benefit of AMP for children and adolescents with cancer and their families
- service organisation.

The following summarises the key findings of the literature review.

The literature review reflected that there was limited high level evidence to demonstrate the definitive impact of art, music and play therapy interventions on hospitalised children and / or children or adolescents being treated for cancer. There may be a number of reasons for this:

- Relatively limited research in this area.
- Traditional research methods and approaches may be inappropriate and less able to capture the impact of AMP therapy interventions.
- It is difficult to separate out the impact of a specific AMP intervention from that provided within the general clinical environment or from the impact of the clinical treatment itself.
- The difficulty in controlling for the diverse factors within the child and family that may impact on the acceptability and benefit of the AMP therapy intervention.

While much of the evidence available is based on case-studies, it does provide a good starting point in identifying the role and benefits of AMP therapy.

5.1.1 The role and benefits of art, music and play

A number of clear roles for the use of AMP therapy were identified in the literature as follows:

Assessment: AMP assessment can be used both to identify the needs, therapeutic goals and expected outcomes for a specific therapy as well as identifying a range of issues that could affect the child's overall ability to cope with treatment. In this way, AMP therapy may not only guide the provision of AMP care but also the care given by other service providers.

Promotion of optimal development: AMP may facilitate the development of fine motor skills, language, reading, creativity and social interaction. Given that music participation has been linked with neurological development in the general population, it has been suggested that playing a musical instrument may be beneficial in minimising any long-term cognitive deficits as a result of the disease (e.g. brain tumours) or treatment such as cranial irradiation.

Communication: AMP may promote enhanced communication between the child, their parents and other adults caring for them.

Procedural preparation and management: While there is strong empirical evidence for multi-faceted interventions to manage procedural pain, it is more difficult to isolate the specific benefit of individual AMP therapeutic approaches from broader programs. However there is some evidence of the benefit of specific AMP interventions in:

- decreasing the use of sedation or anaesthesia for non-painful procedures like Magnetic Resonance Imaging and radiotherapy
- using a range of distraction techniques to reduce distress with procedures
- the use of music to distract, soothe and encourage visualisation of positive images.

The following short, medium and long term benefits of AMP therapy have been identified.

- Short-term benefits**
 - the opportunity for self expression
 - alleviation of loneliness and isolation of the child
 - normalisation of the environment
 - the opportunity to exercise choice and control
 - reduction in anxiety
 - increased safety for the child
 - increased positive mood of the child.
- Medium-term benefits**
 - reduced anxiety with repeated procedures
 - the discovery of new skills
- Long-term benefits**
 - a reduction in post-traumatic stress syndrome
 - creation of happy memories and tangible evidence of their illness experience for the child or the families of those children who die.
 - the ability to reduce long-term anxiety about medical treatments.

AMP therapy is not only beneficial for the child but can also be helpful for the parents or other family members enabling enhanced family interactions, an increased understanding of the child's experience and assisting parents to help their child through procedures.

A number of factors were identified in the literature that may influence the child's response to AMP or identify those children who may need increased AMP support (see Table 2).

This information should be interpreted cautiously as the studies were low-powered with small numbers.

Table 2: Factors that may influence AMP outcomes or the need for increased support.

Factors	Evidence
Age	<ul style="list-style-type: none"> • Children under 1 year are more easily distracted by music. • One interactive music therapy program was found to be effective for reducing anxiety and improving mood in younger children and adolescents but not for children aged 6-10 years. • Play therapy is beneficial in reducing need for sedation for MRI in children aged 4 – 8 years. • Increased age at diagnosis is associated with an increased likelihood of later post-traumatic stress disorder symptoms.
Higher levels of pain sensitivity	<ul style="list-style-type: none"> • Children identified with higher levels of pain sensitivity may experience greater anxiety and pain prior to and during procedures.
Parental behaviours	<ul style="list-style-type: none"> • A range of parental approaches may increase a child's distress during procedures.
Previous medical experience	<ul style="list-style-type: none"> • Previous negative experiences of medical procedures increases child's distress with subsequent procedures.

In addition evidence from other literature highlights the following points, which may be relevant when considering the provision of AMP services for the future.

- Survivors of childhood cancer were more likely to use special education services if they were diagnosed under the age of 6 years, had a CNS tumour, leukaemia or Hodgkin's disease¹¹.
- Longer periods of treatment tended to be followed by poorer coping in long-term survivors¹².

¹¹ Mitby PA, Robinson LL, Whitton JA et al. 2003. Utilisation of special education services and educational attainment among long-term survivors of childhood cancer. A report from the childhood cancer survivor study. *Cancer*. 97:1115-1126.

¹² Bornan K, Bodegard G. 2000. Long-term coping in childhood cancer survivors: influence of illness, treatment and demographic background factors. *Acta Paediatrica*. 89 (1): 105-111.

5.2 Factors influencing a future service model

Clearly the numbers of children and type of cancers treated (see 4.1) will impact on the service model and the level of resources required within an individual service.

However stakeholders also identified a number of other factors that need to be taken into consideration when establishing the service model for the future and the appropriate level of resources required at each PICS service site. Many of these factors align with those identified within the literature and include:

- Disease and treatment factors
- Factors within the individual child
- Family circumstances.

Elements of these factors are summarised below.

Table 3: Factors influencing the level of AMP services for individual children and adolescents with cancer

Disease and treatment factors	Factors within the child or adolescent	Factors within the family
<ul style="list-style-type: none"> • Children with brain tumours because: <ul style="list-style-type: none"> o surgery / other treatment may result in cognitive or other impairment o some brain tumours require very intensive and aggressive treatment o the nature of brain tumours may be more 'emotionally' threatening to families. 	<ul style="list-style-type: none"> • Age and developmental stage. Very young children (less than 12-18 months) and adolescents may be particularly vulnerable. • Age may also be a factor that may determine which type of AMP support is most appropriate. 	<ul style="list-style-type: none"> • Single parent families or families where there have been previous bereavements.
<ul style="list-style-type: none"> • Children with acute myeloid leukaemia who require very extensive periods of hospitalisation over an initial six month period. 	<ul style="list-style-type: none"> • Pre-existing developmental delay or disabilities 	<ul style="list-style-type: none"> • A range of social and cultural factors including families from lower socio-economic or culturally and linguistically diverse backgrounds and families with pre-existing complex and diverse social issues.
<ul style="list-style-type: none"> • Children with bone tumours have aggressive treatment and can be very ill over an extended period. Some may also have an amputation or limb sparing surgery that will require extensive rehabilitation. 	<ul style="list-style-type: none"> • The child / adolescent's emotional response with those with higher levels of anxiety, distress and / or withdrawal requiring additional support. 	<ul style="list-style-type: none"> • High and ongoing emotional impact of the disease on the family so that parental needs may exacerbate the child's experience or limit their capacity to respond to the child's needs.
<ul style="list-style-type: none"> • Children requiring bone marrow transplant, who will require an extensive period in isolation. 		<ul style="list-style-type: none"> • In some instances, family support or natural 'resilience' within the child/ family may reduce the impact of disease / treatment factors

From an individual child or adolescent's perspective, their needs and therefore the level of AMP services required, will be dependent on a complex interaction between all of the above factors.

5.3 Current AMP services across PICS

Across all PICS sites, there is currently 4.7 EFT specifically allocated and funded to meet the AMP therapy needs of children with cancer. This includes general AMP providers as well as those involved in the current 'Comfort First' trial for procedural pain management.

Table 4 provides the profile of the disciplines within PICS sites.

Table 4: Current AMP resources specifically funded for children with cancer

Discipline	PICS Sites EFT			Total
	RCH	MMC	Peter Mac	
Educational play / Comfort First	0.65 EFT (general) 1 EFT (Comfort first)	0.8 EFT		2.45 EFT
Music therapy	0.6 EFT (25 hours)	0.8 EFT	0.2 EFT (funded but not yet appointed)	1.6 EFT
Art therapy	0.6 EFT			0.6 EFT
Total	2.85	1.6	0.2	4.65 EFT

Attachment 1 provides more detail on how these AMP resources are allocated within individual PICS services.

The following additional points are made:

- Current AMP services provide general therapeutic support for groups of children or adolescents as well as on an individual basis.
- There are limited adolescent specific resources. It can be difficult for an adolescent to relate to a service provider if they have observed them working with younger children
- The participation of AMP therapists in the more general group activities (e.g. in OPD clinics) allows them to develop some initial rapport with a child or adolescent. This can be built on if and when the child / adolescent is an in-patient and has additional needs
- The *Comfort First* providers are specifically involved in the management of procedural pain.
- Based on the above figures, the ratio of all PICS AMP therapy providers to newly diagnosed children per annum is 1: 35 children. Overall this compares favourably with interstate and UK data¹³.
- Within PICS, clearly the ratio of AMP providers to newly diagnosed children with cancer is currently higher at MMC than at the other sites. Factors influencing this include:
 - being part of establishing and strengthening the MMC Children's Cancer Centre
 - initiation of the *Comfort First* Program
 - the service sits within a general hospital service where adult care is the predominant focus.
 - The younger age of the population of MMC children
 - An expectation that patient numbers will increase over time and the AMP staff: new patient ratio will be similar to that of other PICS sites.
- The specific PICS AMP therapy resources are supported by:
 - recreational / diversional play therapist at MMC who is funded and employed through an external support agency.

¹³ The following data was reported in the PICS Psychosocial Services Project, Final report. July 2006. In the UK the median ratio across eighteen services was 1:43 (range 1:18-1:220) At Princess Margaret Hospital, WA the ratio was estimated to be 1:36 Adelaide Women's and Children's Hospital the ratio was estimated to be 1:60.

- o MMC play, art and music therapists who provide services to the population of children within MMC's in-patient paediatric service, and may provide some services to children with cancer when in-patients. It is difficult to formally assess what proportion of this EFT could be allocated to working with children with cancer.
- o Volunteers and students who may support AMP providers at different sites
- o Parent / family liaison officers who may support AMP activities / resources in different ways within RCH and MMC.
- o Increased skills of other staff such as nurses to utilise strategies identified through the *Comfort First* program.

5.3.1 The therapeutic intent

For the non-AMP service provider it can be difficult to differentiate the work of the AMP therapists from those involved in more diversional and recreational play.

Following significant discussion with key stakeholders, it became clear that for AMP service providers, the primary intent of their interventions is 'therapeutic', as identified within 5.1.1. For diversional or recreational therapists or volunteers, the primary intent is recreation. However, within this context it is recognised that these diversional activities may also have therapeutic effect.

Box 2: Mary's story

Mary was 11 years old with acute myeloid leukaemia. She has had multiple admissions and has had a bone marrow transplant with many complications, including partial blindness.

She had significant difficulties with managing procedures with high levels of anxiety. She had an overwhelming sense of loss. During long term admissions, she became very depressed and withdrawn and little motivation to get out of bed.

Music therapy was used to help Mary in a variety of ways including:

- gaining skills to manage her anxiety around procedures
- diversional therapy to provide a more positive experience in hospital to balance her sense of loss
- singing was used effectively as a physical and emotional outlet
- writing and recording her own songs to express her feelings, hopes and dreams
- dancing and moving to music to encourage physical activity.

Mary now continues to use music as a positive outlet throughout her life.

5.3.2 Prioritising need

Where there are relatively limited AMP resources, an emphasis for some AMP providers has been on prioritising care for children and adolescents identified with greater needs. This limits the amount of time available to provide AMP services to the broader population of children and families.

For others within the same service, the focus is on the needs of the wider group of children (e.g. in-patients) and has meant that more intensive support of children with greater needs is not possible.

5.4 Common AMP therapy recommendations for improvement across PICS sites

The following summarises the common recommendations for improvement identified by stakeholders across PICS sites.

Resources

- Increase AMP therapy resources to address resource gaps particularly within RCH and Peter Mac.
- The need to ensure that the AMP workforce is well trained, skilled and coordinated.
- The lack of facilities such as adequate play areas, consultation rooms, AMP equipment.

Referral

- There are limited formal referral pathways / processes with a high reliance on ad hoc referral or an assumption that every child sees every therapist.
- There are limited criteria for assessing need and the required level of intervention.
- The need for formalised referral pathways / processes was identified.

Level of care / services

- The lack of clarity about children who should be prioritised for more intensive AMP support.
- Appropriate support for adolescents.
- The need to offer or strengthen a 'consultancy' / educational service for parents and other carers to assist them to support their child.

Continuity of care

- The need to enhance access to a consistent therapist with individual children across the pathway and at different service points e.g. OPD, day oncology, in-patient services
- Information flow about child's AMP needs across services e.g. Peter Mac.
- Linking children / families back into community based services e.g. kinder, local music therapist / teachers, palliative care MT / art therapy services.
- Possible role of PICS AMP in providing care / support to children at end of treatment e.g. 'getting on with life' post treatment and / or role in palliative care.

Organisation and coordination of AMP care

- The need for consistent promotion of the AMP services available.
- Currently children may receive the full range of services or have minimal access.
- The need for a balance between a structured and flexible approach.
- The need for stronger coordination of services through timetabling of activities available within services e.g. group programs, or timetabling of services for individuals.
- Organising specific group activities e.g. pre-school music group or adolescent group.
- Consideration of one AMP provider being the key contact for a child / family.
- Role delineation to ensure the best use of resources in the context of recent increases in resources (MMC) and more limited resources (RCH).
- Strengthening access to AMP resources at Peter Mac given its variable volume and the nature of the treatment in a specific point in the pathway.
- The need for a cohesive, state-wide service.
- Enhanced communication between AMP providers and other health service providers.

Staff education

- Other health care providers need increased knowledge about the role and benefit of AMP and the referral criteria / patient priorities.
- Training and support of other staff to develop and maintain skills to support child and family especially in management of procedural care.
- AMP providers may need increased understanding of those disease and treatment factors that may influence the level of AMP therapy services required.

Need for research

- There is limited high level evidence to guide practice
- The need to develop a stronger evaluative / research base

5.5 Opportunities

A number of opportunities have been identified that will assist strengthening AMP services within and across PICS and the development of a service model for the future.

5.5.1 The *Comfort First* Program

The *Comfort First* Program is a pilot program aimed at optimising the management of procedural pain for children. After an initial pilot program within RCH, the program has now been extended to MMC.

This intervention study is being evaluated with early indications that it is beneficial to the child and family, is increasing other health professional skills in the management of procedural pain, and is potentially achieving service efficiencies (see Box 2).

The ability to demonstrate service efficiencies and therefore financial savings may go some way to facilitating better access to core funds within each PICS service in the future. In addition, there have been anecdotal reports that staff anxiety has been reduced as a result of improved strategies of managing procedural pain.

Box 3: Kurt and his first CT

Kurt aged 4 has leukaemia and had significant anxiety associated with scans such as x-rays and CT scans. The *Comfort First* assessment indicated that Kurt was scared of the noise in the scanners and did not understand how the pictures were taken. He needed a CT scan in the following week.

The *Comfort First* clinician organised for Kurt and his family to visit the CT machine and environment and discuss how it worked with staff. In addition the *Comfort First* clinician worked with Kurt using his calico doll and drawings to discuss his fears. It was clear that his anxiety had reduced significantly even at this stage.

Kurt had his scan successfully without anaesthetic or sedation and was very excited to tell everyone how well he had done.

5.5.2 Increased integration across PICS sites and regional services

There is increasing communication and integration between the PICS service sites overall, which has been further enhanced by the introduction of the *Comfort First* program at MMC.

The development of this AMP service model brought together AMP therapy service providers across sites and demonstrated a clear interest and commitment to strengthen relationships and further enhance outcomes for children and their families.

In addition, the current developments in the Regional Outreach and Shared Care Program (ROSCP) are enhancing relationships and communication between PICS and regional services. These relationships will enhance the opportunities of AMP approaches used with a child within a PICS service to be continued within the regional service.

5.5.3 Funding opportunities

There is an interest in some of children's cancer charities in supporting children / adolescents with cancer and their families through more comprehensive and sustainable funding approaches to art, music and play therapy programs.

The development of a PICS wide service AMP service model together and a more strategic approach by PICS to funding bodies may assist to gain the additional funding required in an ongoing way.

6 Making the journey better – the AMP service model

The AMP service model includes the vision, principles and key approaches to practice. It also links in with PICS broader psychosocial service model.

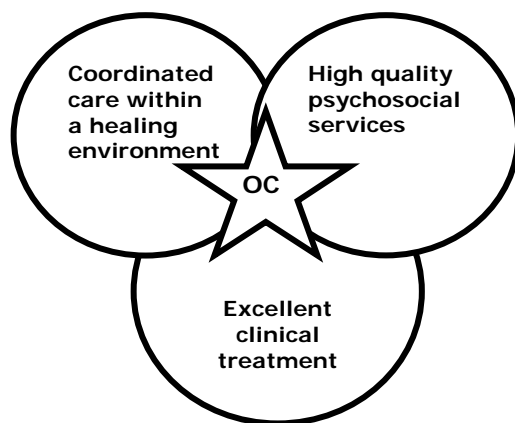
6.1 Links with the psychosocial service model

The PICS psychosocial service model was developed as part of the PICS Psychosocial Services Project 2006. This broader model articulated that the core business of the PICS Children's Cancer Centres and associated services is to:

'treat children / adolescents with cancer in a way that optimises their quality of life both now and in the future and to provide quality care to the children who die'.

There are three overlapping components of care, which when blended together provide optimal care (OC) – see Figure 1.

Figure 1: Achieving optimal care: the core business of PICS Children's Cancer Centres



The core values are to work as an effective **team** together to provide optimal **family-centred** care.

The AMP service model endorses these values and the accompanying set of principles and standards that guide practice for all PICS service providers¹⁴. The following standards are of particular relevance to the development of the AMP service model:

- A skilled and diverse workforce
- An environment conducive to healing and coping
- A multidisciplinary approach for assessment and responses to psychosocial needs.

6.2 The vision for AMP therapy services

Working within a child and family centred approach, all children / adolescents and their families will have access to developmentally appropriate experiences based on assessed need that will:

- Facilitate the child's normal growth, learning and development
- Reduce the impact of the illness and treatment on the child and family

¹⁴ Paediatric Integrated Cancer Service. 2006. Strengthening psychosocial care: a blueprint for the future. Final report.

6.3 The principles guiding AMP practice

The following principles will guide AMP service provision:

- All children / adolescents have the right to access an environment and activities that will enhance their normal developmental experiences in an age appropriate manner.
- All children / adolescents and their families have access to a range of techniques including art, music and / or play therapy that will minimise the trauma of procedures and other treatment experiences
- All children / adolescents and their family's will have access to services in an empowering manner that maximises their own skills to effectively manage their experiences in the future for themselves or for their children
- High quality services will be offered:
 - in a manner that balances 'normative' experiences with targeted interventions
 - in an equitable manner based on and tailored to assessed needs and preferences
 - flexibly to accommodate the changing needs of children and families
 - in an integrated and coordinated manner within and across PICS sites and regional services, across the continuum of care
 - that strengthens and empowers children and families and builds resilience, independence and healthy adjustment
 - creates links with and supports the child's normal community based services and programs e.g. kinder, schools and crèche, to support the child and family in their community.
- The AMP services are underpinned by a commitment to evaluation, continuous quality improvement and research, in order to improve future services for children and families.
- Services will seek ways to streamline processes and systems that will optimise the effective use of limited resources within and across services.
- All AMP service providers will be suitably qualified in line with the appropriate grades and competencies for their professional disciplines for their role.
- The AMP and related team members will work in a multi / interdisciplinary approach that values and respects the skills of all team members within and across services, sites, and regional services.
- The AMP service providers will work with other non-AMP team members to strengthen their skills and capacity to support children and families in an appropriate and complementary manner.

6.4 A tailored approach based on need

There is increasing emphasis in health care overall and psychosocial care in particular to develop service frameworks that consider the diverse needs of the population of patients / clients and ways that services can best be delivered that respond appropriately to these needs.

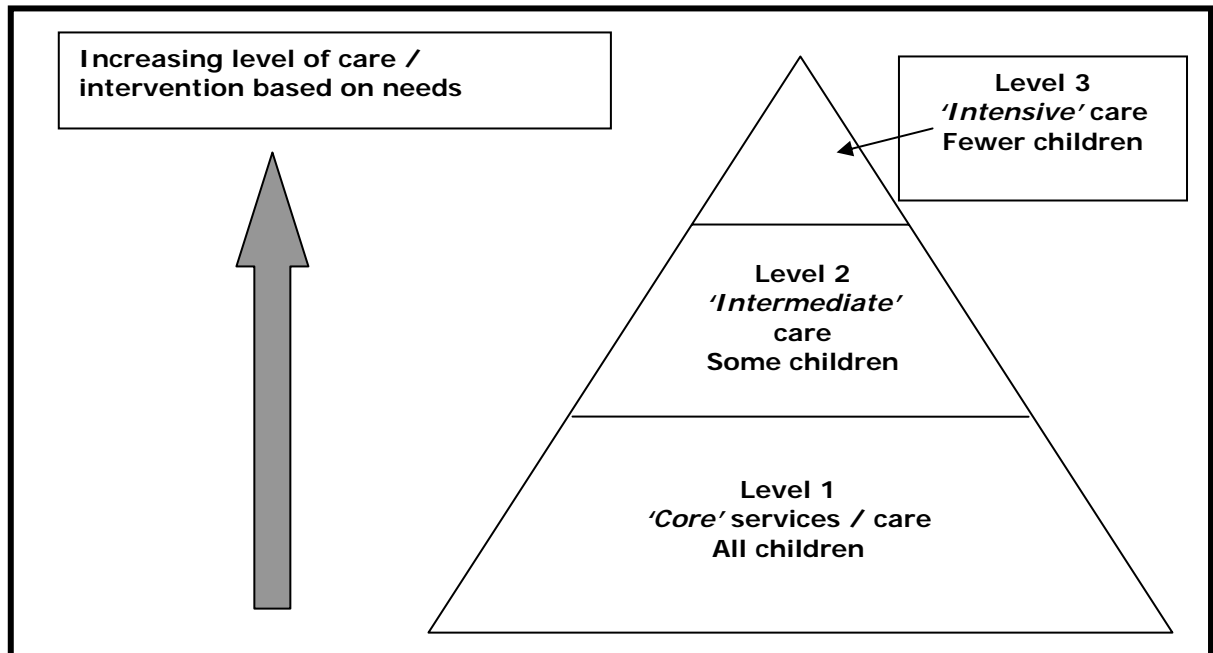
Within Victoria, this approach has been adopted by the Department of Human Services to inform the development of psychosocial services in cancer care. Different levels of service are provided based on needs, with the aim being to provide the greatest level of services to a relatively small group of the total population served, with the greatest level of need.

Within PICS, stakeholder feedback indicated that the current approach to access to AMP therapy is quite adhoc, with some children gaining access to a full range of AMP resources and some to very few. In addition, limited AMP resources means that services have had to focus to some extent on 'high priority' children and adolescents and their families.

The tiered approach to service development and delivery provides a more systematic framework for the provision of AMP therapy services for the future.

Figure 2 illustrates a proposed three tiered model for providing AMP therapy services to children and adolescents with cancer and their families.

Figure 2: A tiered approach to the provision of AMP therapy services



Level 1 of this model identifies the range of core services that must be available for **all** children / adolescents and their families. This provides the foundation for all AMP therapy services and creates a supportive and child / adolescent friendly environment.

Level 2 provides a higher level of service for a smaller group of children / adolescents (*some* children) based on assessed needs. In addition to Level 1 activities, these children have access to a range of additional AMP therapy services, in particular more formalised individualised sessions for a limited time period.

Level 3 provides more intensive therapeutic interventions for those children / adolescents and families that are assessed to have the highest level of need. Again these interventions for a smaller group of children / adolescents (*fewer* children) build on Level 1 & 2 services and offer a range of more intensive and coordinated activities over longer time periods. The following key points of the framework are emphasised.

- The model is designed as a framework for thinking about the needs of children, adolescents and their families. It should not be used in an overly prescriptive manner.
- All children / adolescents will gain access to a range of core services.
- High quality Level 1 services may also strengthen the system overall and potentially reduce the numbers of children / adolescents or families that need higher level AMP therapy services.
- The child / adolescent may move up or down the levels as they go through the pathway, based on assessed changing needs.
- While a child or family may be assessed for a higher level of care, they may not accept or be able to accept this level of care because of illness or psychosocial factors within the child or family (see Box).

Box 4: Cameron's story

Cameron was 12 months old when he was diagnosed with cancer. He has two siblings both under 10 years of age.

Cameron was a bubbly and interactive child who required significant hospital care both in the ambulatory care setting and as an inpatient throughout the course of his treatment.

Cameron and his siblings participated in regular group music therapy sessions within the ambulatory care service. This helped Cameron and his siblings to:

- express themselves vocally and musically
- maintain fun interactions with each other
- experience a sense of normalcy
- reach developmental milestones through exploring a range of instruments
- gain new skills through the medium of music

While Cameron may have benefited from more intensive AMP therapy when hospitalised (i.e. Level 2 or 3), there were many complicating factors relating to his treatment that prevented Cameron from receiving the services as an inpatient. The flexibility of the programs allowed the family to accept or decline how and when they would like to receive an AMP service at various stages throughout treatment.

6.4.1 The levels of need and services

As indicated in 5.2, a number of factors may influence children / adolescents and their family's needs for AMP therapy. Work was undertaken by the PICS stakeholders to identify the potential criteria for the different levels of need and the services that would be provided for these levels.

Given the significant commonality across the three levels, both the criteria and service levels have been collated and summarised. Table 5 summarises the key criteria for both general AMP services and the *Comfort First* program. Table 6 considers those services required to meet the different service levels.

This separation between general AMP and *Comfort First* is somewhat artificial. It is recognised that currently general AMP therapists may also be involved in supporting procedural pain management within different services. Over time and with the evaluation of the *Comfort First* trial, it would be expected that the two Program components would blend effectively together.

These criteria and levels of service are seen as 'preliminary' and a guide only. Over time, the criteria and levels of service should be reviewed and adjusted.

Table 5: Preliminary criteria for the different levels of AMP therapy services

	Level 1 services – ‘core’ care	Level 2 services – ‘intermediate’ care	Level 3 – ‘intensive’ care
Criteria for general AMP	<ul style="list-style-type: none"> All children, newly diagnosed and accessing services. Some differentiation of children’s AMP needs based on age e.g. <ul style="list-style-type: none"> Play < 8 years Art I/P ind – 3-18 years Art I/P group – 13-18 years Art OPD – 3-12 years. Music - all ages 	<ul style="list-style-type: none"> Disease / treatment factors Children with brain tumours, AML, HD, Bone tumours, amputation Children on steroids / medication side effects. Length of treatment Child / adolescent factors: <ul style="list-style-type: none"> Age: < 1 year; under 5; older children needing expressive medium All adolescents Pre-existing conditions e.g. developmental delay, Down’s syndrome, visually impaired Distress: moderate anxiety / agitation, withdrawn, physical needs Length of hospital stay: > 1 week Family and social factors: family not coping well. 	<ul style="list-style-type: none"> Disease / treatment factors Bone marrow transplant and other children in isolation Palliative treatment Significant distressing physical symptoms, cognitive and physical impairments. Extreme restlessness, breathlessness Child factors: Depressed, isolated children Complex psychological problems Strong need for self-expression or expression of feelings to family Length of stay: > 3 weeks Family and social factors: significant psychosocial / family concerns.
Criteria for <i>Comfort First</i> program	<ul style="list-style-type: none"> Child with ‘easy temperament’. No behavioural history or emotional difficulties ‘Well functioning’ parents able to support and soothe child. Sense that child and family will be able to adapt. No specific concerns identified by other service providers. 	<ul style="list-style-type: none"> Child has previous negative experiences More anxious temperament. Relapsed child Young children. Higher level of parental anxiety Specific concerns expressed by other service providers. 	<ul style="list-style-type: none"> Pre-existing anxiety disorder or behavioural – emotional issues Significant negative experiences including needle phobias. Child needing very intensive, multi-modal therapy Significant family issues or concerns by SPs.

Table 6: Preliminary range of services available for the different levels of AMP therapy services

	Level 1 services – ‘core’ care	Level 2 services – ‘intermediate’ care	Level 3 –‘intensive’ care
Range of general AMP services available	<ul style="list-style-type: none"> • Range of developmentally appropriate AMP for groups of children in inpatient services and waiting areas for treatment, procedures including radiotherapy planning, lumbar puncture and bone marrow clinics and OPD clinics. • Peter Mac – access to MT twice weekly during treatment • Focus on group activities to enhance social participation, creating a ‘child friendly’ environment. • Access to music library. • ‘Informal’ / one-off individualised approach. 	<p>Plus:</p> <ul style="list-style-type: none"> • Individual services at ward or OPD level • Regular and formal contact during admission (1-2 times per week) • Targeted groups (e.g. adolescents) • Interactive music making • Active use of music / play to reduce agitation and promote relaxation. • Provided with resources to support ongoing use of therapy (e.g. drawing book, access to musical instrument) • Work with community providers to create program within local service and support funding applications. 	<p>Plus:</p> <ul style="list-style-type: none"> • More intensive, ongoing, targeted interventions e.g. 3-5 sessions per week as in- patient or attending several days per week. • Continuation of therapy from in-patient to out-patient. • Emphasis on individualised programs outside of usual clinic times. • Strong emphasis on active music making, including instrument playing and movement to music • Therapy used to assist parents / family members within context of child’s care. • Parent / child participation in group programs facilitated by AMP and non-AMP provider • Home visits to handover to palliative care MT.
Procedural pain management	<ul style="list-style-type: none"> • Screening assessment 8 yrs and under • Development of plan. • <i>Comfort First</i> ntervention for initial 1-3 procedures. • Minimum of one parent education session for children aged 9+ • Psycho-education re: procedures and coping. 	<p>Plus:</p> <ul style="list-style-type: none"> • Plan developed and <i>Comfort First</i> clinician attends a number of procedures with child and parents • Ongoing liaison between nursing staff and <i>Comfort First</i> staff to monitor child and family coping. 	<p>Plus:</p> <ul style="list-style-type: none"> • Individual plan and intervention for older children. • Consider mental health referral via <i>Comfort First</i> or alternative mental health clinician.
Initial contact /assessment / or therapy coordination	<ul style="list-style-type: none"> • Promotion of AMP services available • Triaging / initial screen by non-AMP providers • Introductory ‘session’ with new child and family for information and / or more detailed assessment. This may be AMP discipline specific or generic. • Introductory session for groups of new families (AMP specific or linked with more general introductory sessions). 	<ul style="list-style-type: none"> • Suggest one therapist provides more intensive approach based on child’s needs, with back-up from other therapists in coordinated way. • Suggest level of intervention is for ‘prescribed’ relatively short period. • Clear goals of therapy with individual care plan developed. 	<ul style="list-style-type: none"> • One or two therapists provide intensive approach, working together to agreed goals with child and family. • Consider opportunities to work formally with child / parent with other non-AMP disciplines e.g. social worker. • Individual care plan developed and implemented

6.5 Promotion, assessment, referral and care planning

The tiered level of care provides a level of guidance to support the initial assessment of children, adolescents and families. A number of approaches may be used to facilitate this and these may be supported by a range of communication and promotional activities. These processes may include:

Initial communication and promotion: As part of their introduction to the Children's Cancer Centre, children, adolescents and families need to receive information about the availability of the range of AMP therapy services and how they may be accessed.

This promotion may take place with individual families, as part of an individual discussion about the broader range of services available, or as part of a group information session for 'new' families. Promotion may also include the provision of information through brochures and posters. Depending on the context, an AMP therapist will be involved in the promotion of the range of AMP services.

Triaging: The need for AMP therapies is part of the psychosocial assessment undertaken by social workers and / or the general assessment undertaken by nurses and medical staff, on the child's initial diagnosis, on relapse or at other significant times in the care pathway.

All staff should be aware of a range of '*triggers*' within the child or family or unexpected treatment or illness factors, that highlight changing needs and the potential need for increased access to AMP services.

Referral: Clear referral processes need to be established or strengthened between general service providers and AMP therapists. Referral may be strengthened through formal documentation accompanied by regular ward hand-overs, formalized general or psychosocial meetings, active 'case-finding' or informal communication.

Box 5: Sarah's story

Sarah was 6 years old with acute leukaemia and has a supportive family. She is a sensitive and articulate child who when overwhelmed by a hospital procedure, would become withdrawn. She was referred by chance to art therapy because she liked 'art'.

Over a five month period, Sarah participated in 10 art therapy sessions. Four were on an individual basis when an in-patient and the rest as part of the group program within outpatient services. She also accessed some music and play therapy programs.

The aim of art therapy was to give Sarah some sense of control over her life, express her thoughts and feelings and encourage her to actively create and participate in art therapy.

Assessment: Based on the initial triaging or later screening, an AMP provider may undertake a more detailed assessment of the child and family's needs. This may be undertaken as part of an 'introductory session' about AMP services with individual families or a more formal and separate assessment.

Wherever possible, the AMP therapy assessment should be undertaken by the most appropriate person for that child but should also take an 'inter-disciplinary' approach. Multiple assessments by art, music and play therapists should be avoided. Further work needs to be undertaken to ensure that assessment for AMP services links with broader psychosocial assessment processes.

Care planning: Psychosocial meetings may provide a good vehicle for communication about the child and family's needs. This may be supplemented by ward meetings etc.

Consideration needs to be given to the development of an AMP therapy care plan that would include key goals and service coordination. This may build on other care plans (e.g. the *Comfort First* plan or general psychosocial plan) and should be accessible to all disciplines.

A coordinated care plan is important for all children but is essential for children or adolescents needing Level 2 or 3 AMP services.

6.6 Strengthening coordination and continuity of care

Clearly enhanced promotion, assessment and referral processes and care planning will do much to strengthen coordination of AMP therapy services.

A number of other strategies were identified as key components of the model of care to strengthen coordination and continuity of care. This includes service coordination within and across each PICS site and time-tabling of AMP therapies for groups or individual children / adolescents and families.

A key AMP contact within a service. Given the actual or potentially future increase in AMP resources, there is a need to consider the role of a key contact for children or adolescents and their families. This may be particularly important for children or adolescents receiving intermediate or intensive levels of care. A specific AMP provider may be identified as the key contact for an individual and this is known by the team and by the child / adolescent and their family.

The role of the key contact might be to:

- Provide a range of more individualised care for the child / adolescent with continuity of provider
- Monitor the child / adolescent / family needs
- Coordinate the care plan and changes within it
- Be a contact point for the child / adolescent and family
- Communicate with all members of the AMP and extended team.

Psychosocial / case conferencing meetings. The active role of the AMP therapists in formal psychosocial or general case-conferencing / multi-disciplinary team meetings is essential. These meetings should ensure that:

- clear and agreed actions are set
- responsibility for the actions is allocated to the relevant provider
- reporting back mechanisms are established.

Timetabling of activities: Additional opportunities for timetabling a range of ongoing or time-limited group activities within a service and potentially with different disciplines (either AMP specific or with other disciplines) is actively encouraged.

Although AMP providers may have to 'compete' with clinical demands, opportunities to timetable AMP activities for individual children or adolescents should be actively explored. This may take increasing the knowledge of the medical, nursing and other clinical staff about the role of AMP therapy and negotiation with them.

Timetabling for groups or individuals should not be so inflexible that it '*excludes meeting the child's needs in the moment*'.

Box 6: Nathan's story

Nathan is four years old and had a brain tumour. Nathan lives with his parents and two older siblings.

Although well, he had some behavioural issues and his parents found it difficult to place boundaries around these behaviours during his treatment. Nathan was not attending kindergarten and had little social experiences with his peers.

Nathan and his mother were invited to participate in a ten week music and social work program for children aged 2-4 years and their parents. This program was co-facilitated by a music therapist and social worker.

Nathan responded extremely well to the structure of the program and enjoyed drum playing, movement to music and increasingly interacted with the other children. The social worker provided support for his mother and Nathan's behaviour and social skills improved significantly.

6.7 Managing transitions

Part of service coordination is managing the transitions of care that the child / adolescent and their family may experience.

The key transitions may occur between:

- The MMC and RCH Children's Cancer Centre and Peter Mac
- Between the MMC and RCH Children's Cancer Centres and regional services
- Between RCH Children's Cancer Centre and MMC Children's Cancer Centre
- Between PICS services and general community and educational services
- Between MMC and RCH Children's Cancer Centre and community based palliative care.

In addition to clinical information, the communication and information flow between these services should include information about the child's AMP therapy needs in general, as well as specific information about the management of procedural pain.

However, AMP providers indicated that they rarely knew of when children or adolescents were being referred to other services.

A number of strategies may be used to strengthen AMP therapy communication and information flow between services.

Service 'flags'. It should be possible to flag those children who:

- will require radiotherapy as part of their definitive treatment and the timeframe for this
- are eligible for regional shared care
- may be linked with community based palliative care.

These flags should alert both the AMP therapists of this potential and other service providers (e.g. nurse coordinators) and assist in the preparation of information transfer.

Transition care plans: Both general and procedural pain AMP requirements for each child should be integrated into referral or information transfer documentation.

A key service contact: A key AMP service contact point should be identified at each service site to further facilitate communication and information transfer across sites. This should be an interdisciplinary contact.

Common policies and procedures. Wherever possible, common policies, procedures and documentation should be developed across PICS service sites.

Communication with community services including schools and kindergartens. Routine communication with schools and kindergartens should include information about the child's needs both during treatment and on completion of treatment. Where a child or adolescent has

significant needs and issues, further communication mechanisms need to be established with these community resources.

Palliative care policies and procedures: In addition to general policies and information transfer, it may be appropriate in some contexts for AMP therapists to offer time-limited home based care to assist the transfer of this AMP therapy to a community based AMP therapist, linked with the local community palliative care service. Clear policies and protocols need to be developed to ensure that this happens in an appropriate and safe way for the child, family and for the service providers.

6.8 Professional development

Professional development is required for both generalist service providers and for the AMP therapists.

For **general service providers**, information about the role and benefits of AMP therapy, the AMP therapy needs of children / adolescents and families, and referral criteria and processes, need to be integrated into orientation and ongoing professional development.

For **AMP therapists**, information about the different conditions and treatment modalities and timeframes may assist them in identifying children with actual or potential increased needs. A quick referral guide may also be helpful.

In addition, joint professional development opportunities for AMP therapists across PICS will potentially:

- facilitate sharing of knowledge and understanding
- improve service coordination and information transfer across services
- stimulate quality improvement, evaluation and research activities.

6.9 Quality improvement, service evaluation and research

Given the significant interest of stakeholders in strengthening the evidence of the role and benefits of AMP therapy for children and adolescents with cancer and their families, the service model provides an opportunity to address the evidence gaps. This would be done through a quality improvement and service evaluation framework and through research.

Quality improvement initiatives linked in with professional development may help to strengthen aspects of care including more formalised referrals to AMP therapists and enhanced information transfer.

The current work being undertaken in evaluating the '*Comfort First*' program may provide some directions for the future. Current service links with university programs may also provide some opportunities for further evaluation and research as may collaboration with formalized research groups within the service sectors.

While quality improvement, service evaluation and supporting research activities needs to be an integral part of each AMP role, specific resources, some coordination of these activities is required.

7 Resource requirements

To bring the future AMP service model to life, a level of increased resourcing is required. This may come from a combination of core and philanthropic funding.

In developing an AMP service model for the future, the needs of each PICS service site have been reviewed and the required resources identified. A pragmatic approach has been taken to balance between 'optimal' and 'realistic' levels of resourcing. In addition, even in low volume services, there needs to be a minimum level of AMP providers to support an effective service and create an attractive position for an incumbent.

Attention must be paid to both strengthening access to Level 1 'core' services as well as the 'intermediate' or 'intensive' levels of care.

The rationale and the required AMP therapy resources for each service site are detailed in the sections below. The following points summarize the requirements across PICS.

- A total of 8.4 EFT is required to support children / adolescents and their families across PICS service sites. This includes annual leave coverage for all staff. The total EFT represents an overall increase of 3.75 EFT.
- The ratio of AMP providers to new children diagnosed each year across PICS would increase to 1:20 newly diagnosed children (compared with the current 1:35).
- A total of 5.6 EFT is required for the RCH Children's Cancer Centre, which is an increase of 2.75 EFT.
- The MMC Children's Cancer Centre is now relatively well resourced, with the focus being on improving access to art therapy on an as needed basis in the ambulatory care setting and annual leave requirements
- Peter Mac requires an 0.5 EFT position to support children when they are having radiotherapy or other procedures such as PET scans.
- An 0.4 EFT position is designated to support cross-campus professional development, quality improvement and service evaluation and facilitate research opportunities across PICS sites.

Particular attention must be paid to resources required for the three levels of AMP service. However, while it is relatively easy to identify the resources for the Level 1 requirements, it is more difficult to calculate the numbers of children / adolescents that may require additional levels of AMP service (ie Level 2 or 3).

It is possible to estimate the number of children / adolescents with 'higher' risk features e.g. adolescents, particular cancers or intensive treatments such as bone marrow transplants,. However there may be significant overlap between these groups. In addition, some of these children / adolescents and families may have greater levels of family support and resilience. Other children with less disease or treatment 'risk factors' may have higher social or emotional needs.

7.1 Level 1 services

The required services are premised on access to an AMP therapy provider at all key points in the Children's Cancer Centre services. This includes in-patient services, day oncology services, outpatient and the general anaesthetic procedure clinics.

Table 7 summarises the number of hours of AMP service provision by service point. Unless otherwise stated, each 2 hours of direct care are matched with 1 hour of preparation, coordination and other administrative tasks.

Table 7: Number of hours required for Level 1 services at key service points

Service point	Number of sessions per week	Hours per session	Total number of hours per week
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In patient services			
Morning sessions	5	4*	20
Afternoon sessions	2	3	6
Day oncology service	5	3	15
Outpatient clinics	7	3	21
GA procedures clinic	2	3	6
Hours required per week			68

* this is based on 3 hours direct service and 1 hour of preparatory / administrative work.

7.1.1 Level 2 and 3 services

These resources are based on an estimated number of children / adolescents requiring these higher levels of service.

Table 8: Number of hours required for Level 2 and 3 services per annum

Service level	Estimated hours per session per child	Total number of sessions per week	Total number of weeks	Total hours per child	Estimated number of children per annum	Total number of hours per annum
Two - intermediate	1.5	2	5	15	50	750
Three - intensive	1	3	10	30	40	1200
Total number of hours per annum for levels 2 and 3 care						1950

7.1.2 Comfort First Program

Based on the current levels of AMP resources for the *Comfort First* program and the need to expand it to all children and not just newly diagnosed children, 1.9 EFT has been allocated including 0.2 EFT for weekend and leave coverage.

Over time this resource will become more integrated into the general AMP team.

7.1.3 RCH AMP resources

The following summarises the total AMP resources required for the RCH Children's Cancer Centre.

Table 9: Total AMP requirements for RCH Children's Cancer Centre

	Total EFT required
Level One services	2
Level Two / Three services	1.7
Comfort First services	1.9
Total EFT required	5.6

Recommendations

It is recommended that:

- The total AMP resources for the RCH Children's Cancer Centre should be 5.6 EFT. This includes leave cover.
- The increased EFT may be a mix of additional art, music and play therapy resources and could be allocated in the following ways.
 - Educational play therapists 2.6 EFT
 - Music therapy 2 EFT
 - Art therapy 1 EFT.
- While the total EFT has been calculated based on different levels of need and service delivery, in reality each role will provide the full range of service levels. This will enhance continuity across service points.
- Given the particular needs of adolescents, consideration should also be given to at least one role incumbent (or part of a shared role) having significant experience of working with adolescents.
- Increased resources are gradually introduced into RCH to facilitate some of the necessary preparatory policy and process work, any role delineation that may need to occur, and the gradual integration of new roles.

7.2 MMC Children's Cancer Centre

The current resources at MMC Children's Cancer Centre are equivalent to 1.6 EFT. Overall with other support services available, this appears to be adequate to needs, based on the current patient volume.

There is currently limited access to art therapy for children / adolescents within the Children's Cancer Centre. However, art therapy is available in the general paediatric / adolescent in-patient services.

It is proposed that services be 'bought in' to support those particular children and adolescents for whom art therapy might be the appropriate vehicle for their needs.

Recommendation

- A total of 1.9 EFT is required for AMP services at MMC Children's Cancer Centre including leave cover and 0.1 EFT for art therapy services as required.

7.3 Peter Mac services

The major challenge for AMP resources at Peter Mac is the variability of the numbers of children going through the service at any one time. In addition, while there is one particular outpatient clinic per week and a proportion of children are treated early in the morning, children and adolescents may have their treatment at different times throughout the day.

However the regular appointments at Peter Mac over a number of weeks do provide an opportunity for some additional access to AMP services for children and adolescents. In addition, the patient profile includes a higher proportion of children with brain tumours and so may have significant needs. There is also the increasing number of children having PET scans (on average 3-4 per week) for whom access to AMP services may be appropriate.

Overall it is estimated that an average of 0.5 EFT may be required to provide AMP support for children and adolescents during their treatment at Peter Mac. Given the broader music therapy services within Peter Mac for adult patients, and the profile of children and adolescents at Peter Mac, additional music therapy may be appropriate. Another option may be to have an educational play therapist with particular skills in procedural management, as part of the EFT resource.

A shared role between music and educational play therapy may bring a more diverse skill base to Peter Mac to meet the differing needs of children and adolescents. The downside of splitting the role, each with a relatively small time allocation, may be some fragmentation or dilution of therapeutic effect.

Given the variable service demands, the role (whether filled by one discipline or two) needs to be offered flexibly. This flexibility could be achieved in a number of ways. The advantages and disadvantages of a range of ways are identified in Table 10.

Table 10: Advantages and disadvantages of Peter Mac service delivery options

Approach	Advantages	Disadvantages
1. Combined role with RCH	<ul style="list-style-type: none"> • Geographically close together • Potentially allows for a level of continuity of care across services • Enhances communication between services and service providers • Provider brings high level of paediatric expertise • Peer support through RCH colleagues • A joint position across services for children may be able to be funded more easily. 	<ul style="list-style-type: none"> • It may be logistically very difficult to offer a service at Peter Mac, given the variability of needs. • Difficulty to balance RCH and Peter Mac demands. RCH needs may dominate, particularly if times cannot be structured effectively. • Difficulties in role accountability and professional governance.
2. Combined role with Peter Mac young adult / adult services	<ul style="list-style-type: none"> • Allows for more extensive role within Peter Mac. • Role and time can be flexibly organized to accommodate needs of children with other clients. • Position is clearly located within and responsible to Peter Mac. 	<ul style="list-style-type: none"> • No continuity between providers or approach across service sites. • Difficulty in accessing funding for a 'mixed population'. • Child has to get used to a different provider. • It may be difficult for the provider to have the range of skills to accommodate the needs of infants, adolescents, young and older adults. • Combined role is only possible if AMP provider is a music therapist.
3. Combined with AMP QI / evaluation and research role.	<ul style="list-style-type: none"> • Enables provider to support children at Peter Mac in a flexible manner, combined with an additional role. • Brings high skill level to Peter Mac • Strengthens communication between services. 	<ul style="list-style-type: none"> • Provider would need to visit other service sites regularly as part of QI role. May not be available for children at Peter Mac when needed. • Peter Mac may not be seen as the 'natural' place for a significant PICS role. • Difficulties in role accountability and professional governance.

Recommendations

It is recommended that:

- An 0.5 EFT role is required in the future to support children and adolescents having treatment or diagnostic tests. This may be either through a music therapist alone or in combination with an educational play therapist.
- The current 0.2 music therapy role (about to be appointed) links in with the *Comfort First* Program to maximize skills and continuity of care for children across services.
- Opportunities to streamline Peter Mac's service systems to optimize access to AMP services (eg streamlining of radiotherapy treatment or planning appointments)
- That PICS allocates resources to evaluate this role in terms of utilization and capacity to provide the range of needs for children and adolescents, including procedural pain

management. This evaluation will inform future service approaches to the ways in which AMP services can be best offered at Peter Mac in the future in a sustainable manner.

7.4 Professional development and quality improvement role

An 'across PICS' AMP role is proposed to coordinate professional development (for both AMP and general service providers at all sites), quality improvement, service evaluation and research. As an 0.5 EFT role, it could also be combined with another more direct service role.

In addition to driving particular activities across PICS including supporting the initial preparatory work (eg referral processes) at some sites, this role may be able to explore other service evaluation and research opportunities, including additional funding options for research.

This role would work closely with the relevant AMP service managers at each site. The role would not include line accountability of the individual AMP providers.

Recommendation

- That an across PICS role be developed and funded to support professional development, quality improvement and related activities.

7.5 Additional AMP support resources and equipment

Given an increase in staff resources, additional resources will be needed to support this work. These resources could include:

- Music equipment and instruments
- Resources for art and play therapy
- Funding to support professional development.



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