Paediatric Integrated Cancer Service

A statewide cancer service for children

Psychosocial Services Project

The Compendium of Evidence

Summary Report

Original report completed June 2006 by

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Overview

This *Compendium of Evidence* is a supplement to the final report, ***Strengthening psychosocial care: a blueprint for the future',*** for the first stage of the Victorian Psychosocial Services Project, commissioned by the Victorian Paediatric Integrated Cancer Service.

It provides a brief overview of the Project and then summarises the key evidence elicited from the following activities:

- Literature review
- Community consultation
- Site visits
- Other consultations
- National and international comparative data.

This evidence informed the development of the Service Model, the Standards of Practice and the Implementation Plan for the future development of quality psychosocial services for Victorian children and adolescents with cancer and their families.

The full literature review is attached.

1 Introduction

The Victorian Paediatric Integrated Cancer Service (PICS), a partnership between the Royal Children's Hospital, Southern Health (Monash Medical Centre) and Peter MacCallum Cancer Centre (Peter Mac), has been established to improve the quality of and access to cancer care and treatment for children and adolescents with cancer and their families.

As part of its overall strategy, PICS aims to develop a multidisciplinary, multi-campus approach to the provision of psychosocial support services. A twenty week project was commissioned to develop a service model and standards for the delivery of psychosocial care services to children and adolescents and their families across Victoria.

From all the evidence gathered and in consultation with service providers, a Service Model and Standards of Practice were developed. Service strengths and gaps against the Standards of Practice were summarised and recommendations for service improvement articulated. These are presented in the final report.

This *Compendium of Evidence* provides greater detail on the evidence that underpins the Service Model, Standards of Practice and the Implementation Plan.

1.1 Terms of reference

The following terms of reference were outlined in the original Project brief:

- To undertake a review of relevant literature.
- To report the key elements of psychosocial delivery at both international and national sites recognised as providing exemplary models of psychosocial care.
- To identify and review the existing psychosocial services at the PICS sites for children and adolescents undergoing cancer treatment.
- To establish a model of care for delivery of psychosocial services including definitions of minimum service, mandatory components, options for centralisation or decentralisation and without duplication. The model of care should include guiding principles for assessment of competency and credentialing of the professionals delivering the key components of psychosocial services.
- To bring staff together on all sites to review the suggested model of care and work towards consensus.
- To identify the resources required (including staffing, education, research and professional support) to implement the agreed model of care.
- Provide a timeline for the implementation program.

It was agreed that taking a quality improvement approach, optimal rather than minimum standards would be developed to define service delivery. In addition, it was agreed that too early an emphasis on mandatory requirements, competencies and credentialing without sufficient evidence or precedents may be counter-productive to the development of high quality standards within a tight timeframe.

This perspective was confirmed within the later stages of the Project, when the complexity of the different services was also appreciated. There was agreement that the final skill mix within a service and credentialing was part of an ongoing management role.

1.2 Project scope

The Project scope was to address issues across the whole continuum care including initial treatment, long term survival, relapse and palliation. While the original brief was focussed on access to specific specialist psychosocial services, it was agreed that these could not be addressed without reviewing the overall service context. As a result the overlapping domains of psychosocial care to be considered included:

- Communication and information needs
- Practical needs
- Social and environmental needs
- Developmental and psychological needs
- Physical needs
- Spiritual needs.

Figure 1 illustrates these domains of care used to inform the Project.

1.3 Project approach

The Project development and implementation was guided by the following key principles:

- a strong focus on the perspectives of the child and family was maintained
- the Project was developed collaboratively between a wide range of stakeholders including consumers (parents and young adult survivors) and staff from across PICS
- a supportive environment was encouraged to facilitate organisational learning
- a systems approach was used to ensure that the family was seen as the unit of care and how services and programs as a whole respond to the needs of families.

The following structures also guided the Project.

A **Project Advisory Committee** was established with representatives from all PICS sites and met six times throughout the Project.

A **Consumer Reference Group** made up of parents and young adult survivors ensured that the Project remained firmly grounded in the views and needs of consumers. Three rounds of consultation took place with the consumers each of which preceded the Project Working Parties. Between 5-8 consumers participated in each consultation.

Two **Project Working Parties** were established with 40 participants being invited to participate from each of the three services. Over 20 participants attended each of the three consultation rounds in which the Standards of Practice were drafted and reviewed.

1.4 Gathering the evidence

The following activities were undertaken to gather the evidence needed to inform the Service Model, Standards development, service gaps and priorities to address these gaps in the future.

Literature review: this covered an extensive range of evidence about psychosocial needs of the child and family, assessment processes, interventions and service models and standards.

Other documentation: a range of other PICS and related documentation was reviewed such as project briefs for other PICS initiatives and the findings of the recent parent satisfaction survey undertaken by Press Ganey.

Consumer consultation: consumers were consulted through the consumer reference group and individual interviews with parents, young adult survivors and one grandmother. A total of 24 consumers with experiences across all three PICS sites participated.

Site visits: these were undertaken at all three PICS sites and included a review of the patient load, stakeholder interviews, observation of multidisciplinary meetings, clinic waiting rooms and procedure clinics and a review of documentation.

A site report was prepared for each site and data across sites was summarised. Once the Standards of Practice were developed, the data from the site visits was used to analyse service strengths and gaps. From the service gaps, a range of service development strategies were developed with priorities being identified against a range of criteria.

The final individual site reports have been forwarded to each site with a copy of each being provided to the PICS Manager as part of the final reporting requirements.

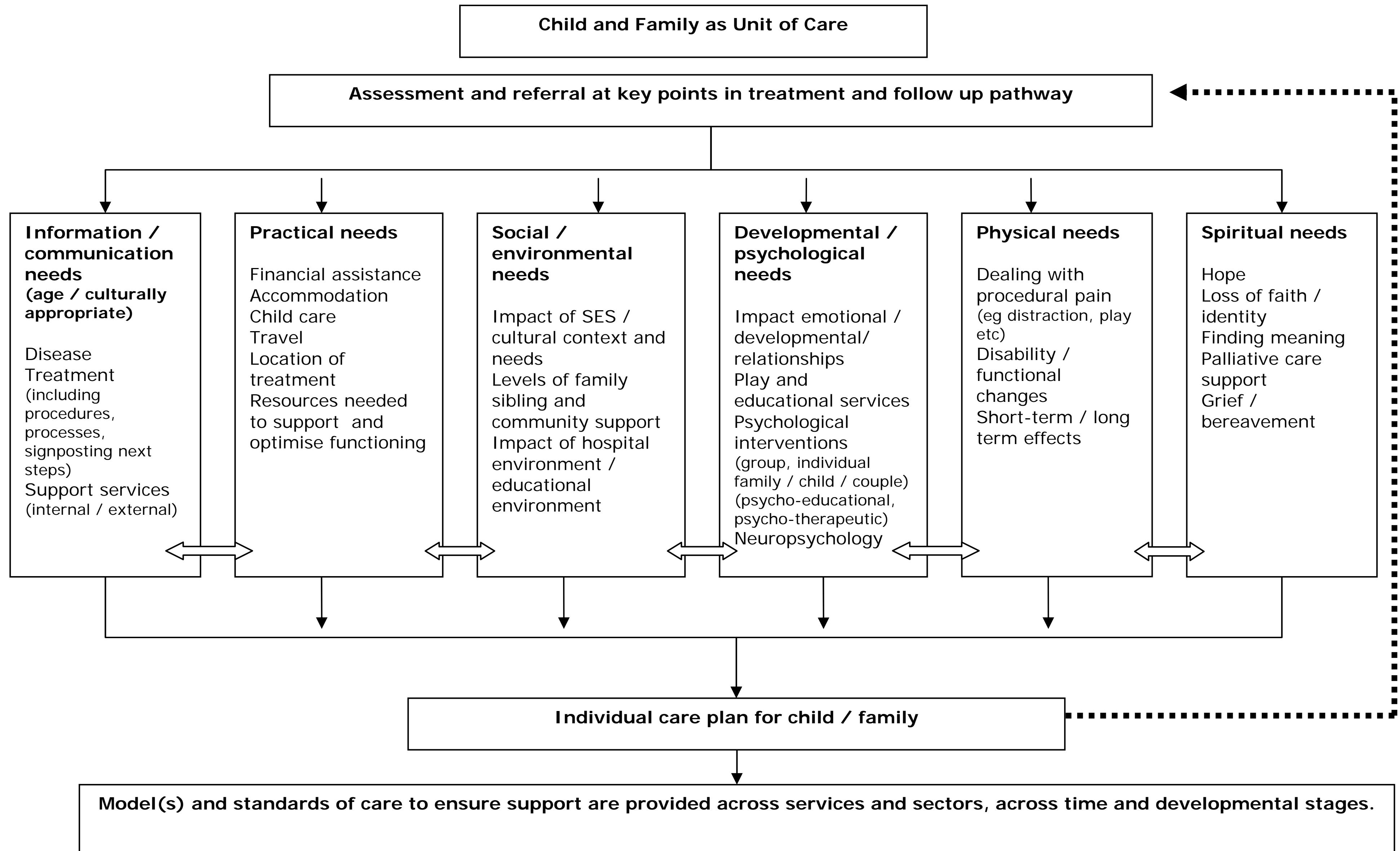
National and international comparative data: staffing information was accessed from national and international children's cancer services both directly and through other documentation in an attempt to review PICS psychosocial staffing against other services.

Other consultation: one interview was undertaken with a regional provider and a meeting was held with the community based children's cancer support organisations.

This document summarises the evidence gathered from all the above sources including a summary of the literature review.

As indicated this evidence informed the development of the Service Model, the Standards and the Implementation Plan, and is a supplement to the project's final report, ***Strengthening psychosocial care: a blueprint for the future'.***

Figure 1: PICS Psychosocial Services Project – Domains of Needs and Care



2 The literature review

The literature review addressed the following key questions:

- What are the psychosocial needs of children and adolescents with cancer, and their families?
- What risk factors impact on the likelihood and severity of psychosocial consequences of cancer on children, adolescents and their families?
- How do service providers assess needs?
- What is the evidence for effective psychosocial interventions currently available for children and adolescents with cancer, and their families?
- What are the international models of best practice in the psychosocial care of paediatric cancer?
- What standards exist for quality psychosocial care and service delivery for children and adolescents with cancer, and their families?

There is significant literature on the impact of a childhood cancer diagnosis on the child and family and their subsequent needs. There is more limited evidence about the most effective interventions to respond to these needs. In addition, there is variability in the quality of the literature with more limited high-level evidence. Results of studies with weaker levels of evidence need to be interpreted with caution.

The full literature review is included in this *Compendium*, with key points being summarised below.

2.1 The needs of children and families

- Childhood cancer has a significant psychological impact on the child, parents, siblings and other family members.
- Children by virtue of their ongoing development have unique needs at different times, requiring different approaches and services. Consideration to maintaining children's normal developmental growth through treatment is essential.
- The type of paediatric cancer, treatment as well as pain experiences can impact on the cognitive and / or emotional development of children and adolescents. Children who may be particularly vulnerable include:
    - younger children because of the immaturity of their brains
    - adolescents because of their developmental stage.
- While young adult survivors of childhood cancer in general report good quality of life, up to 30% of survivors have been seen to have major difficulties.
- Late effects for long-term survivors can include cognitive deficits, body structure and growth changes and infertility. Psychological consequences of treatment experiences in general, and of specific late changes have been identified by survivors.
- There are significant long-term and late effects for young children treated for brain tumours.
- High levels of distress are seen in both mothers and fathers at diagnosis and may persist over time. High levels of anxiety in mothers at diagnosis are predictive of ongoing anxiety five years after diagnosis.
- Significant predictors of parental distress can be identified.
- Siblings may have increased anxiety and reduced quality of life which can persist over time.
- Little is known about the needs of grandparents although their involvement in supporting the family is well acknowledged.

2.2 Assessment of needs

- There is increasing emphasis on the use of formal structured approaches to psychosocial assessment with a range of tools used in both research and practice.
- Neuropsychology assessment is recommended for children with central nervous system tumours.

2.3 Interventions

- Effective, timely and appropriate communication is important for the health care team and the family to reduce stress, increase coping and optimise adherence to the treatment.
- Strong empirical support exists for interventions linked to managing procedural pain and reduction in distress including relaxation, distraction, guided imagery and hypnotherapy.
- Practical, financial, social support and advice can reduce parental burden of care.
- Access to play, music, art and the child's or adolescent's educational programs facilitates ongoing normal development, enhances connections with school peers and optimises educational progress.
- Psychological interventions supported by strong evidence with highly favourable outcomes include:
    - Focusing on enhancing resilience and self-management skills of children and families
    - Providing supportive care to parents during times of distress
    - Facilitating parents' positive coping skills and problem-solving skills and resilience to life-events in order to best look after their child and reduce distress levels
    - Family centred and family focussed care
    - Early introduction of palliative care and symptom management when treatment is no longer curative.
- There is weaker evidence for a wide range of other interventions to provide support to children and families.
- There is a need to facilitate the smooth transition of the young adult cancer survivor into adult health services.

2.4 Models and standards of care

- A range of conceptual and intervention models have been identified that may be useful to inform practice. These include the family system model, Rolland's integrative model, the preventive model, the trauma model and the occupational model.
- Rolland's integrative model[1] considers families in the context of chronic illness, identifying illness phases including crisis, chronic illness and terminal phases. As with other models it draws on a strength-based framework that facilitates collaborative, creative problem-solving to enhance quality of life for families facing illness, disability and loss.
- A range of standards, guidelines and guidance have been identified that have direct or indirect relevance for the care of children and adolescence with cancer and their families. Of most relevance are the guidelines and recommendations of the International Society of Paediatric Oncology (SIOP).

[1] Rolland JS. 2004. Families and chronic illness: an interpretive model. In: Catherall DR (ed) Handbook of stress, trauma and the family. Chapter Five. New: York. Brunner-Routledge.

3 Consumer consultation

A total of 24 consumers were consulted through one or more of three processes:

- Participation in one or more consumer reference group meetings (n=10)
- Individual interviews either face-to-face or by telephone (n=8)
- Attendance at the Grampians Integrated Cancer Services Consumer meeting (this was part of the new PICS regional outreach project and a team member was an observer to the discussions) (n=9).

The following table summarises the profile of all the consumers who participated.

Table 1: Profiles of consumers by consultation approach

Relationship to child or adolescent with cancer	Consumer Reference Group	Interview	Grampians group	Total
Self – young adult who has previously had cancer as a child / adolescent	2	0	2	4
Mother	6	6	7	19
Father	2	1		3
Grandmother	0	1		1
Total	**8**	**8**	**9**	**27**[2]

Families had experienced care in all three PICS sites as well two having experienced care in a regional service.

Data from the individual and group interviews and discussion were collated and the key themes identified. Each theme is briefly summarised below.

3.1 The impact of cancer

The impact of the diagnosis of cancer in a child or adolescent is profound. A range of needs and emotions were expressed by consumers relating to various points in the pathway of diagnosis, treatment, recovery or bereavement. These reflect the needs of the child, parents and siblings as they navigate their way through the most significant challenge of their lives.

The demands of treatment are significant and further stretch the family's emotional, physical and practical resources. Parents were uniformly appreciative of the high level of clinical care provided to their child and were particularly sensitive to and valued service providers whose approach was to see the child, parents and siblings as the unit of care. The need for service providers to communicate with sensitivity and respect with these highly stressed children, adolescents and families was clearly identified.

3.2 Coordination of care and communication

Consumers commented on the difficulty in navigating a complex health system. Excessive waiting times and uncoordinated appointments exacerbated stress and this was even greater for regional families.

The need for stronger coordination, a more streamlined approach, improved communication within and between services as well as additional support to navigate the system is required. Particular attention is needed at points of transition including between phases of care or on completion of treatment and survivorship, and between acute care and community based services, including schools and general practitioners.

[2] Three parents attended a Consumer Reference Group meeting and were also interviewed

3.3 Access to emotional and practical support

Many consumers indicated that they had had excellent communication with service providers particularly around the time of diagnosis. For others, ongoing communication with service providers (particularly the medical staff) was more challenging, particularly once active treatment had been completed, but problems persisted and / or became more significant over time. Access to emotional and practical support

Emotional and practical support is needed for children, parents, siblings and broader family members. In particular parents need to be cared for and supported so that they can support their child. Emotional support for the children through play, music, art and the education program was particularly valued.

While a wide range of support may be available, families were not always aware of these or access was reliant on parents pro-actively seeking them out, at times when they were least able to do so. Parents perceived themselves as important advocates for their children's care but also wanted to be sure that someone was also advocating for their child and themselves within the system.

Key emotional issues for all parents include:

- grief and loss
- a lack of control
- a lack of time together or time alone together
- differences in coping mechanisms
- the impacts of stress leading to conflict and relationship strain or breakdown.

For regional families, physical separation from each other and from their local communities while the child is in hospital further exacerbates the emotional toll.

Interviewees indicated that they wanted greater recognition of the prevalence of depression in parents so that the need to take anti-depressant medication, or seek counselling can be 'normalised'.

Parents valued the community support programs such as Challenge and Camp Quality that were available for their child, siblings or the whole family. Peer support through other families within the oncology service was seen to be valuable but presented challenges at times when other families became overly dependent on their support.

3.4 Information

Consumers clearly wanted a range of information in a variety of formats that was tailored to different needs e.g. story book format for young children, videos, written information and access to relevant web-pages. Information was needed about treatment, support services and practical tips, many of which may come from other families.

3.5 Vulnerable groups

Overall, vulnerable groups as identified during comprehensive consultation included:

- o Survivors of childhood cancer
- o Fathers of children/adolescents with cancer
- o Culturally and linguistically diverse families
- o Bereaved families.

Of the four young adults who participated in the consultation, two had particular ongoing needs that were significant. Their illnesses as adolescents and young adults had resulted in significant loss of connection with their peers and ongoing issues of loss of self-esteem and isolation as well as their disabilities eg deafness.

Two fathers interviewed clearly identified the problem of gaining support for themselves with current services or programs not meeting their unique needs as fathers.

Interviewees also identified that while they were able to articulate their needs, they were aware of other families such as those from culturally and linguistically diverse backgrounds who were completely disenfranchised within the system.

Finally bereaved families are in need of significant support as they come to terms with the loss of their child and endeavour to pick up their lives again.

'There needs to be more for men's grieving needs – we have got through because we are really committed to each other – and we survived because we understood that we had individual needs and there are differences in the way you grieve and that is OK.'

For the bereaved family, factors that influence recovery may included:

- A post-bereavement consultation offered by and taken up with the oncologist
- Formal couples' counselling, initially undertaken *'under the counter'* within RCH services and later in a private arrangement
- Recognition that each parent grieved differently and needed to do so
- Contact with a bereavement support group
- Over time, taking an active role in support programs.

3.6 Ongoing support

The impact of the cancer diagnosis and treatment is ongoing with families reporting that the emotional and practical toll continues to ripple through their lives for some considerable time.

The impact on the family may be even greater when there are ongoing problems for the child treated with cancer. There appeared to be more limited recognition of the longer term toll of a cancer diagnosis and treatment on children and their families.

4 Site visits

Each site visit was undertaken over 2-4 days and provided valuable insight into current services, their significant strengths and some of the challenges that they face.

The following summarises the key findings and issues across all three sites.

4.1 General findings

The three services are quite different in nature and their approach to care is influenced by the service context, the volume and complexity of patients treated and the points in the pathway in which children are treated.

Across all three services there is a strong commitment to providing optimal psychosocial care with an emphasis on tailoring support to meet the needs of each child / family.

4.2 The patient profile

The RCH Children's Cancer Centre treats the vast majority of children across diagnostic groups and complexity. In 2005, 135 new patients were treated at RCH, 17 of whom were from interstate or overseas.

MMC Children's Cancer Centre is much smaller providing care to 25 new patients in 2005; MMC refers children with acute myeloid leukaemia and others needing bone marrow transplant to RCH.

In 2005, Peter Mac provided radiotherapy to 68 new patients referred from RCH or MMC, primarily for curative radiotherapy. A total of 90 children in all were referred to Peter Mac in 2005. Data indicates that just over 20% of children are given radiotherapy for palliation and that the referrals for palliation are increasing. The vast majority of children are treated as outpatients with only a small number (n=11, 2005) being admitted.

The following table looks at the profiles of the children by site.

Table 2: Profiles of newly diagnosed children by site, age and disease category in 2005

		Service					
		RCH		MMC		Peter Mac	
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**[3]	**100%**

4.3 Underlying service models / philosophies / values of care

While there is strong commitment to providing quality care, other factors within the service system or provider disciplines appear to influence how this occurs.

While for many children treatment will continue over a 6-36 month period, the often acute initial presentation and then ongoing emergency admissions (eg for febrile neutropaenia) along with the 'acute care' environment of hospitals, results in an acute, reactive or crisis management model of care. The ability to take a more proactive, preventive or early intervention approach is constrained by the 'next crisis'.

Opportunities for the future include:
- The establishment of some common core values
- The need to better negotiate organisational and discipline boundaries to create a more flexible response and team strategies that are guided by the children and families' needs.

4.4 Environment

Although the RCH Children's Cancer Centre is currently undergoing redevelopment and the environment is thus compromised, it was clear that all PICS sites were committed to creating a physical environment that supported children and family needs; this included a colourful environment and access to a range of play and other activity resources for children. However the environments tend to be oriented towards younger children with less attention paid to *'teenage space'*.

The creation of a safe physical and emotional environment was demonstrated in a variety of ways including:

- availability of accommodation for parents
- children being treated for radiotherapy early in the morning to avoid lengthy waiting times (although this was flexible to meet the child / family needs)

[3] This data was provided early on in the Project's development. 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. This later data is used in parts of the final report. We only have the age or disease breakdown on the original 68 children identified.

- appointment of a family resource coordinator at RCH to support families in a variety of ways
- streamlining of appointments to reduce waiting times eg at the RCH lumbar puncture clinic; in the Day Oncology Unit
- access to music, play or art therapy services within the ambulatory setting
- the use of pagers for families so that they can have coffee etc while waiting for appointments.

The environment also appears to be more subtlety influenced by other factors.

At MMC there was strong emphasis by service providers of their role to '*contain the anxiety of parents and children'*, and the social worker has a strong personalised approach, *'sitting with children and families'*.

In some ways, the Peter Mac service had a sense of being an '*oasis of calm'* – this may result from a number of factors including the structured organisation around the provision of daily radiotherapy for children and the sense that the children were '*special'* and their needs to some extent are privileged over the larger adult client base. At RCH, the demands of the higher volume of children and the complexity of treatment drives a much stronger acute care – crisis intervention model. The future changes in the physical environment and some streamlining of processes may assist to create an environment which is less reactive and potentially more *'calming'*.
A level of sub-optimal coordination or fragmentation of services was identified during the site visits. Encouragingly during the life of this Project, staff have begun to identify a range of ways in which the system can be made more child and family friendly including for example, further streamlining of clinic appointments, developing older children or adolescent clinics, as well as better integration of services within and across sites.

4.4.1 Stakeholder views and challenges

Within the field there is a strong desire for more resources in a variety of areas. In contrast, at the service executive level there was a perception that the paediatric oncology service was relatively well resourced compared to other generalist paediatric units or adult oncology services.

Within paediatric oncology, there was some recognition of the need for the staff to work differently, to take a more systematic approach to the care offered and to draw on other resources that are available eg general practitioners to support families.

The reliance on philanthropic funding is not unique to the PICS environment but occurs both nationally and internationally. The availability of external funding can be seen to strengthen services for children and their families. Regardless of funding source, the emphasis needs to be on ensuring optimal access to and use of high quality services. In addition, for sustainability, there needs to be a move towards gaining additional core funding – in difficult economic times, this will present challenges.

Finally potential changes in the directions of the Child and Adolescent Mental Health Services (CAMHS) across Victoria may potentially have significant implications for access to psychology and mental health services for children with cancer and their families, as well as other children and families with chronic illness. The review at both RCH and MMC is part of a broader review of CAMHS, with DHS directions moving towards prioritising services for children with primary mental health problems.

4.5 Communication, coordination and collaboration

The site visits revealed the need to strengthen communication, coordination and collaboration between PICS service sites including the need to strengthen the provision of timely clinical and psychosocial information to Peter Mac when a child is referred for radiotherapy.

Key points included:

- Ensuring that the views of all relevant providers including music or art therapists are elicited and valued within multidisciplinary clinical and / or psychosocial meetings
- Ensuring that there is clearer articulation by service providers of the proposed plan and outcomes of any psychosocial discussion
- The need for clear documentation that is both accessible to all relevant providers and is sensitive to the privacy of the family
- The benefit of individual case conferences when a child or family have complex psychosocial needs
- The need to strengthen care coordination to ensure that the clinical and psychosocial needs of the child and family are addressed.

There was some evidence of linkages between the acute and community or primary health care sectors. The RCH *Back on Track* Schools Program is a clear example of working with schools to support children's needs. Other examples of linkages across sectors included communication with GPs and case conferencing between providers involved in providing palliative care to children and their families.

Opportunities to strengthen communication across sectors in the future particularly on the completion of treatment need to be explored (see 5.9).

4.6 Psychosocial assessment, planning and referral

4.6.1 Family needs

The key features identified of a psychosocial assessment with the family included: child developmental history, personality and coping styles, family history of cancer, mental health problems, substance abuse, child and family functioning, employment, family and child understanding of the situation, concurrent stressors, resources (eg practical, emotional and social support).

There was evidence of the social workers undertaking a psychosocial assessment at all three sites.

Most if not all families were seen by social work within one week of diagnosis within the two Children's Cancer Centres, or on first clinic appointment at Peter Mac.

For at least some families (often those with no immediate practical problems) there was limited ongoing social work contact following the initial assessment. These families are provided with a range of information about support services and encouraged to contact the social worker if they have concerns. For other families possibly with more immediate and obvious needs, there was a strong, ongoing relationship with the designated social worker.

4.6.2 Children's needs

General needs

It was also recognised across sites that the predominantly female workforce results in a lack of male role models for older and adolescent boys.

Play, art and music

From the child's perspective, access to art, music, play and educational programs support their developmental and psychological needs

At Peter Mac the music therapist provides music during the weekly clinic and where possible, provides support to individual children. At the time of the site visit, she was working closely with one child with a brain tumour who had been traumatised by her previous experiences and would not speak during early radiotherapy planning and treatment. Over time using music to work with the child at the weekly clinic, gradual improvements were achieved and the child was managing radiotherapy without anaesthetic.

An experience that was challenging for a range of play, music and art therapists at one site, was working with a child with complex needs without adequate communication between all providers. As a result of this experience, these providers recommended the benefit of individual case conferencing for children or families with complex needs.

Education programs

Although only a relatively small number of school-age children are treated at MMC, the limited teacher resources within the in-patient setting only make it more difficult to achieve the formal connections between the child and their school program. The teacher is unable to provide support to children being cared for in the ambulatory setting, but not yet well enough to return to school.

The RCH educational program *'Back on Track'* is premised on assisting the child's school to support and maintain connections between the child, their peers and the school.

Procedural pain

There were a range of approaches to manage procedural pain including regular anaesthetic lists and distraction techniques. The RCH *'Comfort First'* Project provides an innovative and systematic approach to working with newly diagnosed children and families in managing procedural pain. Once trialled this program may be transferable across sites.

There is a need to strengthen the transfer of information about managing procedural pain across service sites particularly to Peter Mac when the child receives radiotherapy. A formal plan such as the *Comfort First* procedural pain plan may be a useful vehicle to achieve this communication.

Finally, while MMC has a regular GA list for procedures for younger children, it has more limited services around other mechanisms to support procedural pain. There is a need to strengthen procedural pain management within MMC and this may have benefits for the wider paediatric service.

4.6.3 Mental health referral

There are different views about the appropriateness of mental health referral for children or families. For some there is a need to ensure that a strong preventive or early intervention approach is taken, with the promotion of the mental health staff to families as an important component of the oncology team. From the mental health workers' perspective, late referral makes any intervention much more difficult.

Other factors that influence referral to mental health services include:

- limited resources within the service or within the community (internal services may become more limited by future changes in CAMHS as indicated)
- limited agreed criteria for referral
- the wish on the part of oncology services for an 'oncology specific' mental health consultation and liaison staff member to ensure that trust is built up between providers; in some services this contrasts with the more generic service model being promoted within mental health services.

4.7 Information provision

Clearly the oncology medical staff and nurse coordinators provide significant verbal information to parents and children. This is supplemented by additional and ongoing verbal and written clinical information provided by the nurse coordinators at each site and information about support services given by social workers and other staff.

Other programs that have facilitated families' access to information include the provision of twice yearly parent information days which are open to all families across sites. Other programs

such as *'A Girl's World'* have provided important information and support to older (8+years) and adolescent girls to assist them cope with hair loss and other body image issues.

There appeared to be few resources for families from culturally and linguistically diverse backgrounds. Interpreters as well as other consumers indicated the difficulty of these families in understanding what was happening.

Future opportunities to enhance information provision include:

- Developing additional low-key in-house materials that provide a range of useful tips to families about specific drugs, treatment, side effects, transition processes etc.
- Earlier access to information about radiotherapy for children and families may also facilitate the child and family's transition to Peter Mac.
- Developing or strengthening current resource libraries that are readily accessible to families would be helpful.

4.8 End of treatment transition

While the end of treatment transition is understood to be a crucial one for both children and families, more limited attention is paid to this period.

Some preparatory work with individual families takes place in an ad hoc manner or is addressed in the parent information sessions. The RCH school program specifically focuses on ensuring that children transition back to full-time schooling as soon as possible if they have not already done so.

Supporting the transition period for children and families is constrained by:

- The competing demands of new families within the system
- The lack of relevant information
- Limited communication with relevant community or primary care providers.

4.9 Rehabilitation

The allied health providers across sites identified a clear role in providing supportive care for specific groups of children with cancer including:

- Children requiring high levels of rehabilitation to support them at home and school, including children with brain tumours
- Children with fine motor coordination or functional problems resulting from treatment
- Children who already have some developmental delay issues including speech and language development.

In addition children with pre-existing developmental delay may require additional support and more timely access to existing school-based specialist services.

4.10 Palliative care and bereavement

The Victorian Paediatric Palliative Care Program (VPPCP) provides an important link between hospital services and community based palliative care.

Different models are currently in place. At MMC the VPPCP nurse consultant will work more directly with the family and staff to assess the family's needs and wishes and develop an appropriate plan linking in with community based palliative care services. At RCH, the VPPCP staff work less directly with the family but support staff and community palliative care providers to ensure the child and family have the care that they need. Peter Mac providers may also directly link in the VPPCP to assist families in their care.

While relationships have substantially improved, there remain considerable challenges between acute care and palliative care services including:

- Active treatment continuing until the *'very last minute'*.

- The need to maintain *'hope'* at any cost may result in the concept of the child *'not being cured'* not being openly discussed between staff and family.
- Sometimes the family may want to stop treatment but find this hard to articulate
- The value of early referral promoting the concept of *'hoping for the best whilst preparing for the worst'* is not well appreciated by staff.
- The distress of staff who have looked after a child for a significant period of time has constrained their ability to effectively support families' needs.
- Palliative care services are adult oriented and so need support to provide paediatric care.
- Difficulties in two way communication between palliative care providers and the oncology service and vica versa.
- Late referral reduces the opportunity for the development of a relationship between palliative care providers and the family and early access to community based supportive resources such as music therapy.

There were however some clear examples of excellent '*shared care'* palliative care arrangements with case conferencing with a GP and / or a community palliative care service and the local paediatric oncology service providers.

4.11 Staffing needs

In the same way that parents need to be supported to care for their children, staff also need to be provided with a range of professional development opportunities to support them in their role. A recent PICS survey has been undertaken to identify staff needs across MMC and RCH.

Areas that have been identified include:

- Child development knowledge for generalist providers such as chaplains, radiation therapists and generalist nurses.
- Radiotherapy for the non-radiation therapy staff.
- The integration of psychosocial issues into paediatric oncology nursing programs.
- The need to develop (or formalise) more systematic approaches to providing psychosocial care.
- Communication skills including dealing with difficult situations, encouraging the uptake of a mental health or related referral.
- Brief generalist skills as well as advanced specialist skills in psychosocial assessment.
- Generalist as well as advanced skills in managing procedural pain.
- Access to formal ongoing professional supervision for staff as well '*as-needed debriefing*'.
- Skills in service improvement, process redesign and change management.

5 Other consultation

5.1 Regional service providers

This consultation highlighted the cultural problems that rural families have in coming to metropolitan Melbourne in addition to the practical issues such as travel, accommodation and financial burden. The need to reconnect with their community was seen to be essential for the family's long-term well-being.

While currently improving, the limited adult as well as child and adolescent mental health services in regional Victoria make it difficult for families to gain additional support following treatment.

Participation in the Grampians consumer consultation and discussion with a member of the Consumer Reference Group (see 4) also provided an opportunity to understand the needs of regional families.

5.2 Community based children's cancer organisations

There are many community based children's cancer organisations that provide a range of services within the community and oncology units including:

- Recreational activities for children, adolescents, sibling and families
- 'Make a wish' activities
- Funding support for individual families and for service positions eg music therapy
- Some therapeutic approaches
- Holiday homes / respite.

There is a level of fragmentation and duplication of effort amongst these services that may mirror the fragmentation seen within the oncology services at times. While many families valued the support that they or their children received, they also commented on the competition and duplication of activities between the community-based organisations. The consumers identified that with greater cooperation, the consumer based organisations could potentially fund other initiatives to support families such as providing funding support for community based counselling at the end of treatment or post-bereavement. Given time and ongoing commitment by all providers along with skilled facilitation, it should be possible to establish an effective dialogue with greater *'give and take'* between all providers to improve services for children and families.

6 National and international comparative data

Three national and two international services were contacted with a request to provide information about the range and level of services provided within the paediatric service.

Data was received back from two national paediatric oncology services.

Data from two international sites in the USA was also drawn from the earlier psychosocial service review undertaken in 2003 at RCH, and from UK evidence of staffing ratios for all new children diagnosed annually across 17 sites as reported in the published literature.

Table 3 compares the total EFT reported for different psychosocial service providers within the national, international services and PICS overall as well as the individual PICS services.

The UK data calculated and reported minimum, maximum and median staff:children ratios across all service sites. Based on this, staff:children ratios have also been calculated from the data available from other sites and is reported in Table 4

The UK ratios are based on all positions regardless of whether funded through core or philanthropic funds.

Caution must also be used when comparing EFT and ratios across services as there are differences in the service context, roles and health care systems.

Using the data cautiously, the following key points are noted.

Social work resources

Across PICS, social work resources (1 social worker:33 children) are equal site 4 (Australian), are slightly better than Dana Farber (1:43 – this includes the resource workers used for practical and financial assistance) and fall between the minimum and median ratios in the UK services (1:23 children and 1:55 children).

RCH social work ratio to children (1:38) is lower than MMC (1:25).

Peter Mac social work resources are small and given the relatively short time that children are at Peter Mac, comparisons are not easy to make.

Psychology and associated resources

The current PICS ratio of allocated psychology/ mental health/ family therapy positions to children is 1:48. This compares with 1:43 at Dana Farber (or 1:62 if you exclude the research positions).

If you remove the current vacant CAMHS role of 0.6 EFT, the PICS ratio is 1:60. Excluding Comfort First staff, and based only on the current staffed positions of 1EFT psychologist and 0.2 EFT family therapist, the ratio is 1:112.

All these roles are available only at RCH. Access to psychology / mental health services are based on referral only to CAMHS at MMC or at Peter Mac through its psychology services.

Nurse coordinators

Across PICS, the ratio of current nurse coordinator positions to children is 1:30 with a lower ratio of 1:38 at RCH. One 0.5 EFT is currently unfilled and so the PICS ratio is 1:47 and the RCH ratio is 1:43.

The PICS ratios still compare favourably to the WA oncology nurse liaison role (1:66).

With a potential new 1 EFT being allocated for a regional coordinator and the vacant 0.5 EFT being filled, the ratio of nurse coordinators to children will be 1:26.

The UK paediatric oncology outreach nurse role appears to be different to the nurse coordinator roles and so comparisons are more difficult.

Play, music and art therapy

Currently the ratio of play, music and art therapy resources across PICS is 1 to 64 children. This is similar to the ratio in one Australian site but is a lower staff ratio than another and lower than the minimum and median ratios in the UK.

The ratio of play, music and art therapy to children at RCH (1:93) is lower than at MMC (1:31). There is only an 0.1 EFT music therapy role at Peter Mac to support the weekly outpatient clinic.

The lower ratios in the US services may reflect a different role for child life specialists and so it is difficult to make a comment in this area.

Table 3: Reported EFT for psychosocial support providers for children cancer services across national and international services and PICS.

Service	Estimated number of newly diagnosed patients pa	Social work EFT	Psychology Mental health EFT	Psych-iatry EFT	Neuro-psych EFT	Child life therapists EFT					Nurse coordinators or equivalent EFT	Other EFT
						Play	Music	Art	CLS	ALL		
USA 1	**210***	**3.35 (plus interns)**	**4.85**	**0.5**	**Up to 6 mth wait**		**Available**	**Available**	**2**	**2+**	**Not known**	1.5 resources staff re: practical / $$$
USA 2	**320***	**4**	**4 plus interns**	**referral**	**Use students**				**2 plus assts**	**2+**	**Not known**	
Site 4	**80**	**2.4**	**1**	**[1 EFT not onc specific]**	**-**	**1.8**	**0.4**	**-**		**2.2**	**1.2**	
Site 5	**60**	**1**	**Referral**	**referral**	**referral**	**1**				**1**	**-**	
PICS	**160**	**4.85**	**3.3** (0.6 EFT core vacant)	**0.1**	**0.6**	**0.5** (+ 1 EFT general play at MMC inpatient)	**1.25**	**0.6** (+ 1 EFT generalist art MMC inpatient)	**-**	**2.5**	**5.2**** (0.5 EFT vacant)	Challenge diversional officer 0.3 EFT at MMC OPD
RCH	135	3.6	3.3 (as for total PICS)	0.1	0.6	0.5	0.35	0.6	-	1.45	3.6 (0.5 EFT vacant)	
MMC	25	1	referral	referral	Refer to RCH	(+ 1 EFT general in-patients)	0.8 (+ in patient music)	(1 EFT general in-patients)		0.95	1	Challenge diversional officer 0.3at MMC OPD
PMCC	[68]	0.25	referral	Nil	Nil	Nil	0.1 ExF			0.1	0.6	

* Estimated figures based on data in 2003 Children's Cancer Centre Psychosocial Report ** Additional 1 EFT is being considered for regional nurse coordinator roles.

Table 4: Comparisons of ratios of specific psychosocial staff children's cancer services per child / family newly diagnosed per annum across international, national and PICS sites. .

Role	UK Study			USA 1	USA 2	Site 4	Site 5	PICS	RCH	MMC	PMCC
	Min	Max	Median								
Social workers	1:23	1:157	1:55	1:62 1:43 if include resource workers	1:80	1:33	1:60	1:33	1:38	1:25	(0.25 to 68 patients – most short-term)
Psychologists	1:132	1:1100	1:333	1:43 1:62 (excludes research positions) Also have interns	1:80 (plus interns)	1:80	Referral	1:48 1:60 (excludes 0.6 current vacant position)	1:41 1:50 (excludes 0.6 current vacant position)	Referral only	Referral only
Play specialists	1:18	1:220	1:43	1:105	1:160	1:36	1:60	1:64 1:57 (with MMC Challenge role)	1:93	1:31 1:22 (includes Challenge therapist – not inpatient play / art)	(0.1 to 68 patients mostly short-term)
Paediatric oncology outreach nurses	1:15	1:97	1:33	Not known	Not known						
Nurse coordinators / oncology liaison nurse				Not known	Not known	1:66	nil	1:30	1.38	1:25	1:113
All psychosocial staff	1:6	1:32	1:14								

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