



Paediatric Integrated Cancer Service

A statewide cancer service for children

Optimising nutritional outcomes for children and families

A service model for the future

Summary Report

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Contents

Executive summary	3
1. Introduction	5
2. Project purpose	5
3. Project approach	5
3.1 Project scope	6
4. The service context	6
4.1 The patient profile across PICS	6
4.2 The service profile	7
5. Nutritional support for children with cancer	9
5.1 The evidence from the literature	9
5.2 Current nutritional services at the RCH and MMC Children’s Cancer Centres	15
5.3 Benchmarking against other services	18
5.4 Opportunities	22
6. The future PICS nutritional service model	23
6.1 The vision for PICS nutritional services	23
6.2 The principles guiding PICS nutritional practice	23
6.3 General food services	24
6.4 A tailored approach based on need	24
6.5 Nutritional screening, assessment and decision-making tools	26
6.6 Nutritional interventions	26
6.7 Policies and protocols	28
6.8 Information resources	28
6.9 Strengthening coordination and continuity of care	28
6.10 Peter MacCallum Cancer Centre	28
6.11 Strengthening the service system	29
6.12 Quality improvement, service evaluation and research	29
7.0 Moving forward- recommendations	31

Executive summary

The Paediatric Integrated Cancer Service (PICS) was established in 2004 as a partnership between the Royal Children's Hospital (RCH), Southern Health (SH – Monash Medical Centre [MMC]) and Peter MacCallum Cancer Centre (Peter Mac). 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.

As a result of complex and aggressive cancer treatment, the important role of adequate nutrition has been increasingly recognised to optimise both short and long-term outcomes for children. International evidence however, demonstrates inconsistencies in the ways in which children's nutritional needs are addressed. In addition, PICS identified the need to review nutritional services across the service sites to develop a service model for the future.

Working in collaboration with service providers across the RCH and MMC Children's Cancer Centres and building on the current evidence and local expertise, a best practice service model for nutritional services has been developed.

While recognising the strengths of the current services and service providers, this service model addresses a range of identified service issues including:

- The lack of a systematic approach to nutritional needs as reflected in:
 - variation in practices
 - variability of referral criteria
 - the late identification of significant nutritional problems by generalist staff
 - an ad hoc approach to nutritional interventions by medical staff
- Greater parental appreciation of the benefits of good nutrition and / or high levels of parental anxiety leading to increasing referral to dietetic services
- Significant budgeting resource gaps in dietetic services across services limits the capacity to provide a preventive and pro-active approach to nutritional services for all children and their families, particularly within the ambulatory setting
- Lack of consistent data constrains the capacity to review current practice and identify opportunities for service enhancement
- Limited information flow across services to optimise continuity of care
- Limited research capacity.

Given the forthcoming review of Peter Mac's service model for children receiving radiotherapy, the proposed service model focuses on the two Children's Cancer Centres. How best to respond to the nutritional needs of children while they are having radiotherapy needs to be reviewed once the Peter Mac service model has been agreed.

The service model

The proposed service model is guided by a vision and a set of service principles. The vision is that:

All children and adolescents and their families will have access to high quality nutritional services, advice and support that optimises the children's / adolescents' health and wellbeing including normal growth and development, across the continuum of care.

There are three key features of the service model:

- The use of clear screening, assessment and re-assessment processes
- Different intervention levels based on need and ensures that all children and families gain access to a base level of information and support
- A tailored approach that enables levels of intervention be adjusted to needs.

The service model requires:

- the development of agreed policies and protocols across services
- an agreed information suite for parents and families
- a range of mechanisms to strengthen coordination and continuity of care within and across services
- strengthening of the service system through enhancing education of generalist and specialist providers
- a stronger focus on quality improvement, service evaluation and research.

The service model also requires an additional investment in dietetic resources. Based on the UK NICE Guidance for nutritional services for children with cancer, increase in EFT is recommended across the two service sites.

In addition, a service development / research role (0.4 EFT) is recommended to facilitate service development and research opportunities across PICS services. Initially envisaged as a 2-3 year appointment, there is potential for this position to be funded philanthropically. Such a role will not only fast-track service improvements within and across the individual Children's Cancer Centre, it will potentially position Victoria as a future leader of nutritional services for children and adolescents with cancer and their families in Australia.

Recommendations

1. The PICS Coordinating Group endorses the service model and actively works with the individual services for its successful achievement over time.
2. An implementation plan is developed to identify short and long-term goals within and across services and to regularly review achievements against these goals.
3. Short-term funding resources are allocated or sought to:
 - undertake a clinical audit of current practices of a cohort of children diagnosed 2-3 years ago across tumour groups
 - undertake a clinical audit of children having radiotherapy at Peter Mac to identify what proportion of these children are having concurrent appointments at the referring Children's Cancer Centre
 - further develop the information resource suite for parents / families
 - develop agreed policies and practices across service sites. This includes agreement on the weight criteria (including reference weight) for referral to dietetic services by generalist staff and the decision-making algorithm for nutritional interventions
 - facilitate the further development of the Children's Cancer Centre database to record and review critical patient nutritional data and provide triggers and alerts that will facilitate generalist and specialist practice, and information transfer across services.
4. The service model is reviewed in light of the future Peter Mac service model for children having radiotherapy to ensure that these children and their families have easy and timely access to nutritional services as needed.
5. RCH and MMC Dietetic service managers and associated staff explore and develop a common dataset that will enable evaluation of practice across services.
6. RCH and MMC Dietetic service managers develop business cases within their services to achieve the recommended resources required to support this best practice service model over time.
7. Funding is sought for a service development / research role to support service development and research across PICS and associated services. This role should be for 2-3 years initially with identifiable goals and outcomes. The role should be reviewed at this point and decisions about the ongoing role be made.
8. PICS nutritional services develop partnerships with national and international paediatric cancer services and with local and national research groups to enhance patient outcomes.
9. PICS nutritional services are supported to build their knowledge and expertise to enable them to develop a leadership role for national nutritional services for children with cancer and their families.

1. Introduction

The Paediatric Integrated Cancer Service (PICS) was established in 2004 as a partnership between the Royal Children's Hospital (RCH), Southern Health (SH) and Peter MacCallum Cancer Centre (Peter Mac). 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.

As a result of complex and aggressive cancer treatment, the important role of adequate nutrition has been increasingly recognised. However international evidence demonstrates inconsistencies in the ways in which children's nutritional needs are addressed. In addition, as part of its overall vision for consistent quality services across service sites, PICS identified the need to review nutritional services across the sites to develop a service model for the future.

This report outlines the Project purpose and approach and the service context of current PICS services. It then provides a brief overview of the evidence about nutritional support for children with cancer, current nutritional services across the three PICS services and information about international and national models and service developments in this area.

This then informs the proposed service model for the future.

2. Project purpose

The purpose of this Project is to develop a best practice service delivery model to support the nutritional needs of children and adolescents with cancer across PICS services and associated regional service sites.

The key questions guiding the Project were as follows.

- What is the role and benefit of nutritional support for children and adolescents with cancer and their families?
- Which children and adolescents need nutritional support and how do they currently access this?
- What are the current services and resources?
- What factors are influencing current practice?
- What are the elements of a best practice model?
- What resources are needed for the relevant departments of nutrition and dietetics to deliver the agreed service model to the Children's Cancer Centres and associated services?

3. Project approach

The Project was undertaken by an external consultant working with a senior dietitian across the Children's Cancer Centres at the RCH and Monash Medical Centre (MMC), the Clayton campus of Southern Health. This Project has been guided by:

- an across PICS perspective
- a focus on strengthening the service system as a whole as well as improving access to specialist services
- consideration of workforce issues in particular current and future workforce demands
- a realistic and wise use of resources within the relatively 'well resourced' context of the Children's Cancer Centres.

The key activities for the development of an agreed model of service delivery for nutritional services were as follows.

Literature review: a literature review previously undertaken provided the basis for a brief search and review of more updated evidence. This review focused on recent evidence of the benefits of nutritional support and the different service models and pathway development for nutritional care.

Internal stakeholder consultation: this included consultation with practitioners and / or service managers at all three PICS service sites. This was undertaken via individual interviews, meetings and a workshop for key stakeholders.

Service survey: a brief survey was completed at each PICS site to identify current services and practices, key service strengths and service challenges.

Benchmarking and external stakeholder consultation which included:

- consultation (by telephone and email) with key dietetics service providers and researchers within the Queensland Paediatric Oncology Network and at St Jude's Children's Research Hospital, US.
- circulation of a brief survey to the other interstate children's oncology services to identify current service models and practices. Four interstate services responded.

Feedback from parents: this included reviewing the findings of the recent Press Ganey patient satisfaction survey and seeking informal comment from parents through the CCC Parent Advisory Group (CCCPAG) morning tea program. This latter strategy had limited success due to the families who happened to be at the centres at that time.

3.1 Project scope

Although the Project was to develop a service model across PICS, the primary focus has been on the two Children's Cancer Centres.

While some service information has been accessed about the nutrition service at Peter Mac, it was felt that the nutritional service model for this hospital would be better dealt with as part of the planned review of Peter Mac's paediatric cancer services to be undertaken in 2008.

4. The service context

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

4.1 The patient profile across PICS

Each year, approximately 160 children in Victoria are newly diagnosed with childhood cancer and are managed by the CCC at RCH and SH, 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%¹ and increasing.

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

- 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. Wilm's tumour, osteogenic sarcoma)
- 45% of children are aged 5 years and under at time of diagnosis
- 31% are aged 6-12 years
- 24% of children are aged 13 plus at diagnosis.
- 41% of children treated at RCH Children's Cancer Centre were aged 5 years and younger with just over one quarter being aged over 13 years.
- MMC Children's Cancer Centre tends to see a younger population with 67% of children being aged 5 years and younger. This may reflect that at that time MMC tended to treat the less complex cancers
- Nearly 40% of children having radiotherapy at Peter Mac were aged 6-12 years, with 30% each being in older or younger age groups.

¹ Wallace W, Blacklay A, Eiser C, Davies H, Hawkins M et al. 2001. Developing strategies for long-term follow up of survivors of childhood cancer. **British Medical Journal**. 323:271-274.

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

Category		Service					
		RCH		MMC		Peter Mac ²	
		n	%	n	%	n	%
Age	0-5	55	41%	16	67%	21	30%
	6-12	43	32%	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	46%	16	23%
	Brain tumours	29	21.5%	5	21%	28	41%
	Solid tumours	35	26%	8	33%	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 nutritional services being provided in 5.2.

The **RCH Children's Cancer Centre** is the largest paediatric oncology service in Australia treating approximately 70% of Victorian children diagnosed with malignant cancers, across all diagnostic categories, complexity and age groups. It also provides services to children and families from Tasmania, other Australian states and through international referrals.

In addition to managing children with cancer, the RCH Children's Cancer Centre also manages about 10 children with non-malignant conditions that require bone marrow transplantation. These children represent an estimated 40 % of all bone marrow transplants managed at the RCH.

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. Six outpatient clinics are held weekly with an average of six consultants at each clinic. These are located on the same floor as the in-patient and day oncology services.

The **MMC Children's Cancer Centre** is situated within a large general hospital, as part of a general paediatric service. The Children's Cancer Centre provides care to approximately 25-30 new cancer patients per annum. Children with acute myeloid leukaemia, needing bone marrow transplant and others needing more complex medical treatment are referred to RCH.

² 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 a purpose built ambulatory care facility providing outpatient clinics, day oncology services and general anaesthetic procedure services within the same environment. In-patient care is provided on the two general paediatric wards, depending on the child's age.

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. A weekly children's outpatient clinic is held.

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 very variable.

While there is no direct access to paediatric nutritional services at Peter Mac, the paediatric nurse coordinator usually sees each family up to three times a week during treatment. The child is weighed at the weekly clinic. If there is significant weight loss, the child and family may be referred back to the treating hospital. There was limited evidence of referral to Peter Mac's adult nutritional service.

It should be noted that a small number of children or adolescents are referred very quickly to Peter Mac for radiotherapy as the primary treatment. Treated as ambulatory patients, these children and their families may have had little contact with the broader Children's Cancer Centre team, and allied health providers in particular.

Regional services: currently PICS is developing a Regional Outreach and Shared Care Program (ROSCP) with a number of services in regional Victoria. The PICS funded dietitian is assisting the ROSCP program through the development of organisational processes such as ensuring nutritional information is provided on the Children's Cancer Centre database, providing nutritional education for regional service providers and being available for ongoing advice.

Both the RCH and MMC dietitians assist with information transfer and the coordination of home enteral nutrition for individual children within their care.

5. Nutritional support for children with cancer

This section firstly summarises the key evidence from the literature about nutritional support for children and adolescents with cancer. It then reviews current practice within PICS Children's Cancer Centres.

5.1 The evidence from the literature

Over the past twenty years, as survivorship has increased, there has been increasing evidence of the beneficial role of optimising nutrition in paediatric cancer care.

Both early and continuing research focuses on understanding the benefit of good nutritional care for the individual child or adolescent. More recent literature also focuses on the service systems and processes that need to be in place to optimise nutritional care.

There are two identified limitations to the current evidence. Firstly the lack of high level evidence and secondly the evidence that is available in some areas is quite dated. This more limited current evidence may in part reflect that with the understanding of the importance of nutritional care the ability to undertake high level intervention studies is constrained.

The following provides a brief summary of the key evidence.

5.1.1 The need for and benefit of nutritional support

There is evidence from a number of studies as reported by Ladas et al (2005)³, that a proportion of children (6-50%) will present with significant malnutrition at diagnosis. Children with solid tumours such as Wilm's Tumour, sarcomas and neuroblastomas are more likely to present with malnutrition at diagnosis⁴.

Malnutrition is however more likely to be a consequence of cancer treatment and is complex and multi-factorial in nature. Cancer treatment may result in decreased food intake and nausea, vomiting and anorexia. Malnutrition may be compounded by learned food aversions either developed prior to or following diagnosis and treatment⁵. In addition, nutritional issues may be impacted by the emotional distress of having a cancer diagnosis and treatment on the child and family⁶.

Malnutrition is strongly associated with the nature of the treatment and increases an individual's risk of infection⁷. Children who are underweight or overweight at diagnosis have poorer outcomes compared to children who are well nourished at diagnosis^{8 9}.

Nutritional support aims to sustain and promote normal growth and development at the least risk to the child. In addition the benefits of nutritional support have been seen in fewer treatment delays, improved treatment tolerance¹⁰, and improved survival¹¹. Nutrition support decreases the time to bone marrow recovery, suggesting that this may help to reduce the toxicity associated with chemotherapy¹².

³ Ladas EJ, Sacks N, Meacham L, Henry D et al. 2005. A multidisciplinary review of nutrition considerations in the paediatric oncology population. A perspective from Children's Oncology Group. **Nutrition in Clinical Practice**. 20: 377-393.

⁴ Donaldson SS, Wesley MN, De Wys WD et al. 1981. A study in the nutritional status of paediatric cancer patients. **American Journal of Disabled Children**. 135: 1107-1112.

⁵ Pizzo PA & Polack DG. 1993. Nutritional supportive care. In PA Pizzo and Polack DG **Principles and Practice of Paediatric Oncology**. 2nd Edition. Philadelphia: Lippincott Co.

⁶ Sack N & Oltery F. 1996. Nutrition for the child with cancer. **American Cancer Society Newsletter**. 11 (2).

⁷ Mauer AM, Burgess JB, Donaldson SS. 1990. Special nutritional needs of children with malignancies: a review. **Journal of Parenteral and Enteral Nutrition**. 14: 315-324.

⁸ Pietsch JB & Ford C. 2000. Children with cancer: measurements of nutritional status at diagnosis. **Nutrition in Clinical Practice**. 15: 185 – 188.

⁹ Andrassy RJ & Chwals WJ. 1998. Nutritional support of the paediatric oncology patient. **Nutrition** 1998 14: 124-129.

¹⁰ Ladas et al. 2005. op cit.

¹¹ Donaldson et al. 1981. op cit.

¹² Hays DM, Merritt RJ, White L et al. 1983. Effect of total parenteral nutrition on marrow recovery during induction therapy for non-lymphocytic leukaemia in childhood. **Medical Paediatric Oncology**. 11: 134-140.

Over the past two decades enteral feeding has gained greater prominence as the first form of nutritional support in managing significant nutritional deficits in children with cancer. Parenteral nutrition with its higher risk of infection is increasingly seen as appropriate for those patients who cannot tolerate enteral feeding¹³.

Two further issues are important in terms of providing good nutritional support.

Surveys have reported that up to 84 % of paediatric oncology patients are being given some form of complementary or alternative therapies. Many of these complementary therapies are nutritional or herbal preparations that are postulated to be of nutritional benefit, in some situations these therapies may be harmful¹⁴.

With improving survivorship, obesity is also increasingly being seen as a problem particularly for survivors of acute lymphatic leukaemia and brain tumours¹⁵. Factors that appear to increase the risk of obesity include being female, cranial irradiation, and the age when treated, with children who are younger during treatment being at more risk than older children¹⁶.

5.1.2 Evidence of current services and practice models

A recent study of 125 US Children's Oncology Centres (54% of all institutions sent the study survey), demonstrated significant variability in the nutritional services offered¹⁷. The following highlights some of the study's key findings.

- 46% of all responding institutions completed a nutrition assessment on all newly diagnosed children with cancer
- 77% of institutions reported that nutrition assessment is completed throughout therapy; however 65% of these services indicated that subsequent nutritional assessments were only undertaken when clinically needed.
- 98 services identified the personnel who undertook the nutritional assessment:
 - 78% were completed by registered dietitians
 - 10% were completed by diet technicians
 - 9% were completed by physicians
 - 8% were completed by nurses.
- A diversity of criteria was used to assess nutritional status including weight loss, weight for height, body mass index, and nutrient intake.
- Enteral feeding was not consistently the first form of nutrition support offered to patients. The use of enteral or parenteral nutrition varied according to practitioner (i.e. physician, nurse or dietitian).
- 67% of services reported that nutritional education is provided to all newly diagnosed children. This was undertaken mostly by registered dietitians, but was also undertaken by the diet technician, nurse or physician.
- There was wide variability in the use of specialised diets such as the 'clean diet' for neutropaenic children.
 - 39% of services only used this diet for bone marrow transplant children
 - an additional 33% indicated that they also used it for other oncology patients.
- Dietary recommendations were usually practitioner-specific and standardised protocols were not used.
- Only 38% of services routinely provided information about complementary or alternative therapies.

¹³ Ladas et al 2005. Op cit.

¹⁴ Kelly KM, Jacobson JS, Kennedy DD et al. 2000. Use of unconventional therapies by children with cancer at an urban medical centre. **Journal of Paediatric Haematology and Oncology**. 22: 412-416. Cited in Ladas et al 2006 op cit.

¹⁵ Ladas et al. 2005 op cit.

¹⁶ Rogers PC, Meacham LR, Oeffinger KC et al. 2005. Obesity in paediatric oncology. **Paediatric Blood and Cancer**. 45: 881-891.

¹⁷ Ladas EJ, Sacks N, Brophy P and Rogers PC. 2006. Standards in nutritional care in paediatric oncology: results from a nationwide survey on the standards of practice in paediatric oncology. A Children's Oncology Group Study. **Paediatric Blood Cancer**: 46: 339-344.

- A range of barriers to optimal nutritional care were identified including:
 - availability of a registered dietitian (41%)
 - patient / family related issues (38 %)
 - financial issues (34%)
 - physician issues (27%)
 - education of staff / families (24%)
 - support for families (19%)
 - nursing issues (13%)
 - institutional issues (9%).

5.1.3 Features of service models for the future

In response to the variability of current practice reported in the above study, the researchers recommended the need to:

- develop and validate uniform evidence-based nutritional protocols that are incorporated into cancer therapy protocols to strengthen standardisation of nutritional practice
- improve access to registered dietitians
- utilise a standardised algorithm to facilitate decision-making (see 5.1.4)
- increase clinical trials and research into nutritional support¹⁸.

To achieve a more consistent approach to nutritional decision-making, there is also increasing emphasis on stratifying need based on screening and assessment tools¹⁹. This stratified model (see Table 2) has been implemented and refined at St Jude's Children's Research Hospital, US.

Table 2: St Jude's Children's Research Hospital risk stratification protocols for paediatric nutrition and screening²⁰.

Level	Conditions	Assessment / Care Plan	Re-assessment
1	a. Nutrition support (enteral, parenteral) b. Bone marrow transplant (initial) c. Weight loss (3-5% in past month) d. Nil by mouth > 3 days	Within 24 hours	Minimum twice per week
2	a. Non-chemotherapy induced nausea / vomiting or diarrhoea b. Mucositis / oral problems c. Modified diet	Within 72 hours	Minimum once a week
3	Newly diagnosed treatment on protocols known to result in nutrition problems based on chemotherapy used, diagnosis, location of disease (ie head / neck/brain tumour) and age (3 years or less)	Within 72 hours	As indicated

A critique of this stratification model is that it does not address the requirements of children who may be identified at low-risk of nutritional problems but for whom an initial nutritional screen and education may be of value as a 'preventive' measure.

¹⁸ Ladas 2006, Op cit.

¹⁹ Ringwood-Smith K, Cartwright C & Mosby TT. Medical nutrition therapy in paediatric oncology. In L Elliot, Moise L, P Davis-MacCallum & B Grant (eds). 2006. **The clinical guide to oncology nutrition**. American Dietetic Association.

²⁰ Ringwood-Smith et al. 2006. op cit.

The UK guidelines for children and young people with cancer²¹, also briefly address the nutritional service requirements for children's cancer services including:

- the provision of protocols detailing measures to ensure adequate nutritional support
- provision of specialist dietetic advice / training / interventions
- provision of information on nutritional requirements to patients and parents / carers
- that there should be a minimum of 1 EFT dietitian at each paediatric principal treatment centre (treating 80 new patients per annum).

5.1.4 Screening, assessment and referral criteria

The focus on interventions based on identified need is contingent upon effective screening processes and agreed referral criteria.

In the adult arena, the use of nutritional screening tools has demonstrated enhanced nutritional outcomes. However work in nutritional screening in the paediatric arena is more complex and less well advanced²².

In a small study of children admitted to intensive care, Mezoff et al²³ used a nutritional screening tool (included disease status, age, current weight and height, growth, dietary factors and laboratory data) to identify patients at increased risk of adverse outcomes. The key points were as follows:

- those children identified at low nutritional risk had better outcomes than those identified at high risk.
- an abbreviated screening tool was effective at identifying those children at high risk of some but not all adverse outcomes. This finding supported the importance of a more global nutritional assessment.

In another paediatric study, nutritional risk was assessed in 296 hospitalised children with a simple scoring system which categorised children into three groups: low, moderate and high risk of malnutrition²⁴. The screen was undertaken by nursing or medical staff and the results indicated that the use of the screening tool:

- effectively alerted staff to patients who needed early referral for nutritional support
- highlighted the needs of patients with less severe conditions but in need of some nutritional support. In the absence of a formal screening process, these needs are more difficult to identify and may be neglected
- increased awareness of the importance of adequate nutrition for improved patient outcomes for all patients.

Rather than a screening tool per se, Bowman et al²⁵ have introduced an algorithm (see Figure 1) to facilitate decision-making and referral for nutritional interventions in paediatric oncology. This has resulted in improved consistency of referral and nutritional practice over time.

²¹ National Institute for Health and Clinical Excellence (NICE). 2005. **Guidance on cancer services: improving outcomes in children and young people with cancer**. Accessed on www.nice.org.au. November 2007.

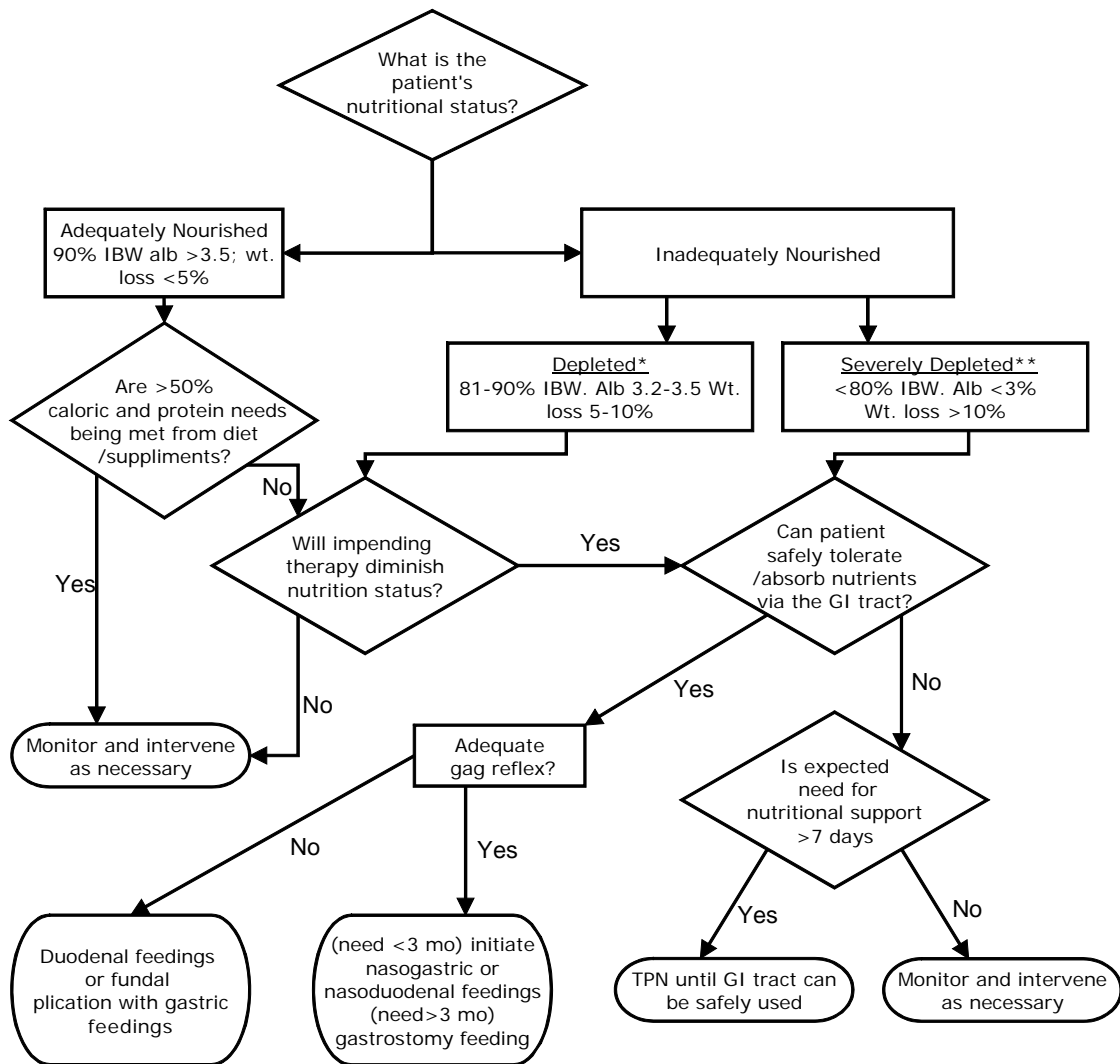
²² Mezoff A, Gamm L, Konek S et al. 1996. Variation in nutritional screen in children with respiratory syncytial virus admitted to an intensive care complex. **Paediatrics**: 97: 543-546.

²³ Mezoff et al. 1996. op cit

²⁴ Sermet-Gaudelus I, Poisson-Salomon A-S, Colomb V et al. 2000. Simple paediatric nutritional risk score to identify children at risk of malnutrition. **Am Journal of Clinical Nutrition**. 72: 64-70.

²⁵ Bowman LC, Williams R, Sanders M et al. 1998. Algorithm for nutritional support: experience of the metabolic and infusion support service of St Jude's Children's Research Hospital. **International Journal of Cancer**. 11: 76-80.

Figure 1: An algorithm for nutritional decision-making and management²⁶



* Must meet 2 of 3 criteria.

** No, if any of the following: vomiting, diarrhoea, gut graft-vs.-host disease, radiation enteritis, strictures, ileus and present or anticipated thrombocytopenia or mucositis.

Reprinted from: Algorithm for nutritional support: experience of the Metabolic and Infusion Support Service of St Jude's Children's Research Hospital, Bowman LC, Williams R, Sanders M, Ringwald-Smith K, Baker D, Gajjar A. Copyright 1998. **International Journal of Cancer**. 11: 76-80.

Finally, while routine screening is increasing, Ladas et al²⁷ identified that in the Children's Oncology Group services surveyed, the assessment of the child's weight was the predominant determinant of a referral for a nutritional intervention.

From the evidence available, there was some consistency in the weight criteria used for referral for nutritional support. A weight loss in one month greater than 5% from the reference weight was seen to be a critical threshold for adverse clinical outcomes^{28 29}.

²⁶ Bowman et al 1998.

²⁷ Ladas et al. 2006. op cit.

²⁸ Mezoff 1996. Op cit

²⁹ Sermet-Gaudelus et al. 2000. Op cit.

However, some variability in weight criteria remains. The St Jude's stratification criteria indicate that a weight loss of 3-5% in the past month would place the child into Level 1, whereas within the algorithm, a weight loss of 5-10% would place the child in the depleted group and > 10% in the severely depleted group³⁰.

5.1.5 Nutritional interventions

It is beyond the scope of this Project to undertake a detailed review on the evidence for a range of different nutritional interventions. Two key points are noted.

- The St Jude's decision-making algorithm is being widely advocated and adopted by the Children's Oncology Group³¹. This algorithm provides decision-making guidance for both referrals for nutritional support and the type of support that is offered³².
- The role of nutritional education or counseling for all parents and / or children / adolescents with newly diagnosed cancer is emphasised³³.

5.1.6 Quality improvement and research

Given the limited high level evidence and the variability in current practice, the important role of clinical trials and research in nutritional support for children with cancer is increasingly emphasised. Key areas for research include trials to ascertain the most effective components of nutrition screening, assessment and intervention and the most effective forms of nutritional intervention³⁴.

Studies within paediatric oncology and general paediatrics have demonstrated the value of educational interventions with generalist staff (non-nutrition staff within paediatric oncology as well as other areas) about nutritional needs. Clinical audit has also been found to be beneficial in stimulating and measuring improvements in practice^{35 36 37}.

5.1.7 The nutritional team

Clearly the evidence and guidelines identify the need to improve access to appropriately trained dietitians to provide quality nutritional support for children with cancer and their families^{38 39}.

The evidence also identifies that other members of the multidisciplinary team may be involved in nutritional support including medical and nursing staff, diet technicians and psychosocial support staff⁴⁰. Their roles may include:

- identifying children at risk or with current needs
- monitoring nutritional intake
- providing nutritional education and counseling
- providing psychosocial interventions to encourage nutritional intake and to support procedural management e.g. insertion of a naso-gastric tube.

Experience from the development of specialist nutrition support teams (with a focus on parenteral nutrition) highlights the importance of nutritional education for all generalist providers. In addition, senior medical engagement has been seen as critical for the effectiveness of these specialist teams^{41 42}.

³⁰ Ringwald-Smith et al. 2006. Op cit.

³¹ Children's Oncology Group. www.cog.org

³² Ladas et al. 2006. Op cit.

³³ Ladas et al. 2005. Op cit.

³⁴ Ladas et al 2006. Op cit.

³⁵ Bowman et al 1998. Op cit.

³⁶ Sermet-Gaudelus 2000. Op cit.

³⁷ Abad-Sinden AR, Vittone SB, Willson DF & Zaglul HF. 1998. Improving timeliness of nutrition intervention through a collaborative quality improvement program in a paediatric intensive care unit. **Nutrition in Clinical Practice**. 13: 235-240.

³⁸ Ladas et al 2006. op cit

³⁹ NICE 2005. op cit

⁴⁰ Ladas et al 2005. op cit

⁴¹ Howard P. 2001. Organisational aspects of starting and running an effective nutritional support service. **Clinical Nutrition**. 20 (4) 367-374.

⁴² Abad-Sinden et al 1998. Op cit.

5.2 Current nutritional services at the RCH and MMC Children's Cancer Centres

In the RCH and MMC services, the dietitians are supported by and closely work with food monitors, patient service assistants and diet kitchen / formula room staff.

The nutritional services are highly regarded by other service providers within each service. At RCH in particular there is recognition that a level of knowledge and expertise has developed since the introduction of the role into the Children's Cancer Centre over the past 10-15 years. The role is seen as an important part of the team.

While there is recognition of its value at MMC Children's Cancer Centre, the role has been less well established. There are a number of barriers to the current MMC services including:

- limited resources that constrains the ability:
 - to attend the Children's Cancer Centre and all multidisciplinary meetings
 - to see all new patients particularly if they are not admitted or only admitted for a short period of time
- the physical location of the Children's Cancer Centre away from the in-patient facility where the dietitian may be managing a range of other children
- there is limited access to the outpatient listings to identify patients that might require nutritional follow-up.

Increasing resources and an increasing presence within the multidisciplinary meeting provides an opportunity for the dietitians to more pro-actively raise nutritional issues.

The dietitians at both services are seen to have a very positive role with children and their families. They may be seen to be independent of the primary treatment decision-making processes and are able to provide clear and unbiased information about the positive benefits of nutritional support. In this way they can empower parents to support their children. Parents are also increasingly asking to see the dietitian at both services.

In addition to basic nutritional advice provided within the common parents' resource, *The Information Book*, both Children's Cancer Centres have a range of other material that may be given to parents to assist them address their child's nutritional needs. The information however, is not consistent across the sites.

In early 2008, work has been undertaken at RCH to facilitate access to the Children's Cancer Centre database. This will enable the dietitian to monitor the weights of children who they are not able to see and will facilitate information transfer between the RCH, MMC and Peter Mac. Further work is also underway to develop a special nutrition screen within this database.

5.2.1 Nutritional services - patient contacts

Given the different information data systems at each service site, it is difficult to assess the range of patient contacts or encounters across the two Children's Cancer Centres in a uniform way and caution should be used in making comparisons between services.

It should also be noted that at both services each child seen by the dietitians may subsequently have multiple dietetic consultations.

From MMC, data indicates that the following contacts with children with cancer (and their families) were undertaken over a twelve month period.

Initial screening, assessment and general information	52 <u>contacts</u> per annum
Oral supplements	249 <u>contacts</u> per annum
Enteral nutrition	163 <u>contacts</u> per annum
Parenteral nutrition	1 <u>contact</u> per annum

RCH do not have directly comparable data to MMC but were able to estimate total numbers of patients seen per annum by similar reasons.

Initial screening and assessment	80 <u>patients</u> per annum
Oral supplements	50 <u>patients</u> per annum
Enteral nutrition	40 <u>patients</u> per annum
Parenteral nutrition	30 <u>patients</u> per annum

Other RCH dietetic service data indicates that over a twelve month period (2007) there were:

- 1723 encounters for in-patient care
- 322 encounters for outpatient care (including telephone advice).

Within these encounters, there were 89 new patient referrals.

The time allocated at RCH for this level of patient care is 1396 hours. This exceeds the patient contact hours of 978 hours expected for this EFT allocation (i.e. 0.8 EFT Grade 2).

Based on six months data, we were also able to calculate the total amount of time per encounter for direct and indirect care, and for 'standard' and complex patient groups (See Table 3). Given some of the limitations of the data, this information should be viewed cautiously.

Table 3: Time for RCH dietetic encounters over a six month period
(Jan-June 2007)

Average time for direct and indirect care for more standard cancer patient encounters	38 mins (direct care: 18 mins Indirect care: 20 mins)
Average time for direct and indirect care for more complex patient encounters	53 mins (direct care: 32 mins Indirect care: 21 mins)

While MMC cannot give us a breakdown of direct and indirect time for their patient encounters, their average time allocated to:

- each paediatric oncology patient encounter is 39 minutes
- each complex paediatric oncology patient encounter is 50 minutes.

Although not directly comparable there is some consistency in these time allocations across sites which will be useful when considering future workloads at both Children's Cancer Centres.

5.2.2 Common nutritional service issues across PICS sites

A range of issues occur across the Children's Cancer Centres.

- Specialist nutritional services must be supported and complimented by good quality and accessible general food services. These are particularly important for those children and families at low risk of nutritional problems.

The recent PICS patient satisfaction survey undertaken by Press Ganey identified a number of areas for improvement within the general food services at both Children's Cancer Centres. This included the quality, temperature, flavour and timeliness of the food service. The survey did not cover the dietetic service specifically.

- Within the specialist nutritional services, there are significant resource gaps (see 5.4) which limits the capacity to:
 - respond to the needs of all children and families when newly diagnosed
 - respond to the needs of ambulatory patients in a timely manner
 - provide proactive education and support in the ambulatory setting to families whose child is booked to have a bone marrow transplant
 - undertake quality improvement activities and research.
- The limited dietetic resource at MMC leads to the role being less visible to the families and other staff, particularly in the ambulatory setting.
- The identification of children requiring nutritional support is often dependent on case finding by the dietitian. Referrals do occur with different degrees of frequency within services but they tend to be verbal and at times 'by chance'. There is the potential for dietetic staff to play a more pro-active role in raising nutritional issues within the multidisciplinary meetings.
- The most frequent criteria quoted for referral to nutritional services was weight loss greater than 10% over the past month. This is in contrast to the evidence in the literature that tends to use the criteria of a 5% loss over the past month.

There was anecdotal evidence that without a clear reference point for the child's weight and for observing trends over time, a child could become nutritionally compromised before a problem was identified. This issue is compounded when an individual child is seen by different medical oncologists over a period of time.

- There are a number of child and family factors that influence nutritional support
 - there is strong resistance to enteral nutrition from some children / adolescents or their family, with extra tubes being seen as another invasion on the child
 - families with children at 'low risk' of severe nutritional problems, have difficulties accessing general advice
 - supplements can be costly for families
 - providing good nutrition is a fundamental role of parenting. In an emotionally charged environment, eating habits can be created that may have long-term consequences (e.g. ongoing poor eating habits or obesity). Providing advice and support in this area can be difficult.
- The capacity to take a systematic approach to nutritional care is constrained by the reactive environment of acute children's cancer services. While there is strong clinical knowledge within the role incumbents and other members of the team, the use of structured approaches such as formal evidence-based protocols to guide referral and clinical practice, is more limited.
- Other evidence also reflects this less systematic approach including:
 - the introduction of new nutritional approaches by medical specialists e.g. the use of Megace, tends to be ad hoc. Introduced to support individual children, some practices become 'routine' almost by default rather than through a clear decision-making process for the service as a whole.
 - Clinical practice is sometimes contingent on individual medical specialists' preferences e.g. the use of parenteral nutrition rather than enteral nutrition, when the latter may be possible; the use of 'clean' or 'semi-clean' diet for children other than transplant children.

- o there were different views on how best to support children (and families) on high dose steroids who had voracious appetites. There was a sense that over-eating would be balanced by the impact of periods of anorexia. However there was anecdotal evidence that eating habits developed during treatment led to ongoing problems for some survivors.
- The lack of access to routine and consistent data across Children’s Cancer Centres constrains the capacity to review current practice and identify opportunities for service enhancement. For example, there is limited evidence on the actual needs of different cohorts of children, their access to nutritional interventions and the outcomes of these interventions e.g. those at higher or lower risk of malnutrition.

In addition, as demonstrated in 5.2, there is variation in the range of information routinely collected at the two service sites.

- There is variable knowledge of when children are transferred to other services which constrains appropriate information transfer. Current improvements underway in access to and recording of nutritional data in the Children’s Cancer Centre database may facilitate information flow across PICS sites and regional services.
- In spite of the evidence that long-term nutritional problems can occur with children following treatment completion, there is limited capacity to provide nutritional advice and support as children complete treatment and enter long-term follow-up.
- Finally there is limited capacity to undertake nutritional research.

5.3 Benchmarking against other services

Given the range of data that was available, we are able to benchmark PICS nutritional services against other paediatric oncology services and against RCH and MMC nutritional services for children with diabetes and cystic fibrosis.

This benchmarking data should be used with some caution for the following reasons:

- some of the interstate children’s cancer services only gave ‘best estimates’ of the number of newly diagnosed children treated at their service annually
- benchmarking against services who may be operating under similar resource constraints as PICS does not necessarily imply best practice
- the NICE recommendations are based on the resources required within a principal cancer centre treating 80 new cancer patients per year. The NICE guidance does not indicate whether children having bone marrow transplants for non-malignant conditions are included or excluded in these figures
- the nutritional needs and resource requirements of children with other conditions such as diabetes may be significantly different to those of children with cancer.

5.3.1 Comparison with children’s cancer services

Table 4 compares key data for PICS as a whole compared with four other national children’s cancer services and benchmarked against the NICE recommendations. The following observations can be made:

- PICS and Site 2 have a similar number of new patients per annum (150-160) and a similar number of resources (1EFT). However for PICS this resource is across two separate service sites (RCH and MMC).
- Two Australian services approach but do not equal the nutrition EFT recommended in the NICE guidance for principal paediatric cancer centres (a minimum of 1 EFT for 80 newly diagnosed children per annum). All other services are below this minimum of resources.
- Most services allocated their resources to different roles:
 - o two services (including PICS [RCH] and Site 2) allocated their resources according to the different tumour types
 - o two services (Site 1 and Site 3) clearly identified that part of their allocated role was research-focused
 - o one service (WA) allocated its resources between in-patient and outpatient services.

- All services indicated a reliance on dietitians actively identifying patients, direct referral from team members or through ward rounds or multidisciplinary meetings.
- The new amalgamated Site 1 is the only service proactively seeking to use a formal nutritional screening tool at present.
- While most nutrition services indicate that they try to see all new patients, most are unable to do so. The estimated proportion of new patients being seen within the diagnostic and early treatment period ranges from 25 – 80% of their population.
- Because of resource issues, several services including PICS service sites identified problems in being able to see outpatients and to provide any service to children on treatment completion or as part of a long-term follow-up program.
- Most services had a range of nutritional information resources to support parents to manage the general nutritional issues that their child may face.

Table 4: Service profile and nutritional resources and practices across PICS, other national children's cancer services and NICE recommendations

Service	Estimated number of new patients diagnosed per annum	Total dietitian EFT	How EFT allocated	Estimated number of new patients and other contacts seen by dietetic service per annum	Screening and referral processes	% of all new patients seen in early diagnostic phase
PICS (RCH and MMC only)	160 (plus 10 non-cancer patients for BMT)	1 EFT (+ 0.2 PICS special projects)	0.8 EFT RCH (EFT for 'liquids' EFT for 'solids' EFT for BMT) 0.2 EFT MMC (across all patients) Predominantly see in-patients	RCH: 89 new referrals and over 2000 patient encounters in 2007 MMC 28 new patients in 2006 with 366 occasions of service	No formal screening processes Referral for weight loss, parents concerns, specific disease groups	RCH between 50 – 75% seen depending on tumour group MMC see about 25% of all new patients
Site 1	130	1.2 EFT	Split between clinical and research role	10 contacts per day (estimated 2600 contacts pa)	Will commence using modified St Jude's screening tool	See about 80% within early diagnostic period
Site 2	150	1 EFT	0.5 BMT 0.5 EFT oncology	~ 80 new referrals pa Outpatients +++		Try to see all new children on diagnosis but do not always manage
Site 3	~ 100	1 EFT	0.5 EFT clinical 0.5 EFT research	~ 50-60 new patient referrals pa	No formal screening process – use COG guidance	Try to see all new children on diagnosis but do not always manage
Site 4	80—120	1 EFT	0.6 in-patients 0.4 outpatients	~ 100 new patient referrals pa ~ 3300 occasions of service pa	No formal screening process; referral based on weight, oral intake, specific protocols	Only see children with specific problems
NICE (UK) recommendations	80 pa for a principal treatment centre	A minimum of 1 EFT				

5.3.2 Comparison with other paediatric services

Table 5 provides information about the resources and workload of nutritional services for two other groups of children, those with diabetes and cystic fibrosis. While not directly comparable, these two conditions were selected because nutritional support is a key component of their immediate and ongoing management.

Table 5: Comparison of nutritional services for PICS services and other RCH and MMC paediatric services

Service	Total number of new patients diagnosed pa	Total EFT for dietitian resources	Funding source
PICS (total)	160	1 EFT	Core
• RCH CCC	[130]	[0.8 EFT]	Core
• MMC CCC	[30]	[0.2 EFT]	Core
RCH diabetes service	120	1.5 EFT	Core and other funding
RCH cystic fibrosis service	25	1.4 EFT	Core and other funding
MMC diabetes service	60-70	1.1EFT	Some resources are supported through HARP funding.
MMC cystic fibrosis service	4-10	0.5EFT	Core

The nutritional staffing resources available at both RCH and MMC diabetes and cystic fibrosis services are greater than the resources available for the Children's Cancer Centre services at both sites.

The similarities and differences between the three patient groups include:

- The number of children diagnosed with diabetes across both services is 160 – 190. This is equal to or slightly higher than all newly diagnosed children with cancer.
- The estimated number of children newly diagnosed with cystic fibrosis across both services is significantly lower (30-35) than those diagnosed with cancer.
- Nutritional intervention is a key component of the 'primary treatment' for all children with diabetes or cystic fibrosis. All or most of these children will require ongoing access to a dietitian.
- Within cancer care, nutritional care may be seen as a 'supportive intervention' to counter the impact of the primary treatment. Not all children will require nutritional intervention. For those who do, the vast majority will require it only during treatment. Limited ongoing nutritional care may be required once treatment has been completed.
- The in-patient and out-patient loads are different across the different patient groups, for example:
 - Much of the RCH Children's Cancer Centre nutrition support is focused on the population of inpatients (28 beds) and day oncology patients (15-35 per day). Approximately 20-35 children are seen in each of the six outpatient clinics per week. It is difficult for the dietitians to attend these clinics routinely.

- o Many of MMC children are seen and treated within the ambulatory setting of the Children's Cancer Centre. In-patients may be treated in the Children's Cancer Centre and then transferred back to the ward. The focus of MMC dietitians looking after children with a range of different paediatric conditions is pre-dominantly within the in-patient facilities.
- o In contrast most of the nutritional support for children with diabetes or cystic fibrosis occurs within the ambulatory setting with much smaller numbers of children being in-patients at any one time. For example,
 - there are approximately 4 diabetic in-patients at RCH at any one time.
 - all newly diagnosed children with diabetes require up to three sessions per week with the dietitian for a number of weeks to stabilise
 - at RCH there are 2 diabetic outpatient clinics per week seeing about 30 patients per clinic plus two dietitian run clinics seeing 4 patients per clinic.
 - at RCH, there are five cystic fibrosis clinics per week seeing between 8-20 patients per clinic, all of whom are seen by the dietitian. In addition there are approximately 6 in-patients at any one time.

While direct comparisons are difficult as there are clear differences in the numbers, patient needs and the degree of nutritional intervention required, overall it would appear that dietetic resources for cancer services are lower than for services for children with diabetes or cystic fibrosis.

5.4 Opportunities

A number of opportunities have been identified that may support the development of a new model for nutritional services across PICS.

- Nationally and internationally there is increasing recognition of the important role of nutritional services for supporting children with cancer and the need for improved research in this area. There appears to be a strong willingness by the national and international services approached as part of this Project, to share their knowledge and expertise.
- As part of this national and international interest, there is also increasing emphasis on the need for a stratified approach to nutritional interventions based on formal assessment of needs. This ensures the best use of limited resources and may potentially demonstrate the need for enhanced services.
- PICS facilitated a one day symposium in 2007 for dietitians, nurses and allied health professionals caring for the child with cancer. The 2008 symposium provides an opportunity to invite an interstate researcher to this forum and facilitate communication across states.
- The annual meeting of Australian and New Zealand Children's Haematology / Oncology Group (ANZCHOG) provides an opportunity for dietitians across paediatric oncology services to come together to exchange ideas and experiences and identify opportunities for collaboration in the future.
- The need to gain local evidence about service needs, current needs and service gaps provides an opportunity for clinical audits and research to identify baseline data that will inform service development and quality improvement.

6. The future PICS nutritional service model

The PICS nutritional service model includes the vision, principles and key approaches to practice. It is complimentary to the overall vision and service model for PICS.

6.1 The vision for PICS nutritional services

All children and adolescents and their families will have access to high quality nutritional services, advice and support that optimises the children's / adolescents' health and wellbeing including normal growth and development, across the continuum of care.

This vision will:

- maximise the child's tolerance of treatment and reduce the treatment burden
- optimise the child / adolescent's nutritional and developmental health and growth during treatment
- empower the parents and the child / adolescent (as appropriate) to take an optimal role in managing their child's or their own nutritional care.
- facilitate a pro-active approach to addressing the long-term effects of cancer and its treatment as children and adolescents become long-term survivors
- enhance the child and family's quality of life through the palliative phase.

6.2 The principles guiding PICS nutritional practice

The following principles will guide nutritional service provision.

Child and family centred principles

- All children / adolescents and families who are facing a new cancer diagnosis (initial diagnosis or recurrence) are assessed for their current and future nutritional needs and a nutritional care plan established within an agreed time frame.
- The nutritional needs of all children / adolescents will be reassessed at regular intervals in accordance with established protocols and changing needs.
- All children / adolescents with cancer have access to a high quality general food service that caters for the needs of children and adolescents as well as the specific nutritional needs of children / adolescents with cancer.
- All children / adolescents identified at high risk of nutritional problems or with identified needs (and their families) will receive nutritional interventions in accordance with established protocols across PICS and associated service sites.
- All families have ready access to:
 - a range of high quality general and specific nutritional information that is standardised and consistent across PICS
 - the relevant dietitian contact number
- Nutritional support is provided in a way that is appropriate to the age and developmental needs of the child / adolescent.

The service system

- Consistent and high quality systems are established to support the timely identification and management of children / families who may require initial and / or ongoing nutritional support. These include:
 - agreed and consistent criteria and triggers for referral
 - agreed management protocols and algorithms for different patient groups
 - clear and consistent documentation of nutritional care within the patient medical record and other patient record systems (e.g. Children's Cancer Centre database)
 - systems to facilitate timely information transfer across PICS service sites and regional services.
- Services will seek ways to streamline processes and systems that will optimise the effective use of limited resources, within and across services.

- All nutritional staff will be suitably qualified in line with the appropriate grades and competencies required for their roles and have specific knowledge and skills in paediatric care.
- Generalist staff (e.g. paediatric oncologists, nursing staff, food monitors) make a significant contribution to supporting the nutritional needs of children and families across services. Their knowledge and skills will be supported through professional development and the agreed protocols as appropriate.
- All nutritional care is informed by an evidence-based approach and changes in practice are introduced with consideration of the broader system implications.
- Nutritional services are underpinned by a commitment to evaluation, continuous quality improvement and research in order to improve future services for children and families. Opportunities for collaboration with local, national and international clinical and research colleagues will be actively sought.

6.3 General food services

The PICS nutritional service model is built on the provision of a high quality general food service. It is essential that nutritional staff at all services continue to work with the food service management and related service executives to:

- optimise the quality of the service
- ensure flexibility to enable parents to support the nutritional needs of their own child wherever possible
- ensure that parents have a good understanding of and comply with the policies and procedures that the health service must adhere to in regard to food services.

6.4 A tailored approach based on need

To ensure that children / adolescents and their families have access to a range of services tailored to their need. The service model and patient pathway has the following key features.

Firstly, the use of **clear screening, assessment and reassessment** processes. The initial screening of all children with a new or recurrent cancer diagnosis will place them at different levels of risk of malnutrition risk (low, moderate or high). Ongoing screening and re-assessment at regular points in the pathway will enable changes in risk and need categories and resulting intervention levels.

An initial two step triage process is proposed for all newly diagnosed children (see 6.5).

Secondly, **different levels of intervention** are identified. Level 1 is the base level service that all children / adolescents require. Level 4 is the highest level of service which a relatively smaller number of children / adolescents will require.

The higher levels of service require the highest levels of expertise.

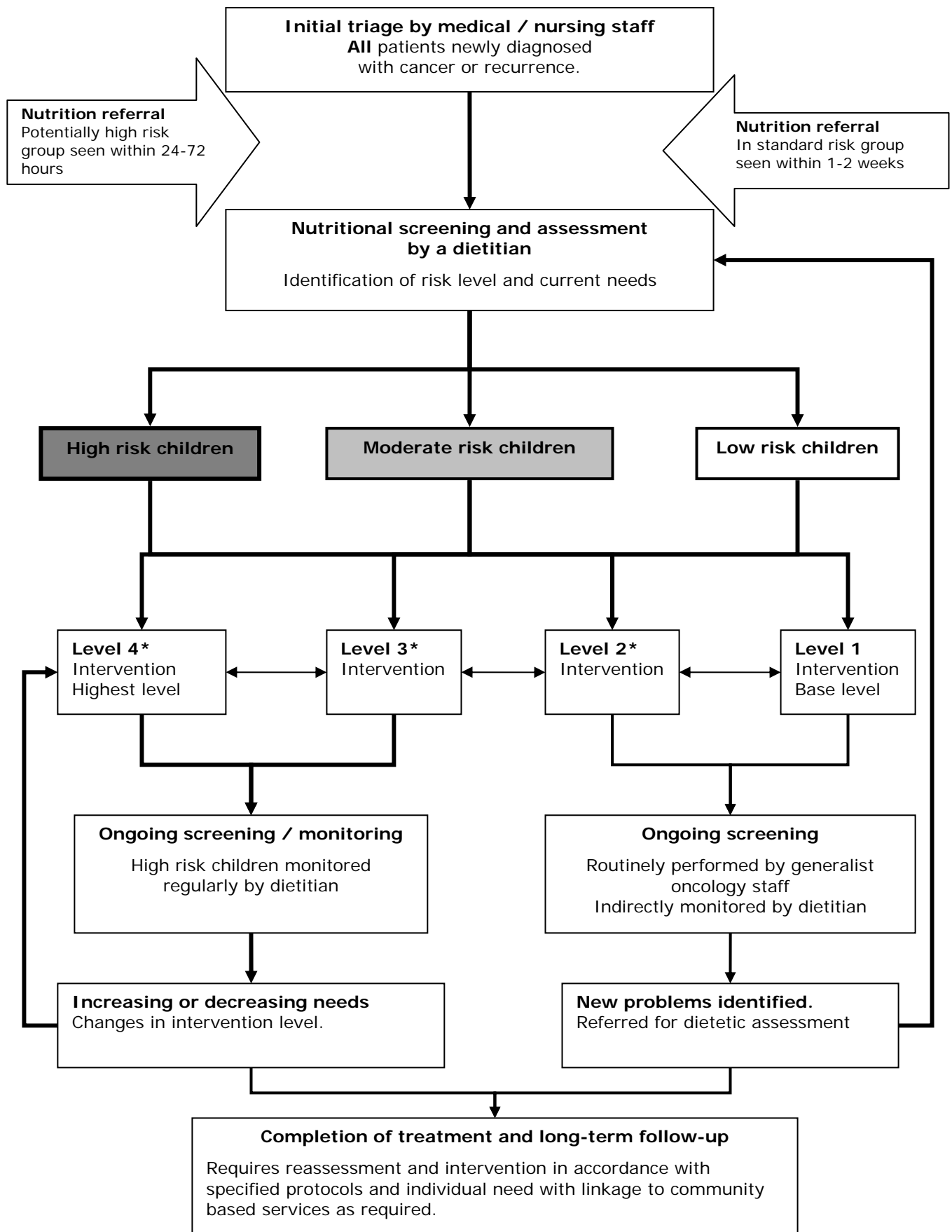
The third element of the model is **a tailored approach** that recognises that while some children / adolescents may be initially screened at a higher or lower level of risk, the level of intervention required for each child / adolescent at any point of time may vary. For example:

- a child in a 'high risk' category for malnutrition may not automatically require the highest intervention level.
- a 'low risk' child may have some unexpected nutritional problems that require a higher level of intervention than expected for their 'risk category'.

Clearly ongoing assessment and monitoring needs to be undertaken in accordance with agreed local protocols.

Figure 2 provides an overview of the patient pathway for all patients newly diagnosed with cancer or with a disease recurrence.

Figure 2: Nutritional pathway and service model



* Intervention decision-making will be informed by the decision-making algorithm.

6.5 Nutritional screening, assessment and decision-making tools

An essential component of a tiered or stratified model of nutritional services is based on effective screening, assessment and decision-making. Common tools and processes should be integrated across the PICS Children's Cancer Centres and associated services.

A two-step process is proposed for **all** children newly diagnosed or with a new recurrence.

Firstly, an initial triage is undertaken by medical or nursing staff based on clear criteria, with the aim being to prioritise those children that need a very immediate consultation with a dietitian and those who require a less urgent consultation. The criteria would be based on:

- specific diagnosis and proposed treatment plan
- age of the child (i.e. high priority for all children under 1 year).

In the second step, all children / adolescents will be seen by a dietitian within the agreed timeframe e.g. within 24-72 hours for those who may be in a potentially high risk group, and within 1-2 weeks for those seen to be at 'standard risk'.

The dietitian will undertake an initial screening and assessment consultation. Links with the nutrition services using the St Jude's screening tool may be used to develop the tool. Based on developing an accumulated score, children are identified as low, medium or high risk of nutritional support. However, the scoring system would appear to bring a very high number of children automatically into the 'high risk' category.

While this screening tool provides a useful framework and starting point, further work may need to be undertaken to clarify the process and criteria for both initial and ongoing screening. This may include:

- further consultation with St Jude's Children's Research Hospital to clarify the criteria and scoring system
- an audit of a cohort of children diagnosed two to three years ago to assess the need and use of nutritional interventions during treatment within different diagnostic categories (see 6.12)
- further discussion to agree on the weight criteria for ongoing screening during and following treatment by generalist providers and subsequent referral for dietetic assessment and services, as needed (see 6.6).

The St Jude's decision-making algorithm (p 13) should inform the service model. This algorithm needs to be reviewed and modified if necessary by PICS prior to its integration into the PICS service system.

6.6 Nutritional interventions

Based on the initial screening and assessment process, children and adolescents will be provided with a range of service according to their assessed level of need and risk of future nutritional problems.

Table 6 provides some examples of the different levels of intervention based on a four tiered model. Of particular importance is the Level 1 service that ensures **all** families gain access to a base level of information and service.

Further work may need to be undertaken to clarify the types of services offered within each level. Policies and protocols also need to be developed to guide practice (see 6.7).

Children / adolescents requiring Level 1 or 2 services must be regularly screened by members of the generalist oncology staff. Triggers and alerts built into the Children's Cancer Centre database may assist these practitioners in monitoring weight changes and changing nutritional needs over time.

Table 6: The four levels of nutritional intervention

Level	Range of nutritional interventions (examples only)
1	<p>All children / adolescents/ families are provided with a range of consistent general information about nutrition and useful tips on how to deal with common problems as they arise.</p> <p>Information about complementary therapies is also included.</p> <p>All families are provided with information about when they should seek advice (e.g. key triggers) from their medical, nursing or dietetic team member.</p> <p>All parents will be given the dietitian contact number.</p> <p>'Level 1' children are regularly screened for nutritional needs by general oncology staff, with oversight by the dietitian.</p> <p>All children and families are provided with information about healthy eating following</p>

Level	Range of nutritional interventions (examples only)
	treatment completion to enhance long-term outcomes.
2	<p>Additional information and advice is provided to families to deal with specific issues that have not resolved with the use of Level 1 strategies. The child is not significantly malnourished.</p> <p>Specific issues may include: poor eating behaviours / food refusal; managing a voracious appetite; complementary therapies and alternative supplements; high parental stress re: nutrition.</p> <p>Nutritional supplements may be prescribed for some children.</p> <p>'Level 2' children are regularly screened for nutritional needs by general oncology staff, with oversight by the dietitian.</p>
3	<p>These are children / adolescents who require a level of therapeutic dietary modification. This may include:</p> <ul style="list-style-type: none"> • Lactose / wheat-free diets • Supplementary fluids to maintain calorie intake <p>It may also include:</p> <ul style="list-style-type: none"> • Children on enteral feeding who are now stable and require ongoing monitoring and care such as home enteral nutrition or on a 'clean home diet'. • All high risk children currently on 'lower' intervention levels are regularly assessed by dietitians. <p>All Level 3 children are regularly assessed by dietetic staff.</p>
4	<p>These children require intensive interventions with the introduction of enteral or parenteral nutrition.</p> <p>Their nutritional needs are currently unstable and complex and require ongoing monitoring and adjusting.</p> <p>These children may include those requiring bone marrow transplant or other intensive treatment, or those who have not responded to lower levels of intervention.</p> <p>These children / adolescents are regularly assessed by dietetic staff.</p> <p>As their condition stabilises they can be moved to lower levels of service.</p>

6.7 Policies and protocols

To support this service model a range of written policies and protocols that guide nutritional service provision across all service and service providers, need to be developed. Of critical importance is that:

- all service providers (specialist or generalist) adhere to an agreed decision-making algorithm
- treatment protocols and nutritional practices are reviewed regularly to ensure that children are accessing appropriate levels of support. Changes in treatment protocols may increase or decrease the need for nutritional interventions.

These policies and protocols will also guide regional centres and paediatricians participating in a shared care model through the ROSCP.

6.8 Information resources

The Children's Cancer Centre 'Information Book' provides a base level of information to help parents address a range of nutritional issues. This information should be expanded to create a series of information resources that are available to address particular issues including:

- encouraging healthy eating patterns
- managing voracious appetites induced by steroids
- managing food refusal and related issues
- nutrition for promoting health in survivors.

Information should be consistent across Children's Cancer Centres and associated services. A contact number of dietetic services should be provided to all parents.

Finally consideration needs to be given to the regular provision of general nutritional information sessions that may help to answer the concerns of parents whose child has less acute nutritional needs.

6.9 Strengthening coordination and continuity of care

The coordination of care within the Children's Cancer Centres will be maximised by dietitians being available to attend in-patient ward rounds, outpatient clinics, the multidisciplinary team meetings and by having access to the Children's Cancer Centre electronic information.

Flags to identify those ambulatory children in need of regular nutritional review need to be developed to facilitate appropriate consultation. In addition, the dietitians' formal presence within the ambulatory care settings may:

- maximise the identification and referral of children with significant nutritional problems
- facilitate timely review
- provide brief consultations to 'lower risk' children and families.

Access to the Children's Cancer Centre database will also facilitate monitoring of children's weights by the dietitian, when face-to-face contact is not needed or difficult to arrange.

The service model also needs to pay attention to enhancing continuity of care across services.

Given the increasing two-way transfer of children between the Children's Cancer Centres and shared care with regional centres, a continuing relationship between the nutrition staff at services needs to be maintained.

The use of common protocols, good information flow and preparation for the child / family for transfer to another service is essential to enhance continuity of care. Access to the Children's Cancer Centre database may also facilitate information flow.

Similarly timely communication, information transfer and providing advice and support to regional centres or to Peter Mac is essential to optimise care for the child and family at these different services.

This communication across Children's Cancer Centres, Peter Mac and regional centres can only be achieved if the nutritional needs of the child / family are flagged as part of the information required for transfer. Again, the Children's Cancer Centre database may facilitate this.

6.10 Peter MacCallum Cancer Centre

Given the future work that Peter Mac plans to undertake to explore its model of care in providing radiotherapy services to children with cancer, it is difficult at this point to make clear recommendations about how the nutritional needs of children having radiotherapy should be best met.

Consideration must be given to:

- information transfer from the referring service

- accessible nutritional services that take into consideration:
 - that families are visiting Peter Mac daily for up to six weeks
 - may have only intermittent visits to the referring Children's Cancer Centre while having radiotherapy
 - may have been referred almost immediately to Peter Mac and have limited contact with staff at the referring Children's Cancer Centre.

Depending on Peter Mac's future service model for paediatric radiotherapy services, consideration may need to be given to the Children's Cancer Centres providing an outreach service. Factors that might influence this, is an understanding of:

- what proportion of children having radiotherapy are being seen concurrently by service providers at the referring Children's Cancer Centre?
- how often these children are being seen at the Children's Cancer Centre during this period?

A clinical audit of medical records of a sample of children / adolescents who are having or have had radiotherapy could answer these questions and may provide evidence for future service models for nutritional services. Such an audit would also be helpful for considering access to a range of other allied health services for children during treatment at Peter Mac.

6.11 Strengthening the service system

All generalist staff working within Children's Cancer Centres need to have:

- a base level of knowledge about the need for good nutritional care for children with cancer and approaches that will support the child's fluid and nutritional intake
- consistent information to support parents in addressing general nutritional problems such as 'food refusal' or other poor nutritional habits that may lead to short or long term nutritional deficiencies or other problems
- the skills and knowledge to identify those children who are developing specific problems that require nutritional referral and intervention.

All new staff (medical, nursing or others as appropriate) need to be orientated to the Children's Cancer Centre's nutritional policies and protocols.

General and specialist staff (where appropriate) at Peter Mac and regional centres also need a base level of knowledge and skills to support children and families in their care.

A critical role for the dietetic staff at the Children's Cancer Centres is to provide professional education and support to staff within their own services as well as to those in associated services.

Finally there is the need for the specialist dietetic providers to have access to additional professional development. This could include:

- formal and informal peer exchange and support across the Children's Cancer Centres and associated services
- potential 'secondment' of staff across the Centres to facilitate skill development
- formal visits to interstate or possibly overseas Centres of Excellence
- active encouragement of leadership and research roles.

6.12 Quality improvement, service evaluation and research

The service model will have a strong commitment to quality improvement, service evaluation and research. Box 1 lists some key research questions that were identified through the development of this service model.

Box 1: Questions for future quality improvement or research initiatives

- What % of all new patients present with evidence of malnutrition?
- What proportion of all new patients are seen by a dietitian on diagnosis and within a given time period?
- What % of children within different diagnostic groups require different levels of nutritional care? What are some of the additional factors that impact on the child's nutritional status? Are any of these factors predictable?
- What are the needs of 'low risk' children? What proportion of these 'low risk' children subsequently are referred for a higher level of nutritional care? What factors influence these needs?
- Which children are currently 'slipping through the net'?
- Are there any patterns in the use of complementary medicines?
- What % of children require enteral nutrition – at what points in pathway – was this anticipated or unexpected?
- What % of children have nasogastric tubes versus PEG? What are the advantages and disadvantages of each?
- What % of children are being given complementary medications (e.g. iron supplements)

- Consumer satisfaction with food and dietetic services.

Strategies to answer these questions and to strengthen an overall quality improvement and research agenda include:

- Undertaking an audit of the nutritional needs and interventions for a cohort of children diagnosed with different cancers two to three years ago. This will provide good baseline data to:
 - o improve understanding of the different levels of need and intervention within different groups of children
 - o identify factors that appear to influence the uptake of nutritional interventions and the number of service contacts
 - o identify opportunities to streamline services and contacts.

This audit should be undertaken with some urgency to facilitate the further service development based on local practice evidence.

- Undertaking a prospective audit of practice of newly diagnosed children over a three to six month period to assess current practices.
- Identifying opportunities for service improvement (e.g. introducing a more structured screening process or the development and provision of new information resources for families) within and across services and evaluating their impact.
- Identifying opportunities for collaboration for research with interstate children's cancer services or with local research groups.
- Engaging a medical champion at each site.

Consideration has been given to identify the resources required to support the dietetic service model for children and adolescents with cancer.

A pragmatic approach is recommended based on the recommendations of the NICE Guidance in which a minimum of 1EFT for a principal cancer centre treating 80 new patients per annum

7.0 Moving forward – recommendations

This service model to develop and enhance a consistent and quality service approach to nutritional services for children / adolescents and their families across services has been developed in line with best practice evidence and in collaboration with key service providers from both the RCH and MMC Children's Cancer Centres.

It is recognised that this model may be achieved over time.

The following recommendations are made to progress the achievement of this service model over time.

1. The PICS Coordinating Group endorses the service model and actively works with the individual services for its successful achievement over time.
2. An implementation plan is developed to identify short and long-term goals within and across services and to regularly review achievements against these goals.
3. Short-term funding resources are allocated or sought to:
 - undertake a clinical audit of current practices of a cohort of children diagnosed 2-3 years ago across tumour groups
 - undertake a clinical audit of children having radiotherapy at Peter Mac to identify what proportion of these children are having concurrent appointments at the referring Children's Cancer Centre
 - further develop the information resource suite for parents / families
 - develop agreed policies and practices across service sites. This includes agreement on the weight criteria (including reference weight) for referral to dietetic services by generalist staff and the decision-making algorithm for nutritional interventions
 - facilitate the further development of the Children's Cancer Centre database to record and review critical patient nutritional data and provide triggers and alerts that will facilitate generalist and specialist practice, and information transfer across services.
4. The service model is reviewed in light of the future Peter Mac service model for children having radiotherapy to ensure that these children and their families have easy and timely access to nutritional services as needed.
5. RCH and MMC Dietetic service managers and associated staff explore and develop a common dataset that will enable evaluation of practice across services.
6. RCH and MMC Dietetic service managers develop business cases within their services to achieve the recommended resources required to support this best practice service model over time.
7. Funding is sought for a service development / research role to support service development and research across PICS and associated services. This role should be for 2-3 years initially with identifiable goals and outcomes. The role should be reviewed at this point and decisions about the ongoing role be made.
8. PICS nutritional services develop partnerships with national and international paediatric cancer services and with local and national research groups to enhance patient outcomes.
9. PICS nutritional services are supported to build their knowledge and expertise to enable them to develop a leadership role for national nutritional services for children with cancer and their families.



Paediatric Integrated Cancer Service

A statewide cancer service for children

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