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Contributing photographers include the Educational Resource Centre at The Royal Children's Hospital, Trudi Spence of the Paediatric Integrated Cancer Service, Alex Bialocki of Encore Productions and Toby Phillips. The PICS would like to thank Chaos Ink for producing this report.

For more copies of this publication or to provide feedback please contact Amy Shelly, PICS Strategic Planning Coordinator via amy.shelly@rch.org.au or visit www.pics.org.au
I am very pleased to introduce the 2009-10 Annual Report of the Paediatric Integrated Cancer Service (PICS). This report showcases the breadth of work undertaken by the PICS, which is a vibrant partnership between The Royal Children's Hospital, Monash Children's Cancer Centre at Southern Health and the Peter MacCallum Cancer Centre.

A highlight for the PICS in 2009-10 was the launch of our Strategic Plan 2009-2012. This plan was prepared after extensive consultation with parents, staff and other key stakeholders. It outlines the commitment by the PICS to support the three health services to provide timely and high-quality care, consistent with established paediatric oncology care pathways. I was also very pleased to chair the first PICS Annual Forum, held at The Royal Children's Hospital in February 2010.

In this report, you will find many impressive examples of the work undertaken by the PICS. The PICS has worked diligently over the past 12 months, leading a number of initiatives to provide more comprehensive and co-ordinated paediatric oncology services across Victoria.

Many thanks to Associate Professor David Ashley for his contribution to the PICS since its establishment in 2004 and, in particular, for his contribution as Medical Director. Associate Professor Ashley stepped down from this role in May 2010. On behalf of the PICS, I wish him every success and happiness in his future endeavours. I now look forward to working just as closely with Dr Peter Downie, who was subsequently appointed as Medical Director.

Many thanks also to Jane Williamson, our tireless Program Manager, and her committed staff. The members of the PICS Governance Executive and Clinical Advisory Committees contributed strongly during the year and I am grateful for their support, advice and guidance.

On behalf of the PICS, thank you for your interest in, and support of, our work. I look forward to keeping you informed about our various initiatives.

I commend this report to you.

Craig Bennett
Chair
Paediatric Integrated Cancer Service
A message from our Program Manager

Over the past 12 months the PICS has worked to establish a formal framework with a change to the organisational structure and the development of the PICS Strategic Plan 2009-12. Documentation of clear priorities and goals has provided the health services and the PICS with clear guidance of the projects with which to work towards in partnership. This has been an important outcome for us all over the past 12 months.

I would like to make mention of the enormous contribution made by Associate Professor David Ashley. I am grateful for his vision and foresight in working to establish what has become a very successful statewide oncology service. We will miss him greatly, but wish him the very best in his future endeavours at Barwon Health.

As Program Manager I am looking forward to the next year, with increased specialist PICS staffing and for the first time, psychosocial representation at a governance level, through the appointment of Dr Maria McCarthy to the PICS Clinical Advisory Committee. We have a busy year planned with further work in consolidating the Long Term Follow-up Program, establishment of Peninsula Health as a regional partner and development of the Paediatric Surgical Oncology Program as a cross campus surgical program.

Documentation of our commitment to education of staff working in children’s cancer and development of a psycho-oncology education program will be completed in the next 12 months. The PICS, together with the health services, will document a service and workforce plan and will amongst other projects, determine with staff and our consumers, a coordinated approach to the provision of road maps and treatment plans.

Finally, I would like to personally recognise and thank the many health service staff who work closely with the PICS to achieve better outcomes for children with cancer and their families across Victoria.

Jane Williamson
Program Manager
Paediatric Integrated Cancer Service

A message from our outgoing Medical Director

After a long history with both The Royal Children’s Hospital (RCH) and the PICS I decided to step down in May 2010 as PICS Medical Director and Director of the Children’s Cancer Centre (CCC) at the RCH, in order to move on to new and exciting endeavours in cancer leadership at Barwon Health and Deakin University.

During my time as Director of the CCC, I have been privileged to work with the PICS in the capacity of Chair and Medical Director. Since its introduction in 2004, the PICS has achieved significant outcomes in the area of paediatric cancer, working alongside the health services to ensure the delivery of best practice services to our patients and families. In particular, I would like to make mention of the Regional Outreach and Shared Care Program, which allows children to access services as close to home as possible and the Long Term Follow-up Program, which provides formalised and much needed services to survivors of childhood cancer.

It has been a privilege working alongside the PICS team and I look forward to supporting them in the future.

Associate Professor David Ashley
Outgoing Medical Director
Paediatric Integrated Cancer Service
A major achievement in 2009-10 was the development of the PICS website, which is now live and available to the general public. The website aims to keep consumers and stakeholders informed of PICS activities and initiatives. On the website you will find information on our strategic direction, statewide programs, models of care, education and professional development, as well as information for consumers.

We encourage you to visit us at www.pics.org.au

As a partnership between The Royal Children's Hospital (RCH), Monash Children’s at Southern Health (SH) and the Peter MacCallum Cancer Centre (Peter Mac), the PICS is the only statewide Integrated Cancer Service (ICS).

The integrated service model is based on the following DH principles:

- services will be population based
- individuals will have access to the full range of services from prevention, screening, diagnosis, treatment, rehabilitation, supportive care and palliative care
- referral pathways are clearly defined for the range of services required
- care is multidisciplinary and coordinated
- high quality care requires a ‘critical mass’ of expertise and leadership.

The PICS is guided by the DH's 'Victoria’s Cancer Action Plan' (VCAP) and the ICS initiatives which include:

- supportive care
- care coordination across the cancer care pathway
- multidisciplinary care
- reducing unwanted variation in practice.

At its core, the PICS is committed to ensuring all children and adolescents with cancer throughout Victoria have access to consistent and coordinated services, which are based on a child and family-centred model of care. This is illustrated through the PICS vision which is:

“To provide the best care in the best facility as close to home as possible, extending across the whole cancer care pathway from diagnosis to long-term survival or palliation, and through the many developmental stages of the child or adolescent’s life.”
The PICS vision is to provide the best quality care, in the best facility, as close to home as possible.
The PICS partnership extends across both metropolitan and regional health services, ensuring integrated cancer care for children throughout Victoria.
Our partners

Monash Children’s at Southern Health (SH)

SH is Victoria’s largest health service. It is unique in providing primary, secondary and tertiary health services in one organisation. The Children’s Cancer Centre at Monash Medical Centre (MMC) is an integral part of the new Monash Children’s Hospital and cares for 30 percent of Victoria’s childhood cancer patients. The centre is capable of providing complex cancer care, and incorporates purpose-built treatment rooms, medical consulting rooms, a day treatment facility and an innovative facility capable of providing general anaesthesia for minor oncology procedures.

Peter MacCallum Cancer Centre (Peter Mac)

Peter Mac is the only site in Victoria offering radiotherapy to children under the age of 16. It is Australia’s only public hospital solely dedicated to cancer treatment, research and education. Peter Mac’s Paediatric and Late Effects Service receives referrals for 50 to 60 new patients each year and treats an estimated 70 to 80 patients annually. A small number of children (one or two per month) are admitted to Peter Mac, usually for total body irradiation in preparation for bone marrow transplantation.

The Royal Children’s Hospital (RCH)

The RCH is a specialist paediatric hospital, providing a full range of clinical services, tertiary care and health promotion and prevention programs for children and adolescents. The RCH Children’s Cancer Centre (CCC) is the largest partner in the PICS and provides complex children’s cancer care. It is the only provider of paediatric stem cell transplantation in the state of Victoria. The RCH CCC is recognised as an international leader in the research and treatment of childhood cancer, each year treating around 70 percent of Victoria’s newly diagnosed cancer patients under the age of 16 and continuing to provide follow-up for the many new children receiving ongoing treatment and/or active patient follow-up.

As part of the Regional Outreach and Shared Care Program (ROSCP) the PICS has formed shared care partnerships with seven regional health services, to coordinate the shared care of children and adolescents with cancer living in regional Victoria. The PICS shared care partners include:

- Goulburn Valley Health
- Albury Base Hospital
- Ballarat Health Service
- Barwon Health
- Bendigo Health Care Group
- South West Healthcare
- Peninsula Health.
Our organisational structure

The PICS is governed by the PICS Governance Executive Committee (GEC) and reports directly to the Department of Health (DH). The GEC takes its clinical advice and leadership from the PICS Clinical Advisory Committee (CAC).

In this past year we have three newly elected positions to the PICS CAC:

Dr Mark Norden, Paediatrician from Albury Base Hospital represents our regional partners. Dr Norden is a Senior Consultant Paediatrician at Albury Wodonga Health. He sits on the Victorian State Neonatal Services Advisory Committee and the Neonatal Emergency Transport Service Advisory Committee. Dr Norden has also been an Advanced Paediatric Life Support (APLS) Instructor since APLS’s inception 11 years ago. He has worked in regional areas in general paediatrics, neonatal services and aboriginal health and has been the managing partner of the Albury Wodonga Paediatric Group for the past 10 years. He is passionate about regional care and ensuring children and young adults have equitable access to services in regional Victoria and has welcomed the PICS philosophy since its inception.

He joins the PICS CAC with the view of further raising the voice of the rural patient at a statewide governance level.

Ms Jenny Haig has replaced Mr Asanga Lokusooriya as Chair of the CCC Parent Advisory Group (CCCPAG). Jenny comes with considerable experience, both as a parent of a son treated at the centre for four years, and a member of the CCCPAG team for more than three years. The PICS together with the staff at the CCC at both the RCH and Monash Children’s are most grateful to Mr Lokusooriya for his work on the group and his term as the Chair and wish him well with the future.

A new position approved by the GEC for recruitment to the PICS CAC is that of a psychosocial representative. After an open recruitment process, Dr Maria McCarthy has been selected for this position. Dr McCarthy is the Director of the psycho-oncology program at the RCH and has worked with the PICS since its inception. Under her leadership and guidance the psycho-oncology program at the RCH has grown from a half-time position to a service that includes mental health, neuropsychology and procedural pain clinical services.

She has also been the primary lead in a research program that now has a number of completed and ongoing research projects. She has been successful in obtaining philanthropic funds and competitive grants to enable this clinical and research program to thrive. We are delighted to welcome Dr McCarthy to the PICS CAC.
In May 2010, Associate Professor David Ashley resigned as the PICS Medical Director and Chair of the PICS Clinical Advisory Committee. The PICS would like to express their thanks and gratitude to Associate Professor Ashley, for his support, guidance and expertise since the inception of the PICS.
In 2009-10, 209 children and adolescents were diagnosed with cancer and treated at The Royal Children’s Hospital (RCH) or Monash Children’s. Data collated for a review of the Regional Outreach and Shared Care Program (ROSCP) maps the activity of the Children’s Cancer Centre (CCC) at the RCH and Monash Children’s over the past six financial years. The report included inpatient activity, evidenced by data relating to episodes of care. An episode of care in basic terms, can be thought of as "the number of inpatient treatments".

Also reviewed was the number of bed days and the number of medical outpatient visits. A summary is provided as part of the PICS Annual Report to highlight patient activity across the PICS and ROSCP sites.

**Graph 1**
- Inpatient episodes of care have increased for the RCH, Monash Children’s and the regional centres since 2004-05.
- Of the total number of inpatient episodes across all centres, the RCH accounted for 65 percent in 2009-10, as compared to 73.5 percent when the ROSCP commenced in 2005-06. This 8.5 percent difference can be explained by the gradual increase in capacity and activity at Monash Children’s.
- Regional inpatient activity increased by 62 percent over the six years. This equates to approximately 19 inpatient episodes per year growth, across the four centres.

Graphs 1 and 2 detail inpatient activity and Graph 3 highlights outpatient activity.
In 2009-10 the RCH length of stay (LOS) had more than doubled as compared to 2004-05 data. This can be explained by the change in patient acuity as children are surviving longer and are requiring more complex care, resulting in extended inpatient admissions.

At Monash Children’s the LOS increased by 54 percent in the last financial year. This indicates a similar and corresponding increase in inpatient episodes and LOS over the period reviewed, suggesting a gradual increase in capacity and activity.

Inpatient LOS activity at the regional sites has stabilised over the last four years after a marked increase from 320 to 645 between the 2005-06 and 2006-07 periods, which is when the ROSCP was formally introduced.

Since 2005-06 there has been a steady increase in outpatient (OP) attendances at Monash Children’s, with a marked increase of 17 percent in 2009-10.

The RCH has increased OP attendances at an average rate of four percent per year.

As a percentage of the total OP medical consultations, when compared to 2004-05, Monash Children’s has experienced an increase in percentage, now accounting for 25 percent of the total outpatient activity, which can be explained by the increased service capacity at Monash Children’s following the expansion of the day facility.

Reported regional medical consultations rose to 170 this financial year.

Approximately 232 patients attend the 27 regional outreach clinics each year. Support for attendance at regional clinics has been facilitated by the provision of the ROSCP car, provided by the Sporting Chance Cancer Foundation and is gratefully acknowledged.
Our strategic direction

In 2009, the PICS undertook a strategic planning process to identify and document the key target areas for the three years, 2009-12.

The plan has been devised to ensure that PICS initiatives are prioritised and scheduled to respond to the issues and outcomes identified by staff, patients and their families and other key stakeholders. The identified goals and priority areas will guide ongoing service program development aimed at ensuring that Victorian paediatric cancer services are at the forefront of the very best, evidence-based practice.

The development of the Strategic Plan included a comprehensive consultation process, involving consumers and staff as well as major philanthropic and community support organisations and the Department of Health (DH). The PICS worked with stakeholders to formulate four strategic goals of which the key priorities, actions and outcomes for the 2009-12 period are documented.

One year on, the PICS has not only released the Strategic Plan, but in the past six months has addressed many of the strategic priorities including meeting the objectives of the Paediatric Surgical Oncology Program, completion of the annual patient satisfaction survey, implementation of the recommendations of the Peter Mac paediatric service review and continuation of the Long Term Follow-up and Regional Outreach and Shared Care Programs. In 2010-11 the PICS will focus strongly on supportive care and research, in line with our strategic goals. The Strategic Plan is an important phase in the development of an ongoing service program and offers an exciting future for the PICS.

The plan was officially launched by Mr Craig Bennett, PICS Chair, at the first PICS Annual Forum, held on 25 February 2010.

This annual report outlines the major PICS achievements in the 2009-10 period, in particular the development of the PICS Strategic Plan 2009-12.
Strategic Goal 1

To facilitate the provision of sustainable services that are of the highest international standard and which are based on a child and family-centred model of care where children and families are active participants in their care.

From January 2011, the LTFP will run an additional clinic at the RCH, resulting in one LTFP clinic per week across the two sites (priority 1.1, PICS ref 4)

• undertook the Press Ganey Patient Satisfaction Survey for inpatients and outpatients across the RCH, MMC and Peter Mac for the fifth year running (priority 1.3, PICS ref 16)

• completed the documentation of a model of care for Bone Marrow Transplant. The PICS is now working with the RCH to implement recommendations as appropriate (priority 1.1, PICS ref 7)

• developed a consumer registry, allowing the health services to disseminate information and seek participation in consultation activities as appropriate (priority 1.3, PICS ref 15)

• completed a best practice service model for nutritional services: ‘Optimising nutritional outcomes for children with cancer- A service model for the future’ (priority 1.1, PICS ref 1).

As part of the Peter Mac paediatric service review (priority 1.1, PICS ref 9), the PICS has worked with Peter Mac to:

• develop a paediatric anaesthetic service memorandum of understanding between the RCH and Peter Mac (in final stages of review and approval)

On the following pages we have highlighted two projects within Goal 1, the Paediatric Surgical Oncology Program (PSOP) as well as a project related to nutritional outcomes for children and their families. These projects demonstrate how the PICS is working towards achieving the priorities as outlined in Goal 1 of the Strategic Plan.
Goal 1 of the PICS Strategic Plan aims to ensure that services are sustainable, family centred and of the highest international standard.
Paediatric Surgical Oncology Program (PSOP) (priority 1.1, PICS ref 8)

The surgical and oncology units at the RCH and Monash Children’s at SH recognised the need for improved surgical services for children and adolescents with cancer and improved methods of working between multiple surgical sub-specialities and the Children’s Cancer Centres. A proposal with a series of recommendations to develop a Paediatric Surgical Oncology Program (PSOP) was submitted to the Department of Health (DH), Cancer and Palliative Care Unit in 2008. As a result, the DH provided the PICS with a 12 month grant to fund a Project Officer to commence implementation of these recommendations.

To date, PSOP work has included:

- completion of a three month baseline audit of Hickman site infections at the RCH with recommendations to implement consistent dressings
- implementation of a standardised external central venous access device (CVAD) dressing and stabilisation device across both the RCH and Monash Children’s
- the development of paediatric CVAD recommendations and guidelines
- a baseline audit was commenced at Monash Children’s for comparison with the RCH data including a review of Monash Children’s needs and priorities within PSOP
- research and evaluation of new technologies available for ports and the introduction of Power Port technology
- implementation of an agreed template for documentation of multidisciplinary patient reviews and discussions
- the development of an electronic request for CVAD insertion which will result in improved patient safety
- representation at the RCH Division of Surgery Monthly Quality Review Meeting and Quarterly RCH CVAD Executive Committee meeting.

An example of the work being done by the PSOP involves the standardisation of central line dressings. Families and staff had reported the method of applying and changing dressings varied widely resulting in inconsistencies in practice. Directed by Mr Michael Nightingale, RCH Paediatric and Neonatal Surgeon and Renai Eldridge, PICS PSOP Project Officer, different techniques and dressings were trialled with the aim of identifying a suitable dressing appropriate for infants, children and adolescents. The team then introduced an alternative locking device for central lines which is changed weekly when the routine CVAD maintenance occurs, resulting in a reduction in the number of patient visits.

The locking device is easily removed, comfortable to wear and can be positioned for convenience. Most importantly, the locking device and dressing are now consistent across sites, are easier to replace and provide patients with the confidence that their lines are secure.

In 2010-11 the PSOP will continue to strengthen paediatric surgical oncology services across the RCH and Monash Children’s by:

- completing an audit of biopsy procedures and reviewing patient referral procedures
- piloting a multidisciplinary risk stratification model for high risk solid tumour groups
- establishing combined surgical and oncology medical clinics for major solid tumour groups at the RCH and Monash Children’s
- reviewing options to improve timely access to theatre for insertion of central lines including access to after hours medical imaging and anaesthetics
- implementing strategies for combined procedures to reduce the incidence of general anaesthetic occasions
- developing a statewide paediatric surgical oncology special interest group
- developing parent information resources for CVAD
- trialling a neonatal and infant Hickman line dressing with stability locking device that is size appropriate for this age group.
Nutritional outcomes for children, adolescents and families
(priority 1.1, PICS ref 1)

In 2008, the PICS commissioned a project to develop a best practice service model for nutritional services: ‘Optimising nutritional outcomes for children with cancer - A service model for the future’. The documented and agreed model is based on the St Jude’s Children’s Research Hospital, USA and the adapted model utilised by the Queensland Paediatric Oncology Network.

The vision of the service model 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.”

Following the development of the service model, a two year funding grant was provided for the RCH by the Leukaemia Auxiliary at the RCH (LARCH), and a joint five year funding arrangement between SH and the KOALA Foundation was negotiated to expand dietetic services. As a direct result of this funding, every child now has access to a nutritional assessment and education session at diagnosis. Following this assessment, the child is provided with a risk adapted program as required. Prior to this project there was no routine outpatient dietetic service at either hospital and patients were seen only on referral.

The funding now ensures that families treated at both sites have access to consistent general information about growth and nutrition and are provided with useful tips on how to deal with common problems such as weight loss, nutrient deficiencies, alternative diets, nausea, vomiting, fussy eating etc.

In addition to improving access to dietetic support, this project will answer some important clinical research questions including:

- quantifying the number of children within different diagnostic groups who require different levels of nutritional care
- determining the percentage of children who present with evidence of malnutrition at diagnosis
- testing of the screening tool to determine its application to our patient population, and to establish whether this tool can improve the nutritional management of children with cancer.
The PICS will support quality research and evaluation through goal 2 of the Strategic Plan.
The PICS acknowledges the important role that research and evaluation play in ensuring paediatric oncology services are based on best practice models. Goal 2 of the Strategic Plan places emphasis on robust databases of research and clinical data, increased enrolment in clinical trials and benchmarking effectiveness of care. In 2009-10 the PICS has worked towards the priorities of Goal 2 through the following projects:

- **audit of medical records against minimum Department of Health (DH) criteria (priority 2.4, PICS ref 26)**
- **review of new diagnosis minimum communication and documentation requirements (priority 2.4. PICS ref 25)**
- **establishment of the Adolescents and Young Adults (AYA) Working Group and survey (priority 1.1, PICS ref 5 and priority 2.1-2.3, PICS ref 21-24)**
- **support of translational clinical research through Trackwell and improving education outcomes for those who have been treated for a paediatric brain tumour (priority 2.1, PICS ref 21).**

On the following pages we have highlighted five projects within Goal 2. These examples demonstrate how the PICS is working towards achieving the priorities as outlined in Goal 2 of the Strategic Plan.

**Medical record audit (priority 2.4, PICS ref 26)**

In 2009, the PICS participated in three DH required medical record audits. The purpose of the audit is to measure progress against specific criteria as determined by the DH:

- documented evidence of patient consent to multidisciplinary discussions
- documented evidence of the multidisciplinary discussion
- evidence of communication of the treatment plan to the GP
- documented evidence of supportive care screening.

Each of the three audits required the review of 20 medical records. At the time of the last audit, 11 of the 13 RCH patients had completed consent forms. Southern Health (SH) consent forms were implemented after this audit. Furthermore, at the time of the last audit in November 2009, 90 percent of patients audited had evidence of communication of the initial treatment plan to the GP, the second highest audit result when compared to the adult Integrated Cancer Service (ICS). The PICS recorded 90 percent of patients audited had documented evidence of supportive care screening, as compared to the DH benchmark of 20 percent.

**Planning services for young people: What are they telling us? (priority 1.1, PICS ref 5 and priority 2.1-2.3, PICS ref 21-24)**

The PICS Adolescent and Young Adult (AYA) Working Group is a multidisciplinary group established to target opportunities for improved access to enhanced services specifically orientated to AYA. In order to provide preliminary information about the experience and needs of young people with cancer, the working group developed a survey-based research project designed specifically for the study.

The 45 question survey was approved by the RCH Ethics Committee in April 2010 and is now open for recruitment. The survey is targeted at young people aged 12-21, treated at the RCH Children’s Cancer Centre (CCC) and will explore the following research domains:

- information-related experiences and needs
- preferences around communication with physicians
- references around treatment decision-making
- experiences of services/facilities
- impact of cancer on education or work
- influences of demographic, diagnostic or treatment related factors.

Preliminary results of a small sample of 18 young people indicate that the final results will be informative to the team in making recommendations for change within the system. Survey results will inform a baseline data set, guide future interventions, underpin the development of an AYA model of care, contribute to further research and facilitate collaboration in areas of clinical care, research and education.
New diagnosis checklist (priority 2.4, PICS ref 25)

Variations in practice were identified within the multidisciplinary team (MDT) and across sites with respect to communication and documentation of key events at diagnosis. A multidisciplinary Steering Committee was convened to coordinate this project and establish agreed minimum documentation and communication events at diagnosis, with agreed responsibilities for completion, including time frames.

Establishing an agreed range of communication events at diagnosis, and a time frame for completion, combined with mechanisms to support consistent documentation and follow-up, is anticipated to improve the service delivery and care coordination for children newly diagnosed with cancer. The auditing profile developed will enable data collection to demonstrate the impact of this initiative.

Furthermore, the auditing system has been established as an ongoing process to document and prompt staff to complete the key communication events.

This system aims to support a sustainable initiative, ensuring continued best practice in the coordination of new diagnosis communications for a child with cancer.

The below table documents the minimum agreed documentation and communication events and the agreed maximum timeline for completion.

<table>
<thead>
<tr>
<th>Timeline for completion</th>
<th>Key documentation and communication events</th>
<th>By whom</th>
</tr>
</thead>
<tbody>
<tr>
<td>At diagnosis</td>
<td>• Patient demographics</td>
<td>• The Clinical Nurse Coordinator (CNC)</td>
</tr>
<tr>
<td></td>
<td>• Presenting medical history</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• New patient referral email sent</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Primary Consultant nominated</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Clinical Nurse Coordinator (CNC) documented</td>
<td></td>
</tr>
</tbody>
</table>

| Within one week of diagnosis | Diagnosis, date of diagnosis and family history documented | • The CNC |
|                              | • Signed MDT consent form                     |         |
|                              | • Parent handbook provided                    |         |
|                              | • Family education modules 1 & 2              |         |
|                              | • GP/Paediatrician identified and correspondence sent |         |
|                              | • Emergency letter provided to family        |         |
|                              | • Social work checklist completed            |         |

| Within two weeks of diagnosis | Family education module 3 completed and DVD provided | • The CNC |
|                              | • Roadmap provided to families                |         |
|                              | • Copy of roadmap in medical record          |         |
|                              | • Letter to GP/Paediatrician sent by consultant/fellow |         |

| Within three weeks of diagnosis | Specialist communication documented in the Haematology Oncology Database | • The CNC |
|                               | • Comfort First Plan completed                |         |
|                               | • Nutrition and Dietetics summary sheet       |         |

| If regional patient:          | • Shared care pack sent to regional centre   | • The CNC |
|                               | • Teleconference held with staff at regional site | • The Regional CNC |
Trackwell: A neuropsychological screening program to identify cognitive and academic difficulties in patients treated for childhood cancer (priority 2.1, PICS ref 21)

This study aimed to establish prevalence rates for neurobehavioural difficulties in our population of childhood cancer survivors, and to compare this with performance in a newly diagnosed cohort of patients. Neurobehavioural outcomes were assessed using a tailored screen which targeted known areas of vulnerability for late effects. Recruitment of patients and families commenced on 26 November 2008 and proceeded throughout the following 18 months. A total of 167 families of survivors participated in the study (participation rate of 61 percent of eligible survivors) and 61 newly diagnosed families (62 percent participation rate).

The findings of this study are currently being analysed, and a healthy group of age and gender-matched children are being recruited to compare to the illness groups. Preliminary analyses suggest that approximately one third of survivors experience cognitive difficulties in fundamental learning skills which places them at risk of adverse long-term educational and vocational outcomes.

Funding for the Trackwell study was received for the first year as a special grant from the Department of Human Services, Metropolitan Integrated Cancer Services and Palliative Care Programs Branch. At the termination of this first grant (July 2009), the PICS provided a further six month grant of $43,568 to enable the project to be completed. A further $16,000 was then contributed by the Critical Care and Neurosciences theme of the Murdoch Childrens Research Institute to fund collection of a healthy comparison sample.

Targeted intervention at a systems level can potentially stem the cumulative impact of cognitive impairment on development of academic, vocational and social abilities. The PICS provided the funds required to prepare an application to the Victorian Cancer Agency, Palliative and Supportive Care Capacity Building Grant in April 2010. The grant requesting $58,007 was successful and the team was notified in July 2010.

The capacity building grant will establish a model of service provision to provide comprehensive care to school-aged paediatric brain tumour survivors with the aim to improve their quality of life. This funding grant provides the first 12 months funding of this project.

Improving educational outcomes for individuals who have been treated for a paediatric brain tumour (priority 2.1, PICS ref 21)

Paediatric brain tumours and the treatment required to effect cure have the potential to result in lasting brain damage that evolves and changes over time. As a result a significant proportion of survivors experience cognitive deficits that become a lifelong burden.
The PICS emphasises the importance of a positive work culture, striving to work with the PICS partner health services to coordinate professional development opportunities to strengthen the workforce. In 2009-10, the PICS undertook several initiatives to support the workforce and encourage professional development and a stronger workforce including:

- supporting an application by Southern Health (SH) to the Victorian Nurse Practitioner Project Round 4.4 and 4.5. (priority 3.1, PICS ref 28)
- facilitating the implementation of the staffing related recommendations of the Peter Mac paediatric services review (priority 1.1, PICS ref 9)
- adolescents and young adults (AYA) service provision (priority 1.1, PICS ref 5)
- the Victorian Paediatric Oncology Service Plan (priority 3.2, PICS ref 29)
- education and professional development (priority 3.1, PICS ref 27).

On the following pages we have highlighted six initiatives within Goal 3. These initiatives demonstrate how the PICS is working towards achieving the priorities as outlined in Goal 3 of the Strategic Plan.

Nurse practitioners (priority 3.1, PICS ref 28)
The PICS has endorsed the SH application to the Department of Health (DH), Victorian Nurse Practitioner Project. The proposal prioritises scoping a model for ambulatory paediatric oncology within the Children's Cancer Centre (CCC) at Monash Medical Centre (MMC). In addition, the proposal includes the scoping of a general paediatric palliative care nurse practitioner role, with linkages to the Victorian Paediatric Palliative Care Program (VPPCP). If successful, the PICS will work with SH to implement the nurse practitioner model. Notification from the DH is expected in September 2010.

Medical Oncologist at Peter Mac (priority 1.1, PICS ref 9)
In 2008-09, the PICS sponsored a review of the Peter Mac Paediatric Service: 'Developing a Safe, Quality and Sustainable Service Model for Children and Adolescents and their Families.' The review identified service gaps, opportunities for service improvement, and nine key recommendations. The Paediatric Services Steering Committee has been established to implement the recommendations.

One of the recommendations: ‘Strengthening the Overall System,’ suggested a range of ways in which Peter Mac could enhance the Paediatric Service, ensuring high quality and safe practice. It proposed increased access to paediatric oncology. The PICS has provided a 12 month grant to Peter Mac to fund an appointment to help address this issue. The outcomes of this additional position are expected to include:

- paediatric oncology consultations within future joint clinics as part of the shared care model between Peter Mac and The Royal Children’s Hospital (RCH)/Monash Children’s
- attendance at the weekly chart round and the paediatric weekly clinic
- opportunity to streamline appointments, avoid unnecessary and duplicated appointments, and potentially to provide clinical reviews (e.g. pre-chemotherapy) at the Peter Mac clinic
- on-call service and back-up cover for inpatients
- advice on general clinical issues and service improvement initiatives from the paediatric perspective.
The PICS is committed to working with the health services to deliver professional development opportunities to strengthen the workforce.
Adolescent and young adult (AYA) service provision
(priority 1.1, PICS ref 5)

The PICS has as a priority within Goal 1, to facilitate the development and implementation of a comprehensive service for adolescents with cancer with links to and collaboration with the Statewide Adolescent Service, the OnTrac@Peter Mac Victorian Adolescent and Young Adult Service and the Youth Cancer Network (YNC). The YCN has allocated funds to the PICS to appoint a joint Project Officer. Dialogue has commenced between stakeholders and an appointment will be made in the 2010-11 year.

Specific outcomes for this Project Officer are to:

• build on the AYA specific expertise of the workforce within the CCC at PICS sites with education and training
• assist in the development of a formalised model of care that reviews current care pathways, availability of services and develops an understanding of specific issues affecting this population
• increase participation in clinical trials for AYA
• work with the health services to introduce appropriate screening and consistent assessment for supportive needs
• work with the health services to improve AYA care as informed by the AYA research survey outcomes: ‘Planning services for young people: What are they telling us?’, (please see page 19).

Victorian Paediatric Oncology Service Plan
(priority 3.2, PICS ref 29)

The PICS will work together with the health services to develop a service plan and model for the future delivery of paediatric oncology services across Victoria. At the June 2010 PICS Governance Executive Committee (GEC) meeting, a project outline was approved which incorporates a workforce planning component, modelling of a 10 year statewide workforce plan within specialities and professional groups. This workforce component will allow individual health services to plan for the future workforce requirements of their individual service. The PICS GEC endorsed SH to take the lead at the June 2010 meeting, working with the PICS to develop this plan over the 2010-11 year.

Below is a listing of the courses supported by the PICS in 2009-10

<table>
<thead>
<tr>
<th>Course name</th>
<th>Duration</th>
<th>Number held at RCH</th>
<th>Number held at MMC</th>
<th>Number of attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td>An Introduction to Paediatric Oncology: study day for nurses</td>
<td>1 day</td>
<td>3</td>
<td>1</td>
<td>84</td>
</tr>
<tr>
<td>Chemotherapy Accreditation study day</td>
<td>1 day</td>
<td>4</td>
<td>2</td>
<td>67</td>
</tr>
<tr>
<td>Paediatric Bone Marrow Transplantation</td>
<td>2 days</td>
<td>1</td>
<td>-</td>
<td>11</td>
</tr>
<tr>
<td>The Children with Cancer Short Course</td>
<td>5 days</td>
<td>2</td>
<td>-</td>
<td>18</td>
</tr>
<tr>
<td>Children with Cancer: a half study day for allied health and support staff</td>
<td>½ day</td>
<td>1</td>
<td>1</td>
<td>31</td>
</tr>
<tr>
<td>12 week nursing fellowship</td>
<td>12 weeks</td>
<td>3 attendees working across sites</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Regional Courses (as part of the ROSCP)

<table>
<thead>
<tr>
<th>Course name</th>
<th>Duration</th>
<th>Number held</th>
<th>Number of attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regional medical and nursing information evenings</td>
<td>3 hours</td>
<td>6</td>
<td>90</td>
</tr>
<tr>
<td>Video conference sessions: monthly</td>
<td>1 hour</td>
<td>12 p.a.</td>
<td>672</td>
</tr>
</tbody>
</table>
ANZCHOG

The Australian and New Zealand Children’s Haematology and Oncology Group (ANZCHOG) is a multidisciplinary, cooperative organisation of professionals working in the fields of paediatric blood diseases and cancer. The Annual Scientific Meeting brings together professionals from diverse backgrounds, allowing for collaboration and sharing of knowledge.

In June 2010, the PICS funded a total of 19 health professionals and consumers to attend the ANZCHOG 2010 Annual Scientific Meeting held in Sydney, Australia.

Staff included:
- PICS: Program Manager, Regional Nurse Coordinator, Long Term Follow-up CNC and Occupational Therapist
- RCH and Monash Children’s: one nurse and allied health staff member from each site
- Peter Mac: allied health staff member
- From each of the seven regional sites: one nursing representative

Some of those sponsored by the PICS to attend this meeting have provided their thoughts on their experiences and the value of this opportunity below:

“I was a fabulous conference; the diversity of presentation topics was both surprising and refreshing addressing everything from music therapy to haemophilia! I came away with new contacts in Shepparton, San Francisco, Brisbane, Adelaide and Memphis to list but a few. Many thanks to the PICS for generously supporting the attendance of regional based “shared care” partners at this conference. Auckland 2011 is looking pretty enticing!”

Pete Timms
Clinical Nurse Educator: Paediatrics
Ballarat Health Services

“I found ANZCHOG to be a great opportunity to meet and chat with other Clinical Research Associates from around Australia and New Zealand. Attending ANZCHOG was a fantastic educational experience, where everyone was willing to share their expertise and knowledge.”

Angie Cutajar
Clinical Research Coordinator/ Data Manager
Children’s Cancer Centre, The Royal Children’s Hospital

“I am very appreciative of the support provided by the PICS which allowed CCCPAG representatives to attend the ANZCHOG conference. It allowed us (the parent representatives) to gain a greater understanding of the roles and achievements of staff, the directions in which they are endeavouring to move the field of paediatric oncology and the science and culture within this specialty area. The opportunity to network with consumer representatives from other centres was beneficial, and we are hoping to strengthen links over time within the suggested ANZCHOG consumer participation framework.”

Jenny Haig
Chair
Children’s Cancer Centre Parent Advisory Committee

“ANZCHOG allowed me to network with other Oncology Dietitians from around Australia and together we documented and brainstormed common problems and practices across the nutrition services. Primarily we discussed nutrition issues that are appearing through Late Effects or Long Term Follow-up clinics, feeding during and post bone marrow transplants, current Percutaneous Endoscopic Gastrostomy (PEG) protocols for solid tumour groups across Australia, and the enteral feeding of paediatric patients during hyperhydration protocols. As a result of ANZCHOG we will be pooling data with the RCH Brisbane and the Sydney hospitals for different research projects in the future.”

Erin Dobinson
Dietitian
The Royal Children’s Hospital
Special Events
PICS Annual Forum 2010

The first PICS Annual Forum was held on 25 February 2010 at the RCH. Chaired by Mr Craig Bennett, the Forum was addressed by the Minister for Health, the Hon Daniel Andrews MP, and paediatric surgeons Professor Yves Heloury from SH and Mr Michael Nightingale from the RCH. The forum provided staff across services and disciplines with the opportunity to learn more about the work undertaken by the PICS.

The forum was attended by approximately 60 staff from the RCH, SH, Peter Mac and the DH, with representation from other services including adult ICS, the CCCPAG and community agencies.

The next Annual Forum will be held on 24 February 2011 at Monash Medical Centre, Southern Health. For more information, or to receive an invitation please contact Diana Cardona on 03 9345 5659 or diana.cardona@rch.org.au
Strategic Goal 4

To increase PICS governance, reporting and organisational capability, relationships with philanthropy, support organisations, government and community agencies.

Goal 4 of the PICS Strategic Plan relates to governance and relationships. The PICS is committed to strengthening PICS governance, reporting and accountability as well as building relationships with adult cancer services and the Integrated Cancer Service (ICS), philanthropy, support organisations and consumers. In 2009-10 the PICS worked towards Goal 4 by undertaking the following:

- completion of the PICS Strategic Plan 2009-12
- inclusion of a Psychosocial Representative on the PICS Clinical Advisory Committee (CAC)
- representation on the Victorian Cancer Survivorship Program Steering Committee - PICS Program Manager (Jane Williamson)
- representation on the State-wide Adolescents and Young Adults (AYA) Advisory committee - PICS Medical Director (Dr Peter Downie)
- representation on the State-wide Consumer and Carer Participation in the ICS Project Board - PICS Program Manager (Jane Williamson)
- representation on the State-wide Strengthening Care for the Child with a Life Threatening Condition – PICS Program Manager (Jane Williamson)
- Royal Children’s Hospital representative for the Victorian Comprehensive Cancer Centre - RCH CEO (Professor Christine Kilpatrick)
- Chair of the Australian and New Zealand Children’s Haematology and Oncology Group (ANZCHOG)- PICS Medical Director (Dr Peter Downie)
- Chief Executive of the Australian Children’s Cancer Trials (ACCT) – ex-PICS Medical Director (Associate Professor David Ashley).

Psychosocial representative on the PICS CAC

Guided by the Department of Health’s Supportive Care Policy for Victoria and as part of the PICS Strategic Plan 2009-12, the PICS is committed to strengthening supportive care services for children and adolescents with cancer throughout Victoria. To this end, the PICS CAC has appointed a psychosocial representative to join the committee. The psychosocial representative will advise the PICS CAC and the PICS Governance Executive Committee (GEC) on matters surrounding new and existing psychosocial and supportive care initiatives taking place in the PICS partner health services.

Specifically, the role of the psychosocial representative will be to advise the PICS on initiatives related to supportive care, including the review and implementation of a supportive care screening tool for patients and families i.e. stress/distress/risk and the development of a psycho-oncology education program for Children’s Cancer Centre staff at PICS sites.
PICS will work with staff and the parent advisory group to deliver the outcomes of the Supportive Care Grant in 2010-11.
Towards the end of 2009, the CCCPAG in collaboration with the PICS and Children’s Cancer Centre (CCC) staff recognised the need for improved supportive care services for children and adolescents with cancer and their families. The CCCPAG was asked by the Minister of Health to submit a document outlining the supportive care needs for children, adolescents and families identified through the CCCPAG consumer consultation processes. The PICS was then requested by the Department of Health to submit a proposal for funding.

The aim of the one-off grant is to support the development, implementation and evaluation of initiatives that address issues raised by the CCCPAG. Over the next 12 months the PICS together with the CCCPAG and CCC staff at both The Royal Children’s Hospital (RCH) and Monash Children’s will:

- establish an online computer-based information library, which will be accessible on the wards and in outpatient areas at both the RCH and Monash Children’s, providing access to electronic information and links to relevant community support agencies
- develop standardised medication leaflets and introduce a standardised pharmacy outpatient education program across the RCH and Monash Children’s CCCs
- develop nutrition and dietetics information resources
- explore the potential to develop information resources in languages other than English
- review current access to community counselling services and scope the potential for a training and education program for community service providers
- together with relevant adolescent and young adult services, review and improve access to services appropriate for adolescents for both inpatients and outpatients
- review access to and appropriateness of consumer information relating to complementary therapies.

Looking forward

At the PICS Annual Forum, held on 25 February 2010, the Minister for Health, the Hon Daniel Andrews MP announced a grant of $250,000 to be awarded to the PICS to undertake work related to supportive care as identified and prioritised by the Children’s Cancer Centre Parent Advisory Group (CCCPAG).
Awards

To increase PICS governance, reporting and organisational capability, relationships with philanthropy, support organisations, government and community agencies.

Fellowship

Susan Skinner, the PICS Long Term Follow-up Clinical Nurse Coordinator was awarded the Inaugural Rosemary Kelley Fellowship for Professional Development in April 2010. The fellowship supports registered nurses in Victoria to undertake courses, professional development or research activities to advance their knowledge and skills in haematological malignancies and other forms of cancer. Offered through the Nurses Board of Victoria, this fellowship provides a one-off grant for professional development purposes.

In June 2010, Susan used this grant to attend and present on the Long Term Follow-up Program (LTFP) at the Fourth International Nursing Conference on Children and Adolescent Cancer Survivorship.

Susan also attended the International Conference on Long Term Complications of Treatment of Children and Adolescents for Cancer in Virginia, USA and the Cancer Survivorship Research Conference: Recovery and Beyond, in Washington, USA. Furthermore, Susan visited several internationally renowned hospitals to observe their long term follow-up services including Dana Faber (Boston), Sloan Kettering Memorial Cancer Centre (New York) and the Children’s Hospital of Philadelphia.

This fellowship has provided Susan with professional development opportunities, and has also ensured that the PICS LTFP continues to be modelled on the highest international standard; ensuring survivors receive the very best care possible.
Winner

The PICS together with The Royal Children’s Hospital (RCH) and Peter Mac won the 2010 Premier’s Excellence Award in Improving Cancer Care for the application titled: ‘GA? No way! Minimising the use of general anaesthesia in radiotherapy mask production for children: an innovative child friendly approach’.

The objective of this work was to implement an improved procedure for radiation mask manufacture that avoided the need for general anaesthesia.

Children under the age of six, requiring radiation treatment usually require a general anaesthetic, for the stabilisation mask to be made. A multidisciplinary team designed a new three stage process:

1. The RCH Batten Foundation 3D Imaging Centre (within the RCH Educational Resource Centre) acquires a 3D image of the child’s head and upper torso, a process that takes a fraction of a second and is performed using five digital cameras.

2. Images are then sent electronically to the prosthetist who mills a bust out of high density polyurethane foam using a computer aided design prosthetic carver.

3. The bust is then couriered to Peter Mac where the mask is moulded directly to the bust.

This process negates the need for a general anaesthetic for mask construction and reduces time required to manufacture masks by two days and more than five hours of labour. Child anxiety is reduced and treatment time is reduced from two hours to 40 minutes. Of the four children where this revised procedure was provided, 92 GA’s were negated. For details of the submission see the PICS website.
# Financial summary 2009-10

## PICS allocation of funds

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<tr>
<th>Revenue</th>
<th>Other Revenue</th>
<th>$900</th>
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<tbody>
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<td>Grants - State</td>
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<tr>
<td><strong>Revenue total</strong></td>
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<td>$1,316,320</td>
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<tr>
<td>Expenditure</td>
<td>Salary and Wages</td>
<td>Oncosts including LSL, superannuation and workcover, annual leave</td>
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<tr>
<td></td>
<td></td>
<td>Clinical salaries including on costs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Secretariat and Health Service Administrative support including on costs</td>
</tr>
<tr>
<td></td>
<td>General Expenses</td>
<td>Telephone, video conferencing, computer software &amp; upgrades</td>
</tr>
<tr>
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<td></td>
<td>Motor vehicle expenses</td>
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<td>General administration</td>
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<td>Printing and stationary</td>
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<tr>
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<td>Food, meeting and Medical Mentoring expenses</td>
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<td>Project Expenses/Consultancy</td>
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<td>Staff Training and Development</td>
<td>Nursing Fellowship</td>
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<td>Training and development (inc ROSCP and ANZCHOG)</td>
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<td>Travelling expenses</td>
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<td>Consumer attendance ANZCHOG</td>
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<td>Special functions for training</td>
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<td><strong>Expenditure total</strong></td>
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<td><strong>Surplus/(deficit)</strong></td>
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## PICS Long Term Follow-up allocation of funds

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<td><strong>Revenue total</strong></td>
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<td>$517,174</td>
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<tr>
<td>Expenditure</td>
<td>Salary and Wages</td>
<td>Oncosts including LSL, superannuation and workcover, annual leave</td>
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<tr>
<td></td>
<td></td>
<td>Clinical salaries including on costs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Secretariat and Health Service Administrative support including on costs</td>
</tr>
<tr>
<td></td>
<td>General Expenses</td>
<td>Computer software &amp; upgrades</td>
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<tr>
<td></td>
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<td>General administration</td>
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<td>Printing and stationary</td>
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<td></td>
<td></td>
<td>Food, meeting and Medical Mentoring expenses</td>
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<td>Project Expenses/Consultancy</td>
<td>Neuropsych testing tools</td>
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<tr>
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<td>Rental of premises</td>
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<td>LTF consumer interviews</td>
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<td></td>
<td>Staff Training and Development</td>
<td>Training and development</td>
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<td>Travelling expenses</td>
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<td><strong>Expenditure total</strong></td>
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<tr>
<td><strong>Surplus/(deficit)</strong></td>
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<td>$75,811</td>
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Posters and Presentations

Posters

Coordination and Communication at diagnosis- a crucial beginning! National Cancer Care Coordination Conference (March 2010, Surfers Paradise)

Regional Outreach and Shared Care Program: Highlight of a Formal Regional Partner. Rural Health Conference (April 2010, Ballarat)

Abstract accepted: Nursing education: improving care for the paediatric oncology patient in a general paediatric ward. ANZCHOG (September 2010, Sydney)

Abstract accepted: Long Term Follow-up Program – Model of Care. 42nd Congress of the International Society of Paediatric Oncology (October 2010, Boston, USA)

Presentations

A Medical Mentoring Program for Regional Paediatricians sharing the care of Children and Adolescents with Cancer. Rural Health Conference (April 2010, Ballarat)

Long Term Follow-up Program (LTFP). Fourth International Nursing Conference on Children and Adolescent Cancer Survivorship (June 2010, Virginia, USA)

Abstract accepted: Computerised Image Capture and Moulding in the Manufacture of a Radiation Therapy Stabilisation Device- a Multidisciplinary and Multisite approach. ANZCHOG (September 2010, Sydney)

Abstract accepted: Having their say - Planning cancer services for adolescents within a paediatric setting. ANZCHOG (September 2010, Sydney)

The PICS would like to thank all those involved in the development of this year’s annual report, in particular the children and families whose photos have featured in the report.
The Integrated Cancer Services are funded by the Victorian Government as part of Victoria’s cancer reforms.