

# PICS

Paediatric Integrated Cancer Service



Paediatric Integrated  
Cancer Service

A statewide cancer service for children

Annual Report 2008–09



# Welcome

to the Paediatric Integrated Cancer Service (PICS)  
Annual Report 2008 – 09

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HENRY

# Joint opening message

On behalf of the Paediatric Integrated Cancer Service (PICS) we are pleased to present the 2008–09 annual report

This annual report provides background information regarding the history of PICS, its vision, mission and principles of care. The report offers a snapshot of our patient population with specific emphasis this year on our regional families and data collected from one of our regional partnership sites. It includes an overview of key PICS projects and some of the work undertaken over the past year. In this annual report we have chosen to highlight the implementation of the Long Term Follow-up Program, the review of paediatric services at Peter MacCallum Cancer Centre and our commitment to the engagement of consumers. In addition we have included a short outline of the PICS Nursing Children with Cancer Fellowship and the nurses who have completed the program over the past four years.

We are very proud that the PICS Regional Outreach and Shared Care Program was announced as the joint winner of the 2009 Premier's Excellence Award for Improving Cancer Care in Victoria. This award honours an initiative that is at the forefront of cancer care improvement and is a tribute to the many health professionals working together across Victoria to achieve the "best care in the best facility, as close to home as possible".

Importantly, we would like to extend our thanks to members of the PICS Coordinating Group who have been instrumental in guiding PICS since it was established in 2005. We would like to welcome the new PICS Governance Executive Committee, who will provide leadership and vision for the future development of PICS and the Clinical Advisory Committee who will continue to provide clinical leadership. We have taken the opportunity to outline the new Governance structure, its membership and responsibilities in this annual report.

We thank all those who have contributed and continue to contribute to the work of the Paediatric Integrated Cancer Service. We maintain the strong commitment to the provision of safe, effective and high quality children's cancer services across Victoria.



A handwritten signature in black ink, appearing to read 'D Ashley'.

**Associate Professor David Ashley**  
Chair, Paediatric Integrated Care Service



A handwritten signature in black ink, appearing to read 'Jane Williamson'.

**Jane Williamson**  
Program Manager,  
Paediatric Integrated Care Service

# Introduction



PICS was established in 2004 as part of the Victorian State Government's 'Caring for Children' package and is now part of the Department of Health's (DH) broader cancer reform strategy known as the Victorian Cancer Service Framework. The Integrated Cancer Services (ICS) are funded by the Victorian Government as part of Victoria's cancer reforms.

As a specialist service supporting all children with cancer in Victoria, PICS is the only statewide Integrated Cancer Service. The Royal Children's Hospital (RCH), Southern Health (SH) and the Peter MacCallum Cancer Centre (Peter Mac) form the PICS partnership.

The Victorian Government's Cancer Services Framework outlines an integrated service model for metropolitan and rural cancer services, which centres on delivering the right treatment and support to consumers as early as possible in the cancer journey. Four key priorities for reform have been identified as the focus for service improvement at the ICS and statewide levels:

- Multidisciplinary care
- Care coordination across the cancer pathway
- Supportive care
- Reducing unwanted variation in practice

The Victorian Government's 'Victoria's Cancer Action Plan 2008–2011' (VCAP) builds on cancer reform work to date, outlining a medium-term vision for cancer reform that will offer standardised and high-quality cancer care to all Victorians, regardless of whether they live in metropolitan, regional or rural Victoria. VCAP is a comprehensive action plan with measurable targets across four key action areas:

**Action Area 1:** Reducing major cancer risk factors in the population and maximising effective screening.

**Action Area 2:** Ensuring rapid translation of research into effective treatments and clinical care.

**Action Area 3:** Investing in innovative treatments and technologies and sustainable integrated care systems.

**Action Area 4:** Supporting and empowering patients and carers throughout their cancer journey.

The goal of PICS is to improve outcomes for children with cancer and their families through achieving consistent medical, nursing, allied health and psychosocial services across the PICS partnership. In 2005, the PICS Coordinating Group (PICS-CG) together with the Department of Human Services (DHS) established the following seven key target areas for PICS.

No.	Key target areas
1	To improve the delivery of statewide specialist paediatric cancer services through the establishment of a statewide PICS.
2	To ensure safe, low risk, best practice, efficient and high quality services to all PICS sites.
3	To enable quality improvement, consistent clinical practice and maintenance of professional expertise across the PICS partnership.
4	To improve coordination and sharing of expertise across all three paediatric cancer sites.
5	To create the capacity to improve statewide trials, coordination and associated data management within the statewide PICS.
6	To develop a multidisciplinary/multi-campus approach to the provision of psychosocial support services.
7	To provide support for regional and community cancer services.

In the 2009/2010 year, PICS will undertake a strategic planning process to identify and document the key target areas and activities for the next three years. Wide consumer and staff consultation in addition to consultation with the major philanthropic and community support organisations will be included in the process. It is envisaged the strategic plan will be completed by December 2009.

# A short history of PICS

2004	Paediatric Integrated Cancer Service (PICS) funding commenced
2005	PICS secretariat staff commenced
	"A vision of Care and Roadmap to Guide the Victorian PICS from 2005–2008" completed
	Development of a Statewide Paediatric Oncology Specific Patient Satisfaction Survey
2006	Regional Outreach and Shared Care Program commenced (June)
	"Strengthening Psychosocial Care: a blueprint for the future" completed (June)
	"Together we do it better: Developing a consumer participation model" completed (December)
2007	"Art, Music and Play Therapy: A service model for the future" completed (August)
	"Optimising the health and well-being of survivors of childhood cancer: A model for the future" completed and submitted to DHS for consideration (September)
2008	"Paediatric Surgical Oncology program" business case completed (January)
	"Optimising Nutritional Outcomes for Children and Families: A service model for the future" completed (April)
	"Developing services for adolescents attending the Children's Cancer Centres at The Royal Children's Hospital and the Monash Medical Centre" proposal completed (August)
	Long Term Follow-Up Program funding secured and program commenced (September)
	"Paediatric Surgical Oncology Program" recommendations and final report completed (December)
2009	"Strengthening services for children with cancer and their families from a culturally and linguistically diverse background (CALD)" completed (January)
	"Developing a best practice service model for Bone Marrow Transplant in children" proposal completed (January)
	"Developing a safe, quality and sustainable service model for children and adolescents and their families" completed (February)
	"Strengthening access to paediatric palliative care: Developing a best practice model for the future" completed (May)
	PICS Strategic Planning Process 2009–2012 commenced (June)

## Our vision of care

The PICS vision 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 death, and through the many developmental stages of the child or adolescent's life.

The PICS mission is that all Victorian children and adolescents with cancer and their families have access to high quality, safe and effective clinical and psychosocial care that is well coordinated and provided in environments that are conducive to healing and coping. This will:

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

# Art, music and play therapy

Art therapy and the process of art making can provide an effective method and means of symbolic expression of experiences of pain, hospitalisation, anxiety, depression, hopes and concerns. PICS completed documentation of a Model of Care for Art, Music and Play therapy in 2007. Responding to the recommendation of a need for increased staffing resources at the hospitals, hours have been increased for all disciplines. Thanks to the generous contribution made by the KOALA Foundation, we have been able to commence an adolescent art therapy group and increased access for both in and out patients to the therapies. PICS has included examples of the children's art in this annual report and we would like to thank all of the children who have allowed their artwork to be featured.



# Our partners

## The Royal Children's Hospital

The Royal Children's Hospital (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 is the largest partner in the PICS and is the only provider of complex children's cancer care and stem cell transplantation in the State of Victoria. The RCH Children's Cancer Centre is recognised as an international leader in the research and treatment of childhood cancer, each year treating around 70% of Victoria's newly diagnosed cancer patients under the age of 16 and continuing to provide follow up for the many children receiving ongoing treatment and/or active patient follow-up.



## Southern Health

Southern Health (SH) is Victoria's largest health service uniquely providing in one organisation, primary, secondary and tertiary health services. 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% of Victoria's childhood cancer patients. The centre 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. In addition to indoor play areas, the cancer centre has an outdoor playground.



## Peter MacCallum Cancer Centre

Peter MacCallum Cancer Centre (Peter Mac) is the only site in Victoria offering radiotherapy to children under the age of 16 years, and is the largest paediatric radiation centre in Australia. It is a public hospital solely dedicated to cancer treatment, research and care. Each year the paediatric unit receives referrals for 60–70 new patients and treats approximately 90 patients. A very small number of children (1–2 per month) are admitted to Peter Mac usually for total body irradiation in preparation for bone marrow transplantation.



# PICS shared care partners



While the RCH and SH provide the majority of care for Victorian children diagnosed with cancer, PICS has developed the Regional Outreach and Shared Care Program (ROSCP). This program enables children to access care in regional centres where it is safe and appropriate to do so. Formal regional partners of this program include:

- Goulburn Valley Health (GVH)**, a 280 bed acute and extended care facility which services the city of Shepparton and surrounds and offers a range of services including paediatrics. GVH became a formal ROSCP partner in 2007.
- Albury Base Hospital**, part of the Greater Southern Area Health Service is a 157 bed hospital providing acute and community health care services to a surrounding community spanning 166,000<sup>2</sup> km and has been a formal ROSCP partner since 2007.
- Ballarat Health Services** provides acute, sub-acute, residential and community care as well as psychiatric and rehabilitation services to the Ballarat and Grampians region and became a formal ROSCP partner in 2007.
- Barwon Health** provides a range of acute and community health services to more than 450,000 people in Geelong and South Western Victoria and has been a formal ROSCP partner since 2008.
- Bendigo Health Care Group**, a multi-service regional health organisation offers health services to Bendigo and surrounds and has been a ROSCP partner since 2008.
- South West Healthcare**, a leading Victorian regional hospital, providing surgical, medical, obstetric, rehabilitation, emergency, psychiatric, allied health and community health services to the south-west region of Victoria became a formal ROSCP partner in 2008.

# Our organisational structure for the future



The Department of Human Services (DHS) undertook a review of the governance of the Integrated Cancer Services (ICS) in April 2008. One of the recommendations of the review was that the Chief Executives of the health services providing cancer care within the ICS be members of the ICS Governance Committee.

In line with the DHS requirement, 30 June 2009 marked the cessation of the PICS Coordinating Group (PICS CG) and the introduction of the PICS Governance Executive Committee (GEC). The PICS GEC will be supported by the PICS Clinical Advisory Committee (CAC).

**A message from the incoming Chair of PICS – Craig Bennett,  
Chief Executive Officer, Peter MacCallum Cancer Centre**

I am very pleased to have been asked to chair the PICS Governance Executive Committee for the next two years. I am keenly aware of the good work undertaken on behalf of PICS throughout Victoria in 2008–09 and would like to thank Associate Professor David Ashley (Medical Director), Jane Williamson (Program Manager) and all the PICS directorate staff for their commitment and contributions.

I look forward to working with you over the next two years.

I commend this report to you.



*Craig Bennett*

**Craig Bennett**

CEO, Peter MacCallum Cancer Centre



## A summary of the role of the PICS GEC

- Provide leadership and vision for the ongoing development of PICS.
- Ensure communication and reporting processes exist with the host health service and member health service boards, chief executives, other ICS and the Department of Health.
- Provide advice to individual health services within PICS about cancer service issues, development and sustainability.
- Ensure the planning is consistent with the principles outlined in the Cancer Services Framework for Victoria.
- Take responsibility for, and endorse, the development, implementation and monitoring of a strategic plan for PICS.
- Ensure engagement with other key services from the community, primary and private sectors.
- Take overall responsibility for PICS service development, quality and performance monitoring.
- Plan for PICS sustainability.

### PICS GEC members

#### Chair: Mr Craig Bennett

Chief Executive Officer, Peter MacCallum Cancer Centre

#### Professor Christine Kilpatrick

Chief Executive Officer, The Royal Children's Hospital

#### Ms Shelly Park

Chief Executive Officer, Southern Health

#### Ms Julie Tate

General Manager Radiation Oncology, Peter MacCallum Cancer Centre

#### Dr Peter McDougall

Director, Division of Medicine, The Royal Children's Hospital

#### Associate Professor Nick Freezer

Medical Program Director, Women's and Children's Program, Monash Children's and Southern Health

#### Associate Professor David Ashley

Director CCC, The Royal Children's Hospital and Director (Medical), Paediatric Integrated Cancer Service

#### Ms Jane Williamson

Program Manager, Paediatric Integrated Cancer Service

A representative from the Host Agency (Southern Health) and the Department of Health are also invited to attend the PICS Governance Executive Committee meetings. This committee meets quarterly.

## A summary of the role of the PICS CAC

- Develop and implement a strategic plan.
- Establish PICS cross campus and multidisciplinary groups.
- Coordinate the connections between RCH, SH and Peter Mac in the provision of paediatric services. In particular oversee service planning, quality improvement, consistent clinical practice and maintenance of professional expertise across the PICS partnership.
- Understand cancer service requirements for children with cancer across the State.
- Provide advocacy for best practice paediatric clinical care and paediatric cancer research across the state.
- Continue to identify regional needs and to ensure the continued development of the PICS ROSCP.
- Continue to improve access to statewide trials coordination and associated data management.
- Continue to facilitate and enhance approaches to a multidisciplinary, multi-campus provision of psychosocial support and palliative care for children with cancer.
- Advise the PICS Governance Executive Committee on matters relating to cancer service reform and activities to improve the quality of cancer services within PICS.
- Participate in the ongoing development, implementation, monitoring and evaluation of activities associated with the implementation of the PICS Strategic Plan (2009–2012).
- Plan for PICS sustainability.

Importantly, the CAC includes representation from our consumers and from our regional partners. The Chair of the CCC Parent Advisory Group and a regional paediatrician are members of the CAC. This committee meets quarterly.

### PICS CAC members

#### Chair: Associate Professor David Ashley

Director CCC, The Royal Children's Hospital and Director (Medical), Paediatric Integrated Cancer Service

#### Ms Julie Tate

General Manager Radiation Oncology, Peter MacCallum Cancer Centre

#### Dr Greg Wheeler

Chair of Paediatrics/Late Effects, Peter MacCallum Cancer Centre

#### Mr David Willis,

Research Radiation Therapist, Peter MacCallum Cancer Centre

#### Dr Peter McDougall

Director, Division of Medicine, The Royal Children's Hospital

#### Dr Sharon De Graves

Nurse Program Manager, The Royal Children's Hospital

#### Associate Professor Nick Freezer

Medical Program Director, Women's and Children's Program, Monash Children's and Southern Health

#### Ms Kym Forrest

Operations Director and Director of Nursing, Southern Health

#### Dr Peter Downie

Director, Paediatric Oncology and Haematology Unit, Southern Health

#### Ms Jane Williamson

Program Manager, Paediatric Integrated Cancer Service

#### Mr Asanga Lokusooriya

Chair, CCC Parent Advisory Group

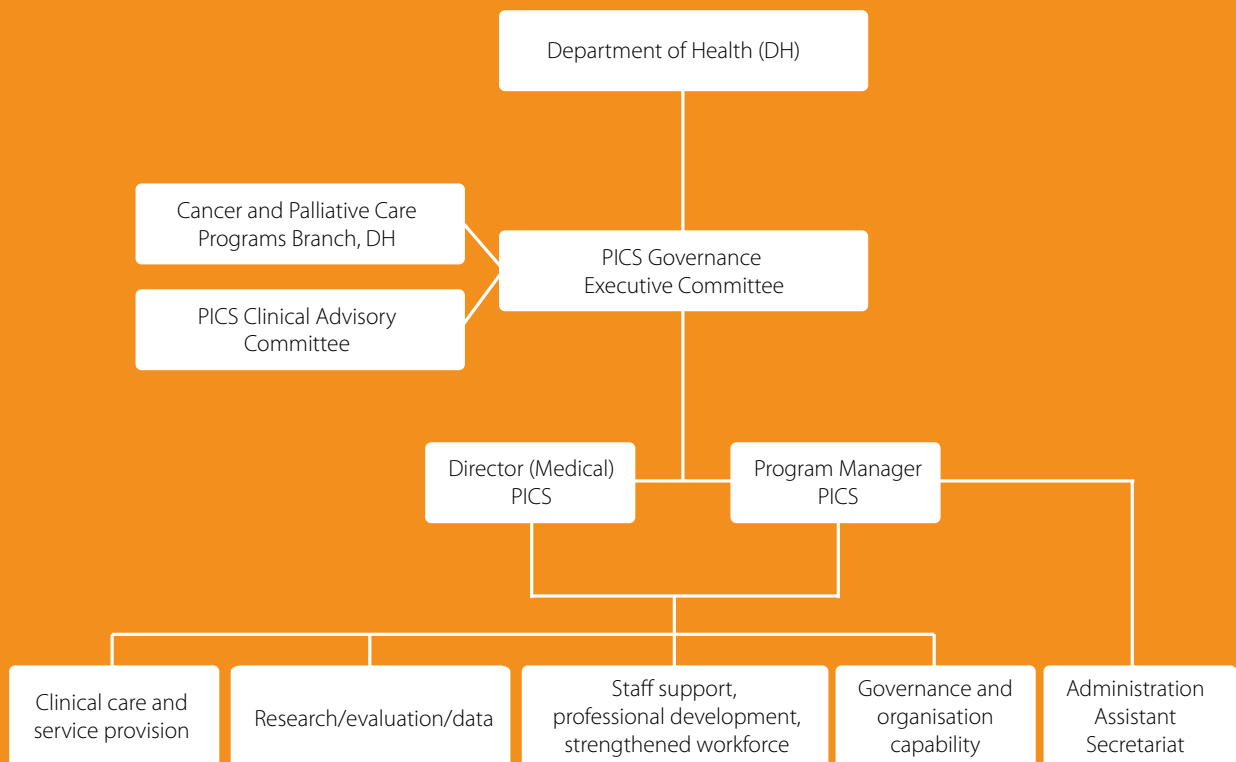
#### Regional Paediatrician

To be appointed.





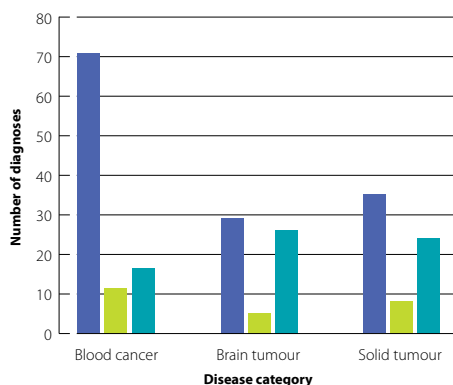
# PICS governance structure



# A profile of our patients: a regional focus

When the PICS was first established, a thorough audit was undertaken of the patient population accessing the services at the RCH Children's Cancer Centre and SH. Since then, the number of newly diagnosed children with malignancies has been rising in line with the population growth in children. In 2005, 159 children were diagnosed with cancer at RCH and SH, this number, in 2008–09 is estimated to be close to 180. The types of cancers being treated at the RCH and SH remains consistent with the data collected in the first year that PICS was operational (Figure 1).

**Figure 1: Profiles of newly diagnosed children by site and disease category in 2005**

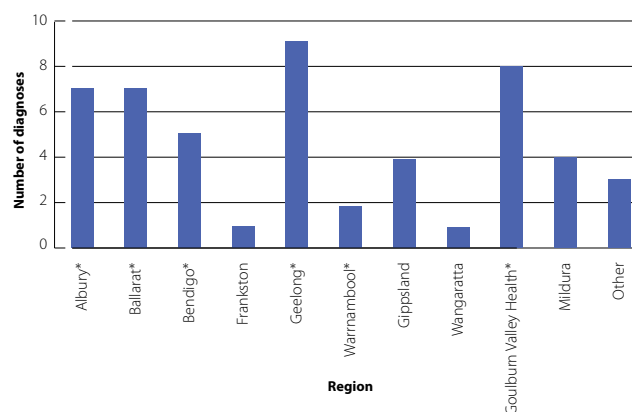


\* This data was initially provided as part of the PICS Psychosocial Services Review Project in early 2006. Updated data accessed from Peter Mac in June 2006 indicated a total of 71 children or adolescents were treated in 2005 for a total of 82 separate treatment courses.



A particular focus of PICS work in the 2008–09 year was the Regional Outreach and Shared Care Program (ROSCP). As part of this work, an audit was undertaken of new diagnoses by postcode and grouped by major regional centres. In the 2008 calendar year, there was 51 new diagnoses of childhood cancer from regional centres, (Figure 2). In addition, data compiled for the 2004–05 year demonstrated that approximately 22% of the CCC patients live more than 100km from the Melbourne CBD.

**Figure 2: Number of new regional paediatric oncology diagnoses at RCH in 2008**

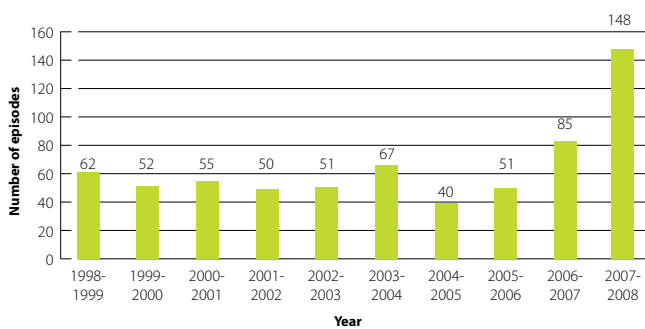


\* Indicates that the regional centre is a formal regional partner of the CCC. Note: Does not include patients from Tasmania or overseas



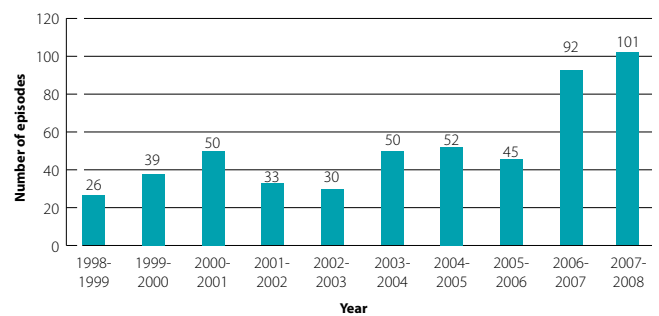
The ROSCP was piloted at Goulburn Valley Health (GVH) in Shepparton. Since the implementation of the ROSCP at this health service, paediatric oncology inpatient episodes of care have risen from 51 in 2005–06 to 148 in 2007–08 (Figure 3). Outpatient episodes of care have risen from 45 in 2005–06 to 101 in 2007–08 (Figure 4). The data provided by GVH illustrates the impact of shared care to a regional centre and indicates that the desired outcome of providing care closer to home has occurred.

**Figure 3: Paediatric oncology episodes of care (inpatient) – Goulburn Valley Health**



PICS will, as part of the Strategic Plan 2009–2012 commence a project to review the current methods of data capture across the PICS and will work with the health services to develop a strengthened and robust data management and collection system.

**Figure 4: Paediatric oncology episodes of care (outpatient) – Goulburn Valley Health**



\*Dedicated Paediatric Oncology Clinics did not commence until September 2006

The next eight pages will provide an overview of some of the PICS lead initiatives, projects or activities.

## Highlight: consumer participation

PICS acknowledges the valuable role that consumers play in supporting health policy development and service delivery and is committed to maintaining an organisational culture that values consumer participation. A PICS initiative in 2005 expanded the RCH Parent Advisory Group to include parents from MMC and Peter Mac and resulted in the new Children's Cancer Centre Parent Advisory Group (CCCPAG).

### The Children's Cancer Centre Parent Advisory Group

The CCCPAG are a group of parents who meet on a monthly basis with key staff from the PICS and the Children's Cancer Centres (CCC). Specifically the CCCPAG aims to:

- Respond to comments or suggestions from families of the CCC or other relevant bodies.
- Promote opportunities for partnership between families and hospital staff.
- Identify priorities for issues to be addressed by the PAG committee, according to the needs communicated by families and identify potential solutions to issues raised.
- Promote opportunities for all in the CCC community to participate in the ongoing development and improvement of clinical services.
- Actively seek input from particular groups, i.e. rural families, adolescents, culturally and linguistically diverse (CALD) families, community support organisations as appropriate.

Over the past 12 months the CCCPAG has engaged consumers and supported the CCC through hosting parent morning teas, ward 'meet and greet' sessions and attendance at functions and charity events associated with the CCC. In addition, the CCCPAG responded to a request by the Minister of Health, the Hon Daniel Andrews MP in July 2009 to participate in a small workshop to provide the Department with a consumer response on a range of issues.

### Consumer consultation

Over the past three years, PICS has been privileged to talk with over 75 parents and young adult survivors to gain their input into a range of PICS service improvement programs.

Our consumer and family input has helped to guide:

- A model to strengthen psychosocial care: a blueprint for the future.
- A Consumer Participation Model to ensure the best quality service for children and families.
- The Regional Outreach and Shared Care Program (ROSCP).
- The Long Term Follow-up Program (LTFP).
- The Peter MacCallum Cancer Centre review of paediatric services.
- A proposal for a best practice service model for bone marrow transplantation.

In 2006, the PICS undertook a project looking at how consumers can and should be included in our activities. The project resulted in the development of a consumer participation model, which helps to guide the involvement PICS has with consumers.



## PICS Children's Cancer Centres' consumer participation model

'Together we do better'

### Our consumers

- We use the term 'consumers' to describe the children and adolescents with cancer that we treat, their immediate and extended families and social networks.
- There are a range of other internal and external consumers of our services including philanthropic organisations, children's cancer community charities, regional providers, specialist providers such as Peter Mac and others. We will seek to engage effectively with these groups to benefit children and families.

The former group are the primary focus of this model.

### Values

Our approach to consumer participation is underpinned by the following values:

- We value the unique and common experiences of children/adolescents with cancer and their families and the expertise that comes from these experiences.
- We actively seek to draw upon consumer expertise for the provision of input into both individual care and broader service development in a variety of ways.
- We will listen to our consumers and work to build open dialogue within a culture of mutual respect and trust.

- We acknowledge that in the process of actively involving consumers we will face challenges and will not always be able to resolve differences. We will face these challenges openly and will acknowledge and respect ongoing differences.

### Policy

- The Children's Cancer Centre(s) is committed to providing high quality care for our diverse population of children and adolescents with cancer and their families.
- Our work recognises and aligns with the relevant whole-of-service approaches to consumer participation and actively supports the service-wide Consumer/Family Charter(s) of Rights and Responsibilities.
- Within a family-centred framework, we work in partnership with consumers in guiding and supporting the clinical and psychosocial care of each child and adolescent with cancer whom we treat and their families.
- We actively encourage and seek feedback from children/adolescents, their families and their communities to inform areas for improvement and to assist us in continual improvement of the services we provide.

- We incorporate active consumer involvement into our formal service planning and decision making processes.
- At a service development and planning level, we engage with consumers to develop family-centred policies and practices and to build effective and diverse mechanisms for consumer participation over time.
- We will train, support and develop the capacity of consumers to facilitate their active participation in a range of activities designed to inform service improvement and planning.
- We will also train, support and develop the capacity of our staff to promote adherence to this policy and underpinning values and to work effectively with consumers to enhance service improvement and planning.
- We will ensure that we actively respond to consumer feedback and have consumer advisory mechanisms that are clearly linked with the decision-making processes within the Children's Cancer Centre(s) and within the wider health service.
- In all instances we will act responsively and in an accountable and transparent way.

## Consumer and carer communication

PICS is currently working with the CCCPAG to develop a consumer database. This database will house details of families and children (over the age of 14) who have requested to be included. This database will allow PICS to distribute relevant information and communication in a fast, direct and efficient manner to consumers and carers. In addition, consumers can select an option which will permit the CCC and PICS to request feedback or participation from time to time.

### The CCC newsletter

PICS produces a newsletter for patients and families at RCH, SH and Peter Mac. Following consumer input on the format, material and context of the newsletter, the newsletter was revamped in 2008. The Community Liaison Manager at the RCH Children's Cancer Centre manages the newsletter which is published quarterly.

### The patient satisfaction survey

PICS undertakes an annual patient satisfaction survey to review both in-patient and out-patient experiences at all three PICS sites. Key objectives of undertaking this satisfaction measure include:

- To determine the perceptions of children and their families as they progress through the care process.
- Determine the effectiveness of efforts to improve the perceptions of patients care and services.
- To identify and recognise performance excellence and opportunities for improvement.
- To identify issues for goal-setting and program planning and to compare from year to year improvements against key criteria for satisfaction.

# Highlight: Peter MacCallum Cancer Centre paediatric service review

Whilst the Peter Mac is predominately an adult-based service, it is the only provider of paediatric radiotherapy in Victoria, offering services to Victorian, interstate and international children and adolescents. Given the challenges of and commitment to the provision of safe, quality paediatric services within a largely adult-centred service model, the PICS commissioned an external review of the current paediatric service in August 2008.

The recently completed service review proposes a shared model of care where children and adolescents with cancer will have access to improved and strengthened high quality radiotherapy and associated services.

#### Key features of the service model include:

- Paediatric services will be acknowledged more formally as part of Peter Mac's core business.
- Development of a family-centred care model.
- Improved access to specialist and other services that minimises the burden to families as much as possible.
- An agreed clinical pathway between Peter Mac services and the CCCs (RCH, SH).
- An identified staff training and support program for safe paediatric care.

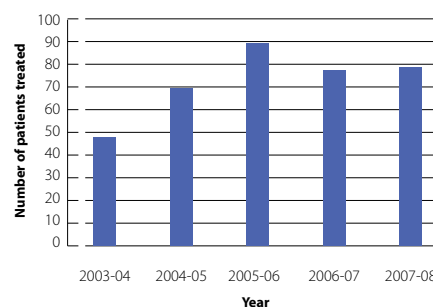
#### The service review recommendations include:

- Improving the provision of anaesthetic services.
- Strengthening the overall system including in-patient services.
- Strengthening service implementation and governance.

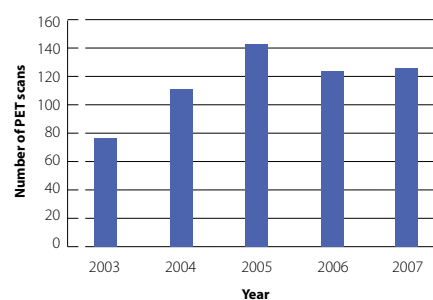
#### To date the following improvements have been implemented:

- Improved care coordination between the Children's Cancer Centres and Peter Mac.
- Improved resources for the provision of general anaesthetics to children, including better recovery processes and the availability of recovery nurses.
- Increased availability of paediatric qualified nurses where needed as well as increased nursing resources in the Paediatric Unit from 0.6 to 1.2 full time.
- The provision of basic paediatric life support training.
- The recruitment of a project officer to be employed in the last half of 2009 to coordinate the implementation of the review recommendations.

**Figure 5: The number of children/adolescents treated with radiotherapy at Peter Mac over five years**



**Figure 6: The number of PET scans provided for children aged 0-16 years 2003-07**





TRILOGY

NAME \_\_\_\_\_

**STICK**  
**WIT!**

HI THERE KIDS AND WELCOME  
TO THE THRILLING ADVENTURES OF...

**DR DAVE**  
AND HIS AMAZING  
RADIOTHERAPY MACHINE!

# Highlight: the Long Term Follow-up Program



On 17 December 2008, Victoria's Cancer Action Plan 2008–2011 was announced by the Premier, the Hon John Brumby MP and the Minister for Health, the Hon Daniel Andrews MP. As part of the plan, Long Term Follow-up (LTF) has been recognised as an area of high importance and PICS has been funded to develop a statewide program for survivors of childhood cancer.

The program will be accessible to all paediatric and young adult survivors of childhood cancer living in Victoria. It will provide each individual with a tailored approach to meet their ongoing needs, in the environment best suited to the level of care required and with an appropriate transition plan to adult-based community or hospital services.

#### Key features of the program include:

- An integrated clinic structure in the health care setting most appropriate to individual needs.
- Development of a hand held record that details the treatment received, subsequent events and a roadmap for future survivorship care.
- Access to resources including a comprehensive website, a companion edition to The Information Book and health-related literature.
- Information, resources and training programs for primary and community health care providers.
- Development of a database to collate data relating to the late effects of cancer treatment.
- A program to facilitate transition to adult community and hospital-based health care providers.



Left to right: Mr Craig Bennett, Chair PICS; Anne Kay, CCC Parent Advisory Group; Mr Tony Beddison AO, Chairman, The Royal Children's Hospital Board; the Hon Daniel Andrews MP, Minister for Health

The Long Term Follow-up Program was officially launched on 22 July 2009 at the RCH by the Minister for Health, the Hon Daniel Andrews MP. Sam McFarland and Jacqui Bell shared the day with the Minister.



Left to right: Jacqui Bell, the Hon Daniel Andrews MP and Sam McFarland

# Highlight: the PICS Nursing Children with Cancer Fellowship

In 2005, PICS identified the need to develop a comprehensive clinical and practical program for nurses working with children diagnosed with cancer. The PICS, together with the CCC Education Team at RCH developed the Nursing Children with Cancer (NCwC) Specialty Clinical Practice Program.

NCwC is a 12-week specialty clinical practice subject accredited with the University of Melbourne at a postgraduate level. Clinical practice is undertaken within the RCH Children's Cancer Centre and MMC and paediatric services at Peter Mac. The aim of the NCwC is to provide nurses with an opportunity to increase their understanding of the care of children with cancer and their family, thus contributing to enhanced practices for this patient population. PICS funds the salary of the nurses undertaking the course.

To date, 11 nurses have completed the Fellowship. Many of the participants have enhanced their paediatric oncology careers by continuing with further study or gaining more senior nursing positions.

**Participants have provided positive feedback with nurses indicating that this opportunity has assisted them:**

- To gain insight into the role of the multidisciplinary team.
- To enhance knowledge and learn new skills (i.e. bone marrow transplantation, radiotherapy, multidisciplinary care).
- To consolidate and expand on previous skills.



**Nurses who have completed the fellowship assisted their workplaces through:**

- The provision of education sessions run by graduates of the program.
- Clinical assistance for colleagues.
- The development of clinical practice guidelines and information booklets.
- Enhanced collaboration and communication between treatment teams.

*"The NCwC course gave me the opportunity to explore multidisciplinary teams and to understand treatment outside the RCH Children's Cancer Centre, as well as improving clinical practice and symptom management."*

– Mei Ling, nurse (pictured above)

*"The PICS NCwC Fellowship provided me with invaluable education and knowledge that I wouldn't have been able to access if it weren't for the course."*

– Shanelle, nurse (pictured left)

# Key areas: integrated cancer service work

Service delivery	Description and outcomes	DH priority area
<b>Quality</b>	<ul style="list-style-type: none"> <li>• PICS Quality Project Officer appointed September, 2008.</li> <li>• PICS involved with the CCC Quality Working Group.</li> <li>• Review of outcomes undertaken of the PICS Vision (2005–2008) completed.</li> <li>• Audits required by DH of new diagnosis/multidisciplinary meetings completed.</li> </ul>	Multidisciplinary care, care coordination, supportive care and reducing unwanted variation in practice
<b>Capacity Expansion</b>	<ul style="list-style-type: none"> <li>• New diagnoses managed at MMC increased from 10 in 2005 to 42 in 2008.</li> <li>• Medical examinations at MMC increased from 1,500 to 2,000 over the past three years.</li> <li>• Days of service increased from 3 days to 5 days.</li> </ul>	Care coordination
<b>Clinical guidelines</b>	All regional and MMC services have agreed to use RCH clinical guidelines.	Reducing unwanted variation in care
<b>Coordination of care</b>	<ul style="list-style-type: none"> <li>• Pathways and responsibility agreed for new diagnoses and referral to radiotherapy.</li> <li>• Pathways for emergency care documented for each regional site.</li> <li>• Regional clinics established at all shared care sites (annual, biannual or monthly depending on need).</li> <li>• LTF Neuro-oncology clinic strengthened and LTF clinics commenced at RCH, MMC and a pilot in regional centres.</li> </ul>	Multidisciplinary care, care coordination, supportive care and reducing unwanted variation in practice
<b>Multidisciplinary Care</b>	<ul style="list-style-type: none"> <li>• Multidisciplinary meeting template developed for reporting and documentation purposes.</li> <li>• Review of consent and documentation to commence July 2009.</li> </ul>	
<b>Peter MacCallum Cancer Centre Paediatric Service Review</b>	Review of paediatric services at Peter Mac completed in January 2009. The paediatric clinical nurse coordinator increased by 0.6 to 1.2 full time and a Project Officer to be recruited.	



Statewide programs	Description and outcomes	DH priority area
<b>Regional Outreach and Shared Care Program (ROSCP)</b>	The ROSCP now has formalised partnerships with six regional centres: <ul style="list-style-type: none"> <li>Goulburn Valley Health</li> <li>Albury Base Hospital</li> <li>Ballarat Health Services</li> <li>Barwon Health</li> <li>Bendigo Health Care Group</li> <li>South West Healthcare</li> </ul>	Multidisciplinary care, care coordination, supportive care and reducing unwanted variation in practice
<b>Paediatric Surgical Oncology Program (PSOP)</b>	DH funding was provided for an initial scoping exercise to better understand the issues and identify opportunities for improvement. Completed in December 2008, the report highlights a number of significant organisational and clinical opportunities to improve the quality and coordination of care.  Further funding has been allocated by DH to employ a Project Officer. The Project Officer will be responsible for coordinating the implementation of report recommendations.	
<b>Long Term Follow-up Program (LTFP)</b>	Funding secured to develop a statewide LTFP for survivors of childhood cancer. The program will be accessible to all paediatric and young adult survivors of childhood cancer living in Victoria. The LTFP commenced with first clinics held in August, 2009.	
<b>Palliative and Bereavement Care</b>	Development of a costing and approach proposal to undertake a model of care completed September, 2009.	
<b>Bone Marrow Transplant (BMT) Services</b>	A model of care for BMT service is due for completion in November 2009. The purpose of the review is to identify current and future service demand, review current service delivery, identify key elements of best practice, quantify the resources needed for information accreditation, literature and benchmarking review and involvement of consumers in the process of service review and model development.	
<b>Nutrition and Dietetics Model of Care</b>	Model of care for nutrition and dietetics completed. Two-year project funded by LARCH to test the model of care in the outpatient setting.	

Education, training and sharing of expertise	Description and outcomes	DH priority area
<b>Symposiums</b>	Palliative care one day symposium held at MMC, Barwon Health and Goulburn Valley Health, 2008.	Care coordination, reducing unwanted variation in practice
<b>Nursing Fellowship</b>	Four Fellows undertake the program each year.	Multidisciplinary care, care coordination, supportive care and reducing unwanted variation in practice
<b>Professional continuing education programs including regional centres</b>	<ul style="list-style-type: none"> <li>Introduction to paediatric oncology workshops held at RCH, SH and Warrnambool.</li> <li>Full day chemotherapy accreditation training held at RCH and SH.</li> <li>The Child with Cancer short course held at RCH three times in 2008–09.</li> <li>Paediatric Hematopoietic Stem Cell Transplantation short course held at RCH.</li> <li>Medical information evenings held annually at each ROSCP partner site.</li> </ul>	Care coordination, supportive care and reducing unwanted variation in practice

Consumer focus and engagement	Description and outcomes	DH priority area
<b>Access to consistent information</b>	<ul style="list-style-type: none"> <li>The Information Book (2nd edition) reviewed in 2009 with the inclusion of regional hospital information and standardised medication leaflets.</li> <li>Family education program and DVD for new families due for completion November 2009.</li> <li>Development of a companion edition to the Information Book and a suite of information and resources for survivors of childhood cancer.</li> </ul>	Care coordination, reducing unwanted variation in practice
<b>Patient Satisfaction Survey</b>	Statewide paediatric and oncology specific survey. Implemented across RCH, SH and Peter Mac annually, 2005–2008.	

# PICS awards, posters and presentations 2008–09

## WINNER

### Premier's Excellence Award for Improving Cancer Care in Victoria

#### **Regional Outreach and Shared Care Program**

The Regional Outreach and Shared Care Program (ROSCP) was awarded joint winner of the 2009 Premier's Excellence Award for Improving Cancer Care in Victoria at the 2009 Victorian Public Healthcare Awards. The Premier's Excellence Awards honour initiatives that are at the forefront of health improvement in the priority health areas identified by the Premier of Victoria: tackling chronic disease and improving public health and improving cancer care in Victoria.

The award was presented by the Premier, the Hon John Brumby MP on 10 September, 2009 and recognises the hard work and commitment of the PICS and all those involved in the ROSCP, in both the metropolitan and regional health services.



Left to right: Professor Christine Kilpatrick, Ms Jane Williamson, the Hon John Brumby MP, Ms Shanelle Scriven and Dr Peter Downie

## Posters

A Medical Mentoring Program for Regional Paediatricians Sharing the Care of Children and Adolescents with Cancer. ANZCHOG (June 2008, Adelaide)

Regional Outreach and Shared Care Program: Highlight of a Formal Regional Partner. ANZCHOG (June 2008, Adelaide)

Made to Measure – How a Patient Satisfaction Tool Can Help Drive Service Improvement. ANZCHOG (June 2008, Adelaide)

Implementation of a Professional Development Program for Nurses Caring for Children with Cancer in Victorian Regional Centres. ANZCHOG (June 2008, Adelaide)

Strengthening Services for Children with Cancer and their Families from Culturally and Linguistically Diverse Backgrounds. ANZCHOG (June 2008, Adelaide)

Mapping the Future – New Directions for a Statewide Long Term Follow-up Program. ANZCHOG (June 2008, Adelaide)

A – Z of Paediatric Oncology Nursing. ANZCHOG (June 2008, Adelaide)

Sharing Clinical Learning Experiences – A Nursing Fellowship. ANZCHOG (June 2008, Adelaide)

## Presentations

A Regional Outreach and Shared Care Program for Victoria (ROSCP) A PICS Partnership Initiative. Healthcare Innovation in Victoria Showcase Conference (April 2009, Melbourne)

Regional Outreach and Shared Care Program: Using Multimedia to Share the Care of Children across Victoria. Cancer Nurses Society of Australia, 12th Winter Congress (June 2009, Newcastle)

Regional Outreach and Shared Care Program: Establishing Regional Link Nurses to Share the Care of Children with Cancer. Cancer Nurses Society of Australia, 12th Winter Congress (June 2009, Newcastle)

Computerized image capture and moulding in the manufacture of a Radiation Therapy Stabilisation Device – a multidisciplinary and multi-site approach. Peter MacCallum Cancer Centre, PICS and The Royal Children's Hospital. Pediatric Radiation Oncology Society Congress (July 2009, Montreal)

# Financial summary 2008–09

## PICS allocation of funds

<b>REVENUE</b>	Other Revenue Total			\$235
	Grants - State			\$1,131,163
<b>Revenue Total</b>				<b>\$1,131,398</b>
<b>EXPENDITURE</b>	Salary and Wages	Clinical salaries including on costs	\$585,930	\$920,507
		Secretariat and administrative salaries including on costs	\$334,577	
	General Expenses	Telephone, video conferencing and pagers expenses	\$4,643	
		Computer software and maintenance	\$7,360	
		General medical and surgical supplies	\$560	
		General administration	\$29,275	
		Printing and stationary	\$1,019	
		Annual report	\$9,561	
		Food and meeting expenses	\$1,250	\$53,668
		Project Expenses/ Consultancy	Models of care and consultancy for Palliative Care, BMT, Peter Mac Service Review, Dietetics, Surgical Oncology, Social Work and CALD	\$145,038
	Annual Patient Satisfaction Survey		\$9,275	
	Regional Program		\$15,131	
	Neuropsychology, Trackwell Grant		\$43,568	\$213,012
	Staff Training and Development	Statewide Nursing Fellowship Program	\$35,448	
		Conferences, professional development	\$6,925	
		General travel expenses	\$284	\$42,657
<b>Expenditure Total</b>				<b>\$1,229,844</b>
<b>Surplus/(Deficit)</b>				<b>(\$98,446)</b>

## PICS Long Term Follow-up allocation of funds

<b>REVENUE</b>	Grants - State			\$561,000
	Grants - Paediatric Surgical Program			\$45,000
<b>Revenue Total</b>				<b>\$606,000</b>
<b>EXPENDITURE</b>	Salary and Wages	Clinical and administrative salaries including on costs	\$338,998	\$338,998
	General Expenses	Computer software and maintenance	\$12,765	
		General administration	\$7,003	
		Special functions	\$15,000	
		Rent/outgoings	\$31,080	
		Printing and stationery	\$3,953	
		Food and meeting expenses	\$44	\$69,845
		Staff Training and Development	Conferences	\$1,842
	Benchmarking, travel and international review		\$39,661	\$41,503
<b>Expenditure Total</b>				<b>\$450,346</b>
<b>Surplus/(Deficit)</b>				<b>\$155,654</b>
<b>Paediatric Surgical Program funding c/fwd to 2009/10 – PICS</b>				<b>\$45,000</b>
<b>Paediatric Integrated Cancer Service at 30 June 2009 Surplus/(Deficit)</b>				<b>\$12,208</b>



## Thank you

PICS would like to extend a special thank you to the families and staff who have allowed us to capture their experiences in this report.

It is with great appreciation that we thank the members of the PICS Coordinating Group (PICS-CG) for their effort in supporting the service since its establishment.

PICS would also like to thank The Royal Children's Hospital Educational Resource Centre for producing this annual report.

### PICS-CG 2005–09 members

#### The Royal Children's Hospital

David Ashley  
Jacqui Williams  
Peter McDougall

#### Southern Health Monash Medical Centre

Helen Gillies  
Nick Freezer  
Peter Downie

#### Peter MacCallum Cancer Centre

Greg Wheeler  
Julie Tate  
David Willis

#### Department of Human Services

Jackie Kearney  
Jane Miller  
Spiri Galetakis

#### PICS Program Manager

Jane Williamson

#### Host Agency (Finance)

Southern Health,  
Chris Lean, Noel Thane

[www.pics.org.au](http://www.pics.org.au)

