



Paediatric Integrated Cancer Service

A statewide cancer service for children

'Together we do it better'

Ensuring the best quality service for our children and families

Developing a consumer/carer participation model

Summary Report

Original report completed December 2006 by



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Executive summary

There is increasing recognition of the valuable role that consumers/carers play in supporting health policy development and service delivery. However achieving effective consumer/carer participation remains a challenge.

In 2004 the Royal Children's Hospital's (RCH) Children's Cancer Centre (CCC) established a Parents' Advisory Group (PAG) to support service development. More recently under the umbrella of the Paediatric Integrated Cancer Service (PICS), the PAG was extended to include parents from Southern Health's Children's Cancer Centre. Other opportunities for consumer/carer participation have included the development of a short-term consumer/carer reference group for the 2006 Psychosocial Service Project and a parents' satisfaction survey across all three PICS service sites.

While the Parents' Advisory Group has evolved over time and there have been significant achievements, a number of issues have been raised that need to be addressed. Of greatest prominence have been the need to develop a network of parents (and other consumers) from diverse backgrounds to participate in a range of activities and the need to address the organisational support and processes required to optimise effective consumer/carer participation.

In 2006, a Project was commissioned to address these and other issues and to develop a consumer/carer participation model for PICS and in particular a *'consumer/carer participation charter'*.

To achieve this, the Project team consulted with internal stakeholders involved in children's cancer care and with both the parent and service provider members of the Parents' Advisory Committee. The Project team also consulted with service providers and consumers involved in other consumer advisory mechanisms within the health sector and drew on the increasing evidence on effective consumer/carer participation.

The consultation findings reflected the evolution of the Children's Cancer Centre Parent Advisory Group (CCCPAG) with its achievements resulting from the commitment of both the parents and service provider members who have contributed over the past two years. Of importance has been:

- a shift in the organisational culture where there has been improved valuing of the contribution that consumers/carers can make to the service
- increasing clarity about the role of the CCCPAG as an internal advisory committee with the capacity to advocate within the system as well as provide a level of support for new families.

A number of issues were also identified including the need to:

- further strengthen the organisational culture to support and value consumer/carer participation
- develop a range of different approaches to gain diverse consumer/carer input from parents, young adult survivors and children as appropriate
- gain further clarity on the role and membership of the CCCPAG as it evolves

- facilitate a more strategic and pro-active role to meet future service needs
- clarify and strengthen decision-making and accountability mechanisms to optimise two-way communication
- address the burden on current CCCPAG members
- strengthen the organisational support for consumer/carer participation.

In looking to the future, a broader approach to consumer/carer participation is proposed in which a model with a number of coordinated mechanisms is developed to facilitate feedback and advice from consumers/carers in a variety of ways. A consumer/carer participation 'Charter' has been developed that identifies the values and key policy statements that will inform the proposed consumer/carer participation model.

The proposed model which addresses many of the issues identified in the consultation is ambitious and provides a vision for the future.

To implement the model in its entirety is a significant task and requires substantial resources which may not be forthcoming in the immediate future. However, with a staged approach, the model can be implemented as additional resources become available. Accessing these resources will be facilitated if the costs for supporting consumer/carer participation in new projects are integrated into funding proposals.

Of greatest priority in the short-term is the need to:

- Establish the network of consumers/carers (parents and young adults) who are interested in contributing to service development and quality improvement in a variety of ways.
- Strengthen organisational support for the current CCCPAG.
- Provide enhanced support and training for consumers/carers to take up their roles.
- Develop policies and processes to strengthen current and future consumer/carer participation activities.

Linking in with:

- the work of the Southern Metropolitan Integrated Cancer Service Consumer Participation Model
- consumer training being funded in 2007 through the Cancer and Palliative Care Unit (Department of Human Services) and
- the Cancer Council of Victoria's Cancer Connect Program

offers a number of opportunities to support this priority work.

Linking in with these priorities and opportunities, there is a need to develop some clear goals and milestones to ensure that progress is made in the short term to strengthen current systems and processes as well as progress towards implementing the proposed consumer/carer participation model over time.

In addition, ongoing strong organisational executive and clinical leadership and commitment is required to ensure that consumer/carer input is increasingly integrated into service development.

Finally as the benefit of consumer input continues to be demonstrated, its value will further emerge and be increasingly recognised. This in turn will stimulate increasing consumer/carer engagement and participation and will build stronger partnerships between service providers and consumers/carers to ensure the best quality service for children and families in the future.

1 Introduction

In 2006 the Paediatric Integrated Cancer Service (PICS)¹ commissioned a project to review and strengthen its approach to consumer participation within the two PICS Children's Cancer Centres (CCC) and its associated services within Peter MacCallum Cancer Centre.

This report firstly provides a brief background to the project, the approach and findings of a consultation with a range of relevant internal and external stakeholders. It then outlines the proposed consumer participation model including the proposed policy and principles, mechanisms to facilitate consumer/carer participation and the resources required to support the proposed model.

The consumer/carer participation model proposed in this report is an ambitious one and will take a significant level of initial investment to ensure that consumer/carer participation becomes an integral part of PICS core business and does not result in a tokenistic approach. This investment is challenging when there are competing service demands. However by keeping the vision in mind, small steps can be gradually made while opportunities for short-term funding to support the broader agenda are identified.

In addition, funding to support active consumer/carer participation must be integrated as a core component of a range of other projects and service improvements.

2 Background

There is increasing recognition of the valuable role that consumers/carers play in supporting health policy development and service delivery. Consumer/carer participation may come in many forms and includes a range of formal and informal mechanisms.

2.1 The CCC Parents' Advisory Group

In late 2004, the Royal Children's Hospital's Children's Cancer Centre established a Parent's Advisory Group (PAG) to support service developments. The development of the Parents' Advisory Group has been evolutionary and in its initial development drew on the advice of the RCH's Consumer Liaison Officer. The development of the RCH Parents' Advisory Group paralleled that of the development of the RCH Consumer Advisory Committee.

More recently under the PICS umbrella, this Parents' Advisory Group was extended to include parents from Southern Health's Children's Cancer Centre. Southern Health has a very strong commitment to consumer/carer participation with a range of well established consumer advisory mechanisms.

The CCC Parents' Advisory Group (CCCPAG) is made up of 10 consumers/carers and six staff members, four of whom have voting rights along with the parent members. The CCCPAG which meets monthly is chaired by a consumer/carer, with meeting coordination and some administrative support being facilitated by the RCH Community Liaison Manager.

¹ Paediatric Integrated Cancer Service was established in 2005 as a partnership between the Royal Children's Hospital, Southern Health (Monash Medical Centre) and Peter MacCallum Cancer Centre.

There are established Terms of Reference for the Parents' Advisory Group.

2.2 Other consumer/carer participation mechanisms

In addition to the Parents' Advisory Group, a parents' satisfaction survey was undertaken across all three PICS partner services in early 2006. A short-term consumer advisory committee made up of parents and young survivors was developed to support the recent PICS Psychosocial Service Project.

3 Project approach

The Project's purpose was to develop an agreed 'charter' or model of consumer/carer participation that articulates the way in which PICS recruits interested consumers (parents, young adult survivors and others) for a range of consultation processes, and values and supports consumer engagement, feedback and partnerships to enhance future service development.

3.1 Objectives

- To identify the key issues for consumers/carers and service providers in strengthening participation and partnerships
- To identify the different ways in which consumer/carer feedback and input can be effectively elicited and addressed.
- To identify a method of establishing a consumer/carer reference group database for CCCs
- To clarify the agreed roles of the Parents' (or consumer) Advisory Group
- To identify the training and support needs of consumers/carers and staff
- To clarify how the agreed consumer/carer advisory mechanisms link in with other consumer advisory mechanisms e.g. RCH consumer advisory committee
- To provide a charter or model for use by the CCCs which underpin ongoing project work and guide the work of the CCC in including and utilising consumer/carer resources.

3.2 Method

Consultation with key internal and external stakeholders was undertaken and included:

Internal consultation

- An initial meeting with the PICS Manager and the CCCPAG Chairperson
- Meeting with the Parents' Advisory Group – parents and service providers
- Interviews with service providers involved in the CCCPAG (n=6)
- Interview with staff involved in RCH Diabetes Services Support Group
- Interviews with an Executive staff member at RCH and Southern Health
- Consultation meeting with the CCCPAG parent members.

External consultation

- Interview with the staff member supporting BreastScreen Victoria's Consumer Advisory Committee
- Interview with the staff and consumer members of Southern Health's Breast Services Consumer Advisory Committee
- Discussions with key members of Cancer Voices, Breast Cancer Action Group and CanTeen
- Interview with a Health Issues Centre staff member involved in range of consumer participation projects including Southern Metropolitan Integrated Cancer Service and the DHS Cancer and Palliative Care Unit.

In addition to the consultation a range of policy documents and reports were reviewed, including documents supporting specific consumer participation committees.

The findings of the consultation and the draft principles and service model were discussed with a meeting of the CCCPAG parent members in early October and with the CCCPAG service provider members in early November.

4 Summary of key findings

There have been a number of major achievements in the current PICS consumer/carer participation approach and the establishment of the CCC Parents' Advisory Group. These are summarized in Box 1.

Box 1: Key achievements in PICS/CCC consumer/carer participation

- Establishment and extension of the Parents' Advisory Committee
- Improving processes and gaining role clarity and skills
- Input into a range of specific projects including the Parents Information Resource, the psychosocial services project, patient/ parent education, procedural pain and arts projects
- Increasing the profile of Parents' Advisory Committee through communication with the RCH Board, establishment of the Ward morning teas and conference presentations
- Successful advocacy for the RCH hospital redevelopment
- Feedback to staff has resulted in improvements in services and communication processes
- Service providers are more actively seeking consumer/carer input into a number of resources/programs
- Implementation of the Parents' Satisfaction Survey across PICS partners.

Box 2 lists some critical success factors identified by external providers involved in the development of effective consumer/carer participation and advisory mechanisms.

Box 2: Critical success factors for effective consumer/carer participation

- A clear and agreed purpose
- Organizational and clinical leadership
- A culture that values active consumer/carer participation
- Links with active decision-making processes
- Development of a range of mechanisms to gain feedback and advice from diverse consumer/carer voices
- Good organizational support
- Orientation and ongoing training and support for consumers/carers and staff
- Recognition that it is an evolving process and everyone is learning
- Establish a regular review process
- Have fun!

The following discussion highlights some of the key challenges in consumer/carer participation that were identified from the data gathered. These challenges inform the broader aspects of consumer participation as well as the specific role and work of the CCCPAG which presently is the primary, regular mechanism of PICS/CCC consumer/carer feedback and advice.

4.1 Creating a culture for consumer/carer participation

As indicated there is an increasing emphasis from the Department of Human Services (DHS) on active consumer/carer participation to ensure services are of high quality and are accessible and relevant to the community. However, this focus can be challenging for service providers.

Where active and successful consumer/carer participation in other services has evolved, there has been strong endorsement by clinical and executive leaders and valuing of the contribution that consumers make to the service. Over time as achievements come to fruition, the important role of feedback and advisory committees are increasingly valued by staff members.

From the internal service providers interviewed there were a range of views and a lack of clarity on how the CCCPAG evolved.

Service providers were clear about the value of consumer/carer participation:

'We tell the children/families what they need, we need to ask them what they need and what they would like'.

While the service provider interviewees saw the CCCPAG as being of '*great value*', some reported lack of knowledge, concerns or ambivalence in other service providers, suggesting consumer/carer participation was not on the '*radar screen*' of some service providers

Where the value of consumer participation was recognised, sometimes there was inadequate time or preparation put into seeking CCCPAG input into new initiatives. This led to a level of frustration by the CCCPAG members and by service providers wanting a quick response.

The importance of valuing consumer/carer input was clearly articulated by one service provider:

'We need to involve consumers in diverse ways – we need to be aware of professionals' behaviours – we have got to behave better with consumers – they have important things for us to hear and we need to include them not just when we like.....'

The CCCPAG parent members highly valued the participation of the service providers within the CCCPAG structure and wanted to ensure that they were seen by service providers:

'not as a band of rabble rousers but as singing off the same hymn sheet as them.'

Finally, the value of consumer/carer participation in other services was also demonstrated in the resources and support allocated to their consumer/carer strategies (see 4.5.1).

Recommendation for strengthening the organizational culture

- The creation of an organizational culture that values consumer/carer participation needs to be further endorsed and strengthened through executive and clinical leadership and continuing staff training and education.

4.2 Who are our consumers? Issues of representation

The issue of representation is a challenge for all participation approaches and one that the CCCPAG parents and service providers had shared concerns. Internal service providers saw consumers as:

- Children and adolescents with cancer
- Parents and siblings
- Wider family and the family's community.

Service providers and the parents identified that strengthening the connections between the CCCPAG and stakeholder groups such as Koala and the Children's Cancer Centre Foundation are important strategies.

Experience from other consumer advisory stakeholders also reflected the challenges of gaining diverse views within a small committee. Inviting a member from a 'minority group' was not always appropriate and if that representation is tokenistic, it can be counterproductive and disempowering.

Key tips to strengthen representation and diversity of views included:

- Linking in with community based organisations that serve different groups (e.g. ethno-specific community services)
- Using different approaches to consumer/carer participation
- Where possible, having consumer/carer members that are members of other related communities/groups
- Developing a mind-set that thinks about how a 'minority' group may respond
- Increasing the number of members on advisory groups to facilitate the diversity of views
- Developing strategies to ensure that quiet members within a group have a voice.

4.2.1 Involving children, adolescents and young adults

Within children's cancer services, there was recognition that creative ways were needed to ensure that the voice of children and adolescents with cancer and young adult survivors were heard. Their perspectives may be similar and different to those of their families.

There was a perception that those service providers who were '*cynical*' about the CCCPAG with its parent focus, may be more responsive to feedback from children and adolescents.

- Recent experiences perhaps demonstrate the value of developing opportunities to hear the 'child/adolescent cancer patient' perspective.

A preliminary discussion with CanTeen indicated their interest in facilitating feedback from adolescents with cancer. This is perhaps in line with CanTeen's current strategic directions in advocating for improved services for adolescents and young adults with cancer. In NSW, CanTeen have recently implemented an advocacy training program '*Rocking the Boat*' for young people with cancer to support these directions.

4.2.2 Developing a consumer/carer network

The notion of developing a 'database' of consumers has been on the RCH/CCCPAG agenda for some time and its lack of progress has resulted in some sense of frustration. It is clear that the focus should be on gradually developing the network with a database or spreadsheet being the tool to facilitate future contact with interested consumers/carers for the purposes of participation. A simple spreadsheet is all that is needed in the first instance.

A number of sources of potential consumers/carers were identified to start the network establishment (see 8.1).

Recommendations to strengthen access to the breadth of consumer/carer voices

- Develop and implement a range of different approaches to gain consumer input
- Explore opportunities to integrate young adult survivors into consumer advisory mechanisms
- Approach CanTeen to explore opportunities of working in partnership to gain input from adolescents with cancer
- Develop a consumer/carer network that over time will draw in parents and other consumers/carers with diverse views to participate in a variety of flexible ways
- Ensure that feedback from children and adolescents is integrated into overall decision-making processes of the CCCPAG and other decision-making processes.

4.3 Purpose and role of the Parents' Advisory Group

External service providers clearly indicated that the success of any consumer/carer participation model was in part dependent on the articulation of a clear and agreed purpose. The purpose and the role of a consumer/carer advisory mechanism may change over time and requires ongoing review and negotiation.

In the establishment of the CCC Parents' Advisory Group, there appeared to be a lack of clarity about its purpose by both the parents and the service provider members. Given the evolutionary nature of consumer participation, this is perhaps not unexpected. Significant progress has been and continues to be made in clarifying its purpose and role.

'We need to know what we want to be and how do we do it? How do we meet and how do we do our business'.

4.3.1 An advocacy, advisory or support role?

The lack of clarity in the CCCPAG's role resulted in significant discussion about whether the Group's purpose was as an advocacy group, an advisory group or as a support group for parents and families. Interestingly another consumer group within RCH facing the same issue has evolved into a support group with more limited advocacy or advisory roles.

There was an agreed view that the primary purpose of the PICS/CCC Parents' Advisory Group is to provide advice and support to the PICS/Children's Cancer Centres to *'ensure the best quality service for children and families'*. The parents clearly saw their role working with service providers to advocate on behalf of families to enhance the service system.

There are however some grey areas between advocacy and advisory roles which are common to a range of consumer/carer participation models. The CCCPAG has been established by the Children's Cancer Centre and as such is seen as an internal CCC committee rather than an independent external consumer/carer advocacy group. In this context, when potential conflicts arise, there needs to be clear communication between service providers and CCCPAG parent members (see Section 4.3.4).

While providing support for families was not seen as its primary purpose, the CCCPAG parent members have recently clearly identified the relationship between 'support' and gaining feedback and advice from other families. By engaging with new /inpatient families and offering 'a level of support' through the CCCPAG Morning Tea program, CCCPAG members were able to interact with parents and families and provide encouragement, gain their feedback on a new resource and through this, increase the profile and understanding of the role of the Parents' Advisory Group.

This type of activity is likely to encourage increased consumer/carer participation in service improvement in the future. However both parents and service providers agreed that some support needs to be routinely offered to CCCPAG members to facilitate their role in this area.

4.3.2 A strategic or operational role?

Both service providers and parents agreed that the role of the Parents' Advisory Group (or a broader consumer/carer reference group) should increasingly take a strategic rather than an operational role. Some of the challenges to achieving this include:

- The lack of other consumer/carer involvement to provide a range of input
- The service providers' ongoing demands on the CCCPAG to gain feedback into specific issues, often not in a timely manner, results in a more reactive approach. The parent members were clear that they wanted to be able to take a more proactive rather than reactive role.
- The lack of clearly defined mechanisms to deal efficiently with more operational issues
- The consumer/carer perspective does come from 'concrete experiences' and there is a role for the staffing support to help translate 'operational issues' into a 'strategic' agenda
- The limited time for the Parent members to identify their strategic priorities for the future.

Recommendations for strengthening the role of CCCPAG

- As an evolving mechanism, the role of consumer/carer participation and the CCCPAG requires regular review.
- A regular strategic planning process be implemented that will facilitate the uptake of a more proactive rather than reactive or operational role
- That priority initiatives/services are identified that require CCCPAG input and that processes are put in place to ensure that the CCCPAG are adequately prepared to provide input in a timely manner
- That mechanisms are developed to ensure that agreed strategic directions are operationalised with ongoing input from the CCCPAG members or other consumers/carers.

4.3.3 The role of the service providers

The CCCPAG is made up of both consumers (i.e. parents) and service providers. A total of six service providers are members of the CCCPAG. However there was a lack of clarity by the CCCPAG service providers about their own and others' roles within the CCCPAG.

The service providers interviewed had different views on how and who should be providing the coordinating and administrative support for the CCCPAG. Some service providers saw that they or others played a role in facilitating discussion or providing 'emotional support' to parent members if needed. Others saw their role more in terms of representing the hospital or their discipline. In subtle ways, there was a sense that some part of the service provider role was to keep a level of control around the process.

From the consultants' perspectives for this Project, the CCCPAG with its significant number of service provider members is an unusual model for a consumer/carer advisory group. Other participation models have one staff member who has the clear responsibility to support the consumer advisory group, coordinate orientation and ongoing support of members and act as a conduit between other service providers and the advisory group. While an Executive member may attend all or some of the meeting, other staff members only attend meetings to present particular issues. One service also facilitates time for the consumers/carers to meet alone prior to the formal meeting; this enables some networking and free discussion of issues to be addressed within the meeting and the development of their agreed position.

While the CCCPAG parent members strongly appreciate and value the participation of the service providers in the meetings, there are some perceived downsides. The presence of the service providers at some level negates the need for formalised communication and decision-making process within the PICS/Children's Cancer Centre(s) structures. As a result, there is an assumption that the service providers have 'heard the issues' and taken them away for action. However from the parents' perspectives, there was not always good feedback on how an issue had been progressed (see Section 4.4 as well).

In addition, there was a perception that the presence of the service providers may impact on the consumer/carer discussion. Interestingly, at least one parent member reflected on the quality of the discussion that evolved during the 'parents only' meeting held as part of this current project. Issues were debated at length in a constructive and productive manner.

While they identified these issues themselves, the parent members were reluctant to change the current service provider involvement.

Some options for creating a space for the parents to discuss issues on their own include:

- Service providers only attending alternate meetings
- Service providers only attending the first hour of the meeting
- Parents going out for dinner after the meeting
- Parents meeting for an hour before the service providers attend (this may be difficult because of the time of the meeting).

In addition, feedback from the parent members both at the initial consultation and to the draft report reflected their diversity of view in this area. Continuing discussion may be needed about the role of the service providers as the CCCPAG and the future consumer/carer participation model evolves.

Recommendations for the role of service providers

- That the role of service providers involved in the current Parents' Advisory Group be reviewed with the evolution of the Group.
- Ways that parent members can be given opportunities to have some free discussion time on their own be considered.

4.3.4 Creating effective dialogue

'Diamonds are produced under great heat'

Service providers and consumers/carers bring different perspectives to the table and at times, differences in opinions will occur which are challenging to both groups. Such differences should be seen as healthy. If differences do not occur, it may be that the consumer/carer participation model is tokenistic and ineffective.

Experience from other consumer advisory mechanisms indicated that the effective resolution of these differences sometimes required a significant investment in both time and processes. The resolution often resulted in improved outcomes for those consumers who were to be affected by the controversial issue.

Working through the differences over time to gain better understanding of each others' perspective and wherever possible reach agreement by consensus, should also facilitate and strengthen mutual trust and respect between consumers and service providers.

The development of time and space in which the consumers (and service providers) can discuss issues in private, before meeting together may also facilitate a more considered and less reactive approach. However it may still require some considerable negotiation.

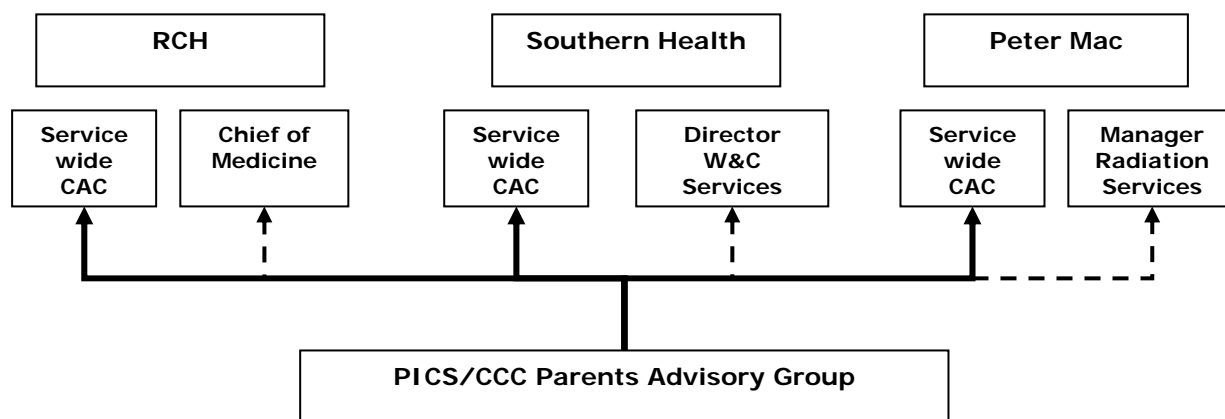
'We need to include them [consumers] not just when we likewe need to get down together with them and get dirty with them and be part of the group.....'

4.4 Structure, processes and decision-making

Learnings from other consumer/carer advisory mechanisms indicate the need to have strong links with the service's decision-making processes. Often this is achieved by having representatives from a broader consumer/carer reference group on Executive Boards or on service or project steering committees. In the absence of these links, a consumer/carer participation model may become less effective.

In spite of the service provider representation at the CCCPAG, parent members indicated that they were not always clear of how some issues or actions were taken forward within PICS or the individual service partners.

In the development of the CCCPAG, the following reporting structures were developed.



Key
 —▶ Six monthly reports
 - - ▶ Twelve monthly reports
 CAC Consumer Advisory Committee
 W&C Women's and Children's Services

In addition to the formal reporting mechanisms, the minutes of the CCCPAG meetings are sent to the three Executive members identified as well as to a range of other service providers. Given the relative newness of this structure it is not clear whether the first six monthly reports have been sent to the relevant Consumer Advisory Committees.

While this structure reflects a reporting mechanism, it appears to be a one way process.

The structure does not appear to reflect adequate formal linkages with established decision-making processes or service-wide consumer advisory mechanisms. The Parents' Advisory Committee does not have representation on or direct links with any such decision-making processes within PICS or within each service. Parents reported more limited follow-up feedback to the CCCPAG following specific discussions or when advice has been provided.

However informally links do exist; for example, the CCCPAG has made successful representation to the RCH Board about the new hospital redevelopment.

Finally, given its initial development, the larger number of children treated at RCH and the fact that all meetings are currently held at RCH, the CCCPAG is very 'RCH-centric'. Opportunities to ensure that the CCCPAG addresses issues within or across all three service sites are critical.

Recommendation for strengthening decision-making links

- The formal links between the CCCPAG and decision-making processes within PICS and CCCs need to be clearly articulated and consumer/carer representation in these processes encouraged.
- That good feedback and accountability mechanisms are clearly established as an integral component of a consumer/carer participation model.

4.5 Support and training

Consumer/carer participation can be challenging for both consumers and service providers. The most successful consumer participation models appear to be those in

which services make significant investment in resources to support the process from both a consumer/carer and service provider perspective.

4.5.1 Supporting consumer/carer advisory groups

The amount of support required for a service-initiated consumer/carer participation model differs from a support group model which encourages self-sufficiency by consumers or an independent advocacy group, initiated and coordinated by consumers/carers.

The initial development of the Southern Health Breast Services Consumer Advisory Group facilitated:

- the development of the essential policies and procedures
- recruitment of consumers
- development of formal orientation programs for consumer representatives
- initial coordinating support for the Advisory Committee
- promotion of the Consumer Advisory Group to service providers.

In addition to internal orientation and training support, some services provide support for consumers/carers to attend conferences and to participate in formal '*consumer science and advocacy training programs*'. Such programs have been run through breast cancer and other cancer organisations as well as generalist consumer/carer advocacy organizations such as the Health Issues Centre. It is understood that in 2007 the DHS Cancer and Palliative Care Unit are supporting the implementation of Consumer Science and Advocacy Training for consumers/carers involved in the Victorian Integrated Cancer Services.

The Health Issues Centre can also tailor programs to meet the specific needs of an organization and can provide training for both consumers/carers and service providers.

4.5.2 Supporting the Parents' Advisory Group and other consumer/carer participation models

A number of key issues were identified with the coordination and support of the CCC Parents' Advisory Group. They include:

- Limited administrative and coordinating support for the CCCPAG
- A difference between service providers' and consumer/carers' expectations about the role of the parent members. Service providers had a stronger expectation that the parents '*would do the work with limited additional support from staff*'. Parents expected greater work to be undertaken by staff.
- While service providers recognised that some support was needed, there was not an agreement on whose role it was to provide that support
- The need for greater clarity in documenting agreed actions, responsibilities and timeframe for actions
- The need to enhance and clarify recruitment processes for new consumer/carer members
- Lack of formal orientation and training for new consumer/carer members
- Limited access to ongoing training and support for consumers/representatives
- Costs mean that parent members are unable to participate in major fundraising activities where there is an opportunity to increase their profile with the wider children's cancer community
- Lack of training for staff in working with consumers/carers.

Recommendations to strengthen support for the Parents' Advisory Committee

- That the staff support roles are clearly articulated and supported
- That further strengthening of documentation is required to clearly identify issues, agreed actions and responsibilities and a timeline to facilitate communication and feedback
- That a specific orientation and training program be developed and implemented to support new and ongoing consumer/carer participation.
- That a small fund be established to support the consumer members to participate in activities that will increase their profile within the community
- Develop and implement a communication/training strategy for staff to promote the value of consumer/carer participation as an important strategy for service improvement.

See 8.5 for opportunities that may facilitate the development of policies and procedures and access to training to support the current Parents' Advisory Committee.

The findings from the consultation process and review of the key policy documents and associated literature have informed the development of the proposed consumer/carer participation policy and model.

5 Consumer/carer participation policy

The key elements of the consumer/carer participation policy include:

- Identification of the consumers/carers of children's cancer services
- The values underpinning the policy
- Key policy statements.

The following box details the PICS/CCC consumer/carer participation policy.

Paediatric Integrated Cancer Service - Children's Cancer Centres

Consumer/carer participation model

'Together we do better'

Our consumers/carers

- 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 carers 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 policy.

Values

Our approach to consumer/carer 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 and carers 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 and carers 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 and carers to develop family-centred policies and practices and to build effective and diverse mechanisms for 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/carers to enhance service improvement and planning.
- We will ensure that we actively respond to consumer feedback and have 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.

6 Consumer/carer participation model

A model of consumer/carer participation has been developed as a vehicle for bringing the above values and policy statements to life. The model comprises a series of flexible mechanisms for:

- representation
- feedback
- support
- information provision

The model is designed to:

- provide a range of mechanisms for consumer/carer involvement,
- ensure broad representation of those who are actively engaged in formal consumer/carer representative roles,
- be flexible in providing a range of opportunities to meet the diverse needs and preferences of consumers with respect to participation
- promote the sharing of roles and responsibilities thus minimising the potential burden of participation
- promote accessibility to a broad base of interested and active consumers/carers over time
- embed consumer/carer participation as part of core business for the CCCs in Victoria

The model includes a series of mechanisms that are undertaken routinely or on an ad hoc or periodic basis (See Figure 1).

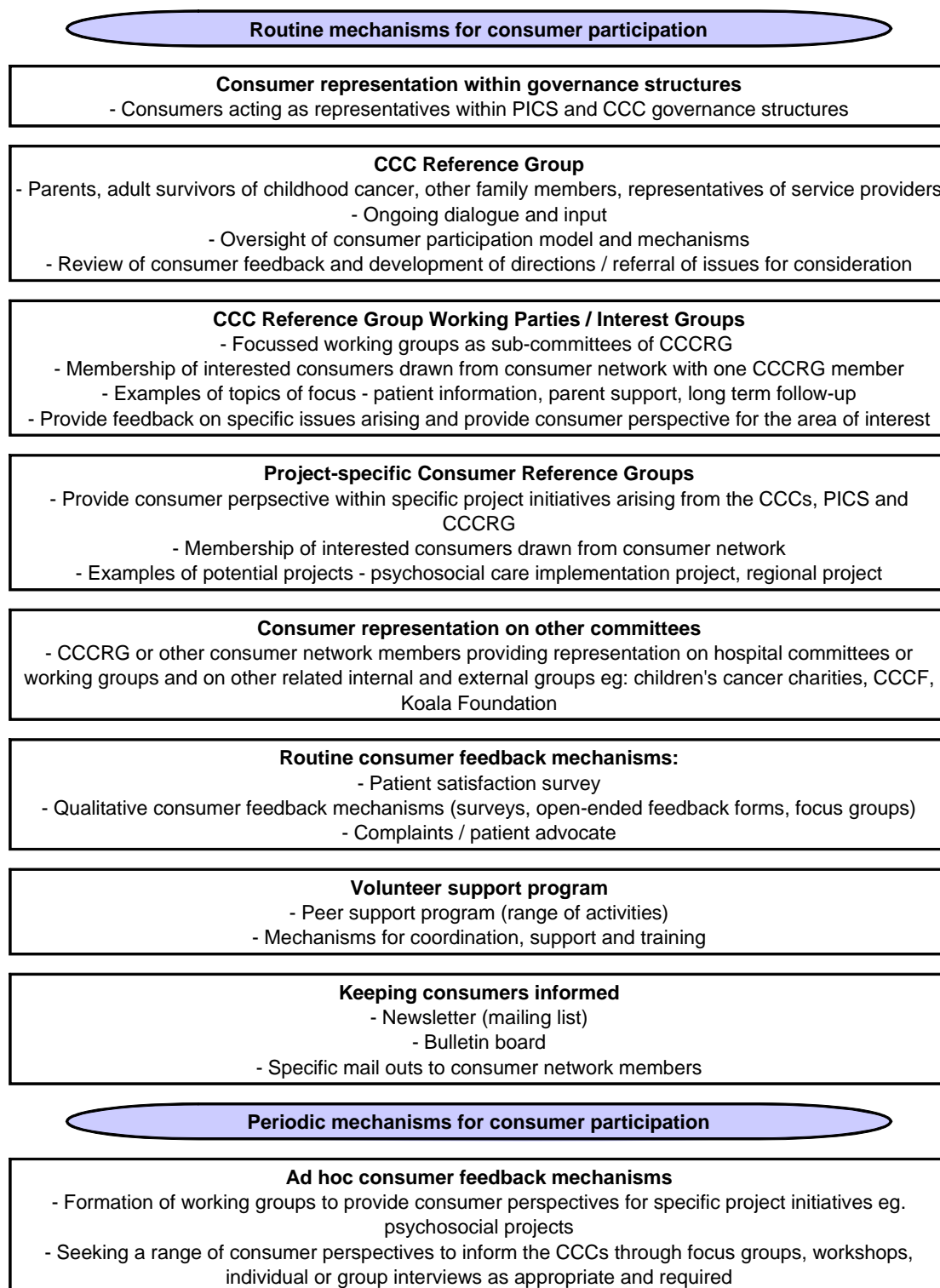
The model also sits within the broader structure and decision-making processes of the PICS service partners (see 7).

Special note:

It is considered that progress towards full implementation of this model will take some time. The systems and structures which support this will also evolve over time.

A staged approach can be taken that aligns with the resources available. In line with this key milestones need to be developed to gradually progress the uptake (and its evolution) of this consumer/carer participation model.

Figure 1. Consumer/carer participation mechanisms



Each consumer/carer participation mechanism is further described below:

6.1 Consumer/carer representation within governance structures

Two members of the CCC Reference Group (chair and one other) will represent consumers/carers within key PICS/CCC governance structures.

The role of the consumer representatives will be to contribute a consumer/carer perspective to governance issues and to further facilitate communication between service providers, the CCCRG and broader network of consumers. The flow of information would be two way.

6.2 CCC Reference Group

The Children's Cancer Centre Reference Group is the principal consumer/carer advisory mechanism for the CCCs and PICS. The Reference Group comprises parents, adult survivors of childhood cancer² and other family members and will evolve out of the current Parents' Advisory Group. The consumer/carer members of the group meet on a monthly basis to discuss key areas of interest and to forward their agenda. This also allows the group to be responsive to service providers seeking their input on key areas of work. On a quarterly basis, clinical representatives from CCCs will participate in a joint meeting with the CCC Reference Group as a direct mechanism for open dialogue and decision making. This group will be supported by the Consumer Participation Project Officer.

Key elements of the work of the CCC Reference Group include oversight of the implementation of the consumer/carer participation model and mechanisms as they are developed and an ongoing role in the review of consumer feedback and the identification of areas for possible service improvement.

The members of the CCC Reference Group will develop portfolios of work which over time will be undertaken with these members leading specific working parties/interest groups.

6.3 CCC Reference Group Working Parties/Interest Groups

A series of standing Interest Groups and project-specific working parties provide a mechanism for focused work in a particular area of need. An example of a permanent Special Interest Group might be a group that focuses on information provision/communication with children and their families or consumer feedback. An example of a Project-Specific Working Party is the consumer Reference Group formed for the PICS Psychosocial Services Project. These groups would each comprise one or more representatives from the CCC Reference Group and other interested parties drawn from a broader pool of consumers/carers with an interest in participation. The groups would provide a brief report of their progress on a routine basis to the CCC Reference Group.

The CCC Reference Group Working Parties would be supported by a staff member, either the Consumer Participation Project Officer and/or another member of the staff team with relevant or expertise in the area of interest.

6.4 Consumer/carer representation on other committees

Other committees within RCH and MMC or with key internal stakeholder groups such as the CCCF and the Koala Foundation may request consumer representation on their committees or working parties over time. This will be proactively encouraged by the CCC Reference Group in their interactions with these groups on an ongoing basis. Mechanisms for information flow and the sharing of experiences and issues across the various consumer mechanisms will be encouraged.

² Aged 18 years or older who have completed active treatment for greater than five years

6.5 Consumer/carer feedback mechanisms

A series of mechanisms for gauging feedback from diverse groups of consumers/carers will be developed and implemented over time. This includes routine processes such as the receipt of complaints, contact made with a hospital's patient advocate or ad hoc feedback provided to members of the clinical team or CCC Reference Group members. Other mechanisms such as the use of feedback forms, suggestions boxes, individual interviews, surveys or focus group activities may also be used periodically to gauge additional or more in depth feedback.

Information generated through consumer/carer feedback activities will be channelled into the CCC for consideration and to promote the identification of specific incidents requiring follow-up or general areas for improvement.

6.6 Volunteer support program

A peer support program is proposed that would comprise mechanisms for broader dialogue with families who are undergoing active treatment e.g. morning teas with an emphasis on areas of specific focus that might be played out by the provision of information or the seeking of information on a particular topic of interest to the CCC Reference Group at the time. In the first instance, these opportunities for contact and connection with other families would be undertaken by CCC Reference Group members. Over time, it is anticipated that this would shift to other parents or survivors of childhood cancer who may volunteer their time for the provision of support in this way.

6.7 Keeping consumers/carers informed

A newsletter (modified version of the existing newsletter) would be developed as a vehicle for broad communication with the consumers of the CCCs. The newsletter would include information about consumer activities and ways that consumers/carers may become involved. This would be a key component of building a consumer/carer network (see section: Bringing it all to life).

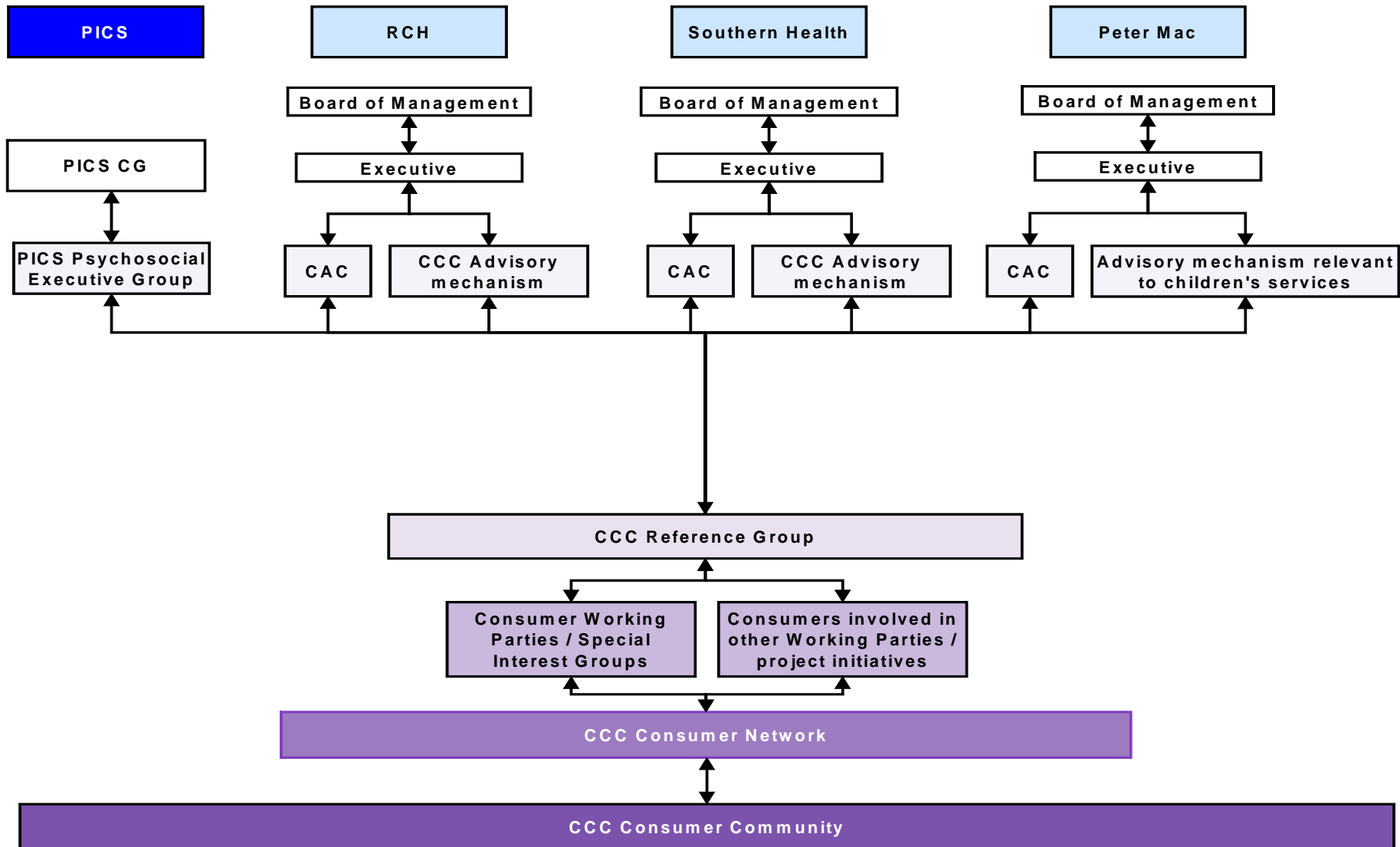
7 Consumer/carer participation model - structures and decision-making processes

These consumer/carer participation activities need to sit within a broader framework or structure that guides information flow, decision making and linkages between consumer/carer participation mechanisms, health services and PICS. A structure is proposed in Figure 2.

Within this structure, consumers are represented in a range of committees and working parties. Starting from the entire consumer/carer population, mechanisms for representation and capturing feedback from consumers feed into each level of involvement so that the consumers who are actively involved have as their basis, the voices of all consumers/carers. The flow of information throughout this structure is two way. Consumer feedback would be channelled through both consumer/carer advisory and service advisory mechanisms. Lines of reporting are established between the various committees and stakeholders at each participating hospital and with the PICS governance structures overall. This may be through the provision of reports or referral of issues or via the representation of consumers/carers on these committees. (It is important that any reporting is meaningful and low burden so as to not negate the value of the open communication that may result.)

This structure represents an ideal process to facilitate the flow of dialogue and information. Its achievement also represents a significant task that will evolve over time as the value of consumer/carer involvement becomes further embedded into health services in general and PICS /CCC more specifically

Figure 2. Consumer/carer participation structure



8 Consumer/carer participation model - bringing it all to life

In order to bring this policy and model to life, a phased process is proposed whereby a plan for gradual implementation of change and growth in consumer/carer participation activities is developed.

A series of foundations need to be laid to enable this growth to occur effectively. These include:

- Developing a consumer/carer participation network
- Support and training for consumer participation
- Establishing and implementing consumer/carer feedback mechanisms
- Staffing support for the development, implementation and maintenance of consumer participation activities

Each of these areas is described further below.

8.1 Developing a consumer/carer participation network

To strengthen PICS /CCC consumer/carer participation model, a CCC Consumer/Carer Network of interested consumers (parents, young adult survivors and others) will be developed. This work is **critical in the short-term** and significant investment (mostly in terms of some time, energy and a team effort) is needed to achieve the initial development of this network, and then its ongoing maintenance.

Based on interest this network of consumers can then be drawn on to contribute to a variety of activities in the way that matches service needs and consumer/carer interest.

The **purpose** of the network will be to:

- Establish a broad group of consumers/carers who wish to be kept informed of CCC activities and mechanisms for consumer/carer participation
- Identify those with an interest in specific consumer participation activities including:
 - Routine mechanisms such as the CCC Reference Group or working party membership
 - Peer support volunteering
 - Ad hoc feedback or participation in focus groups, short term working parties or other activities.

To **support** the network a range of strategies may be undertaken:

- The development/revision of any current newsletters may provide consumers/carers with an update on a range of services and activities within the Children's Cancer Centres. It could include patient stories, useful tips for children and families, information about forthcoming events as well as promotion of fund-raising events
- A simple database needs to be developed to support the network communication and maintenance of contacts and other details as required
- Linkage and discussion with the RCH Family Liaison staff member (or similar staff member at Southern Health CCC or other staff) who may be able to promote the consumer/carer participation model with families in a non-threatening way and at appropriate times

- The development of periodic promotional efforts (e.g. for a one month period, all families seen in the ambulatory setting will be provided with information about the Network)

The following describes the **process** by which consumers/carers will be invited to join the network.

- At an appropriate time parents and other consumers/carers will be asked whether they would like to go on the CCC mailing list
- The mailing list registration will ask for key information, any relevant qualifications, experience or interests in which the parent or other family members might like to be involved. There will be a range of options for involvement from those who would like to receive newsletters but do not have any further interest in involvement to those who might indicate interest in a range of areas
- Interested parents, family members or young adults are placed on the network database and their preferences for involvement recorded
- Interested consumers/carers will be forwarded a regular newsletter or other mail outs that may include invitations to join the network listing and may advertise opportunities to contribute to service developments and provide feedback
- Based on their interests and preferences on how they would like to be involved, people on the database may be specifically contacted and invited to participate in new initiatives or roles

Opportunities to start the 'network' include linking in with:

- Parents involved in the internal cancer fundraising groups
- Parents involved in the CCV Parents' Connect Program
- Parents and young adults involved in the psychosocial services project.

Note:

To support the initial establishment of the consumer/carer participation network the following have been drafted and included as part of the final deliverable for this Project:

- A letter of invitation and expression of interest form
- An Excel spreadsheet (sent as electronic copy).

Reference to the provision of a newsletter has been excluded from these drafts, but may be included if this is a viable option in the short-term.

8.2 Support and training for consumer/carer participation

The level of training and support required for individual consumers/carers will be dependent on their expected role and the experience that they may bring to the activity. The more extensive the role, the greater the need for initial and ongoing training and support.

Over time as consumers/carers become more experienced, they may need less support for themselves, may take up strong leadership roles and play a mentoring role for new consumer/carer participants.

The type of support and training activities that need to be considered include:

- Orientation/initial training
- Mentoring
- Additional training e.g. for participation broader governance committees, providing 'information and support' to parents of newly diagnosed children via the 'morning teas' or other activities
- Debriefing
- Reimbursement of expenses incurred as a part of participation activities
- Other funding support

It should also be noted that some of the ongoing support and/or debriefing needs can be informal – the offer of informal support (e.g. a chat over a coffee) and/or the offer of access to additional support communicates a '*valuing of the consumer/carer role*'. Formal support or debriefing mechanisms may only be taken up on a minority of occasions.

Other activities that will also reflect the organisation's commitment to and valuing of consumer/carer participation include:

- Provision of refreshments
- Small tokens of thanks and recognition
- Provision of project reports or summary of key findings to participants and other mechanisms for open communication over time
- Facilitating consumer/carers' profile in activities such as conference presentations.

Finally, work needs to be undertaken to increase staff's understanding of the value of consumer/carer participation. The aim will be to provide them with the skills and understanding needed to take on a role to work with consumers/carers in a different way from their usual 'service provider' role with children and families. Such a role may take them out of their '*comfort zone*' and they need to feel supported to do this. This work with staff will require strong leadership with a clearly demonstrated commitment to engaging with consumers for service/quality improvement. From this the value of consumer participation will clearly emerge.

See 8.5 for opportunities that may assist with this training and support work.

8.3 Establishing and implementing consumer/carer feedback mechanisms

A key element of the consumer/carer participation model is the ability to hear a diverse range of voices of those who have experienced the children's cancer services. It is important that the CCCs proactively seek regular and timely consumer/carer feedback about current services and advice into new services. The approaches made would also need to match the needs and interests of the parents/family. Creative and developmentally appropriate ways in which feedback and input can be sought from children and adolescents with cancer and young adult survivors should also be explored.

Embedding the value of consumer/carer feedback within the culture of the service and the reflection on feedback as a part of core business of the service will be an important step in ensuring effective consumer/carer participation. It provides a mechanism whereby representativeness can be assured, where on a routine basis, a service and consumer representatives can hear directly from the experiences of the consumers who are being treated within their service.

In addition to feedback through compliments, complaint processes and suggestion boxes, a regular survey of consumer/carer experience is undertaken on an annual basis and service improvements initiated in response to the feedback.

Consideration should be given to the development and implementation of other routine feedback tools that can be used to provide more regular qualitative feedback that may be gleaned at key points in the treatment pathway e.g. at the end of intensive treatment, six months after diagnosis. Such feedback could also be embedded into the routine psychosocial assessments of families going through and completing treatment.

8.4 Staffing support for the development, implementation and maintenance of consumer/carer participation activities

In the early phases of growth of this consumer/carer participation model, it will be essential for a significant level of resources to be allocated to support the structures and processes required to sustain an active and effective consumer/carer participation process. Down the track, a lower level of resources may be required to maintain these structures and processes once fully operational.

A Consumer Participation Officer may have a role that includes:

- Organisation of meetings
- Preparation and circulation of meeting minutes and papers
- Liaison with personnel within CCCs in relation to items to be presented/discussed at CCCRG meetings
- Follow-up – may include:
 - Facilitation of consultation with a broader group of consumers/carers via database, arrangement of focus groups and facilitator, assist in write up etc.
 - Coordination of working party meetings (compilation of papers, venue, catering etc.)
 - Coordinate reporting from working groups to CCCRG
 - Coordination with staff – provision of feedback and follow-up for response
- Develop and maintain orientation and training packages and processes for consumers/carers
- Develop policies and procedures to guide the consumer/carer participation model
- Provide/facilitate a support and mentoring role for consumers/carers
- Raise profile of CCCRG and consumer/carer participation mechanisms in CCCs/PICS
- Administer recruitment processes for CCCRG and other reference groups/representatives required
- Ensure that consumer/carer database is developed and maintained
- Coordinate development of newsletters and bulletin boards
- Provide support for the development of consumer/carer feedback forums (e.g.. focus groups)
- Synthesise consumer/carer feedback data for CCCRG, working parties and other committees/groups within CCCs and PICS
- Development of reports for other RCH/MMC/Peter Mac committees

In addition to the above role, administrative assistance may be required to support the routine components of this work such as:

- Booking venues and catering
- Set up of rooms and IT

- Typing and formatting of newsletters and other resources as required
- Maintenance of CP database and mailing list
- Mail outs

It would be expected that if consumer/carer input is required for particular projects, staff responsible for those projects would have a role to support the consumers/carers participating in advisory groups.

Aside from staffing resources, an additional budget allocation would be required for:

- Costs for developing orientation/training programs or facilitating attendance at external training processes
- Reimbursement of consumer/carer expenses
- Supporting consumer/carer attendance at key functions/conferences
- Development of database for consumer/carer network if resources are not available in-house. This will not be required until a substantial number of parents and other consumers/carers have been enlisted.

8.5 Opportunities

A number of opportunities arise that may assist PICS and the Children's Cancer Centres to strengthen their consumer/carer participation model including:

- The Southern Metropolitan Integrated Cancer Service has recently completed the first phase on an extensive consumer/carer participation model. A resource that is expected to contain a range of materials including policies and protocols is to be released shortly. It is expected that this will be a resource that other services can draw on and adapt to their particular context.
- The Cancer Council of Victoria's Cancer Connect Program (includes Parent Connect) provides training and support for this peer program. It is understood that the number of links between parents with newly diagnosed children with cancer and Parent Connect Volunteers has been quite limited. However, the parents currently involved in Parents Connect may be interested in contributing in other ways e.g. the proposed volunteer program and/or the Cancer Connect training can be adapted to support other parents interested in becoming part of the volunteer program. Finally the employment of a new coordinator of the CCV's Cancer Connect program in early 2007 provides a new opportunity to explore future options.

8.6 Developing goals and milestones

While it is recognised that a staged approach will be necessary to implement this consumer/carer participation model, clear goals and milestones need to be developed to ensure that progress is made. Suggestions for such goals may include:

- The number of consumers/carers recruited to the consumer/carer network each six months
- The development of a formal orientation package for all new consumer members of CCCPAG/consumer reference group within three months
- The development of key policies and processes for the CCCPAG/consumer reference group within a given period

- Participation by 1-2 CCCPAG members in the DHS Consumer Training Program in 2007
- Communication with the CCV on ways in which links can be made with the Parents Connect Program.

These goals and milestones need to be initiated by the nominated CCCPAG coordinated and developed as a collaborative process between the service provider and parent members.



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