



CONSUMER PARTICIPATION: FROM PASSIVE TO PARTNERSHIP

The Consumer Participation Spectrum

INFORM	CONSULT	COLLABORATE/ PARTNERSHIP	EMPOWER
<p>Consumers are the recipients of information.</p> <p>N.B. It's important to be sure that the information you provide to consumers is accessible and easy to understand.</p>	<p>Consumers are asked for their views, which may be taken into account.</p> <p>N.B. Consultation is only participation when information gathered can influence the outcomes of the project.</p>	<p>Consumers are partners in an activity.</p>	<p>Consumers have decision-making power.</p>
<p>Objective</p>	<p>Objective</p>	<p>Objective</p>	<p>Objective</p>
<p>To convey information. For example, to communicate factual information about a policy, program or service.</p> <p>Generally a decision has already been made and the public needs to know about it, although there is no opportunity for influence.</p> <p><i>Activities at this level support consumer participation but are not considered participation.</i></p>	<p>To seek, listen to and gather information on consumers' views.</p> <p>Decisions are still being shaped and should be based on the feedback consumers provide through consultation.</p>	<p>Techniques at this level are used when there is a need for discussions about complex issues.</p> <p>There is a larger scope for consumers to shape decisions that affect them.</p> <p>There are open time frames for deliberation on issues and the options generated together are respected.</p>	<p>Activities at this level are aimed at partnering with consumers.</p> <p>There is a need for consumers and consumer groups to manage the process.</p> <p>There is an agreement at the outset to implement solutions generated by consumers and groups and to develop policies and programs in partnership.</p>
<p>Examples</p>	<p>Examples</p>	<p>Examples</p>	<p>Examples</p>
<ul style="list-style-type: none"> • Advertising • Mail-outs • Brochures • Posters • Information kits • Web postings 	<ul style="list-style-type: none"> • Focus groups • Surveys • Discussion papers seeking submissions • Public meetings/forums • Interviews 	<ul style="list-style-type: none"> Working groups Workshops Public forums Round tables 	<ul style="list-style-type: none"> Advisory councils Consumers on committees Consumers involved in planning Consumers setting the agenda for improvement and research.







Increasing level of consumer input



CONSUMER PARTICIPATION & PARTNERSHIPS PROGRAM

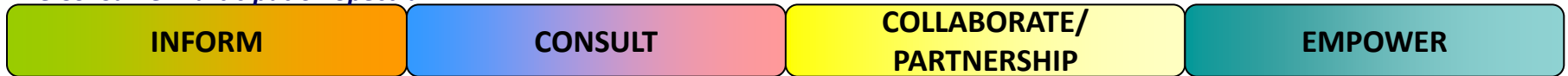
Table of Elements



	Information for patients & families
	Information for staff
	Consultation with patients & families
	Staff training on involving consumers
	Working in partnership with consumers
	Empowering families

Rights & Responsibilities: Adults, Teens & Children								FAC Handout to families
Ward information sheets	A Day in the Life of a Family Advisory Council					Community reps on Public Accountability Committee	Community reps on Health Care Quality Committee	Consumer advocacy training
Handbook for Families	Carers at Kids newsletter (Carer Support Program publication)	Fact sheets			Involving children & families in improvement	Family Advisory Council	Youth Advisory Council	Consumer participation conference
Grace (NICU) newsletter	DAM (Adolescent Medicine publication)	Consumer participation policy	NSW Health Patient Survey	Quality Improvement Surveys	Family-centred care orientation video	Grace Parent Advisory Council	Rehab Parent Advisory Council	Oncology Parent Advisory Council
The Chemo Chronicle (Oncology publication)	Rights & Responsibilities: Adults, Teens & Children	Consumer participation guidelines	Suggestion box feedback	Adolescent Satisfaction Survey	How to conduct a survey	How to run a focus group	ED Email Advisory Panel	Families Online

The Consumer Participation Spectrum



Increasing level of consumer input

Newsletters

carers at kids

the children's hospital at Westmead

Newsletter August 2010

Productivity Commission Inquiry – Long-term Disability Care and Support Scheme

What's it all about?

The Productivity Commission was asked by former Prime Minister, Kevin Rudd, to explore ways to better fund disability services. This includes looking at suggestions, such as a National Disability Insurance Scheme or a population-wide levy, similar to the Medicare levy. The Productivity Commission will also be looking at how funding is distributed. One of the key suggestions is to give people with a disability and their carers the option of directly receiving funding to purchase the services they need.

NSW Health has made a submission, which The Children's Hospital at Westmead and the Carer Support Program contributed to. However, the best feedback will come from the families and carers who will be most affected by these changes. We would strongly encourage you to make a submission if you can find the time. This is the biggest opportunity in many, many years to improve the disability service system for the better, so make sure you have your say!

Everything you need to know in order to make a submission can be obtained at the websites listed below.

The Commission has extended the due date for initial submissions to Monday 16 August 2010.

Terms of reference:

www.pc.gov.au/projects/inquiry/disability-support/terms-of-reference

Disability Care and Support Public inquiry:

www.pc.gov.au/projects/inquiry/disability-support

How to make a submission:

www.pc.gov.au/projects/inquiry/disability-support/make-submission

Online registration of interest:

www.pc.gov.au/projects/inquiry/disability-support/register

You can also send submissions by mail, fax or audio cassette and arrangements can be made to record oral submissions over the telephone.

Mail:

Disability Care and Support Productivity Commission
GPO Box 1428
CANBERRA 2601

Fax:

(02) 6240 3377

Email:

disability-support@pc.gov.au



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G R A C E

Parents & Carers Newsletter

Edition 3, Winter 2010



IN THIS EDITION:

- Staff Profile – Susan Clarke
- Patient Profile – Dominic Azzopardi
- New Child Restraint Rules
- Grace Gala wrap up

The Family Advisory Council & Family-Centred Care

Also contains info about other CHW consumer advisory councils



The screenshot shows the 'parents' section of the Children's Hospital at Westmead website. The page is titled 'The Family Advisory Council' and includes a search bar, a navigation menu, and a list of links. The main content area features a heading 'The Family Advisory Council' followed by a sub-heading 'Who are we?'. Below this is a paragraph describing the FAC as the peak consumer group at the hospital, composed of families whose children are current or past patients. It also mentions that the FAC is supported by CHW staff and has an executive sponsor, the Director for Clinical Governance. A list of current members is provided, including Lisa Ainsworth (Chair), Robin Grindrod (Deputy Chair), Cecily Waterworth, Anthony Bucco, Karen Callinan, Jenny Ascopelli, Jennie Bucco, and Anne Cutler (representing the Association for the Wellbeing of Children in NSW/Queensland/ACT). Other members listed are Joyce Murphy (CHW Consumer Participation Coordinator), Katherine Stone (CHW Care Support Coordinator), and Lizz Hammett (CHW Head of the Service Improvement Unit). A photograph shows a group of people sitting around a table in a meeting. Below the photo is a video player with a play button and a progress bar showing 0:00 / 0:00. The video is titled 'A Day in the Life of a Family Advisory Council'. At the bottom of the page, there is a section titled 'What do we do?' which describes the FAC's role in providing a family perspective on planning, policy, service development, and improvement at CHW. It states that the FAC is the formal mechanism for a partnership between families and staff, focusing on improvement and planning. A final paragraph notes that through the FAC, staff and parents work together to make the Children's Hospital at Westmead a better place for children and their families.

search our site

Feedback - settings

Home - About - Contact Us - Services - News - Jobs

parents

The Family Advisory Council

Who are we?

The Family Advisory Council (FAC) is the peak consumer group at The Children's Hospital at Westmead. It is made up of families whose children are current or past patients of the Children's Hospital at Westmead (CHW). FAC is supported by CHW staff and our executive sponsor is the Director for Clinical Governance.

Current members are:

- Lisa Ainsworth - Chair
- Robin Grindrod - Deputy Chair
- Cecily Waterworth
- Anthony Bucco
- Karen Callinan
- Jenny Ascopelli
- Jennie Bucco
- Anne Cutler, representing the [Association for the Wellbeing of Children in NSW/Queensland/ACT](#)
- Joyce Murphy - CHW Consumer Participation Coordinator
- Katherine Stone - CHW Care Support Coordinator
- Lizz Hammett - CHW Head of the Service Improvement Unit



A Day in the Life of a Family Advisory Council

What do we do?

The FAC provides a family perspective with regards to planning, policy, service development and improvement at CHW. The FAC is the formal mechanism for a partnership between families and staff with a focus on improvement and planning.

Through the Family Advisory Council, staff and parents work together to make The Children's Hospital at Westmead a better place for children and their families.

www.chw.edu.au/parents/fac/

Rights and Responsibilities

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Your rights and responsibilities



At The Children's Hospital at Westmead, we are committed to family-centred care. An important part of this philosophy is to support the rights and responsibilities of patients, their families and staff.

What you can expect of us

We will:

- Introduce ourselves to you and your child and tell you what we do
- Give your child safe and high quality health care
- Give you and your child care that meets your individual, cultural and social needs
- Include you as an important part of your child's health-care team
- Give you clear, understandable information about your child's care
- Answer any questions you have about your child's care
- Listen to your views about your child's care
- Respect the privacy and confidentiality of your child and your family
- Ensure that you have a say in decisions about your child's treatment

What we expect of you

We expect you will:

- Let us know of any special needs your family has, so that we can try to meet them
- Ask questions if there's anything you don't understand
- Attend appointments, or tell us in advance if you can't
- Follow the instructions for your child's treatment, or discuss with us if you are not able to
- Help us identify where we can improve our services to you

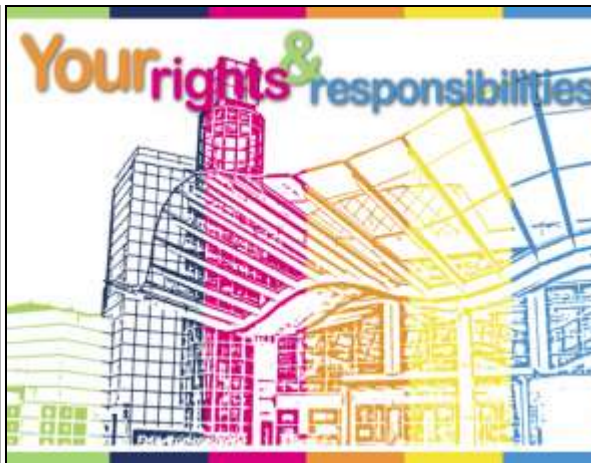
Making The Children's Hospital at Westmead a safe and supportive place

We want The Children's Hospital at Westmead to be a safe and supportive environment, so we ask everyone (staff, families, patients and visitors) to:

- Treat others with the utmost care, consideration, courtesy and respect
- Respect the Hospital's policy on smoking and alcohol use
- Behave in a manner that is not aggressive or offensive
- Take care of personal property and respect Hospital property

Physical or verbal abuse of staff, patients, family members or visitors will not be tolerated. If necessary, Hospital security will be called.

We encourage you to voice any concerns you have about the care your child and family are receiving at The Children's Hospital at Westmead. In the first instance, please speak with a member of your child's health care team or the nursing unit manager of your ward. If you're not satisfied, you can contact the Patient's Friend on 9845 3535.



Your rights as a child or young person are:

- To receive safe and high quality care
- To have someone you love with you when possible
- To have a say in decisions about you and have your views taken into account
- To be given full information about your condition and treatment in a way that you can understand
- To ask questions and be given answers you understand
- To have your privacy respected
- To be able to do things you enjoy, even if you have to stay in bed
- That people are honest with you
- That people caring for you understand your needs and try to meet them
- That you are safe

the children's hospital at Westmead

- That you are respected as a person with rights of your own
- That your best interests and wellbeing are always the most important things

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- Take care of personal property and respect Hospital property

Your rights & responsibilities

Kids rights & responsibilities



Kids in our Hospital have special rights

Rights are things that you deserve and can expect.

If you're looking after me, look after my rights:

- "I want to know what's going to happen, before it happens"
- "I want to know who you are and what you're going to do"
- "You should talk directly to me, not just to my mum or dad"
- "Don't keep secrets from me, I don't like surprises"
- "I want to be able to see you, so I can see you questions"
- "I want you to give me all the information, good or bad"
- "Tell me if it's going to hurt"
- "I want you to listen to my ideas and questions"
- "If you don't do what I want, I want you to tell me why"
- "I want you to listen to what my mum or dad says"
- "You should be gentle with me all the time, especially if I'm asleep"
- "Tell me things in a way I can understand"
- "I should be able to tell you if there's something I'm not happy about"
- "I want you to give me a choice, where possible"
- "It's important for me to do fun things"
- "Try and stick to my routine or tell me if you can't"
- "I want you to give me the best care"
- "I want you to treat me really"
- "It's important that my mum or dad are able to spend time with me"
- "I want you to keep information about me private but it's okay to share my information with my family and other staff looking after me"



At this Hospital, your well-being is the most important thing to us. We also know how important your family is so we will look after them and include them in your care.

Everyone looking after you must protect and respect your rights and those of your family. If there is something you're not happy about, or you think we could do better, we want you to tell us! Talk to the nurse, doctors or other staff looking after you and if you still don't feel happy you can call the Patient's Friend on 02 9846 3026 or 05536 from the phone beside your bed.



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Information for Staff

- Fact sheets
 - Family-centred care
 - Surveys
 - Focus groups
 - Consumer forums
 - Consumer interviews
- Consumer Participation policy
- Consumer Participation guidelines

Suggestion Box Feedback

What you told us - and what we've done about it!

We are always trying to improve the care and service we provide for your child and family.

The feedback you give us on the suggestion box forms is an important part of our efforts to make the hospital a better place for children and their families.

In the past three months, **51** suggestion box forms were filled in by patients or family members in the Hospital. Here's what you told us.

WHAT WAS GOOD

- ◆ Book Bunker
- ◆ Starlight Room
- ◆ Toys for kids
- ◆ Compassionate doctors
- ◆ Lovely hospital grounds
- ◆ Politeness and commitment of staff
- ◆ Professional staff
- ◆ Nurses attentive
- ◆ Emotional support from staff
- ◆ Social workers
- ◆ Volunteers
- ◆ Getting treatment

WHAT WAS NOT SO GOOD

- ◆ Breakfast food for babies
- ◆ Waiting times
- ◆ Getting medications
- ◆ Felt bored
- ◆ Squeaky furniture
- ◆ Didn't receive pain medication when needed
- ◆ Food arrangements for parents & carers
- ◆ Air conditioning
- ◆ Safety

WHAT NEEDS IMPROVING

- ◆ Waiting time in pharmacy
- ◆ Keeping appointments to time schedule
- ◆ Plastic baby spoons instead of metal
- ◆ SMS to confirm appointments
- ◆ Entertainment for older children

FINAL COMMENTS

- ◆ Experience was great
- ◆ Great staff
- ◆ Display meal and visiting times on wards
- ◆ Security should be improved

HOW WE'VE USED YOUR FEEDBACK

- ◆ We shared your feedback with the Public Accountability Committee, chaired by the CEO and the Family Advisory Council
- ◆ Told maintenance about your equipment concerns
- ◆ Told domestic services about your cleanliness concerns
- ◆ Outpatients Department now using an SMS to send appointment reminders and confirmations
- ◆ Wards will soon be locked overnight, allowing access to parents and carers only. The ICUs will be locked 24 hours a day.
- ◆ Pharmacy is now being notified of discharge earlier, to begin preparing medications
- ◆ Nurses are doing rounds in each ward every hour to check on patient comfort and assess need for pain medication

Got any questions?

If you'd like more information about anything you've read here, please talk to the Nursing Unit Manager on your ward or phone the Service Improvement Unit on ext 53442.

In the parent/carer rooms on the wards





Consumer Advocacy Training

Feedback from the training

- All participants rated all aspects of the training as either 'useful' or 'very useful'.
- Some comments:
 - Very informative and great to meet other Advisory Groups
 - The shared learning from all of the training participants and their various perspectives were excellent in drawing out additional learning.
 - Very worthwhile - thank you. Good suggestions, useful resources and a great balance of knowledge and flexibility in facilitation style.
 - Has motivated me to get more structure around what I do.
 - Great day. Learnt a lot. Thank you for giving us the opportunity

Staff training

- Involving children & their families in improvement
- How to conduct a survey
- How to run a focus group
- Family-centred care orientation video

Save the date!

Monday 25 October 2010

We're having a
**Consumer Participation
Conference**

- Half day conference
- Staff & consumers
- Learn about current activities & projects
- Break-out sessions to discuss key issues
- Networking opportunities

More details to follow

Joyce Murphy

Consumer Participation Coordinator

02 9845 2097 joycem@chw.edu.au

Consumer Advisory Councils

- Family Advisory Council
- Youth Advisory Council
- Grace Parent Advisory Council
- Oncology Parent Advisory Council
- Rehab Parent Advisory Council

Online advisory groups

Have your say: Families Online



Would you like to help make the Hospital
a better place for children and families?

Do you have internet access and an email address?

If you answered "Yes" to these questions, we invite you to join our Families Online email advisory panel.

What is Families Online?

Families Online is a group that provides the Hospital with feedback on projects that will affect families. This could be posters, possible changes to parts of the Hospital, information sheets and so on.

How does it work?

We'll email you our questions, or ask you to take an online survey, and you tell us what you think. We promise not to send out more than one or two emails per month. Your email address and details will be kept confidential. Hospital staff and other members of Families Online will not be able to view your details.

Who can join?

Families from all backgrounds and living in all parts of NSW who have a child being treated at the Hospital or who has received treatment in the past. We want to hear from as many families as possible about how The Children's Hospital at Westmead can be made even better.

Want more information?

For more information or to register, please call Joyce Murphy, Consumer Participation Coordinator, on 9845 2097 (52097 from any Hospital phone), email joycem@chw.edu.au or log on to www.chw.edu.au/parents

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Have your say about the Emergency Department (ED)

Would you like to help
make the Emergency
Department (ED)
a better place for
children and families?

Do you have internet
access and an email
address?

If you answered "Yes"
to these questions,
we want you to
join our ED Email
Advisory Panel!

What is the ED Email Advisory Panel?

The ED Email Advisory Panel is a group that provides the ED with feedback from a family perspective on any projects or issues in the ED that may affect families.

How does it work?

You can expect to receive no more than one email every two months and your membership would be for a maximum period of 12 months. Your email address and details will be kept confidential; ED staff and other members of the ED Email Advisory Panel will not be able to view your details.

Who can join?

Any parent/carer who has come to the ED. We want as many families as possible who can tell us how the ED at The Children's Hospital at Westmead can be even better.

Want more information?

For more information or to register, please call Joyce Murphy, Consumer Participation Coordinator, on 9845 2097 (52097 from any Hospital phone) or email joycem@chw.edu.au



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FAC Handout to families

- How to deal with issues
- What to do if you have any concerns or want to make a complaint
- How to manage your relationship with staff
- How to give feedback about your experience
- How to show thanks, if you wish
- You can get involved with making the Hospital a better place for children and their families
- You have an important role
- The parent/carer resource centre
- About the Family Advisory Council

Expanding the program

- Consumers on key hospital committees (planning, advocacy, web steering, cultural diversity)
- Using Facebook to interact with young people

Thanks!

