

# PATIENT AND FAMILY ENGAGEMENT - GOVERNANCE POLICY®

## DOCUMENT SUMMARY/KEY POINTS

Patients', carers' and families' partnership in health care supports improved health outcomes. Health care services better meet families' needs when they have been designed in partnership with families, as only they can tell us what those needs are.

There is a broad policy context mandating that staff engage and work in partnership with consumers, most notably Standard 2 of the National Standards on Safety and Quality in Healthcare, [Partnering with Consumers](#). **Compliance with Standard 2 is mandatory.**

For further instruction on how to practice Patient and Family Engagement and Partnership, staff should refer to the Clinical Governance intranet page.

The Sydney Children's Hospitals Network (SCHN) Patient and Family Engagement Team (in the Clinical Governance Unit) are available to advise and support staff and consumers in any consumer participation or partnership endeavour.

Further detail regarding patient and family involvement opportunities can be found on the SCHN Website: <http://www.schn.health.nsw.gov.au/parents-and-carers/get-involved>

If patients, parents and carers would like to be involved, they should contact the Patient and Family Engagement Team to discuss opportunities and options. They can do this directly via emailing SCHN-CGU@health.nsw.gov.au.

## CHANGE SUMMARY

- The document has been updated to reflect the change in name of the "Consumer Engagement Team" to the "Patient and Family Engagement Team" and general links

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

<b>Approved by:</b>	SCHN Policy, Procedure and Guideline Committee	
<b>Date Effective:</b>	1 <sup>st</sup> June 2019	<b>Review Period:</b> 3 years
<b>Team Leader:</b>	Network Manager – Patient and Family Engagement	<b>Area/Dept:</b> Clinical Governance

# READ ACKNOWLEDGEMENT

- This document is for all SCHN staff and SCHN patient and family representatives
- This document is available online for SCHN patient and family representatives, and those who wish to become representatives.

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## 1 Why partner with patients and families?

Staff and services at The Sydney Children's Hospitals Network (SCHN) are here first and foremost for the benefit of sick children and their families, and focus on providing patient- and family-centred care, which is an approach to health care that empowers patients and their families and fosters independence. Patient- and family-centred care supports family care-giving and decision-making, respects patient and families' choices and their values, beliefs and cultural backgrounds and builds on individual and family strengths. Involving patients and their families in planning, delivery and evaluation of health care services is an important aspect of patient- and family-centred care.

Patient and Family partnership means involving families, patients and carers in decisions about the planning, provision and evaluation of health care services and facilities. Engaging with our patients and families is critical to successful partnerships and better health outcomes. It is not enough to have good intentions of engaging the community and patients and families. Making it meaningful is the key, which means that patients and families should be involved from the early stages of a project or improvement process.

Meaningful partnership is a complex and continual process. It is not simply a technique or model; it has to be a mindset, an attitude and requires ongoing commitment. This is championed by the SCHN Executive team and the Clinical Governance Unit.

Partnering with patients and families is not only best practice which leads to improved outcomes, it is also mandatory (See Section 3 for further detail).

## 2 Benefits of Patient and Family Engagement

The benefits of partnerships between health service organisations and local communities are widely recognised.

Patients and families benefit from being engaged by:

- An increased awareness of health services and outcomes that affect their (or their children's) wellbeing and health
- Increased health literacy which leads to a better understanding of health issues and health services
- Being able to provide input into local health activities and influence the health services provided at SCHN
- Receiving improved healthcare that meets their needs
- Having a greater sense of ownership over services and their own health
- Better understanding of governing policies, complexity and funding restrictions, which can limit the ability of the health service to make changes

SCHN benefits from patient and family engagement by:

- Improved responsiveness, safety and quality of health services based on meeting patient and family needs and priorities

- Improved health outcomes for patients as they, and their families, are empowered and supported to manage their own health care
- Inclusion of valuable insights from families which may not otherwise be apparent, or may be significantly different to those held by health professionals
- Improving the responsiveness and efficiency of business operations in relation to funding, accreditation, quality, safety and patient satisfaction
- Improvements in the way in which the health system meets the needs of people from diverse, disadvantaged and marginalised backgrounds
- Potential for reduction in number of complaints
- Potential for improved job satisfaction, staff retention and morale due to positive and proactive relationship with consumers and patients
- Better understanding of the patient, parent and carer experience and requirements

### 3 The Context

There is a broad policy framework at local, state and national levels that strongly support and mandate family partnership in healthcare.

#### 3.1 Australia

- [The Australian Commission on Safety and Quality in Health Care Standards – Standard 2: Partnering with Consumers](#) - A nationally consistent standard to create health services that are responsive to patient, carer and parent input and needs.

Compliance with Standard 2 is mandatory. SCHN is assessed against this standard as part of its accreditation. See the Clinical Governance Unit's intranet page for more information about accreditation.

- [The Australian Charter of Health Care Rights](#) – Patient's rights are known and respected to ensure safe and high quality care
- [Charter on the Rights of Children and Young People in Healthcare services in Australia](#) - outlines the specific rights of children and young people in a paediatric health setting

#### 3.2 New South Wales

- [NSW State Health Plan: Towards 2021](#)
  - Specifically Direction Three: Delivering Truly Integrated Care - Empower patients to be partners in their care
- [Your Health Rights and Responsibilities](#): A Guide for NSW Health staff - The rights and responsibilities of NSW Health services and staff, and patients and carers, in particular the right to participation, to be included in decisions and choices about health care.
- [The Clinical Excellence Commission – Partnering with Patients Program](#)

- The Partnering with Patients program supports local health districts (LHDs) across NSW to transform services, by including patients, family and carers as health team members and to champion consumer engagement with the aim of improving safety and quality in health care. It provides strategic advice, guidance, program materials, practical support and training.
- [The Agency of Clinical Innovation \(ACI\) – Patient Experience and Consumer Engagement \(PEACE\) Team](#)
  - The [Patient Experience and Consumer Engagement: A Framework for Action](#) outlines how the PEACE Team works with consumers, families, carers and staff to make healthcare better in NSW. This Framework provides tools for staff to plan engagement activities when designing, implementing or evaluating improvements, activities, products and services.

### 3.3 SCHN

- [SCHN Values](#)
  - The CORE values of SCHN / Ministry of Health, “Collaboration”, “Openness”, “Respect” and “Empowerment”, describe principles of working in partnership with families to provide patient and family-centred care
- [SCHN Strategic Plan 2017 – 2022](#)
  - The 2017 – 2022 Strategic Plan highlights that to get to the next era, we will be “driving great patient experiences and health outcomes for patients and families”.

## 4 When patient and family representatives should be involved

The extent to which patient and family representatives participate in an activity varies depending on:

- The nature of the issue
- The skills of people involved
- Resources available
- Patient and family interest
- Whether it is a routine and ongoing process, or whether it is a one-off activity for a specific purpose.

[Appendix 1](#) outlines the four levels of consumer involvement.

Noting that SCHN patients are children and young people, our patient and family representatives also involves parents and carers.

The Clinical Governance Unit, in particular the Patient and Family Engagement Team, can provide guidance and support on working with patients and families. The following are requirements under [Standard 2: Partnering with Consumers](#).

Patients, parents and carers should be involved in:

- Governance
- Strategic and operational planning
- Safety and quality performance
- The development of written information and publications for patients and families
- Policy development
- Design / Redesign of care delivery

It should be noted that where appropriate and feasible, patient and family representatives should be engaged in a partnering role from the earliest possible point in a project.

Further detail regarding patient and family involvement, and methods for doing so, can be found on the [Clinical Governance intranet page](#) (for staff) and on the [SCHN Website](#) (for patients and families):

If patients, parents and carers would like to be involved in patient and family partnership, they can contact the Patient and Family Engagement Team to discuss opportunities and options. They can do this directly via emailing [SCHN-CGU@health.nsw.gov.au](mailto:SCHN-CGU@health.nsw.gov.au).

## 5 Governance of Patient and Family engagement

The SCHN Patient and Family Engagement Governance Structure is attached as [Appendix 2](#).

### 5.1 Parent and Family Advisory Groups

There are a number of Parent Advisory Groups throughout SCHN. Parent Advisory Groups are attached to specific areas, and have been initiated by each area in partnership with consumers.

Parent and Family Advisory Groups are a powerful way for services to partner with the patients, parents and families in their area.

Should staff or consumers identify a need for a new Parent / Family Advisory Group to be formed, the Patient and Family Engagement Team can provide support and guidance regarding the appropriate establishment processes.

### 5.2 SCHN Families Online

[Families Online](#) is an online group that provides SCHN with feedback on any projects that will affect patients and their families. This includes posters, possible changes to parts of the Hospital, policies, information brochures, and other projects. Anyone is welcome to join – SCHN is looking for people from a wide range of backgrounds, who live all around NSW and who have used any service that we provide, or would like to be involved in providing constructive feedback to us regarding projects, policies and publications.

Patients, Parents and Carers can sign up to be part of [SCHN Families Online here](#).

### 5.3 Youth Advisory Council

Established in 2017, the SCHN Youth Advisory Council, made up of patient and community members ranging in age from 12 – 24 years old in addition to staff, provides advice to ensure that the Network is responsive to adolescent and young adult input, needs and experiences at a local and Network level.

### 5.4 SCHN Families and Consumer Council

The [SCHN Families and Consumer Council](#) is the peak body for patient and family engagement and has an advisory and strategic role across SCHN. Issues can be escalated from each of the Parent Advisory Groups to the SCHN Advisory Council. The SCHN Families and Consumer Council reports to the SCHN Health Care Quality Committee.

### 5.5 Patient and Family Engagement Opportunities across SCHN

If staff require guidance in relation to patient and family engagement and involvement opportunities across SCHN, they can contact the Patient and Family Engagement Team.

## 6 Patient and family representation to reflect the SCHN population

Patient and family engagement should seek to reflect the demographics of SCHN population, whilst keeping in mind that SCHN provides state-wide services. Staff should endeavour to involve patients and families from a diversity of backgrounds.

This may involve implementing a range of strategies, keeping in mind cultural and emotional sensitivities. It is necessary to identify what the barriers to participation are for particular patient and family / community groups. For groups that are marginalised in mainstream society, it may take time to establish trust.

There are existing organisations in the community and in government that can help with developing working relationships with consumers from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people, young people and other often hard-to-reach groups.

## 7 Feedback to patient and family representatives

When patients and families are involved in an activity, it is important to provide feedback at the end of the project about how their input influenced the final outcome and/or to report on this to the relevant group through the Network Manager, Patient and Family Engagement. This step helps to close the loop, build trust between SCHN, patients and families and foster goodwill for future patient and family participation and partnership activities. It also gives a sense of accomplishment for those patients and families when they are aware of how they made a difference.

The way in which you provide feedback will vary depending on the activity. Further detail regarding feedback can be found on the Clinical Governance intranet page.

Patient and family representatives are welcome to raise their concerns via the Patient and Family Engagement Team if they have not received feedback on their contribution.

It should be noted by both patient and family representatives and staff members that it is not always appropriate to include feedback from individuals (including staff) in documents and activities for a variety of reasons, and when this is the case a rationale should be provided by the author or team leader.

## 8 Patient and Family representative support

### 8.1 Patient and Family representative support

Patient and family representatives should receive individual support, training and education to help them be effective in their roles.

Further detail regarding patient and family representative training can be found on the Clinical Governance intranet page or through contacting the Patient and Family Engagement Team.

### 8.2 Staff training

There are a range of training workshops that SCHN provides on patient and family engagement and patient- and family-centred care. Further information can be found on the Clinical Governance Unit intranet site.

There are external organisations that also provide training on Consumer Participation for both staff and consumers. The Patient and Family Engagement Team in the Clinical Governance Unit can provide further detail on these organisations and guidance around training requirements.

## 9 Available Resources

### For patient and family representatives:

- The Australian Commission on Safety and Quality in Healthcare [Standard 2: Partnering with Consumers Safety and Improvement Guide](#) contains lots of information and examples on how each of the criterion within the Standard can be achieved.
- The [Clinical Excellence Commission – Partnering with Patients Program](#) website provides strategic advice, guidance, program materials, practical support and training to champion consumer engagement with the aim of improving safety and quality in health care
- [Health Consumers NSW](#) - Health Consumers NSW is the statewide voice for health consumers in NSW which helps to shape the health system by representing and involving consumers in health policy and program development, and is a very helpful organisation for all health consumers to access.

- The [Agency for Clinical Innovation – Patient Experience And Consumer Engagement Team](#) have developed a variety of tools to help support patients, families and staff in building partnerships.

**For staff:**

- The [Patient and Family Engagement intranet page](#) contains many resources for staff intending to engage with patients and families.
- [The Agency for Clinical Innovation's Patient Experience and Consumer Engagement Team](#) also have a variety of resources available online for staff.

## 10 Partnership in caring for your child

SCHN recognises that parents are the experts on their child's health and wellbeing, and include parents and carers within their child's health care team. The observations, insights and involvement of parents and family members are vital to their child's diagnosis, treatment, recovery and ongoing wellbeing.

It is expected that parents are involved in the care and treatment of their children during their hospital admission. The expectations relating to care vary on a case-by-case basis, and are managed by the clinical team, the family, and the Ward / Departmental area.

It should be noted that partnership in caring for your child is separate to the governance and purpose of patient and family engagement in health care and is addressed in more detail in the SCHN Policy ["Partnership in Care: Families and Staff Working Together"](#).

## 11 Definitions

### 11.1 Patient and Family Representative

A patient / family representative is any person who uses or has used SCHN patient and family services, including the patient themselves and the patient's family.

### 11.2 Participation

Participation describes "any process that involves [patient and family representatives] in problem solving or decision making and uses the public input to make decisions."<sup>1</sup>

The participation process is an active relationship, enabling patient and family representatives to work with staff to identify and address issues of mutual concern, health service planning, policy development, setting priorities and addressing quality issues in the delivery of health services.

### 9.3 Partnership

A partnership is a relationship between two or more parties based on mutual trust, equality, respect and an understanding of each partner's responsibilities and obligations.

Partnerships with patients, families and carers exist when they are treated with dignity and respect, when information is shared with them and when participation and collaboration in health care processes are encouraged and supported to the extent that they choose.

## References

1. International Association for Public Participation (2006) *Planning for Effective Public P* International Association for Public Participation (2006) *Planning for Effective Public Participation*, International Association for Public Participation, United States
2. National Safety and Quality Health Service Standards – Safety and Quality Improvement Guide, [Standard 2: Partnering with Consumers](#).
3. The Clinical Excellence Commission, Partnering with Patients Program <http://www.cec.health.nsw.gov.au/programs/partnering-with-patients>
4. *Citizen Me! Engaging Children and Young People in Your Organisation*, NSW Office of Communities – Commission for Children and Young People, 2012

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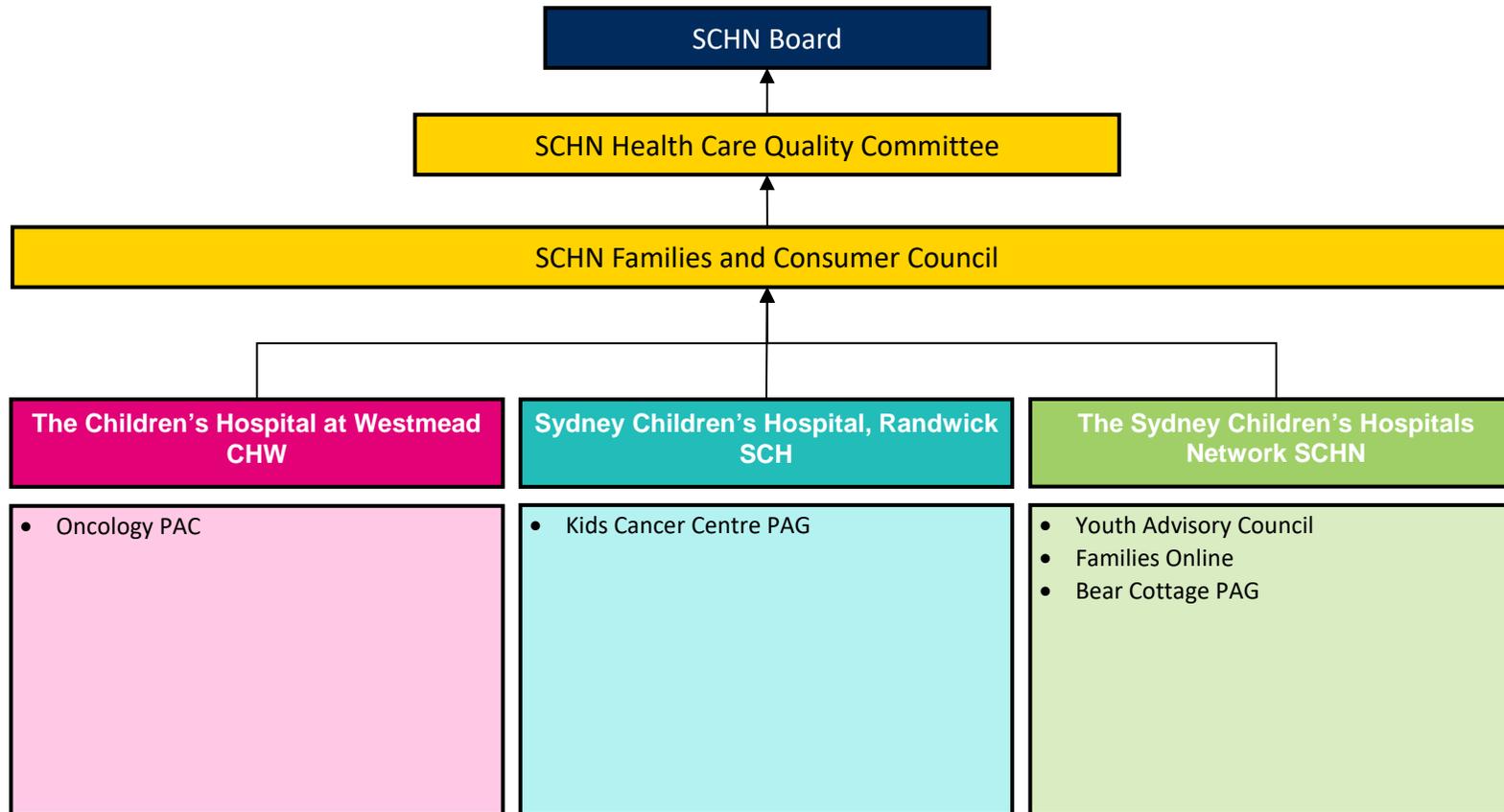
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## Appendix 1: Consumer Participation Spectrum

INFORM	CONSULT	COLLABORATE/ PARTNERSHIP	EMPOWER
Consumers are the recipients of information.	Consumers are asked for their views, which may be taken into account.	Consumers are partners in an activity.	Consumers have decision-making power.
<b>Objective</b>	<b>Objective</b>	<b>Objective</b>	<b>Objective</b>
<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>N.B. 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><i>N.B. Consultation is only participation when information gathered can influence the outcomes of the project.</i></p>	<p>Techniques at this level are used when there is a need for discussions about complex issues. There is a larger scope for consumers to shape decisions that affect them. 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. Consumers and consumer groups 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>
<b>Examples</b>	<b>Examples</b>	<b>Examples</b>	<b>Examples</b>
<ul style="list-style-type: none"> <li>• Advertising</li> <li>• Mail-outs</li> <li>• Brochures</li> <li>• Posters</li> <li>• Information kits</li> <li>• Web postings</li> </ul> <p><i>N.B. It's important to be sure that the information you provide to consumers is accessible and easy to understand.</i></p>	<ul style="list-style-type: none"> <li>• Focus groups</li> <li>• Surveys</li> <li>• Discussion papers seeking submissions</li> <li>• Public meetings</li> </ul>	<ul style="list-style-type: none"> <li>• Working groups</li> <li>• Workshops</li> <li>• Public forums</li> <li>• Round tables</li> </ul>	<ul style="list-style-type: none"> <li>• Advisory councils</li> <li>• Consumers on committees</li> <li>• Consumers involved in planning</li> <li>• Consumers setting the agenda for improvement and research.</li> </ul>

**Increasing level of consumer input**

## Appendix 2: SCHN Patient and Family Engagement Governance Structure



PAG= Parent Advisory Group  
 PAC = Parent Advisory Council