

PARTNERING WITH CONSUMERS

PRACTICE GUIDELINE[®]

DOCUMENT SUMMARY/KEY POINTS

- The Sydney Children's Hospitals Network is committed to providing safe and high-quality care that reflects a positive experience for patients, families and carers - our consumers. Consumers provide lived experience, knowledge, skills and expertise that help improve healthcare delivery. Strategies to partner with consumers should be included wherever health care is provided within SCHN.
- Partnering with consumers can occur in different ways. This guideline aims to provide consistent and equitable approaches to partner with consumers in everyday practice. Partnering with consumers in health service and research design and delivery improves patient outcomes and enables a positive patient and family experience.
- This guideline has been developed with consumer consultation, and supports SCHNs compulsory compliance with the National Safety and Quality Health Service (NSQHS) Standards, most notably, the Partnering with Consumers Standard¹
- For further related information related to partnering with consumers, staff should refer to the [SCHN Partnership in Care policy](#), the [Clinical Governance intranet page](#) or contact the Patient and Family Engagement Team at SCHN-PatientandFamilyEngagement@health.nsw.gov.au

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.

Approved by:	SCHN Policy, Procedure and Guideline Committee	
Date Effective:	1 st August 2023	Review Period: 3 years
Team Leader:	SCHN Consumer Experience Manager	Area/Dept: Clinical Governance Unit

CHANGE SUMMARY

This document has been updated to:

- Reference the following NSW Health guidelines:
 - Elevating the Human Experience Guide to Action
 - All of Us
 - Consumer, carer and community member remuneration
- Provide practical ways for staff to engage consumer representatives locally within their service as well as organisationally within SCHN.
- Outline the consumer onboarding process.
- Include research elements as part of the National Clinical Trials Governance Framework.
- Changed Title and Document type: previously being *Patient and Family Engagement – Governance* policy.

READ ACKNOWLEDGEMENT

- This document is for all SCHN staff

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1 Why partner with consumers

Partnering with consumers means collaborating with patients, families, carers and communities to improve their experience and outcomes of care. This is done by incorporating what matters to them when shaping decisions about health care and services, including the information they receive.

Evidence demonstrates the benefits of partnering with consumer across different levels, from *individual* everyday interactions when planning care, through to partnerships when designing *service* specific models of care, or when establishing formal partnerships across *organisational* governance and processes.² Partnerships have benefits for both consumers and the organisation, including:

- Increased health literacy leading to a better understanding of health issues and the ability to navigate health care settings
- Increased awareness of health and research services and related governing policies enabling quality improvement to models of care, care pathways and organisational priorities
- Improved interactions between consumers and staff through a responsive and accountable organisational culture
- Improved health outcomes and consumer experience

The extent of consumer partnerships will depend on:

- The nature of the issue or activity and the level of consumer partnership required
- The skills of the staff involved and their previous experience partnering with consumers
- Available resources to carry out the project, including reimbursement and/or remuneration for consumers if appropriate
- The level of interest among consumer stakeholders and their availability to be involved
- Whether the activity is routine, ongoing, or a single activity for a specific purpose.

2 How to partner with consumers

Ways to effectively partner with consumers should be defined at the start of any project or research with a focus on health literacy and communication strategies that will support the partnership. Health literacy refers to how consumers understand information about health and health care. It plays an important role in facilitating consumer partnerships as it affects their capacity to use information for informed decision making about the care they receive, as well as enabling them to navigate and access services in the environment where care is provided.

Further information about how to support communication and health literacy are listed in the Resources section of this document.

Three levels over which health literacy should be considered when partnering with consumers are:

- 1. At the level of the individual** - Partnerships between individual patients and families and their healthcare team. E.g. Shared decision-making and care planning between health care teams, the patient and family; informed consent processes for treatment and interventions.
- 2. At the level of a service** - Partnerships between consumers and a specific service or department where health care is provided. E.g. Completing service feedback surveys; participating in focus groups or local advisory groups.
- 3. At the level of the organisation** - Partnerships between consumers and SCHN in organisational governance, policy and planning or redevelopment. E.g. Consumer membership or representation on SCHN Committees and Councils.

2.1 Spectrum of consumer participation

The global reference for defining ways to partner with consumer representatives is the *International Association for Public Participation*³ (IAP2). The IAP2 outlines five levels of consumer participation, each with different levels of consumer influence and participation. The level of consumer participation will vary based on the needs of the activity, project or research. See Appendix 1 for the original IAP2 Spectrum for Public Participation. The Agency for Clinical Innovation (ACI) has adapted this for local use. These resources and toolkits are available here <https://aci.health.nsw.gov.au/support-for-innovation/working-with-consumers/partnership-foundations>.

2.2 Classifications of Consumers for SCHN

Consumers that partner at a service or organisational level may need to be onboarded as a contingent worker with relevant clearances based on these classifications:

- **BAND A*** – Consumers aged 14yrs and above. Consumers are considered for this Band if they are members of a working group, advisory group or committee. In this role, consumers may be provided with formal and confidential documents such as meeting agendas, minutes and papers. Young people 14-18yrs can independently consent to their involvement, however if it is deemed that they do not have capacity, young consumers may require parent/carer consent.
- **BAND B** Consumers of any age who provide one-off or ad-hoc feedback such as being part of a focus group, information session, or completion of a survey.

***BAND A** – Consumer representatives are considered **contingent workers (Volunteer)**. At SCHN, it is the responsibility of the team or department partnering with consumers to coordinate the onboarding process. Band A consumers need to be onboarded as per the SCHN Contingent Worker matrix which can be [found here](#).

It is also the responsibility of the team or department partnering with consumers to offboard consumers at the conclusion of the partnership activities.

3 How to identify consumer representatives

Finding the right consumers ensures their involvement is purposeful and not tokenistic. Defining who is being impacted by your project, initiative or research will help identify where new consumer partnerships can be made or where you can link with existing consumer groups. Examples of ways to identify partnership opportunities include:

- *Networking and referrals* – Most services have current or past consumers who are interested in partnering with teams. Work with your specific area, for example ward, clinic, research team or department, to identify who these consumers might be. Consumer or non-government organisations such as Health Consumers NSW may also be able to assist by referring existing consumers and partners.
- *Advertising* – Use communication platforms to advertise your consumer partnership opportunities. The most appropriate medium will depend on the target population and their communication preferences (e.g. young people and social media).
- *Complaints, compliments and feedback* – Consumers who provide feedback through formal processes may be interested in partnering to improve service and research provision. Identify and approach consumers that have engaged with a specific service for more tailored feedback.
- *Specialised departmental support* - Particularly for underrepresented consumers, creating partnerships with teams such as Diversity Health, Aboriginal Health, specific patient cohorts (e.g. mental health), and community organisations can be an effective way to find out more about your target population and how to reach them.

3.1 Diverse representation of consumers

It is important to identify the diverse profiles of the patient cohorts you work with and ensure you have mechanisms in place to reach and support consumers. Inclusive representation engages people of diverse experiences. Diversity includes, but is not limited to:

- Aboriginal and Torres Strait Islander people
- Different age groups
- Culturally and linguistically diverse populations
- Religious and spiritual beliefs
- People living with disability (physical, intellectual and mental health)
- People who experience and/or have experienced out of home care
- Diverse gender and sexual identities
- People from different geographic locations i.e. metro, regional and rural
- Socio-economic background
- Health literacy levels

Education and training relating to these groups is available through the SCHN Diversity Health team via email SCHN-DiversityHealth@health.nsw.gov.au

3.1.1 Aboriginal and Torres Strait Islander engagement

As part of SCHN's commitment to improve health access and outcomes of Aboriginal and Torres Strait Islander patients, it is vital to bring together the cultures of health and research services with local Aboriginal communities.

Ways to strengthen engagement and partner with Aboriginal and Torres Strait Islanders are listed in the Resources section of this document. This section includes a checklist that helps support the delivery of culturally safe and accessible health services for Aboriginal patients and their families.

4 Ways to partner with consumers

NSW Health has published [All of Us](#), a guide for respectful engagement between staff and consumers. [All of Us](#) includes a range of practical tips including ways of working and checklist tools for facilitating activities with consumers.

Methods for consumer participation should consider the diversity of the consumer population that uses, or may use, the services, including those that have participated in a clinical trial or research project.

Methods for partnering with a diverse range of consumers include:

- Feedback cards left in a suggestion box
- Kiosk machine surveys or rating scales
- Surveys on paper or sent via email or SMS
- Observational activities
- Focus groups
- Podcasts using patient stories
- Filming patient journeys through a health pathway
- Rounding in clinical areas to obtain point of care feedback
- Open house stations set up in clinical waiting areas
- In-depth individual interviews
- Online interactions to share documents and ask consumers specific questions about the content. Allow them to edit in real time or provide feedback on a standardised form that can be collated.
- Patients Reported Measures such as quality of life surveys
- Patient stories shared in forums and meetings
- Story boards that provide a visual representation for consumers from culturally diverse backgrounds
- Photo voice for young children to take photos as a way of explaining what matters to them

- Parent and young people advisory groups
- Consumer representatives on local and organisational working groups and committees
- Establishing a local consumer advisory group for a specific speciality area
- The SCHN Families Online group is available to review documents such as posters, policies, information brochures etc. New consumers are welcome to join this group.
- Social media campaigns
- Annual celebration days or days of significance for specific groups of patients
- Co-presenting with consumers at conferences, workshops, Grand Rounds etc.

5 Consumer representative support

SCHN must provide consumer representatives with individual orientation, support, and training to help them be effective in their roles. Support can also be provided from other consumers, e.g. by a buddy who is linked to their partnership activity. This gives consumers the best opportunity to contribute meaningfully and effectively.

When onboarding consumers as part of the remuneration process (see Section 8) consider levels of support they require when completing forms for levels of literacy, accessibility etc.

Contact the SCHN Patient and Family Engagement Team for more information and ideas specific to your area. [Patient and Family Engagement | The Sydney Children's Hospitals Network \(nsw.gov.au\)](https://www.nsw.gov.au/patient-and-family-engagement)

Both free and fee-paying online training is available through Health Consumers NSW <https://www.hcnsw.org.au/training-events/>.

6 Staff education

SCHN provides staff education on partnering with consumers and patient and family-centred care. The My Health Learning 'Working with consumers and communities' course (Course code: 41749567) is available online.

Health Consumers NSW offer both free and fee-paying online training via <https://www.hcnsw.org.au/training-events/>

NSQHS offers tips on Training for partnerships with consumers via

- <https://www.safetyandquality.gov.au/sites/default/files/migrated/Standard-2-Tip-Sheet-3-Training-for-partnerships-with-consumers.pdf>
- <https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard/partnering-consumers-organisational-design-and-governance/action-211>

The Patient and Family Engagement Team can provide further guidance around training requirements and consumer support.

7 Closing feedback loops with consumers

Feedback should be provided to consumer partners at the end of a project to explain how their input influenced the outcome. This closes the loop to build trust between SCHN and consumers, and foster goodwill for future consumer partnership activities. Outcomes of consumer partnerships should be acknowledged and celebrated in public ways such as 'You Said We Did posters', Quality and Innovation Awards, the SCHN Annual Review and SCHN Safety and Quality Account, and informally in social media stories.

Ways of providing feedback depends on the type of activity. Further details can be found on the [Clinical Governance intranet page](#) and the *National Clinical Trials Governance Framework page* on the SCHN [Research Governance website](#).

If consumers feel they have not received feedback on their contribution to a project, they can raise concerns to the team they are working with, the Patient and Family Engagement Team or for research projects, the Research Quality Manager at SCHN-Governance@health.nsw.gov.au.

If specific feedback cannot be provided to consumers, for example due to privacy, confidentiality or sensitivity of an issue, a rationale outlining this should be provided.

8 Remuneration and reimbursement of consumers

In accordance with the NSW Health [Consumer, carer and community member remuneration Guideline](#), SCHN is committed to remunerating and reimbursing consumers for their time and contributions to agreed engagement activities. SCHN supports eligibility for remuneration and remuneration rates outlined in The Guideline. Costs associated with participating in an approved activity should be paid directly by SCHN where possible. Where this is not possible, consumers are to seek approval to have out-of-pocket expenses reimbursed, prior to the expenditure occurring.

At SCHN, the cost of partnering with consumers is linked to departmental cost centres and budgets. When establishing consumer partnerships, the SCHN staff member, project lead or Committee Secretariat is responsible for:

1. ensuring adequate budget to support remuneration and reimbursement of consumers;
2. ensuring consumers are made aware of the principles for remuneration and reimbursement.

The Ministry of Health have published two factsheets to support staff and consumers through the remuneration and reimbursement processes:

- [Remuneration fact sheet for staff and organisations](#)
- [Remuneration Factsheet for consumers, carers and community members](#)

8.1 How is remuneration/reimbursement made to the consumer?

- The SCHN staff member, project lead, committee secretariat or delegate is responsible for establishing each consumer representative as a vendor in Stafflink. A step-by-step guide to confirm a vendor in StaffLink and register a new supplier is available at [SARA - Create a New Vendor in StaffLink](#).
- When a consumer is onboarded with SCHN (refer to section 2), the consumer is asked to complete an [Australian Tax Office Statement by Supplier Form](#) and submit this to the project lead. These forms enables the consumer to be established as a vendor in Stafflink.
- Following completion of an approved activity, the nominated SCHN staff member, project lead, Committee Secretariat or delegate completes a [NSW HealthShare Form - Invoice Scanning Payment Requisition Form Oracle R12](#). This will open an Excel document. Using the dropdown boxes, select the "Operating Unit" (i.e. organisation) and then "HA and Patient/Non-Employee reimbursement".
- Once the Invoice Requisition Form is complete, click the 'email to AP' button at the bottom of the page. An email will auto-generate to Accounts Payable. The SCHN staff member, project lead, Committee Secretariat or delegate submits the email with the completed Invoice Scanning Payment Requisition and supporting documentation (e.g. confirmation email, attendance minutes, local remuneration record form or invoice) to process the payment.

For assistance with the vendor creation and invoicing process please email:
SCHN-APLiaison@health.nsw.gov.au

8.2 Can I remunerate consumers using gift cards?

Gift cards and vouchers are not recommended for remuneration. However, there will be some individuals that do not have a bank account and may need to be paid in other non-electronic methods. Individual circumstances for the consumer may vary and this should be discussed with each individual. Careful documentation of all monetary and non-monetary payments is required, including signatures on receipt of payment and when passing responsibility for funds internally within health, and then also to the consumer.

9 Evaluating and sustaining consumer partnerships

As part of project or research planning with consumers, processes to measure, evaluate and report on the effectiveness of the partnership should be included. A framework for evaluation will vary, depending on what is being implemented as a result of the activity or research but some examples include:

- Collecting then auditing consumer feedback data, eg. Via routine or adhoc surveys and complaint data, even after the formal timeframe of project has completed
- Auditing the uptake of any newly developed consumer information

- Utilising existing patient experience surveys results from the dashboard on the SCHN intranet to demonstrate consumers feel involved in decision making about care
- Using specific and current patient experience stories in team meetings
- Using staff experience stories to champion the value of consumer partnerships
- Publishing outcomes via SCHN newsletters, on the intranet and SCHN website, via social media, documenting in annual reports
- Hosting an event to share the outcomes of partnering with consumers with project sponsors, governing bodies and other consumers
- Collecting patient reported outcome measures such as health-related quality of life surveys
- Auditing records that are kept for orientating new staff and whether partnering with consumers are included in the content
- Demonstrating consumer remuneration costs
- Auditing clinical notes to demonstrate the use of interpreters when needed

9 Governance

Governance processes such as maintaining welcoming and safe standards for ways of working with consumer partners, should be included in project and research work. In addition, reporting lines for managing risks and complaints should be established with an effective system for communicating these to other stakeholders. This ensures:

- shared responsibility and accountability for the quality of work being undertaken.
- continuous quality improvement, safeguarding high standards of care and minimising risks.
- fostering an environment of excellence in care for consumers.

The organisational structure for consumer partnerships within SCHN is governed through three key groups which report to the SCHN Quality Safety Committee. These Councils can be approached for advice on specific action items that might arise:

- Patient Experience Council
- Families and Consumer Council (FACC)
- Youth Council (YC)

More information about these Councils can be found [here](#), including ways consumers can join.

10 Resources

The [Patient and Family Engagement intranet page](#) contains many resources for staff intending to engage with Consumers. In addition:

10.1 Diversity Resources

- [NSW Health Disability Inclusion Plan \(2021-2025\)](#)
- [NSW Health Multicultural health Policy Directive PD2019_018](#)
- [Sydney Multicultural Community Services Resources](#)
- [NSW's Health LGBTIQ+ Strategy \(2022-2027\)](#)
- [Building capability in NSW health services for people with intellectual disability](#)
- [NSW Refugee Health Plan – 2022-2027](#)
- AHRQ [Health Literacy Universal Precautions Toolkit](#)
- [Planetree Diversity Recruitment Guide](#)

10.2 Aboriginal Health resources

- [NSW Health Aboriginal Engagement Tool](#)
- [Communicating Positively: A Guide to Appropriate Aboriginal Terminology GL2019_008](#)
- [NSW Health Aboriginal Cultural Activities Policy PD209_025](#)

10.3 Youth resources

- [WHY – Guidebook: Youth Engagement in Health Research](#)
- [Listen Carefully Project - Children and young people's right to be heard in healthcare](#)
- [Walking the Talk: Designing Youth Advocacy and Engagement with Young People.](#)
- [Citizen me! Engaging young people in your organisation.](#)
- [Youth Health Framework 2017-24](#)
- [Multicultural Youth Advisory Network](#)
- [Working with young people with disabilities](#)

10.4 Consumer / Carer training resources

- [Health Consumers NSW training resources](#)
- [Health Issues Centre training in Consumer and Community Engagement](#)
- [Cancer Australia Consumer Toolkit](#)
- [NSW Health Literacy Framework - 2019-2024](#)

10.5 Health literacy

- NSW Health - [Health Literacy Hub](#)
- [Australian Commission on Safety and Quality in Health Care](#) on Health Literacy
- SCHN [Factsheets](#) and [Publications](#) policies

10.6 Measuring consumer partnerships

- [Australian Commission on Safety and Quality in Health Care – User Guide for Measuring and Evaluating Partnering with Consumers](#)

11 Definitions

In this guideline the following definitions are used:

Consumer – A person who has used, or may potentially use, health services, or is a carer for a patient using health services.⁴

Consumer Representative – A person who provides a consumer perspective, contributes consumer experiences, advocates for the interests of current and potential health service users, and take part in decision-making processes.⁴

Contingent Worker – A contingent worker is defined as an employee of NSW Health who is not paid through NSW Health payroll. (*NSW Health*)

Partnership - when the health system and clinicians work in collaboration with consumers with the aim of improving patient experience and outcomes.⁴

Patient - a person who is receiving care in a health service organisation

Person (patient) and family-centred care – An approach to working in partnership with patients and families to ensure that care is respectful of and responsive to individual and family preferences, needs and values.⁴

12 References

1. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards (NSQHS), Partnering with Consumers Standard. <https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard>
2. Bombard, Y., Baker, G.G., Orlando, E. et al. (2018). Engaging patients to improve quality of care: a systematic review, *Implementation Science*, 13(98), <https://doi.org/10.1186/s13012-018-0784-z>
3. International Association for Public Participation Australasia (IAP2). *Planning for Effective Public Participation*, <https://iap2.org.au/resources/iap2-published-resources/>
4. Australian Commission on Safety and Quality in Health Care. What is a consumer fact sheet, <https://www.safetyandquality.gov.au/faqs-about-partnering-consumers-nsqhs-standards-second-edition#what-is-a-patient-a-consumer-and-a-consumer-representative?>

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Appendix 1: Spectrum of Consumer Participation

PURPOSE / LEVEL	HOW IS IT USEFUL	EXAMPLES
INFORM <i>(Low level of participation and influence)</i>	<ul style="list-style-type: none"> Health services keep consumers informed with balanced, factual information that is relevant to them. Decisions about the information provided are generally made with minimal opportunity for consumer input. 	<ul style="list-style-type: none"> Fact sheets, newsletters, brochures. Consumers participate as audience members in community forums or via social media.
CONSULT	<ul style="list-style-type: none"> Health services actively listen and seek feedback from consumers. Opinions are sought from a diverse range of consumers. There may be no commitment to make change from the feedback received. 	<ul style="list-style-type: none"> Informal conversations with consumers in clinics as part of regular service delivery. Holding focus groups or forums with consumers. Surveys, anonymous feedback or interviews.
INVOLVE <i>(Mid level of participation and influence)</i>	<ul style="list-style-type: none"> Two way information is shared to ensure ideas are understood. Consumers have an interest in a specific issue and are likely to be affected by the outcome. Consumer feedback influences change. 	<ul style="list-style-type: none"> Consumer feedback is sought for specific issues, their experience is used to enhance project outcomes. Targeted focus groups, consumers participate as panel members to share their story.
COLLABORATE	<ul style="list-style-type: none"> Consumers collaborate with each other about complex issues and develop alternative strategies. Consumers contribute to decision making and setting system agendas. 	<ul style="list-style-type: none"> Expert consumer panels or working groups to input into policies and guidelines. Consumer advisory groups, membership on Steering Committees or interview panels.
EMPOWER <i>(High level of participation and influence)</i>	<ul style="list-style-type: none"> Health services empower consumers to manage the process. Consumers accept the challenge of developing solutions themselves. When there is agreement to implement proposed solutions. 	<ul style="list-style-type: none"> Consumers participate in governance, advocacy, strategy and policy and work collaboratively with health services to resolve issues.