



POLICY

Consumer Involvement in Healthcare Design and Management Policy

Scope (Staff):	All staff
Scope (Area):	CAHS (PCH, CAHMS, Community Health, Neonatology)

Child Safe Organisation Statement of Commitment

CAHS commits to being a child safe organisation by applying the National Principles for Child Safe Organisations. This is a commitment to a strong culture supported by robust policies and procedures to reduce the likelihood of harm to children and young people.

Aim

To ensure the Child and Adolescent Health Service (CAHS) partners and consults with a diverse range of children, young people, parents/carers and community participants in the planning, delivery, evaluation and quality improvement of its health care services, in order to achieve the best possible health outcomes for patients and clients.

The purpose of this policy is to ensure consistency in consumer and carer involvement in healthcare service design and management that is shaped by the organisation's values, guided by best practice, and supports compliance with accreditation and legislative requirements.

Risk

Failure to adhere to the principles of this policy may lead to:

- Development and implementation of services that do not meet consumer needs and lack a quality approach to service improvement.
- Feedback that is not representative of the diverse community that CAHS serves.
- Lack of variety in consumer consultation approaches.
- Reduced ability of consumers to effectively engage in CAHS involvement processes.
- CAHS not meeting accreditation requirements as defined in the National Safety and Quality Health Service Standards.

Background

Consumer involvement in the planning, delivery, monitoring and evaluation of health services leads to improved quality of care, enhanced health outcomes and appropriate and effective health services, priorities and resources¹. Involving consumers in health service decision-making contributes to appropriately targeted initiatives, efficient use of resources, improved safety and quality of care across the range of services provided by CAHS, and ensure services are better designed to meet the needs of the consumers who use them².

Effective partnerships with consumers and the community are most successful when staff from across the health service and consumers are equal partners and treat each other with mutual respect and dignity. Consumers bring valuable and unique perspectives from outside the health system 'looking in', supporting the focus on providing service delivery models that are child and family centred. Engaging children, young people and their families in the health system assists services to understand more about assessing a child's level of maturity and capacity to understand, personality and behavioural characteristics, cultural background and primary language, and conflicting needs, wants and goals.

Involving consumers can include various methods of consultation, such as informal, one-off events, feedback through surveys, workshops and focus groups, in addition to formal and ongoing participation on boards and committees. Consumers can be engaged as individuals, or in small or large groups, and must be reflective of the diversity of the population being served.

The Child and Adolescent Health Service Consumer Engagement Strategy 2020-2022 outlines the commitment of CAHS to develop meaningful and genuine partnerships with consumers both in the governance of the organisation, and in processes to design, measure and evaluate health care.

This policy complements existing policies by outlining CAHS' expectation that staff involve consumers in the planning, delivery, monitoring and evaluation of its services and the methods that can be used to achieve this involvement. In conjunction with this policy, the Consumer Representative Recruitment and Management Policy and Guideline provides detailed guidance on how consumer representatives are governed at CAHS and the Consumer Feedback Policy outlines the process for consumer to provide their feedback about their experiences of services.

Definitions

The terminology used around consumer '**involvement**' can be confusing since it is used interchangeably with related terms like 'consultation', 'participation', 'engagement', 'partnership', 'co-production' and 'collaboration'. A useful way to think of consumer involvement is decision making **with** or **by** consumers, rather than 'to', 'about' or 'for' them³. Involvement encompasses various means of seeking input from a broad range of consumers about a particular topic, through consultation methods including surveys, focus groups, workshops, interviews, public meetings, forums, committees, working groups and councils.

Consumer: A parent, carer, family member, child or young person who has previously accessed (in the last five years), is currently accessing, or who is eligible to access CAHS services in the future.

Consumer representative: A consumer appointed by the health service to formally provide a voice on behalf of consumers and participate in decision-making processes, by being part of a CAHS council, committee, steering group or working group.

Consumer advisory council: A peak group of consumers who represent and provide the perspective of CAHS-wide consumers (as per the definition above) through a formalised partnership within the organisation's governance structure. The two peak CAHS consumer advisory councils are the Consumer Advisory Council (Parents and Carers) (CAC) and the Youth Advisory Council (YAC).

Consumer committees and working groups: Any group comprising a majority of CAHS consumer representatives appointed to work together with staff either on an ongoing basis or on a specific project or subject matter. All consumer groups that are not peak consumer advisory councils (i.e. CAC, YAC) are deemed to be a consumer committee or working group.

Quality improvement activities: Activities designed to generate improvement in consumer care or experiences.

Research activities: Activities intended to test or replicate ideas beyond current knowledge and standard of care.

CAHS staff committee: A committee comprising a majority of staff but may have some consumer representatives on a permanent or temporary basis.

Principles

- CAHS values the unique perspective, knowledge, experience and expertise that consumers bring to the planning, design, delivery, measurement and evaluation of its healthcare services.
- Involvement of consumers is the responsibility of all staff who partake in the planning, delivery, monitoring and evaluation of health services. All consultation activities must occur in accordance with the principles outlined in the CAHS Consumer Engagement Strategy 2020-2022.
- Consumers must be remunerated in accordance with the [CAHS Consumer Representative – Recruitment and Management Policy](#).
- Approaches for involving consumers may vary across CAHS services; however, methodologies chosen must recognise and respect the diversity and unique needs of consumers, particularly for consumers from Aboriginal or culturally and linguistically diverse backgrounds, those with disability and those currently or previously using mental health services.

- Staff must provide consumers with immediate access to information about the purpose of consultation, their role and level of influence, and ensure appropriate support is available to allow consumers to participate meaningfully throughout the involvement process.
- Staff are responsible for reporting how consumer involvement has influenced decisions; this includes reporting back to the consumers that were consulted.
- The skills, capacity and resources available to the staff undertaking the consultation, as well as the needs of the population being consulted, must both be considered when selecting an appropriate consultation method.
- Meaningful consumer involvement requires careful planning and appropriate resourcing.

CAHS processes requiring consumer involvement

CAHS staff are to engage and consult with consumers in the following organisational processes relating to planning, design, delivery, measurement and evaluation of services, where practicable. This includes but is not limited to:

- Clinical service planning, design, improvement and evaluation
- Priority setting and allocation of resources
- Infrastructure and facility design and location
- Information and publications design (digital and non-digital)
- Policy, guideline and procedure development and review
- Program and service planning and design
- Planning, implementation and evaluation of quality improvement and research activities
- Development, design and delivery of workforce training
- Monitoring of CAHS service performance against key performance indicators, and national and state benchmarks
- Evaluation of safety and quality data, including consumer feedback data
- Development of clinical research protocols
- Research priority setting and clinical research protocol development
- Other relevant services (e.g. food, parking, family facilities etc).

Standards for Consumer Involvement

All CAHS services will achieve the following standards when involving consumers in healthcare service design and management:

- **Involve consumers early:** Consumers should be involved as early as practicable, preferably during the planning phase and generation of ideas to

ensure the consultation is meaningful and appropriate. Executive, management and committee chairs must ensure appropriate consumer input has been sought prior to approval/endorsement of projects, policies, publications and guidelines.

- **Clear remuneration:** Consumers must be offered remuneration in line with the CAHS [Consumer Representative – Recruitment and Management Policy](#). Information about remuneration must be included in any advertising or recruitment information for the consultation.
- **Tailor your engagement approach:** The engagement approaches used are suited to the target audience, with reasonable adjustments made to support the safety, connection and engagement of all consumers in line with equity, diversity and inclusion best practice. This may include consideration of trauma informed principles, translation of materials to braille, access to interpreters, ensuring a welcoming environment for diverse groups, creating accessible consultations and information that is compatible with communication devices, offering online consultations, or using plain language. Further advice can be found on the CAHS Healthpoint pages [Finding and Engaging Consumers \(health.wa.gov.au\)](#) and [Consumer Engagement Methods \(health.wa.gov.au\)](#).
- **Representative consumers:** Consultation with consumers that reflects the diversity of the target population. This should include consumers from a range of backgrounds and identities (e.g. different genders, ages, culturally and linguistically diverse backgrounds and abilities). The number of consumers consulted should be appropriate for the activity. For example, a minimum of two consumers should be involved in a committee to provide support to each other but a workshop or forum may involve many more. Further guidance can be found on the CAHS Healthpoint page [Consumer Engagement Methods \(health.wa.gov.au\)](#).
- **Support meaningful input:** Consumers' opinions are respectfully and genuinely considered as part of the consultation process. It is important to be transparent about what can and cannot be changed. Before you start consulting consumers, be clear about what can and cannot be informed by them and gather input on things that can be changed. Always close the loop by providing clear feedback to consumers on the decision's consumers influenced and the overall outcome of your project. Involving consumers means recognising your duty of care in supporting them. See [Guidance and Governance for Engagement](#) on Healthpoint.
- **Plan for success:** Have a written plan that includes allocation of budget (there is no central funding for consumer engagement) and adequate timeframes to implement meaningful consumer involvement activities. Recruiting and developing partnerships with consumers will also include ensuring they are compliant with regulations such as Working with Children Checks.

- **Lived experience:** Consumers involved in all consumer consultations have relevant lived experience and reflect the diverse range of backgrounds in the population of the service. It may be appropriate to engage consumers eligible to use CAHS services.
- **Closing the loop:** The outcomes of consumer engagement activities must be reported back to the consumer/s involved. All consumer engagement activities must be recorded on the consumer engagement register for central reporting, evidence collection for the National Standards, and promoting across CAHS. Support can be found on Healthpoint pages [Guidance and Governance for Engagement \(health.wa.gov.au\)](https://www.health.wa.gov.au/guidance-and-governance-for-engagement) and [What Consumer Engagement is Happening across CAHS \(health.wa.gov.au\)](https://www.health.wa.gov.au/what-consumer-engagement-is-happening-across-cahs)
- **Consumer led projects:** Consumer initiated projects are encouraged. These projects should be derived from consumers and consumers should continue to be involved throughout planning, implementation, and evaluation phases and described in reporting.

Selecting a consultation method

There are several consumer consultation methods that can be used to seek feedback from consumers. Consideration must be undertaken of the following factors when selecting a consultation method:

- [The level of engagement](#) (i.e. inform, consult, involve, collaborate, empower).
- [The characteristics of the consumers that are currently or may be affected by the task.](#)
- The financial resources available for the consultation (see [Finance tips for consumer engagement](#)).
- The timeline for the consultation to take place. Staff must allow for adequate time to plan and organise consumer consultation. The [Consumer Engagement Planning Form](#) guides staff through the planning consumer consultation. Staff can also [contact the Consumer Engagement Team](#) for support in this area.
- The level of skill and capacity of staff in conducting meaningful engagement. (further information can be found on the [Consumer Engagement support page](#)).
- [The support available to participants, particularly where distressing or triggering subject matters are discussed.](#)

A summary of consumer consultation methods is included in Appendix 1 which are linked to 'how to' guides available on the [CAHS Consumer Engagement Healthpoint Hub](#). This list is not exhaustive and does not intend to inhibit the development of new methods of consultation but rather act as a starting point.

Deciding which consumers to consult

The specific consumers to consult with largely depends on the topic or area in which you are working. There are a range of existing groups both internally and externally. Support can be found on the [Finding and Engaging Consumers page](#).

A more complete list is available in the [Identifying and Engaging Consumers Tip Sheet](#).

More information about the consumers for each CAHS Service Unit can be found in the [CAHS Consumer Profile](#).

The Consumer Engagement Team have developed a number of tip sheets for engaging with hard to reach consumers which are available on the [Finding and Engaging Consumers page](#).

Consulting with children under 18

The United Nations Convention on the Rights of the Child (UNCROC) states that children everywhere have the right to say what they think in all matters affecting them and to have their views taken seriously (Article 12); to get and share information (Article 13); and to have access to reliable information that is important to their well-being (Article 17). Supporting this is quality statement 7.3 of the Standards for improving the quality of care for children and young adolescents in health facilities states: Every health facility has managerial leadership that collectively develops, implements and monitors appropriate policies and legal entitlements that foster an environment for continuous quality improvement.

For the purpose of this policy, CAHS considers a child to be under 12 years old and an adolescent to be 12-17 years old.

Staff involving children and adolescents in their work must adhere to the following:

- Consideration of any potential impact of participating in the consultation that may cause distress or be triggering and provision of appropriate support.
- Written consent must be obtained from the child's parent/carer/guardian prior to participation in any consumer engagement activity by providing them with the following minimum information:
 - Role of the people conducting the consultation
 - Purpose of the consultation
 - Consultation process and the role of children
 - How children's personal and contributing information will be used
 - Process for dealing with disclosures
 - Storage of information, including any personal information and results of the consultation
 - Any confidentiality requirement

- Support available to children following the consultation.
- Copies of all consumer representative onboarding documents which can be found on the [Guidance and Governance for Engagement \(health.wa.gov.au\)](https://health.wa.gov.au)
- Children and adolescents must be informed of:
 - The information provided to parents and/or carers
 - Their role in the engagement process
 - Their right not to participate and ability to opt out at any time
 - The limits and boundaries of the engagement process.
- Information provided to children about the engagement activity must be provided in an age-appropriate manner.
- Payment must be offered in line with the consumer representative rates detailed in the Consumer Representative Recruitment and Management Policy and provided in the following way:
 - For children: A certificate of participation should be given, and a family payment should be offered to the parent or carer.
 - For adolescents: Certificate of attendance given, and payment should be offered directly to the adolescent.
- The opinion and voice of children participating in consumer consultation is equal to adults and must be respected and heard.
- Consultation with children must undergo full ethics committee review via the CAHS Research and Development Team.

Roles and responsibilities

All CAHS Executive Directors, Directors and Co-Directors are responsible for:

- Demonstrating and promoting the principles of consumer engagement across their areas of responsibility.
- Reviewing requests for consumer consultations and providing approval where appropriate.
- Ensuring operational processes and structures support meaningful consumer engagement across their region, area or program and that consumer engagement occurs in accordance with the standards set by this policy.
- Reporting on planning and implementation of consumer engagement initiatives and activities, and service improvements in response to consumer feedback and experience.

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- Allocating appropriate support and resources to support consumer engagement processes.
- Ensuring consumer membership on appropriate governance committees and ensuring appropriate resources to allow opportunities for consumers to be involved in planning, design and delivery for services under their management.

The CAHS Director Consumer Engagement and Consumer Engagement Team are responsible for:

- Ensuring organisational support is provided across CAHS to allow meaningful consumer engagement including advice, resources, training, education, and information.
- Establishing and maintaining mechanisms to allow the recruitment of consumer representatives, inclusive of those from diverse backgrounds.
- Provision of timely reporting on consumer experience and feedback data to senior management.
- Providing support to the peak consumer councils including support with terms of reference and induction of new members.
- Maintaining a central register of consumer engagement activities.

All CAHS employees, volunteers and persons who provide health services on behalf of CAHS will:

- Document all consumer involvement on the Consumer Engagement Activity Register.
- Adhere to the aims, principles and standards outlined in this policy and the CAHS Consumer Engagement Strategy.
- Actively participate in the development of an organisational culture that values, supports and prioritises meaningful consumer involvement, in accordance with role and service responsibility.
- Develop and maintain skills and knowledge about best practice in consumer involvement, relevant to their role.
- Engage and support consumer representatives when working on service improvement projects that have actual and potential impacts on consumers.
- Consider the sensitivities of the target audience involved in consumer involvement.

Reporting on consumer involvement

The CAHS Consumer Engagement Team is responsible for the monitoring of activities where consumers have been involved across CAHS through the CAHS Consumer Engagement Activity Register.

When involving consumers across healthcare service design and management, staff must:


- Complete the [consumer engagement activity register](#) for each relevant activity they conduct, including completing the register annually for ongoing committees/working groups.
- Report all consumer representative positions through the '[Request to Recruit a Consumer Representative](#)' form, which is then tabled at the CAHS Partnering with Children and Families Committee.
- Escalate consumer issues from consumer committees and working groups to the Consumer Advisory Council or Youth Advisory Council by emailing CAHS.Consumers@health.wa.gov.au as required.

Related CAHS internal policies, procedures and guidelines
<ul style="list-style-type: none"> • Child and Family Centred Care Policy
<ul style="list-style-type: none"> • CAHS Consumer Engagement Strategy 2020-2022
<ul style="list-style-type: none"> • Consumer Representative – Recruitment and Management Policy
<ul style="list-style-type: none"> • Consumer Representative - Recruitment and Management Guideline
<ul style="list-style-type: none"> • Consumer Feedback Management Policy

References and related external legislation, policies, and guidelines
1. Consumers Health Forum of Australia. "Unique and essential": a review of the role of consumer representatives in health decision-making. 2015.
2. Consumer Focus Collaboration. The evidence supporting consumer participation in health: Commonwealth Department of Health and Aged Care, editor. Canberra, Australia. 2001.
3. Ocloo J; Matthews R. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. BMJ Quality & Safety 2016; Vol. 25, 626-632.
4. Ballarat, Brimbank, Maribyrnong, Melton & Wyndham City Councils, the Western Metro Department of Education and Early Childhood Development (DEECD)) and Kurunjang Primary School. Engaging Children in Decision Making A Guide for Consulting Children

Australia. 2013	
5.	Orygen The National Centre of Excellence in Youth Mental Health. Co-designing with young people: the fundamentals
6.	Chagnon, K; Montreuil, M. Partnering with children in healthcare: no partnership without trust. BMJ open, 2021-03, Vol.11 (Suppl 1), p.A2-A3

This document can be made available in alternative formats on request.

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Standards Applicable:	 NSQHS Standards: NSMHS: 1, 2, 3, 4, 5, 6, 7, 8, 9, 10.1, 10.2, 10.3, 10.4, 10.5, 10.6 Child Safe Standards: 1, 2, 3, 4, 5, 6, 7, 8, 9, 10		

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Healthy kids, healthy communities

Compassion
Excellence
Collaboration
Accountability
Equity
Respect

Neonatology | Community Health | Mental Health | Perth Children's Hospital

Appendix 1: Summary of Consumer Consultation Methods

Consultation method	Description	Level of Engagement	Cost	Audience	Timeline	Skills and capacity of staff
Consumer Survey	<p>Surveys gauge the level of information consumers have about an issue and provide a 'snapshot' of attitudes and ideas at a particular time.</p> <p>Surveys can use questionnaires to collect information, and these can be delivered through:</p> <p>face-to-face interviews, self-completion written forms, telephone surveys, or SMS or email.</p>	Inform/ consult	Low to medium	<p>Dependant on population size.</p> <p>For most project 370 would be sufficient but you can use this Sample Size Calculator to confirm</p>	4-12 weeks depends on staff capacity	<p>Skills needed: Survey development, familiarity with survey tools and analysis of data.</p> <p>Capacity: can be timely to develop and analyse but whilst the survey is running little input is required</p>
Focus Groups	<p>Focus groups are used for exploratory studies. They are a technique used to find out what issues are of most concern for consumers when little or no information is available.</p>	Consult	Low to medium	Up to 10	2-4 weeks	Skills needed: organising focus group, facilitation
Workshops	<p>Workshops are a structured forum where consumers are invited to work together in a group (or groups) on a common issue or task.</p>	Inform/ consult /Involve	medium	11-30	4-6 weeks	Skills needed: considerable organisational skills, a number of

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Consultation method	Description	Level of Engagement	Cost	Audience	Timeline	Skills and capacity of staff
	The goal of workshops is to resolve issues and build consensus for action.					staff with facilitation skills
Consumer Interviews	<p>An interview with key consumers with can provide the opportunity to gain insights from a ‘casual’ conversation. Consumers will need to have good links with the community and will require careful selection.</p> <p>Allows for detailed information to be collected.</p>	Consult	Low to Medium	Up to 10	Depends on accessibility of consumers	<p>Skills needed: Interview skills, good links to the target community</p> <p>Capacity: can be time consuming to organise and transcribe interviews</p>
Public meeting/ forum	A public meeting/forum is the coming together of consumers and staff for a specific purpose e.g. to focus on a particular issue. In general, a public meeting/forum will have a facilitator who encourages two-way communication, and a recorder who records suggestions and issues that are revealed at the meeting.	Inform	Low	Over 30 people	4-6 weeks	<p>Skills needed: promotion and presentation skills</p> <p>Capacity: low</p>

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Consultation method	Description	Level of Engagement	Cost	Audience	Timeline	Skills and capacity of staff
Consumer Representative on staff committees	<p>Having consumers be part of a staff committee as members with status equal to other members.</p> <p>A staff committee consists mostly of staff.</p>	Involve/ collaborate	Low to medium	Not less than 2 consumers	Initial recruitment will take at least 4 weeks.	<p>Skills needed: a person with good chairing skills to ensure the consumer is included in discussions</p> <p>Capacity: time needed by a staff member to debrief the consumer representative</p>
Consumer working groups/ committees	Committees that consist mostly of consumers with some staff	Involve/ collaborate/ empower	Medium to high	3-12 consumers	6-10 weeks to establish a consumer committee	<p>Skills needed: promotional skills, links to the community, organisation of meetings</p> <p>Capacity: time consuming to establish and support</p>