Health Care Consumers' Association

Consumer and Community Participation Framework

Endorsed December 2025

About Health Care Consumers’ Association Inc

The Health Care Consumers’ Association (HCCA) is a health promotion charity and the peak consumer advocacy organisation in the Canberra region. Last year we celebrated forty years of incorporation. HCCA provides a voice for consumers on health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation, and consumer and community consultations,
- training in health rights and navigating the health system,
- community forums and information sessions about health services, and
- research into consumer experience of human services.

More information about HCCA can be found at www.hcca.org.au.

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1. Purpose

The Consumer and Community Participation is a core program for Health Care Consumers' Association's (HCCA).

The objectives of the program are to:

- Create and facilitate opportunities for individuals and community organisations of the ACT and surrounds to participate in health care advocacy, at a systemic level.
- Advise and facilitate relationship building between ACT health delivery, policy and planning bodies, and community bodies.
- Support community organisations to understand and use advocacy channels in healthcare.

This framework sets out our approach to consumer and community participation. This framework guides our internal processes, and

explains our approach to

- our members, consumer representatives and consumers who are interested in, or are, participating in HCCA activities, and to
- external organisations, including consumer and community groups, advocacy groups and government agencies.

Consumer and community participation is core to all HCCA's activities and is a goal in the HCCA Strategic Plan (2025 – 2030):

> **GOAL 2: Improve safety and quality of health services.**
>
> We work with our members, networks and health services to influence strategic priorities, monitor performance and co-design health services that meet the needs of consumers

HCCA is committed to creating a shared culture of partnership with health services that facilitates consumer participation in health services and ensures they meet the needs of all consumers throughout their lives.

This framework sets out:

- HCCA's commitment to supporting the health literacy of consumers so that they can participate in their own care.
- Ways that consumers can have their say about their own healthcare or be involved as partners in the ACT health system. This includes research, planning and design, evaluation and health service governance.
- Guiding principles for consumer participation
- How HCCA facilitate and supports consumer and community perspectives to be included,
- The broader context for health consumer participation,
- Definitions, and related HCCA documents.

1.1. Why participation is important

Consumer and community participation in health services design and decision making is important because it helps to ensure that health care meets the needs of those who use health services.

Research shows that participation leads to:

- improved communication between health professionals and patient,
- improvements to existing services and the quality and safety of care provided
- better design of new policies, programs and services.[1]

2. Guiding Principles

2.1. The right to participate

We are strong advocates for consumer and community participation.

HCCA is committed to the principle that health care consumers have a right to have a say in the way their health care is shaped and offered.

This principle underpinned the establishment of HCCA in 1978 and accords with the Declaration of Alma-Ata, which was pivotal in articulating peoples' right to participate in the planning and delivery of their health care.[2] The Australian Charter of Healthcare Rights similarly states that consumers have a right to comment on their care and participate in decisions that affect them.[3]

2.2. Participation is meaningful

HCCA recognises that lived experience is a valid and important source of knowledge and is committed to meaningful consumer participation. This means:

- Genuine and thoughtfully planned participation opportunities - not tokenistic.
- Consumers voices are respected and authentically represented.
- Information for consumers and the ACT community is accurate and helpful, and it does not seek to manipulate opinion or quash concerns.

2.3. Participation is transparent

HCCA's participation process is transparent.

HCCA ensures that consumer participants understand what will happen to their input and the impact of it. This includes:

- How their input will be used.
- How their input might influence a decision, action, policy or research outcomes, and the limits of this influence.
- the outcome of their input – that is, how it influenced a decision, action, policy or research outcome.

2.4. Participation is supported

HCCA supports consumers to be effective in their participation by providing:

- Consumer representative training through HCCA's Consumer Representation Program.
- Individual support for consumer representatives with strategy and content of advocacy topics, with a staff member or an experienced consumer representative mentor.
- High quality consumer information and resources.
- Training, education and adult learning opportunities (for example, workshops on health topics),
- Opportunities to apply for financial support to attend relevant conferences.
- Transport assistance for representation opportunities (on a case-by-case basis).

HCCA supports participant and safety in research[4] by:

- Providing clear and appropriate information to participants.
- Protecting privacy and confidentiality.

We are committed to research that is safe and accessible. We make it clear:

- how researchers will minimise unintended harm and what they will do if anything happens
- there are different ways to participate
- people can exit at a time of their choosing.

2.4.1. Reimbursement of expenses

Consumer and community participation in HCCA activities is voluntary.

HCCA recognises that consumers should not be out of pocket to participate in improving the health care system.

HCCA works with health services, community services and research institutions to advocate for reimbursement of consumers as best practice in partnering with consumers, and provides information and support about how to do this.

Where consumers participate in funded project work with HCCA which directly advises a health service or health project, HCCA will reimburse them in accordance with the ACT Government consumer reimbursement policies.

HCCA ensures all consumer representatives are aware of the remuneration and reimbursement policies of the services they wish to contribute to.

2.5. Participation is inclusive

HCCA supports consumer and community participation that reflects the diverse communities of the ACT and surrounding region, and the diversity of health care needs.

HCCA encourages participation by:

- Actively building relationships with local consumer and community organisations who represent the interests of different community cohorts.
- Periodically reviewing its membership and stakeholder profile and developing engagement strategies to reach under-represented and/or vulnerable community cohorts.
- Funding community liaison officers to work with diverse communities including multicultural , disability, and LGBTIQA+ communities.

3. Avenues for participation

3.1. The ways that HCCA consumers and the community participate

Consumers and the community participate across all aspects of the health care system – quality and safety, workforce, teaching and learning, communications, infrastructure and digital health. It also includes health policy, research, planning and design and health service governance. It also helps consumers participate in their own healthcare or those that they care for.

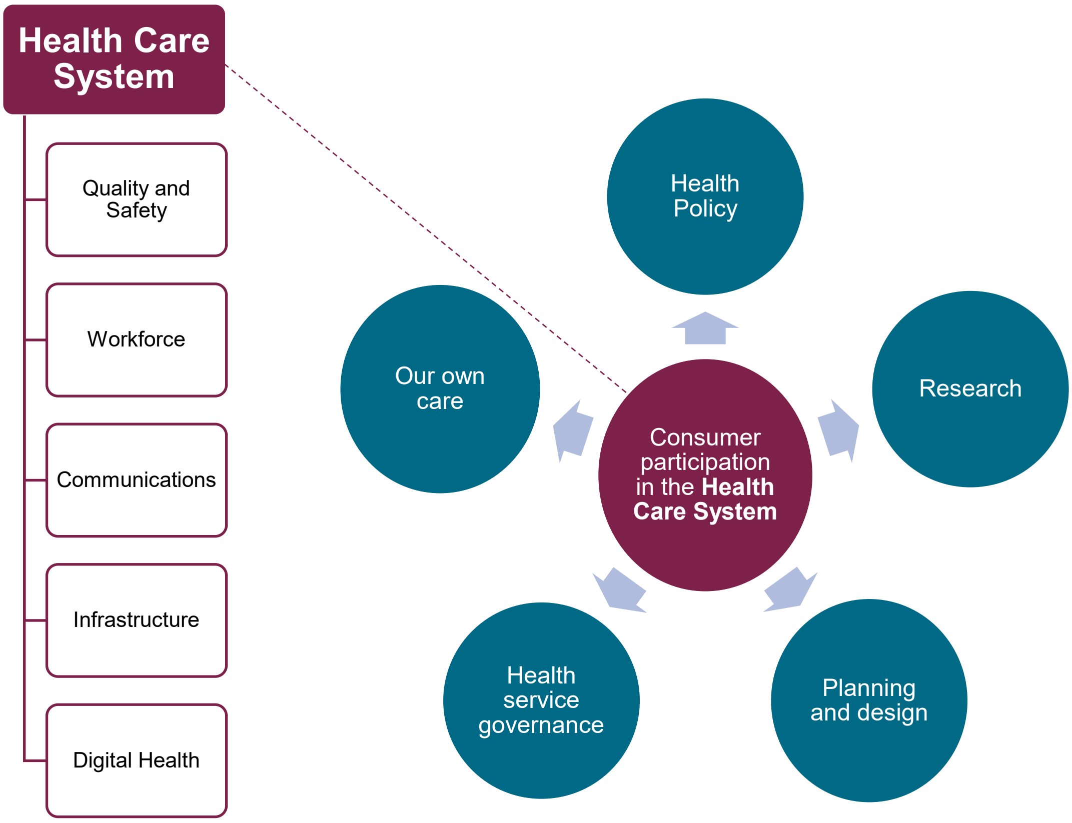

Figure 1: Avenues for participation

3.1.1. Participation in Our Own Care

All consumers have the right to build the skills and confidence to participate in decisions that affect their health and wellbeing. HCCA supports consumers to build their health literacy so that they can participate fully in their own care.[5] That is, to develop an understanding of how the health system works. HCCA helps consumers know about their health care rights and responsibilities so that they can be active participants in their health care choices and decisions.

For health care consumers, individual health literacy describes the knowledge, skills, confidence and motivation that people use make decisions about their health in everyday life. Getting health information, understanding it, and judging if it is right for your circumstances are central to individual health literacy.[6]

HCCA builds individual health literacy through community training, online resources and community outreach (at community events),and by working with health providers so that they have good quality health information available for all people who use their services.

3.1.2. Participation in health policy

HCCA works with consumers and the community to contribute to health policy discussions to ensure that the health system is better able to meet the needs of all health care consumers and communities in the ACT.

HCCA has a process to work with consumers so that we can identify policy priorities and ensure that they are consistent with the HCCA Strategic Plan. Policy priorities are regularly reviewed and updated in response to emerging issues which are important to consumers. We identify changing needs and priorities through our work, that is informed by our consumer representatives and community networks.

HCCA prioritises invitations to make policy submissions according to their fit with HCCA priority areas. At times, HCCA will invite the participation of other community organisations in developing policy submissions to ensure relevant populations are heard.

Consumers participate in policy development through:

- Setting policy priorities for HCCA (Executive Committee, with input from all members).
- Participation on external committees.
- Providing feedback to HCCA (surveys, focus groups, reviewing policy submissions etc).
- Participating on HCCA Consumer Reference Groups.
- Participating in policy monitoring and evaluation.

Consumer and community participation in health policy is guided by the HCCA's Policy Development Framework, which sets out:

- the process for both responsive and HCCA initiated policy development
- the role and functions of the Health Policy and Research Advisory Committee
- an evaluation framework for HCCA policy outputs to enable continuous quality improvement.

3.1.3. Consumer Reference Groups

HCCA has a number of reference groups which inform our advocacy and positions on health policy and identify issues of importance to consumers. The aim is to enhance the overall consumer voice in shaping the health services affecting them, and to ensure that future health strategies and policies are in fact consumer driven.

HCCA Consumer Reference Groups (CRGs) bring together members, consumer representatives and nominees from support groups and health service organisations to inform ACT Government, health organisations including the Capital Health Network, and health services about issues of importance to consumers in the ACT and surrounding region. The Reference Groups provide informed advice to consumer representatives participating on relevant health service committees, and to HCCA's policy work. HCCA staff provide secretariat support to the Consumer Reference Groups.

Current Consumer Reference Groups are:

- Quality and Safety Consumer Reference Group
- Health of Older People Consumer Reference Group
- Planned Care Consumer Reference Group

3.1.4. Participation in research

Consumer and community participation in research is guided by HCCA's Consumer Participation in Research Framework , which sets out:

- What HCCA means by consumer-based research,
- How and when consumers are engaged in research
- What HCCA does to support and encourage consumer-based research,
- How research priorities are determined,
- How research is undertaken, and
- How research findings are disseminated, including what to do next (for example, opportunities for advocacy or implementation).

HCCA involves consumers in all stages of the research process – from setting research priorities, to determining research methodology, to undertaking the research and disseminating research findings. HCCA may involve the broader community in research through focus groups, surveys and interviews or by partnering in research projects with other community organisations.

3.1.5. Participation in health service planning, design and evaluation

Consumer representatives and community members work closely with HCCA staff to ensure we have effective community involvement in service planning, design and evaluation. This includes the design and function of buildings and spaces in health services. We advocate for all health care to support consumer centred care and be sensitive and respectful of the cultural needs of our community.

Consumers participate in health service planning, design and evaluation in different ways. This includes:

- contribute as members of planning and project decision-making committees,
- participate on user groups, which allow them to provide their point of view within the planning and design process. This involvement can vary from contributing to building layout, signage and wayfinding to how the services will be delivered, and
- participate in user testing of design solutions.
- provide feedback based on their experience and knowledge of community needs

3.1.6. Participation in health service governance

The consumer voice brings a valuable perspective to health service governance. It is essential to have consumer input into governance processes like the setting of priorities for organisations, the identification and management of risks, and the expenditure of resources.

Consumer participation in health service governance is often achieved with the inclusion of one or more consumer representative members on governance committees - for example clinical governance committees and advisory groups.

Consumer participation at the level of governance is an opportunity bring more rigorous accountability and transparency to the often unseen processes of governance, and to ensure that governance addresses those issues that are of most importance to consumers.

HCCA trains and supports consumer representatives to participate in health service governance committees and supports health services to understand consumer participation and achieve positive and productive relationships with consumer representative committee members.

3.2. Consumer Representatives Program

HCCA's Consumer Representatives Program (CRP) is an important element in HCCA's participation approach. Through the CRP, HCCA recruits, trains and supports health care consumer representatives to participate on a range of health service committees and in a range of health fora.

HCCA's preference is to place consumer representatives, rather than HCCA staff, on external committees whenever possible. At times, however, a committee may require a skill set, an area of expertise, or time commitment that cannot be met by the existing consumer membership. In these instances, an HCCA staff member may be asked to represent HCCA on an external committee. Staff are expected to be broadly informed by consumer perspectives. Staff in these roles have completed consumer representative training and are connected to consumer views and experiences through the relevant HCCA Consumer Reference Groups. They can use these and other HCCA networks and events to seek consumer input and views on their committee work in the same way as volunteer consumer representatives can.

4. How HCCA enables consumer and community participation

4.1. A spectrum of participation

HCCA seeks consumer and community participation in a range of ways. These require different degrees of activity and commitment from consumers or communities. The spectrum of participation[7] (figure 2) shows the levels at of participation.

As a consumer organisation, HCCA is committed to consumer-led participation (at the active end of the spectrum) and this is reflected in HCCA's governance structures, which place consumer volunteers in decision-making and strategy-setting roles.

HCCA is also committed to extending its reach across the ACT and surrounding region. This means recognising that the capacity of community members to participate will vary greatly. Time, resources, levels of health literacy and social, economic and cultural factors all impact on people's ability to participate. The more ways in which HCCA can invite and encourage participation, the richer the picture of consumer experience, values and views HCCA can bring to its work and to influencing health care in the ACT.

HCCA also recognises that each health service may be at a different stage in their understanding and practice of consumer participation. HCCA is committed to supporting health services as they move towards more impactful consumer participation.

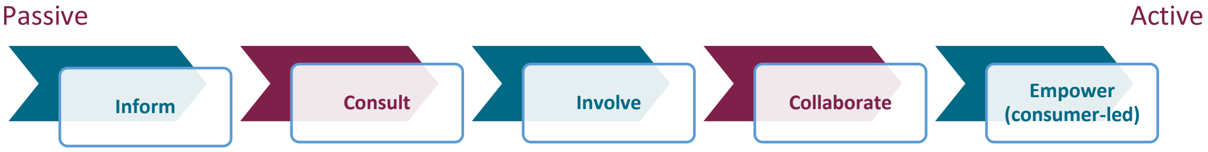

Figure 2: Spectrum of participation IAP2

Inform – This is the most passive form of inclusion. HCCA provides community members with information to help them make informed choices and decisions about their health care. Information is shared in the following ways:

- Resources on HCCA's websites,
- Public forums on specific health issues,
- training in health rights and navigating the health system for community groups,
- HCCA information stands at community events,
- Social media, and
- Via member organisations (newsletters, social media channels etc).

Consult – HCCA seeks consumer and community feedback at all its training and public information forums, as well as monitoring feedback on social media. This feedback helps HCCA build a picture of what is important for the community and what consumers want from their health care system and to advocate on behalf of consumers.

Involve – HCCA works directly with consumers and the broader community to seek input on specific policy, service design and research issues. Consumer and community input informs the work of HCCA. HCCA involves consumers and the community through the following mechanisms:

- Online surveys,
- Focus groups,
- Discussion forums,
- Consultation drafts, and
- Project reference groups.

Collaborate – HCCA collaborates or partners with consumers in policy development and research. Consumers have shared decision-making powers and actively shape the policy and research. Consumer collaboration occurs in a number of ways. Consumers:

- Co-produce research as equal partners with HCCA's researchers,
- Participate on HCCA Consumer Reference Groups to inform our positions on health policy and to identify issues of importance to consumers, and
- Participate on ACT health sector committees.

At times, HCCA Consumer Representatives or staff members will be invited to sit on recruitment panels for senior health service staff.

Empower (consumer-led) – HCCA's governance structures enable consumer-led participation where consumers take the lead on decision-making and setting the strategic direction for the organisation.

HCCA recognises that consumers have diverse needs around the ways they are able to receive information and provide input.

HCCA is committed to providing input opportunities and communication to consumers in a range of different ways including :

- Written and verbal
- Online
- Face-to-face
- With interpreters and other communication aids

Events held by HCCA will usually have online participation mechanisms.

Our preference is for face-to-face meetings, where possible. We recognise online meetings can be a key enabler for some consumers to be able to participate, and will meet this need wherever possible. In addition, online meetings may be necessary because of circumstances such as COVID restrictions.

5. Governance and decision making

5.1. Consumer Participation Committee

HCCA's member-led Consumer Participation Committee governs consumer and community participation activities. The Committee:

- Provides guidance and direction to the HCCA Consumer Participation Team,
- Ensures that participation activities align with HCCA's Strategic Plan,
- Ensures participation activities are of a high standard and consumers are adequately supported,
- Assesses consumer representative nominations to external committees, and
- Monitors the impact of participation activities.

5.2. Prioritisation of consumer participation work

The prioritisation of consumer participation work is guided by HCCA's Strategic Plan, and priority policy areas, which are set in HCCA's strategic planning processes.

HCCA has a Quality Assurance policy and procedure that sets out the approval process for any new work. This includes events, workshops, training, materials and projects.Any HCCA activities need to support the implementation of the Strategic Plan and the objectives of the HCCA Constitution. Other considerations are

- Alignment with HCCA's priority policy areas,
- Anticipated level of impact for health care consumers,
- Whether another organisation is already supporting consumer and community participation on the issue under consideration, and
- Whether the project provides an opportunity to support the education of health service staff in enabling consumer participation
- the most effective and appropriate mode of consumer participation resources including timeframe, budget, HCCA staff capacity, and HCCA access to relevant consumer and community groups to participate.

6. The broader context

The value of consumer and community participation in health service design and decision making is now reflected in the accreditation standards for health services and the expectations that are set for the health services industry.

6.1. National Safety and Quality Health Service (NSQHS) Standards

The National Safety and Quality Health Service (NSQHS) Standards were developed to protect the public from harm and to improve the quality of health service provision. The Standards have included consumer participation since 2011. The second edition of the Standards place increased importance on the partnership and involvement of consumers in their individual care as well as service planning, delivery, improvement and evaluation.

Standard 2, Partnering with Consumers, is:

> "To create an organisation in which there are mutually valuable outcomes by having:
>
> - Consumers as partners in planning, design, delivery, measurement and evaluation of systems and services
> - Patients as partners in their own care, to the extent that they choose."[8]

6.2. Other related standards

The principle of enabling individuals to be active participants in decisions about their own health care and encouraging consumer feedback to improve health care services is now reflected in other standards guiding delivery of health care:

- The *Standards for General Practices (5th edition)* includes a criterion on patient feedback.[9]
- The Australian Pharmacy Council Review of Accreditation Standards Consultation Paper 2, Criterion 3.3, includes consumer and patient input to program planning, design, implementation, evaluation, review and quality improvement processes.[10]
- The Nursing and Midwifery Board of Australia *Registered Nurses Standards for Practice* and *Code of Professional Conduct for Nurses*, highlight person-centred practice that respects the rights and preferences of consumers and empowers consumer choice.[11]
- The Medical Board of Australia's, *Good medical practice: a code of conduct for doctors in Australia*, includes sections on shared decision making with the patient and informed consent.[12]

7. Legal obligations to volunteers

HCCA has legal obligations to health care consumers who volunteer to participate in HCCA activities. This includes:

- Workplace health and safety obligations
- Privacy and confidentiality obligations

7.1. Workplace health and safety obligations

HCCA is required to provide a safe working environment for volunteers (consumer participants) under two sources of law:

- The common law of negligence and the negligence provisions in ACT legislation, and
- Work health and safety laws in the ACT.

Volunteers are not covered by workers' compensation insurance. Therefore, to ensure HCCA meets its health and safety obligations to consumer participants, all HCCA volunteers are covered by HCCA voluntary workers personal accident insurance. HCCA also includes volunteers under its public liability and professional indemnity insurances.

Consumer representatives are covered by the volunteer's insurance of the health services in which they are providing input.

7.2. Privacy and confidentiality obligations

HCCA respects the right of privacy and protects personal information of any individual making contact with the organisation for any purpose, including consumer volunteers. HCCA's Privacy and Confidentiality Policy guides us in meeting our privacy and confidentiality obligations.

8. Definitions

Consumers as patients are people who use health care services, and their families and carers.

Consumers as participants draw on their lived experience to offer insights into health care issues (for example, as focus group participants) but do not necessarily represent a broad range of consumer views.

Consumers as representatives draw on the knowledge they have developed from their lived experience and are expected and assisted by HCCA to seek out and represent – or advocate for – a broad range of consumer views, including vulnerable communities and people living with disadvantage.

The community refers to other consumer and community organisations, and to individuals who do not necessarily self-identify as health care consumers.

Consumer-centred care meets the physical, emotional and psychological needs of consumers, and is responsive to someone's unique circumstances and goals. It also informs consumers, carers and families what they can expect from healthcare providers and the health system.

9. Related HCCA Documents and Policies

HCCA Strategic Plan 2025-2030

Consumer Participation in Research Framework

Consumer-Centred Care Position Statement

Health Literacy Position Statement

Health Policy Development Framework,

Health Promotion Framework

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[1] See for example, Doggett, Jennifer (May 2015), "*Unique and essential": a review of the role of consumer representatives in health decision-making*, Consumers Health Forum of Australia.

[2] International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978, no. iv, https://www.who.int/publications/almaata_declaration_en.pdf, accessed 23 April 2019.

[3] The Australian Commission on Safety and Quality in Health Care (2017) Australian Charter of Healthcare Rights, https://www.safetyandquality.gov.au/wp-content/uploads/2012/01/Charter-PDf.pdf, accessed 25 April 2019.

[4] HCCA (2019), Consumer-based Research Framework, p. 14.

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[5] See HCCA, *Health Literacy Position Statement*.

[6] See Note 2.

[7] The IAP2 Spectrum of Public Participation shows five levels of increasing influence. Within the health consumer context, HCCA frames the fifth level of participation – 'empower' – as 'consumer led', in line with Health Consumers Qld (2017), Consumer and Community Engagement Framework, p 17.

[8] Australian Commission on Safety and Quality in Health Care (2017), The National Safety and Quality Health Service (NSQHS) Standards, p. 14.

[9] Standards for General Practice, QI Standard 1, Criterion QI 1.2, p. 92. https://www.racgp.org.au/running-a-practice/practice-standards/standards-5th-edition/standards-for-general-practices-5th-ed, accessed 21 April 2019.

[10] Australian Pharmacy Council (2019), Consultation paper 2, p. 21. https://www.pharmacycouncil.org.au/standards-review/, accessed 23 April 2019.

[11] Nursing and Midwifery Board of Australia *Registered Nurses Standards for Practice (2016)* and *Code of Professional Conduct for Nurses (2008)*, https://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements/Professional-standards.aspx, accessed 23 April 2019.

[12] Medical Board of Australia (2014), Good medical practice: a code of conduct for doctors in Australia, https://www.medicalboard.gov.au/codes-guidelines-policies/code-of-conduct.aspx, accessed 23 April 2019.