Health Care Consumers' Association Consumer and Community Participation Framework

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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.

Acknowledgements

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1. PURPOSE

This framework sets out the Health Care Consumers' Association's (HCCA) approach to consumer and community participation. It has been developed to guide our internal processes, and to explain our approach to 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.

As a consumer organisation, consumer and community participation is core to all HCCA's activities, and is articulated in Goal 1 of the HCCA Strategic Plan:

> *GOAL 1: Effective consumer participation in health policy development and service design, planning, delivery and evaluation of health services*
>
> — HCCA Strategic Plan 2018-2021

HCCA is committed to creating an environment that facilitates consumer participation in health services and ensures they meet the needs of all consumers throughout the different stages of their lives.

This framework sets out:

- Avenues for participation (consumers' own care, health policy, research, planning and design, and health service governance).
- Guiding principles for participation
- How HCCA enables consumer and community participation,
- Governance and decision-making for participation,
- 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 an important part of ensuring that health care adequately meets the needs of those who use the services. Participation leads to:

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

2. Guiding Principles

2.1. The right to participate

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:

- invitations to participate are genuine and thoughtfully planned; they are not tokenistic,
- the consumer voice is respected and authentically represented, and
- information provided to consumers and the community is accurate and helpful; it does not seek to manipulate opinion or quash concerns.

2.3. Participation is transparent

HCCA's participation process is transparent.

HCCA ensures that participants understand:

- how their input will be used,
- how their input might influence a decision, action, policy or research outcomes; and the limits of this influence, and
- 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 activities by providing:

- consumer representative training through HCCA's Consumer Representation Program (see 2.2),
- one on one support to consumer representatives (with a staff member or an experienced consumer representative mentor),
- access to information and resources (for example, Tips for Safer Health Care and questions to ask your doctor),
- training and education opportunities (for example, workshops on navigating the health system, and understanding Medicare and private health insurance),
- opportunities to apply for financial support to attend relevant conferences, and

- transport assistance (on a case by case basis),

HCCA supports participant control and safety in research by:

- providing clear and appropriate information to participants,
- protecting privacy and confidentiality, and
- modifying the research to reflect the principles of trauma-informed care, where necessary.[4]

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 in order to participate in improving the health care system. When possible, HCCA covers out of pocket expenses. HCCA recommends, but cannot guarantee, that consumers are reimbursed for out of pocket costs by health services for any activities undertaken. HCCA ensures all consumer representatives are aware of the remuneration and reimbursement policies of the health services they wish to contribute to.

2.5. Participation is inclusive

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

HCCA encourages participation across the community 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 (latest in early 2019) and developing engagement strategies to reach under-represented and/or vulnerable community cohorts, and
- funding a dedicated Multicultural Liaison Officer position.

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, communications, infrastructure and digital health – through the avenues of their own care, health policy, research, planning and design and health service governance.

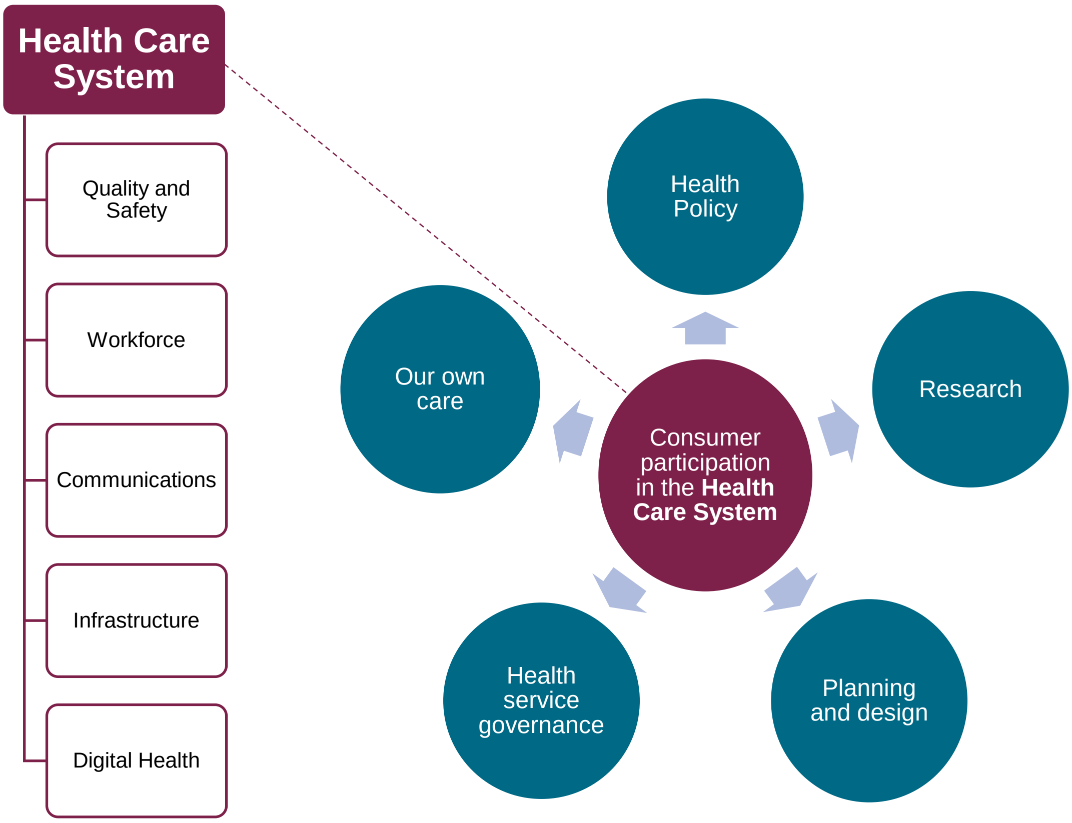

Figure 1: Avenues for participation

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 and their health care rights so that they can be active participants in their health care choices and decisions.

For health care consumers, health literacy involves having:

- access to the information they need, the ability to understand that information, and the ability to judge if the information is right for them.

- realistic expectations of their care
- an understanding of the role of the health care professionals
- the support to ask questions about their care.

HCCA builds individual health literacy through community training, online resources and community outreach (at community events).

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's policy priority areas (2018-21) are:

- Quality and safety of health services
- Primary health care
- Self-management of chronic conditions
- Health of older people
- Out of pocket cost of health care for consumers

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:

- policy priority setting (Executive Committee, with input from all members),
- participation on external committees (see 3.2),
- providing feedback to HCCA (surveys, focus groups, reviewing policy submissions etc),
- participating on Consumer Reference Groups (see 4.1.2.1), and
- 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 Advisory Committee, and
- 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 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:

- ACT Quality and Safety Consumer Reference Group
- ACT Accessibility and Design Consumer Reference Group
- ACT Health of Older People Consumer Reference Group
- ACT Digital Health Consumer Reference Group

3.1.4. Participation in research

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

- What HCCA means by consumer-based 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 and design

Consumer representatives work closely with HCCA staff to ensure we have effective community involvement in setting health planning priorities., All health and community buildings should facilitate consumer centred care, and be sensitive and respectful of the cultural needs of our community.

Consumers participate in health service planning and design in three ways:

- they contribute as members of planning and project decision-making committees, and
- they 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.
- They participate in user testing of design solutions.

3.1.6. Participation in health service governance

The consumer voice brings a valuable perspective to health service governance. This is achieved through consumer participation on health service committees - for example clinical governance committees and advisory groups.

3.2. Consumer Representatives Program

HCCA’s Consumer Representatives Program (CRP) is an important plank 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 commitments that cannot be met by the existing consumer membership.

HCCA may not receive any consumer nominations for a role.

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 are connected to consumer views and experiences through the relevant HCCA Consumer Reference Groups, and can use these and other HCCA networks and events to seek consumer input and views on their committee work.

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 that require different degrees of activity and commitment from consumers and communities. The spectrum of participation[6] (figure 1) shows the different levels at which participation can occur.

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 informing health care in the ACT.

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

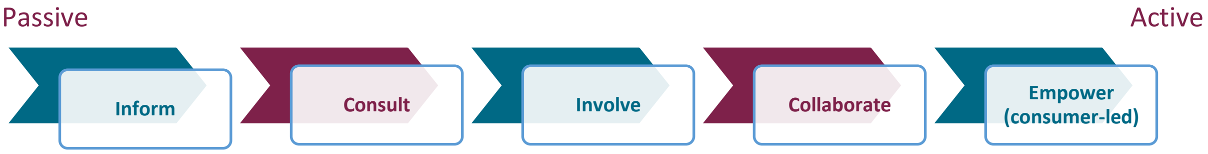

Figure 2: Spectrum of participation IAP2

Inform – 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,
- Health Issues Groups (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 and research issues. Consumer and community input inform the policy and research work. 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 but recognise online meetings can be necessary, depending on the circumstances, for example because of 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 all 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 undertaken by the Executive Committee every four years in consultation with members.

The following considerations inform HCCA's decisions on undertaking specific consumer participation research and policy projects:

- alignment with at least one of HCCA's priority policy areas,
- anticipated level of impact for health care consumers if project proceeds,
- whether the issue is specific to the ACT, or one where ACT health care consumers are uniquely positioned to comment,
- whether another organisation is already supporting consumer and community participation on the issue/topic under consideration, and
- whether the project provides an opportunity to support the education of health service staff in enabling consumer participation.

The following considerations inform HCCA's decision on the most effective and appropriate mode/level of consumer participation:

- the type and scale of project, e.g. the purpose of a committee and its level of importance,
- the timeframe,
- the budget,
- HCCA staff capacity, and
- HCCA access to relevant consumer/community cohorts.

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.”[7]

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.[8]
- 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.[9]
- 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.[10]
- 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.[11]

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 volunteers 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

Consumer-based Research Framework, March 2019

Consumer-centre Care Position Statement

Health Literacy Position Statement

Health Policy Development Framework, August 2020

Health Promotion Framework for Health Care Consumers' Association of the ACT, November 2018

Strategic Plan 2018-2021

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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.

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

[6] 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.

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

[8] 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.

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

[10] 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.

[11] 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.