



Consumer Participation^a in Research Position Statement

Health Care Consumers' Association (HCCA) supports consumers who want to participate at all stages and at all levels of research. Consumer participation in health, medical and social services research ensures that consumer priorities are better understood by researchers, decision-makers and the public.

Consumer participation in research is important. The very involvement of consumers in research helps make it seem a normal part of research. It also demonstrates the value of including consumers in decisions and research that affects them.¹

Consumers have the right to be involved in research.² Furthermore, it is the responsibility of Australian researchers and research institutions to encourage and support consumer involvement in their research.^{3,4}

HCCA's commitment to consumer participation in research

HCCA will support consumers who wish to participate in research.

Where HCCA undertakes research, it will accord with its *Consumer-Based Research Framework*.⁵

HCCA will help build the capacity of other organisations who involve consumers in research.

What are the benefits of consumer participation?

Research in which consumers are meaningfully involved is more likely to

- be relevant to community needs,
- deliver greater public awareness of research findings, and
- deliver better health outcomes.⁶

Consumer participation in research benefits consumers because it raises the public and research profile of people's lived experiences of health care.⁷

^a Some national bodies, such as the NHMRC use the term "consumer involvement". HCCA's use of the term "consumer participation" similarly relates to the full extent that consumers can participate in research. The terms are interchangeable in this context.

What does ideal consumer participation in research involve?

Health, medical and social research is improved when consumers are engaged at **all levels** and **all stages** of the research. Ideally, consumers are not just research participants. They are also involved in conducting and governing research. Consequently, consumers are involved from the early stages of deciding what and how to research, through undertaking the research, to disseminating the findings and deciding what to do next.⁸

Authorisation and Review

Endorsed by the HCCA Executive Committee September 2019

Due for review September 2022

¹ Consumer-Centred Care Position Statement. Health Care Consumers' Association. Canberra, Australia: June 2018. Available at <https://www.hcca.org.au/wp-content/uploads/2019/03/20190325-Consumer-Based-Research-Framework-FINAL-WebVersion.pdf> (Accessed 4 June 2019).

² Statement on consumer and community involvement in health and medical research. National Health and Medical Research Council and Consumers Health Forum of Australia. 2016. Available at <https://www.nhmrc.gov.au/sites/default/files/documents/reports/consumer-community-involvement.pdf> page 2.

³ Australian Code for Responsible Conduct of Research. National Health and Medical Research Council, Australian Research Council, and Universities Australia. 2018. Available at <https://www.nhmrc.gov.au/about-us/publications/australian-code-responsible-conduct-research-2018>

⁴ Statement on consumer and community involvement in health and medical research (See note 2)

⁵ Consumer-Based Research Framework. Health Care Consumers' Association. Canberra, Australia: March 2019. Available at <https://www.hcca.org.au/wp-content/uploads/2018/09/Consumer-Centred-Care-Position-Statement-FINAL-.pdf>

⁶ Statement on consumer and community involvement in health and medical research (See note 2)

⁷ Consumer-Based Research Framework (see note 5)

⁸ Statement on consumer and community involvement in health and medical research (See note 2)