

GUIDING PRINCIPLES for Consumer and Community Involvement in Health Research at Sydney Health Partners

ABOUT OUR GUIDING PRINCIPLES

These Guiding Principles were developed by consumer and researcher members of the Steering Committee for the Strengthening Consumer Involvement in Health Research across Sydney Health Partners, Stage 2 Initiative. They were developed alongside the Sydney Health Partners (SHP) Consumer and Community Involvement (CCI) Guiding Framework and Language Guide.



The Steering Committee built on the principles set out in the joint *Consumer and Community Involvement in Health Research Position Statement* of the Australian Health Research Alliance and the Consumers Health Forum of Australia.

Involvement refers to a partnership between consumers and researchers, where consumers are actively involved in the research process. It has been described as doing research 'with' or 'by' people who use health services, rather than 'to', 'about' or 'for' them. Partnership in health research is a community expectation as well as a policy imperative.

Consumers can be involved in research in many ways, including as consumer representatives on a research committee, as co-researchers doing the actual research, or co-writing research reports and presenting at conferences. Involvement in this context means more than being a participant in a study.



CONSUMER AND COMMUNITY INVOLVEMENT GUIDING PRINCIPLES

RESPECT

- Consumers, people with lived experience, and the community have the right to be actively involved in health research.
- The roles and responsibilities of consumers, community members and researchers should be understood and agreed. Involvement in research should be meaningful, rigorous and genuinely contribute to the research process.
- Researchers should use plain language and be mindful of acronyms and jargon.

EQUALITY

- Consumers and the community should be equal partners with health researchers, based on mutual trust with a shared belief in the value of research.

INCLUSION

- Health and medical research should be inclusive to meet diverse consumer and community needs.
- Consumer and community member involvement should be planned from the beginning of the research project, and resourced, monitored and reported.
- Training, support and mentoring (including peer mentoring) should be provided to consumers, community members and researchers to work together effectively.
- The contributions made by consumers and community members should be fairly and appropriately recognised and acknowledged (including authorship and intellectual property rights), as well as remunerated.

EVIDENCE

- Health research involving consumers and community members should both build on and contribute to the evidence base on consumer and community involvement.
- Good practice in consumer and community involvement should be essential components of research excellence and project impact.