

A checklist for researchers

As consumers are set to benefit from the results of MedicineInsight research projects, it is essential that they are included in the research process. Their involvement and influence will also help ensure that the value of any research is optimised. Consumer engagement is a requirement for the MedicineInsight Data Governance Approval process.

The following checklist is a guide to help you get the most out of consumer input for your research project.

What is consumer engagement?

Engagement means involving consumers throughout the research process, from design to delivery. It incorporates the insights, experience and needs of consumers into decision-making and is an increasing requirement for health researchers and funding bodies.

Benefits of involving consumers

Consumers help improve:

- ▶ Research relevance and quality
- ▶ Prioritisation of resources
- ▶ Quality of outcome measures
- ▶ Recruitment and retention
- ▶ Dissemination of findings
- ▶ Translation of research
- ▶ Accountability
- ▶ Cost effectiveness
- ▶ Public confidence

Who are consumers?

Consumers could include:

- ▶ End users of research
- ▶ Potential users of research
- ▶ Those with lived experience
- ▶ Carers and family members
- ▶ Consumer representatives
- ▶ Communities
- ▶ Consumer organisations

When to engage consumers

Consumers can contribute to all stages of your project:

- ▶ Developing research questions
- ▶ Project scoping and design
- ▶ Ethics review
- ▶ Data collection
- ▶ Analysis
- ▶ Publication
- ▶ Dissemination

Strategies and considerations

Participation

- ▶ Advertise opportunities widely
- ▶ Options for varied involvement

Diversity and inclusion

- ▶ Accommodate health literacy
- ▶ Remunerate time and input
- ▶ Address barriers to engagement

Leadership and support

- ▶ Provide training and support
- ▶ Remunerate time and input

Meaningful, mutual benefit

- ▶ Ensure meaningful participation
- ▶ Allow time to engage well
- ▶ Clear communication of roles

Accountability

- ▶ Be guided by evidence
- ▶ Provide feedback on influence

Ethical, respectful, valued

- ▶ Be safe, secure and welcoming
- ▶ Build trust and openness
- ▶ Respect consumer contribution
- ▶ Identify stigma and discrimination
- ▶ Publicly recognise consumer role
- ▶ Offer confidentiality or anonymity

Accessing Consumers

Consumer groups can assist and provide advice for accessing consumers:

- ▶ [Consumers Health Forum of Australia](#)
- ▶ [Health Care Consumers' Association \(ACT\)](#)
- ▶ [Health Consumer Advocacy Network of South Australia](#)
- ▶ [Health Consumers NSW](#)
- ▶ [Health Consumers QLD](#)
- ▶ [Health Consumers Tasmania](#)
- ▶ [Health Issues Centre \(VIC\)](#)
- ▶ [Health Consumers' Council \(WA\)](#)

Note. The above is not an exhaustive list. Other consumer groups that specialise in specific diagnoses or population groups may also be considered.

Other resources

For further information:

- ▶ **NHMRC:** [Statement on consumer and community involvement in health and medical research](#)
- ▶ **The Purple Book:** [Planning for Consumer and Community Participation in Health and Medical Research](#)
- ▶ **The Green Book:** [Consumer and Community Participation in Health and Medical Research](#)
- ▶ **Clinical Trials Alliance:** [Consumer Involvement Pack](#)
- ▶ **Research4Me:** [Consumer database](#)
- ▶ **Effective Engagement: building relationships with community and other stakeholders:** [Book 1](#), [Book 2](#), [Book 3](#)

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