

# The Value of Consumer and Community Involvement in Health and Medical Research

## A Narrative Review



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# Context

The Australian Health Research Alliance (AHRA) Consumer and Community Involvement initiative demonstrates a shared vision and priority activities to enable consumer and community involvement in policy and practice across Australia. AHRA have also collaborated with Consumer Health Forum and the Commonwealth Department of Health.

One of the priority activities within the AHRA research and evaluation program is to identify:

- how to effectively increase consumer and community involvement in health and medical research;
- how to effectively measure the impact of consumer and community involvement in health and medical research; and
- how to effectively measure the efficiency of existing consumer and community involvement.

The initial task aligned with this priority is to develop a paper describing the case for consumer and community involvement in health and medical research, presenting the current evidence on the value of involvement. This paper, developed by Health Translation SA with assistance from SAHMRI, addresses this task.

SAHMRI undertook a review of existing literature which indicates the value and importance of community involvement in health and medical research, using the search method described in Appendix A. The full list of literature identified is presented in Appendix B. SAHMRI then invited consumer and community review via the SAHMRI Consumer and Community Advisory Group; the Committee which has oversight of the SAHMRI Framework for Consumer and Community Involvement and reports on progress against that Framework to the SAHMRI Board.

# Background

## Consumer and Community Involvement in Health and Medical Research

**Consumers affected by, or paying for, health and medical research have an ethical right to be involved in and influence how and what research is undertaken [1-3].**

The NHMRC recognises that community involvement adds value to health and medical research [4]. Community involvement should be a meaningful and impactful active partnership that benefits all, not a tokenistic activity [5, 6].

The Australian Code of Research (2007)[7] states that “Appropriate consumer involvement in research should be encouraged and facilitated by research institutions and researchers.” This is supported by the World Health Organization and United Nations Children’s Fund (UNICEF) Declaration of Alma Ata [8] which declares that “The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.” Involving the community in research also reduces the power imbalances between researchers and patients, which is especially important with marginalised and vulnerable populations [9, 10].

## Benefits for Research Institutions from Consumer and Community Involvement

**Community involvement in health and medical research increases public confidence in research [4] through increased accountability, transparency, and credibility of the research [11-15]. When the community has a greater understanding of the research being undertaken, their trust in the researchers increases [4, 13, 16] and relationships between communities and researchers are strengthened [1].**

Research findings become more accessible to the community through their involvement in research [1, 17, 18]. As a result, the community can become advocates for research and assist with the dissemination of results and building a sense of community [13-16]. Community members can also lobby to ensure that research outcomes are implemented in practice [14].

Community involvement is commonly required in many grant applications [19, 20]. Explicitly describing plans for community involvement in grant applications increases credibility, feasibility, and improves the study design. As a result, the chance of funding increases [1, 18, 21-23]. Community involvement in the review of grant applications also challenges researchers to greatly consider the consumer perspective. This has the potential to result in projects most relevant to the community being funded [2, 24, 25]. Involving the community also ensures that the research being conducted is beneficial for communities, this protects against money and resources being misused [1, 26].

## Benefits for Researchers from Consumer and Community Involvement

**Researchers benefit from community involvement in health and medical research in multiple ways. Community involvement improves the quality of research through the introduction of a fresh and independent perspective [6, 13, 15, 27-29], and ensuring research addresses community needs and policy objectives [1, 2, 4, 6, 17, 30-32].**

Community involvement can benefit researchers at all stages of a research project. Involvement during the early stages can improve the ethical acceptability of the project through the early identification of potential ethical concerns [1, 17, 33]. The community can also assist researchers throughout the study in how they can better deal with sensitive and ethical issues [2, 15, 17, 30]. The recruitment and retention of study participants are greatly improved with community involvement through increased access to marginalised populations, seldom heard groups, those with rare conditions, and the community can help study participants overcome barriers to being involved in research [1-3, 14-16, 18, 21, 34-38]. Consumer involvement during clinical trial protocol development can also provide a financial benefit. Above, increased enrolment, adherence, and retention, involving consumers during protocol development has been found to avoid the need to submit a protocol amendment, which can be a costly exercise [39]. Involving the community during study development improves research tools such as surveys, questions for interviews and focus groups, patient information sheets, and promotional leaflets, through the writing of less jargon-heavy study materials [1]. Community involvement also ensures the appropriate use of outcome measures [1, 14, 16, 33, 40, 41]. This ensures that the correct language is used [42], questions are sensitive to the community and are culturally relevant [17, 36, 43-45], and survey/interview lengths are appropriate [45]. During qualitative data collection (i.e. using the community as interviewers), community involvement can improve validity and result in better quality data through enriched discussions and development of trust with research participants [1, 2, 18, 46-48]. Involving the community in qualitative data analysis can also assist in identifying relevant themes [2, 49-51]. The dissemination and translation of research outcomes can be improved through the community's increased awareness of study results [1, 4, 6, 22, 35, 38, 52, 53].

Importantly, community involvement can increase researchers' confidence in their work [22], motivation to work towards solutions [16, 18], and understanding of the consumer perspective and community health needs [2, 18, 35, 41]. This can also lead to increased work satisfaction through greater awareness of the impacts their research has on communities [15, 54].



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## Benefits for Consumers and Community Members from Consumer and Community Involvement

Engaging the community in research ensures that issues which are important to the community are identified and prioritised, resulting in research that is relevant to community needs instead of research being driven by investigators' interests [4, 6, 14, 15, 18, 19, 55]. The community's quality of life is typically improved through the resulting higher quality research and greater translation of research into practice [2, 6, 14, 56].

Community involvement can provide consumers with a better appreciation of the research process [1, 54, 57], and subsequently increase community research literacy [2, 15, 18, 54, 58]. During involvement in research, the community can develop new skills such as questionnaire design, interviewing, data analysis, computer use, communication, and ability to work in a team [1, 15, 18, 44, 50, 53, 59-61]. There is often a financial reward for community members who become involved in research [1, 62], and the development of these skills can improve members' future employment prospects [2, 13, 46, 48, 50].

The community can benefit from listening to other members stories and connecting them with others who have similar conditions [1, 63, 64]. This improves community members access to information on their conditions [13, 18, 29, 65]. As a result, this can increase consumers self-worth [2, 51, 58], self-confidence [1, 37, 41, 44, 48, 62, 63, 66], make consumers feel empowered [1, 16, 27, 36, 41, 54, 57, 63, 67], and build community support and friendship [1, 13, 15, 41, 56, 57, 59, 63]. Community involvement in health and medical research can also make members feel like their lives have a purpose, that they are doing something meaningful and giving back to the research community [13, 16, 18, 57, 62, 68, 69].

## Conclusion

This paper presents a succinct description of current evidence supporting the value of involving consumers and community in health and medical research. There is widespread acknowledgement and substantial evidence that the case is strong for meaningful consumer and community involvement across all phases and stages of health and medical research.

### Suggested citation:

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## Appendix A: Search Method for Position Statement

In November 2019, the databases PubMed and Scopus were searched using the concepts and keywords in Table 1 with relevant wildcards. The keywords for each concept were combined with OR and the concepts were combined with AND.

*e.g. (consumer OR community OR patient OR public OR client OR user OR lay) AND (involvement OR engagement OR participation OR Collaboration) AND (health OR medical OR bio-medical) AND (research OR evaluation)*

No limits were applied to the searches and search results were ordered by 'best match'. From reviewing titles and abstracts, the relevant results were imported into the EndNote library. Approximately the first 10 pages of results were screened as at this point multiple systematic reviews and papers had been identified, saturation had occurred. The search results were then sorted by 'most recent' to ensure that the most recently published studies were included.

A Google search for grey literature including government documents, research reports and non-governmental organisation papers was also completed.

Table 1: Search Terms

Concept 1	Concept 2	Concept 3	Concept 4
Consumer	Involvement	Health	Research
Community	Engagement	Medical	Evaluation
Patient	Participation	Bio-medical	
Public	Collaboration		
Client			
User			
Lay			

Relevant information for the position statement was extracted from systematic reviews and other major reports. The following information was included in the Excel literature table:

- Author/s
- Year of publication
- Title
- Aim/objective of study/report
- Definition of community involvement
- Why community involvement is important
- Ethical considerations of community involvement
- Organisational benefits of community involvement
- Benefits of community involvement (for researchers and community members)
- Challenges of community involvement (where reported)
- Key elements for effective involvement (where reported)

Data was not extracted from individual studies/reports if they had been included in a systematic review or other major report. Data was extracted from recent individual studies, although it was evident that literature saturation had occurred as these studies did not add any novel information.

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## Appendix B: Full list of literature produced by search [1-108]

- a1. Allen, J., et al., *The Tools to Understand*. 2006. 32(1-2): p. 41-59.
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