

Consumer and community participation in health research

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Consumer and community participation in research is the term used to describe the active involvement of health consumers and community members

as members of research teams, management committees or advisory groups. Many people describe this participation as undertaking research with or by consumers and community members, rather than to or about them.

Creating opportunities for consumers and community members to have a 'voice' at all levels and in all stages of health research has been the driving force behind the consumer and community engagement program at the University of Western Australia's School of Population Health (the School) and then the Telethon Institute for Child Health Research (the Institute).

This engagement program, which began at the School in 1998, was aligned to the recommendations made by health consumers to the National Health and Medical Research Strategic Review (the Wills Review) that consumers should be able to participate in decisions about prioritising health-related research; that those who take part in that research are informed of the outcomes; and that researchers involve the community in decision making relating to research.

In 2002 a joint consumer and community engagement program between the School and the Institute commenced. This joint program was underpinned by the principles outlined in the National Health and Medical Research Council (NHMRC) and the

Consumers Health Forum of Australia (CHF) joint *Statement on Consumer and Community Participation in Health and Medical Research (2002)*¹ and *Model Framework for Consumer and Community Participation in Health and Medical Research (2004)*².

Having a long-term strategic plan to manage organisational and cultural change that is inclusive of both staff and community aspirations and values has resulted in a strong, sustained engagement program that is consistent with, and to a great extent exceeds, the recommendations outlined in the NHMRC and CHF Statement and Framework.

The engagement program at the School and the Institute has included the following components:

- Senior level support and commitment;
- A dedicated Consumer Advocate on staff;
- Development of a formal governance and policy framework for participation, including the establishment of Consumer and Community Advisory Councils at both institutions;
- Budgeted participation activities/roles in research grant applications;
- Development of a range of models for consumer and community participation in individual research projects;
- Creation of training workshops relevant to participation for researchers and consumer representatives;
- Development of resources for researchers, consumers and community members on implementing consumer and community participation; and

- Forums that bring researchers, other professions and consumers and community members together to make decisions about research priorities, methodologies, results and dissemination to the community.

Program Activities

The activities of the engagement program have arisen from a variety of events, forums, workshops, presentations, representation at meetings, training sessions and delegations. Attendees at these diverse events and activities have included researchers, students, consumers, community members and staff from government agencies and non-government organisations.

The Health Consumers' Council of WA has had an integral role in providing advice, mentoring and support for many of these activities.

Since 2004, over 500 consumers and community members have attended events to provide input into priorities for current and future research as evidenced in the graphs below. The steady increase of consumers and community members in attending participation events (Graph 1) as well as the increased formal involvement in research-related committees (Graph 2) demonstrates the immense benefits of this program to both the organisation and the wider community.

Key achievements

Highlights of the consumer and community engagement program to date include:

- Establishing Consumer and Community Advisory Councils at both organisations. The Councils, which include consumers, community members and senior research staff, work together to



develop strategies to increase participation at an organisational level.

- Collaborating with a leading UK Consumer Advocate, Ms Bec Hanley, to publish a resource manual for researchers.³
- Initiating and hosting the inaugural national *Involving People in Research Symposium* in 2008. This event was jointly sponsored by the NHMRC, the Health Consumers' Council WA and four Western Australian universities. The Symposium was attended by over 240 researchers, consumer and community members from across Australia, New Zealand and the United Kingdom.
- The unexpected additional benefits from consumer and community involvement in individual research projects such as a consumer panel highlighting major safety and quality issues relating to non-specific dosing instructions on prescription medicines. This has led to ongoing advocacy with relevant government agencies for changes in national policy to address this unsafe practice.
- Further collaboration with UK Advocate Bec Hanley to develop training workshops for researchers on the 'how and why' of implementing consumer and community participation in research.
- Developing a Fact Sheet Series on Consumer and Community Participation in Health Research in direct response to requests from researchers for simple, easy to access web resources.⁴

The consumer and community

engagement program at the School and the Institute has so far shown a steady uptake from both researchers and consumers who have a common interest in increasing participation in research.

At the *Involving People in Research Symposium*, researchers identified a need for training and ongoing support to enable greater participation. We responded to this request by developing specific training packages on implementing consumer and community participation in health research. A recent addition to this ongoing support has been the creation of a Fact Sheet Series which is now available as a web resource and will complement the training workshops.

In the past two years, over 200 researchers, students and policy and administration staff from across Australia have now attended the training workshops on implementing consumer and community participation in health research. The workshops have proven to be very effective in providing researchers with practical skills and support. Eighty-two percent of attendees indicated they intend to change their practice to increase participation. These claims have subsequently been validated by an increase in requests for advice and support and the adoption of strategies to increase participation.

Our engagement program actively supports researchers as well as providing consumers and community members with appropriate access and supports to be meaningfully involved in a wide range of research projects. There has been a shift in attitude with researchers now asking "how do we do this" rather than the "why do we need to?"

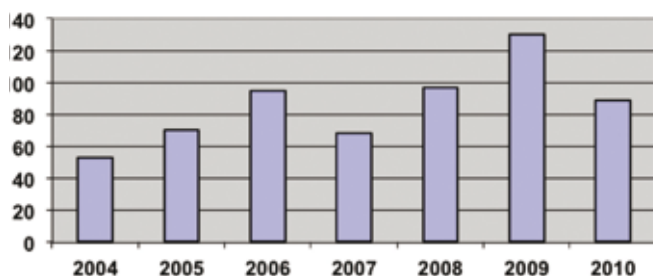


Training workshop for researchers University of Western Australia, April 2009

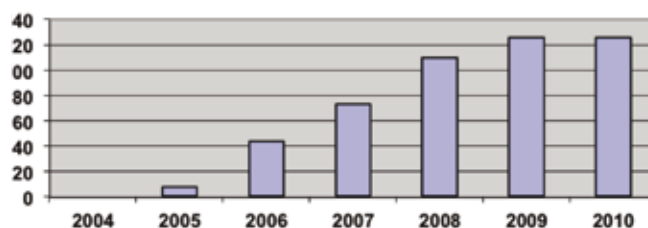
While there is still a way to go before it can be said that consumer and community participation is standard practice in all levels and in all stages of research, there is a definite increase in awareness of the positive benefits and contribution consumers and community members can make to health research at both the School and the Institute.

Anne McKenzie is an experienced consumer representative, and works as a Consumer Advocate at the University of Western Australian School of Population Health and the Telethon Institute for Child Health Research.

- 1 Available online at <https://www.chf.org.au/pdfs/pos/pos-consumer-community-participation.pdf>
- 2 Available online at <https://www.chf.org.au/pdfs/crr/crr-model-framework-for-participation.pdf>
- 3 McKenzie, A. and Hanley, B. 2007. *Consumer and Community Participation in Health and Medical Research: a practical guide for health and medical research organisations*. Perth: The University of Western Australia and The Telethon Institute for Child Health Research. Available online at <http://www.involvingpeopleinresearch.org>
- 4 Available online at <http://www.involvingpeopleinresearch.org>



Graph 1: Consumer and community attendees at events 2004 - 2010



Graph 2: Consumer and community members involved in research committees 2004 - 2010