Consumer and Community Participation Fact Sheet P01: Why Involve Consumers and Community Members in Research?

What is consumer and community participation?
• Consumers, community members and researchers working together to shape decisions about research priorities, practice and policies.
• It is an active partnership that is sensitive to changing needs and priorities.
• It is about being part of the process as well as observing or commenting.
• Conducting research that is with the community rather than to or for the community.

And what it is not….
• Being the participants (subjects) in research.
• A recruiting tool.
• An opportunity to ‘tick the box’.
• Fundraising event or opportunity.

Requirements for consumer and community participation
• Funding requirement.
• Ethics requirement; research that involves Aboriginal and Torres Strait Islander communities in Australia must involve the community in all aspects of the research.
• National Health and Medical Research Council requirement

What are the benefits?
• Research is more relevant to the community.
• Greater transparency, openness and accountability.
• Consumers and community members can help with recruitment of their peers by overcoming barriers to being part of the research.
• Consumers and community members can help to access other people including those who are marginalised.
• May help to avoid making practical mistakes that are obvious to consumers; eg, are you holding a meeting for mothers at 8.00am just as they are preparing children for school?
• Consumers and community members can help to disseminate the results of research and lobby to ensure that changes are made and research is more widely applied.

Researcher’s comments about the importance of participation:

“It’s something that should be done, in my view, simply because it is the right thing to do … my experience in over 10 years now of embracing the ethic of community participation is that it does in fact produce benefits for the researcher … when you come to actually producing your results… the community becomes your ally and they will assist you disseminating and advocating for those results where it really counts”. (Professor D’Arcy Holman)

“If we have the attitude that involving consumers and the community will improve our research … it means our research may be more relevant…we may go into a new research area because the community thinks its important and we respond to it. … The way that we then feed our research back to people means that that will enable them to use the research information in ways that improves their health and their well being”. (Professor Fiona Stanley)