



## Consumer and Community Participation Fact Sheet M02: Reference Groups

### What is a reference group?

A reference group is a group of consumers and community members that can be referred to by researchers throughout the research. Reference groups are sometimes referred to as a Reference Panel.

### Who would be in a reference group?

- Consumers and community members.
- Members of consumer advocacy organisations and/or non-government organisations.
- Other stakeholders of the research (Fact Sheet T01).

### Planning considerations:

- Reference groups can provide advice for all or part of the research project.
- Representatives of the reference group may be on the main research team and report back to the reference group.
- Reference groups can be particularly helpful in getting information out to a large number of people who may have an interest in the research or its findings.
- What support and/or training will be needed or be offered?
- Time for a member of the research team will have to be set aside to organise and support meetings.
- Is there a budget for payment of expenses and/or honorariums? Has it been discussed with the members?
- Provide updated information about the research project to the reference group prior to any meetings.
- Work with consumers and community members to decide what is the right number of people for your group. This will often depend on the size and topic of the research project so it is important to make sure you have enough members to generate a wide range of ideas and perspectives.

**Deciding if consumers and community members of steering groups can also be participants in the research can be a dilemma. It is important for each research project to consider issues about ethics, confidentiality and bias.**



The Infectious Diseases Research Group at Telethon Kids Institute established a community reference group in 2008.

A key task for this group has been to work with researchers on plain language summaries of all research projects.

Although this task took many months to complete it had the added benefit of giving all members of the reference group a clearer understanding of the diverse range of topics being researched.

The reference group is confident the project summaries are now in a format and language that will be more readily understood by the wider community. The summaries will be available on the Institute's website.

### Practical issues:

Develop draft Terms of Reference and a plain language summary (Fact Sheet M11) of the research for the group – be prepared to accept changes from the reference group and be upfront about items that are not open to negotiation.

See other Consumer and Community Participation Fact Sheets for help in:

- Identifying appropriate consumers and community members (Fact Sheet P4).
- Organising the first meeting (Fact Sheet P5).