

**PRIMARY HEALTH CARE RESEARCH EVALUATION AND DEVELOPMENT  
WESTERN AUSTRALIA (PHCREDWA)**

**CONSUMER ADVISORY GROUP**

**GUIDELINES FOR CONSUMER AND RESEARCHER ENGAGEMENT  
IN PRIMARY HEALTH CARE RESEARCH**

**Revised 2008**

PHCREDWA Consumer Advisory Group prepared these guidelines to enhance research associated with the Primary Health Care Research, Evaluation and Development program. The guidelines provide a strategy for consumer participation with researchers in primary health care.

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# **PRIMARY HEALTH CARE RESEARCH EVALUATION AND DEVELOPMENT WESTERN AUSTRALIA (PHCREDWA)**

## **GUIDELINES FOR CONSUMER AND RESEARCHER ENGAGEMENT IN PRIMARY HEALTH CARE RESEARCH**

### **Introduction**

The PHCREDWA Consumer Advisory Group (“Group”) is in agreement with the Consumers’ Health Forum of Australia (CHF) and National Health and Medical Research Council (NHMRC) principle that advocates consumer participation in research.

The Consumer Advisory Group guidelines address:

- Processes by which consumer representatives can participate in and contribute to primary health care research development; and
- Strategies for engagement between researchers and consumers before, during and at the completion of research activity.

The guidelines aim to:

- Provide a framework for Consumer Advisory Group members to identify issues and comment on aspects of primary health care research proposals that are relevant for consumers.
- Encourage researchers in developing research proposals for consumer comment.
- Assist researchers to select, recruit and communicate with consumer representatives and with community participants during the conduct of research.
- Promote consistency in criteria used for consumer feedback.

The guidelines comprise three parts:

Part 1 – Consumer Participation in Research – utilising consumer perspectives

Part 2 – Preparation of Research Proposal – the researcher and consumer  
inter-face

Part 3 – Consumer Checklist – aspects for inclusion

### **PART 1 – CONSUMER PARTICIPATION IN RESEARCH**

Consumer participation in research has the potential to improve primary health care outcomes and can increase responsiveness by researchers to community health needs and to consumer perspectives. In addition, funding bodies may require consumer consultation to be included in primary health care research applications.

Consumer input into primary health care research promotes:

- Evidence based models for consumer participation in research

- Collaborative methods of research and evaluation that may include consumers as part of a research team
  - Incorporation of consumer needs and interests into the primary health care research agenda
- (Adapted from Eyre Regional Health Service 2007)

### **Timing of consumer involvement**

To maximise benefit for the research and to ensure that consumer involvement meets the processes and requirements of the funder, the Consumer Advisory Group recommend that researchers meet with them at the earliest opportunity to discuss any relevant participation by the community. Further meetings can be arranged if requested prior to submission of a proposal for approval by an ethics committee.

### **Confidentiality**

The Consumer Advisory Group members acknowledge the need for confidentiality. Their involvement in any aspect of research precludes them from discussing or providing material associated with a research proposal to any external parties.

### **Conflict of interest**

Where a Consumer Advisory Group representative identifies a potential conflict of interest in relation to a research proposal, they will inform the Group and\* exclude themselves from any discussion pertaining to the area of conflict.

## **PART 2 – PREPARATION OF RESEARCH PROPOSAL**

In preparing a primary health care research proposal for Consumer Advisory Group comment, note the following:

### **Research proposal presentation**

- The nature and scope of a research proposal will determine the extent of consumer involvement in the process. Small scale research may require minimal, if any, consumer input.
- The Consumer Advisory Group recommends that researchers meet face-to-face with them prior to developing a proposal. This meeting would be an opportunity for researchers to outline their proposal and to obtain feedback on those aspects relevant to potential participants and to consumer interests.
- Research proposals for consumer comment should be written in plain English to assist the understanding of any person with limited experience in research.

- The Checklist (Part 3) is a guide for researchers when preparing a proposal, taking into account consumer perspectives.

### **Participant recruitment process**

Consumer Advisory Group members can offer assistance in recruiting participants for a research project, or facilitate access to community networks.

### **Dissemination of information**

Dissemination of research results is important for building confidence between practitioners and communities. Consumer Advisory Group members can advise on the dissemination of completed research to various community groups.

### **Cross cultural community groups**

Primary health care research proposals involving Aboriginal and other culturally and linguistically diverse (CALD) groups should be communicated to representatives of these communities.

## **PART 3 – CONSUMER CHECKLIST**

Researchers may refer to this checklist as a tool to assess consumer interests and/or to submit a summary of their proposal for discussion with the Consumer Advisory Group. On request, and within an agreed timeframe, the Consumer Advisory group will prepare comments and return this feedback to the researcher.

### **The Consumer Advisory Group recommends that the proposal:**

- Briefly explains the need for proposed research in primary health care.
- States the aims, objectives or purpose of the study.
- Describes the proposed participants for the research
- Addresses ethical questions relevant to study participants. For example,
  - Consent
  - Privacy and anonymity
  - Confidentiality
  - Risk of harm
  - Equity
- Provides a point of contact (name, telephone, email) for participants, and a statement regarding any problems or complaints that may arise from participants.

- Outlines the potential benefits for participants and population group represented.
- Plans for feedback to participants and/or follow-up where relevant.
- Includes intentions for disseminating the results of research to consumer groups.
- Uses terminology that is clear, consistent, unambiguous, and non-discriminatory.
- Includes documents relevant for consumer representative comment. For example:
  - Participant Consent Form
  - Information Sheet
  - Lay Summary
  - A copy of the questionnaire to be used (if relevant)
- Where research specifically involves an Aboriginal community, approval is sought from the Western Australian Aboriginal Health Ethics Council (WAAHEC). (Note: this is a mandatory requirement for any research projects specific to Aboriginal people.)

### **Process for requesting CAG comments**

- Proposal forwarded to PHCRED WA Statewide Coordinator and distributed to Consumer Advisory Group with a nominated timeframe for return of individual consumer comments.
- Individual comments compiled and a summary circulated to Consumer Advisory Group for further comment.
- A final summary will be forwarded to researcher.
- Consultation between a researcher and the Consumer Advisory Group can occur at any time as well as prior to submission of proposal and/or following receipt of the final summary.

### **REFERENCES**

Cancer Council New South Wales *Consumer Review of Research Grants: Guidelines for the preparation and review of research grant applications, 2007.*

Consumers' Health Forum of Australia and National Health & Medical Research Council *Summary Statement on Consumer and Community Participation in Health and Medical Research* Commonwealth of Australia 2002

Commonwealth of Australia. *National Resource Pack for Consumer and Community Participation in Health and Medical Research* 2005 available at: <http://www.nhmrc.gov.au/publications/files/r34.pdf>

Eyre Regional Health Service Inc. *About Consumer and Community Participation in Health* <http://www.erhs.sa.gov.au/2programs/downloads/ahac-about.pdf> [accessed 12.2.07]

## APPENDIX

### REPORT

Consumer representative: \_\_\_\_\_

Title of research proposal: \_\_\_\_\_

Chief researcher: \_\_\_\_\_

#### 1. Extent of Benefit

*Does the research have potential to positively impact on human lives? Benefit may include aspects of: disease causation and prevention; physical and/or mental and/or social well being; quality of life.*

**Comments:**

#### 2. Conduct of research

*Is there a clear description of the how the research will be conducted in order to achieve its' aims. Have ethical issues been addressed?*

**Comments**

#### 3. Potential for application of research

*Is there potential for real world application of the research in the long-term, such as improvements in primary health care practice, service delivery for consumers, and/or health care policy?*

**Comments:**

#### **4. Dissemination of results**

*What is the plan for circulating information on the results of the research to other researchers, participants and to the general community?*

**Comments:**