

APPENDIX A: A FRAMEWORK FOR EVALUATING CONSUMER PARTICIPATION

(This appeared as an appendix to the DHS Expression of Interest document for prospective Evaluating Effectiveness of Participation project applicants in February 2007)

The Cochrane Consumers & Communication Review Group has developed a framework which can help in the evaluation of consumer participation in health.

From a practical perspective, during preparation of the Evaluating effectiveness of participation project submissions (EEP), this framework could assist health services (individuals and organisations) in thinking about the evaluation of programs that focus on consumer participation; i.e. thinking particularly about:

- providing a frame of reference generally for evaluation projects
- identifying a quality and safety program area for improvement within the service
- identifying an area already implemented within the service which could be the focus of evaluation
- designing/selecting an intervention to affect change/improvement
- clarifying the purpose of interventions and possible effects
- directing people/health services to further explore Cochrane resources and information

What consumer and carer participation means to us

Consumer and carer participation is a very broad term which covers a wide range of ways that people can be involved in their health, health care and the health system. Broadly speaking, our view is that participation includes two over-arching social processes which are communication and participation.

'Intervention'

Interventions for communication and participation may have one or several purposes. They include those to promote consumers, patients and carers who are:

- More knowledgeable and competent;
- Able to express views and beliefs;
- Making choices alone or with health professionals;
- Supported or supporting;
- Understanding and minimising risks and harms;
- Accessing high quality information and quality health services;
- Participating in planning service improvement and research.

The term 'intervention' means an activity, action or series of linked actions that have a recognised objective to bring about outcomes linked to or caused by those actions. This distinguishes interventions from other sorts of activities where outcomes, or effects of interventions, may be left to chance or not taken into account, quantified or measured in some way. Interventions then might have one or more of these important characteristics:

- Purposeful and planned;
- Formalised;
- Structured and explicit;
- Repeatable;
- Sequenced;
- Modifiable;
- Classifiable.

Interventions for communication and participation to improve quality and safety

Here is an indicative list of interventions in the domain of quality and safety. They are illustrative of purposeful, structured and repeatable actions or activities which have the objective of improving quality and safety and minimising harms associated with treatment.

- Structured, deliberate communication with patients to confirm the site of surgery
- Information pamphlets on medications and their purpose
- Phone service for consumers to check on and report side effects of treatments
- Consumer involvement in safety reviews

Interventions for communication and participation in three policy domains

Here is an indicative list of interventions within the quality and safety domain for the three policy areas being addressed by EEP projects; i.e. in relation to each of the priority action areas outlined in the Department of Human Services policy document.

Individual care level:

- Personalised risk communication for informed decision making about entering screening programs
- Decision aids for treatment or screening decisions
- Interventions, such as education and support, to help people take their medications

Program or department level:

- Methods of involving consumers in the development of health information materials
- Written information for patients discharged from acute hospital to home
- Interventions for improving communication with children and adolescents about their cancer or a family member's cancer

Health service organisational level:

- Interventions for providers to promote a patient-centred approach to consultations
- Involving service users as service providers or as trainers for adult statutory mental health services

Further details of these interventions and links to systematic reviews of these interventions, or reviews in progress (called protocols); please refer to the Cochrane scope at: <http://www.latrobe.edu.au/cochrane/assets/downloads/scope.pdf>

Outcomes of interventions to improve communication and participation

Interventions are deliberate actions and they may have one or more objectives. Their outcomes, or their effectiveness, can therefore be measured. It is important to know the effects of interventions to ensure that society's resources are used wisely, to improve health and benefit all.

Traditionally, only a small range of health outcomes of interventions to improve communication and participation have been measured. Our Review Group (Consumers and Communication) – which combines the input of consumers, carers and researchers - has therefore identified a comprehensive range of outcomes that are important to communication and participation. Our taxonomy of outcomes (<http://www.latrobe.edu.au/cochrane/assets/downloads/Outcomes.pdf>) covers those of consumers and carers, providers, and health service-oriented outcomes. To follow is a list of the taxonomy's outcome categories, where each category can be broken down into more discrete outcomes, depending on the purpose and the interaction.

Consumer- and carer-oriented outcome category

- Knowledge and understanding
- Communication
- Patient and carer involvement in care process
- Evaluation of care
- Skills acquisition
- Health status and well being
- Health behaviour
- Treatment outcomes

Health provider outcome category

- Knowledge and understanding
- Consultation processes

Health service delivery oriented outcome category

- Use of health services
- Cost
- Adverse events

How the Cochrane Consumers & Communication Review Group uses the framework

The overall aim of the Cochrane Consumers & Communication Review Group is to provide evidence on effective ways of communicating with, and involving consumers and carers, in decision making about their health, healthcare services, research and policy.

We use the framework to help us in our main task - which is to coordinate and support researchers preparing systematic Cochrane reviews of interventions for communication and participation. The framework helps us clarify the purposes of interventions and to identify what kinds of effects are possible. You can see examples of Cochrane reviews, synthesising information on the effects of interventions for communication and participation, at www.latrobe.edu.au/cochrane