

Consumer Involvement in Dementia Research

Background

During 2005, more than 200,000 Australians -1% of the population - will have dementia. By 2050, it is projected that over 730,000 Australians will have dementia¹. The Australian Government has committed to making dementia a National Health Priority in recognition of the need for support, quality care, and continuing research for the increasing number of Australians affected by dementia². During the 2005 Federal Budget the Australian Government provided \$320.6 million to the initiative *Helping Australians with dementia, and their carers – making dementia a National Health Priority*. As part of this commitment, the government has allocated \$25 million over the next four years for dementia research. A National Dementia Research Workshop was held in Melbourne on the 29th August 2005 with the theme of promoting consumer involvement in dementia research. This Workshop confirmed that policy makers and research scientists are positive about consumer driven dementia research. A paper providing an overview of the Australian Government's support for Ageing Research and Dementia is at attachment A.

This paper will set the context of dementia research in Australia and identify mechanisms of consumer involvement.

Over the last four years, Alzheimer's Australia has promoted and participated in dementia research in several capacities including:

- advocating for increased investment in research on the basis of social and economic analysis;
- working to make research information more accessible to consumers and increase awareness of key findings and outcomes;
- forming partnerships with many Australian researchers and aiding in several research projects and consultancies; and,
- raising money for research and funding annual research grants.

Issues

Research funding and priorities

It is estimated that \$11.3 million Australian Government funding is likely to be targeted into dementia research in Australia annually. This is based on the Government commitment of \$25 million for dementia research over 4 years, combined with \$24 million over 5 years from the National Health and Medical Research Council (NHMRC), dependent on the applications received. A summary of NHMRC grants for 2004-05 related to Alzheimer's disease and dementia is at attachment B.

¹ *Dementia Estimates and Projections: Australian States and Territories*, Access Economics, February 2005

² *Dementia- A National Health Priority*, Printed and Authorised by B Loughnane, Barton ACT, September 2004

This represents 0.17 % of the total direct and indirect annual cost of dementia – estimated in 2002 to be \$6.6 billion dollars³. A research investment of 1% of the total costs of dementia each year would be \$66 million per annum.

Good information is not yet available about the balance of funding between different areas in dementia research. However, it is estimated that less than 10% of Australian research on dementia examines care and service provision, which have a major effect on the quality of life for people with dementia and their families and carers⁴.

The consumer summit on 5 - 6 October at Parliament House will provide a setting for discussion of consumer involvement in Australian dementia research, consumer research priorities and consumer views about preferences for the distribution of research funding in the areas of Cause, Cure and Care.

Consumer Involvement

Consumers can be involved in every aspect of the research process (Figure 1). The many possibilities for consumer involvement in research can be divided into three main avenues– strategic decision making, specific decision making, and outcome follow-up⁵.

Strategic decision making might involve setting research priorities or determining research strategies to influence the research agenda from the top down. Consumer involvement in specific decision making could involve reviewing proposals and making funding decisions, allowing for a consumer perspective in the allocation of funding. Outcome follow-up is equally important to monitor research progress and outcomes, create opportunities to communicate findings and promote the translation of research into practice. Within these areas, there are many possibilities for consumers to influence the research agenda from both the top and bottom end of the research process.

There are many benefits to consumer involvement in research – both to researchers and consumers. Consumer involvement promotes high quality relevant research with a wider perspective and accountability, high impact dissemination of research outcomes, and increased understanding and support for research. However, consumers and their organisations must be clear about their role and influence in the research process.

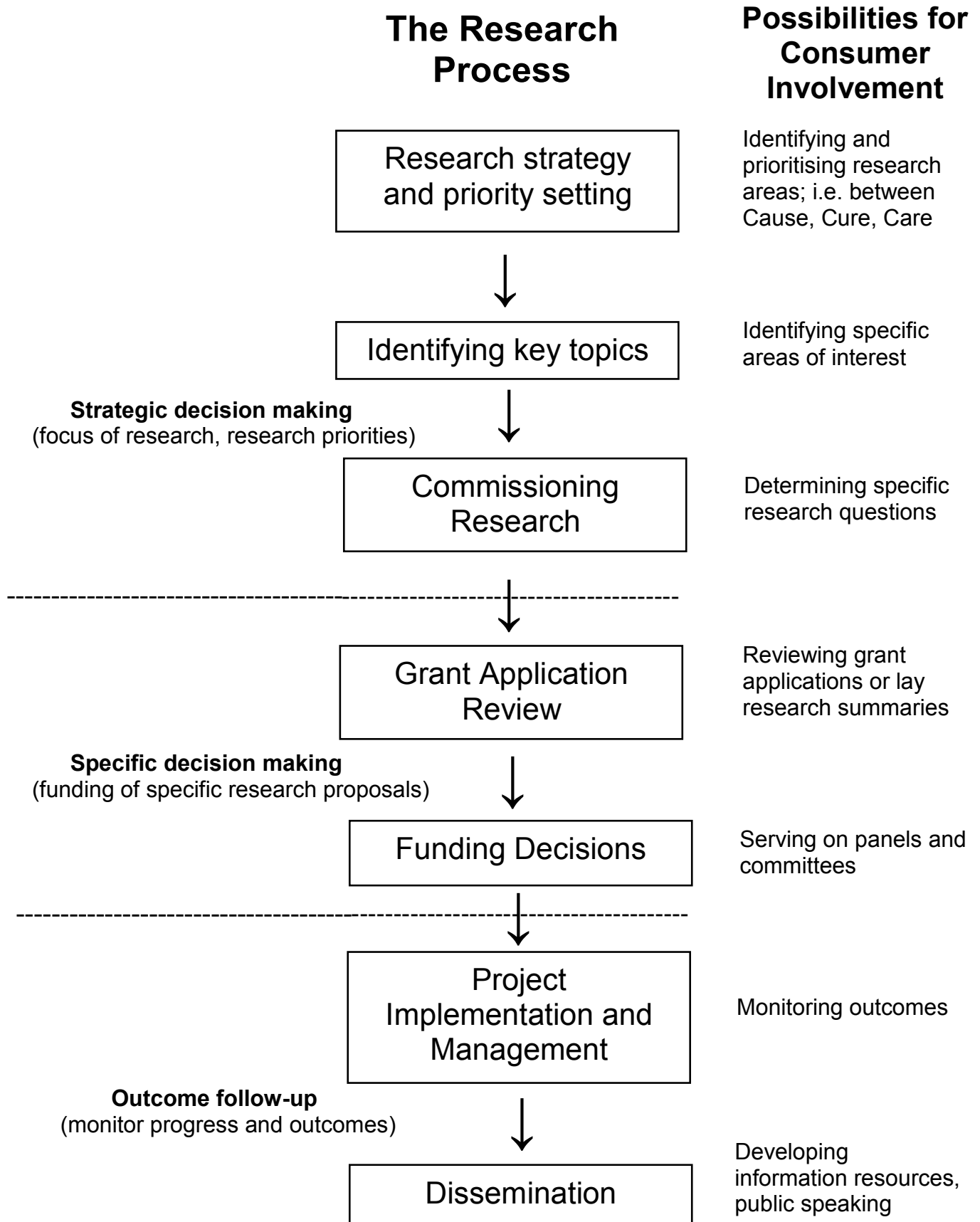
The Quality Research in Dementia (QRD) program of the UK Alzheimer's Society is a good model for consumer involvement in dementia research. The program aims to be an “active partnership between carers, people with dementia and the research

³ *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*, Access Economics, May 2003

⁴ Jorm, A., Griffiths, K., Christensen, H., and Medway, J. (2001). *Research Priorities in Mental Health*. Centre for Mental Health Research, Australian National University. Commissioned by the National Mental Health Working Group and the Mental Health and Special Programs Branch of the Commonwealth Department of Health and Aged Care.

⁵ O'Donnell M and Entwistle V. (2004) Consumer Involvement in decisions about what health-related research is funded. *Health Policy*, 70: 281 – 290.

Figure 1 • Possibilities for Consumer Involvement in the Research Process



community” and achieves this via an advisory network of 150 people with dementia, carers, and former carers. The advisory network is involved in all aspects of the research process, including in setting priorities, commenting on and prioritising grant applications, funding decisions, serving on project monitoring committees and publicising research results. Consumers are equal partners on funding and management committees, and review all applications received. A strong emphasis is placed on training and support for consumers in order to facilitate involvement, including training in communication skills and critical appraisal and education about the research process and funding mechanisms. On the basis of consumer consultations, a list of research priorities in the areas of Cause, Cure and Care is produced annually and researchers are encouraged to consult these priorities before applying for funding.

On the basis of the UK experience, meaningful consumer involvement requires:

- A strong commitment to involving consumers in all aspects of the research process
- A critical mass of consumer involvement
- Support and training for consumers on how research is conducted and funded
- Communication and collaboration between researchers and consumers

The summit will provide an opportunity for consumers to examine the increasing numbers of opportunities for consumer research involvement.

Framework for Consumer Research Involvement

A framework for consumer involvement in dementia research in Australia could be relevant to different sources of research funding, from Alzheimer’s Australia Research, to the NHMRC or Australian Government. Questions to be addressed in the development of such a framework include:

1. What areas of research do consumers want to be involved in?
 - Setting priorities
 - Reviewing specific proposals
 - Outcome follow-up
 - Discussion of funding models
2. What level of involvement do consumers want?
 - Equal involvement with researchers?
 - Involvement in some areas
3. What resources would be needed to support consumers?
 - Education about the research processes and funding
 - Travel expenses
4. Where do we go from here?
 - Consultant led focus groups with consumers and researchers
 - Draft proposal of specific consumer involvement options
 - Development of a consumer research network

The following further specific options might be considered with a focus on consumer involvement in the research work of Alzheimer's Australia:

1. Seeking a view from consumer committees at the state and territory level on research priorities and how to allocate additional research funds
2. Facilitating consumer meetings with Professor Marilyn Albert next year about research priorities and the directions being set in the USA
3. Giving a priority to mapping dementia research as part of the work of Alzheimer's Australia so there is up to date information on Australian dementia research