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# Consumer Involvement in Dementia Research: Alzheimer's Australia's Consumer Dementia Research Network

A report for Alzheimer's Australia  
Paper 22

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**Alzheimer's  
Australia**  
Living with dementia



**An Australian Government Initiative**

**THE Wicking**  
**TRUST**  
JO & JR Wicking Trust

 **DCRC**  
Dementia Collaborative  
Research Centres

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## FOREWORD

There is a great deal of research around the world into the prevention, cause, cure and care aspects of dementia but consumers, being people with dementia and their family or friend carers, sometimes feel that this work proceeds without meaningful partnerships between researchers, funders and themselves.

Consumers travel a part of life's road that is unique. Both their positive and negative experiences impart skills and knowledge that can be harnessed and used to improve the quality of life for others travelling the same road. However, they often feel undervalued for their experiences, skills and knowledge and believe that research could be better targeted and of greater relevance to them if they were accepted as true participatory partners. Some even take the attitude "not about us, without us".

Alzheimer's Australia is endeavouring the bridge the gap between consumers who want to be involved, researchers and funders and has been joined by the Dementia Collaborative Research Centres, the J.O and J.R. Wicking Trust and BUPA in funding the establishment of a National Quality Dementia Care Initiative.

The Initiative has a major consumer focus actioned through a Consumer Dementia Research Network which is managed by Dr Ellen Skladzien, author of this paper on consumer involvement in dementia research. On behalf of consumers, I want to thank Alzheimer's Australia and its supporting organisations for providing this opportunity for consumers to have a role in self determination and in improving the quality of life for others.

In addition, I personally want to thank Dr Skladzien for both taking up the challenge to establish the consumer network and for this paper which so succinctly describes the importance to all stakeholders of involving consumers in dementia research, consumer involvement in other areas of health research overseas and in Australia, and on the establishment, future directions and challenges of the Alzheimer's Australia's Consumer Dementia Research Network.

I commend this paper to anyone interested in consumer involvement in research and if further information is required, I am confident that contact with Dr Skladzien at [Ellen.skladzien@alzheimers.org.au](mailto:Ellen.skladzien@alzheimers.org.au) will be most fruitful.

A handwritten signature in black ink that reads "Ron Sinclair". The signature is written in a cursive, flowing style.

Ron Sinclair

Interim Chair of CDRN

## CONSUMER INVOLVEMENT IN DEMENTIA RESEARCH: ALZHEIMER'S AUSTRALIA'S CONSUMER DEMENTIA RESEARCH NETWORK

The value of consumer input into health research and services has been acknowledged by various organisations and funding bodies in Australia and overseas, including by the National Health and Medical Research Council in Australia, the Cochrane Collaboration, and the Medical Research Council (UK). Consumer involvement can lead to research with greater relevance<sup>i</sup>, improved quality and outcomes, and facilitates translating research into practice<sup>iii</sup>.

Meaningful consumer engagement in research, however, has been challenging and costly to establish. It is much easier to put consumers on a steering committee which is informed on the progress of research every six months, than to encourage and support consumers to provide input into research priorities, design and dissemination. As a result, in most cases, consumer involvement in health research has been limited to passive and often tokenistic roles.

Alzheimer's Australia is committed to *meaningful* consumer engagement in all steps of the research and knowledge translation process. In 2010 Alzheimer's Australia, in partnership with the Dementia Collaborative Research Centres, formed the Consumer Dementia Research Network. The aim of this national network is to support people with dementia and their carers to take an active role in informing the research process and contributing to better dementia care practice and outcomes.

The purpose of this paper is to provide the context and rationale for developing the Consumer Dementia Research Network, as well as describing the Network as an example of a program designed to encourage meaningful consumer involvement in research. The paper is divided into five sections:

- Why consumer involvement in health research is important;
- Consumer involvement in health research in Australia;
- International examples of consumer involvement in health research;
- The Consumer Dementia Research Network; and
- Future directions and challenges.

## WHY CONSUMER INVOLVEMENT IN HEALTH RESEARCH IS IMPORTANT

Consumer involvement can lead to new ideas, innovative approaches and to outcomes that are more relevant to the consumer<sup>iv, v</sup> and have more credibility<sup>vi</sup>.

Consumers are in the unique position to provide the perspective and experience of people who live with dementia every day. Consumers can also advise researchers on the most effective ways of interacting with consumers. From a consumer perspective there is a desire to be respected partners with researchers whose ultimate goals align with their own.

There has been no objective evaluation of the influence of consumer involvement in research. Most reports on consumer involvement are qualitative or descriptive in nature. There is, however, preliminary evidence which indicates that consumer input has had a positive impact throughout the stages of the research process<sup>vii</sup> and that without consumer input, researchers do not focus on topics that consumers indicate are priority areas<sup>viii, ix</sup>. Consumer involvement can occur at various stages including: setting the research agenda, evaluating proposals, commenting on methodology, participating in the research and assisting in the communication of research findings. Descriptive reports find that consumers have made positive impacts when involved in each of these stages.

Often, consumer involvement leads to a wider range of topics being considered for research funding than is considered by researchers alone and their experiences can lead to new research questions<sup>x</sup> or new potential treatments for health conditions<sup>xi</sup>. By being involved in setting the research agenda, consumers help to ensure that the research that receives priority is important to them and therefore to health care, public health, and social-care services as a whole. There are numerous examples of research that have not involved consumers and as a result have produced findings that are not relevant for most people. For example one researcher<sup>xii</sup> noted that most research on osteoarthritis focuses on medically prescribed treatments and largely ignores physiotherapy, educational interventions and complementary therapies that are regularly being used by consumers.

Consumers have also been involved in deciding on project funding through participating in grant review panels. Involvement in the review process can range from providing the first cut of applications to having a single consumer on a large panel of scientists. There has been little research on the effect of consumer involvement in grant reviews, but one investigation found that the consumers on the panel scored grants similarly to scientists. In this same study, the scientists reported that consumers added an important perspective and focused the process on the disease outcomes rather than considering the endeavour as a purely scientific exercise<sup>xiii</sup>.

Research methodology can often be improved through the involvement of consumers. For example, in a study of Parkinson's disease, consumers gave researchers advice about the time of day that assessments should be made, realistic outcome measures and potential problems with administering questionnaires due to visual changes associated with the illness<sup>xiv</sup>. By involving consumers, the researchers in this study avoided a number of potential problems with data collection and also established a more realistic outcome measurement for the effectiveness of the intervention. Similarly, in a study on a stroke

intervention, consumers objected to the outcome measures, as they focused on the physical functions of individuals after a stroke<sup>xv</sup>. Consumers indicated that quality of life after a stroke is not necessarily strongly related to level of disability. Instead mood, problems with communication and cognitive function were considered as more relevant outcomes. The researchers adapted the project accordingly and were able to measure outcomes that were meaningful to the consumer.

Some health researchers report that when consumers have been involved in the communication of results there has been a greater uptake of the findings into practice. This may occur through wider dissemination through consumer networks, increased credibility of findings or consumers providing feedback on appropriate terminology and format for providing information about results to the community<sup>xvi</sup>.

In summary, although there has been no systematic study of the effect of consumer involvement in research, there is descriptive evidence to suggest that this involvement has largely been positive. Some potential challenges of consumer involvement for researchers include the time and costs associated with involving consumers<sup>xvii</sup> as well as knowing how to include consumers and best utilise their experiences. For consumers, the challenges may include being overwhelmed with the amount of work required and also frustration at the level of involvement that is possible. It is important for roles and work levels to be defined early in the process and for consumers to be provided with support and training. In addition, it is important for researchers who are committed to consumer involvement to include costs of consumer involvement in funding applications.

## CONSUMER INVOLVEMENT IN HEALTH RESEARCH IN AUSTRALIA

Although actively engaging consumers in the research process is a challenging and costly endeavour, there has been increased interest in involving consumers in research throughout Australia. This section will provide an overview of three examples of consumer involvement in health research in Australia. We have focused on these three examples, but a number of other organisations are involving consumers in research at some level.

### National Health and Medical Research Council

Australia's largest funding body for health and medical research – the National Health and Medical Research Council (NHMRC) – has shown growing support for consumer involvement in research. In collaboration with the Consumer Health Forum, they have established a statement, a resource pack and a model framework on community and consumer involvement in research which is available on their website. They have also included a statement in the Australian Code for the Responsible Conduct of Research indicating the need for researchers to encourage and facilitate “appropriate consumer involvement in research”. Although it is unclear how widely these guidelines have been adopted, there is at least one example of successful utilisation of these guidelines by the Cancer Council to inform their consumer involvement.

NHMRC continues to support consumer engagement in research. Consumers and community members are included on various committees and councils of the NHMRC. There is a specific Consumer Consultative Group which functions to provide advice to the Council and the CEO on consumer and community participation issues relating to the work of the NHMRC and provide a framework to lead in the engagement of consumers in health and research advice. In their meeting in April 2010 they were asked to provide further advice on the review and implementation of the NHMRC's Statement on Consumer and Community Participation in Health and Medical Research. The NHMRC also has consumer advisors on grant review panels to provide a consumer perspective.

The acknowledgement of the value of consumer involvement in research by the NHMRC is important as meaningful consumer involvement in projects may at some point become part of the criteria for successful funding applications at the NHMRC.

### Cancer Australia

Cancer Australia has developed a National Consumer Advisory Group to ensure that all of their work has a consumer focus. The advisory group is made up of individuals from all regions of Australia with diverse backgrounds and experiences. This group provides advice to Cancer Australia on current and emerging issues impacting on consumers specifically in relation to programs provided by Cancer Australia. One of the priorities of the national advisory group is to enable better consumer involvement and access to clinical trials and research. More specifically the group calls for people affected by cancer to be “viewed as important strategic partners by medical, research, industry, government, and policy-making groups.” (Cancer Australia Consumer Group Consensus Value Statement 2008, p1)



Consumers play an integral role in Cancer Australia's research program. In Cancer Australia's Priority-driven Collaborative Cancer Research Scheme, a requirement for funding is consumer involvement in the design and conduct of research. Applications which do not have the consumer component are considered ineligible for funding. Consumers are actively involved in the assessment of grant applications. They are not involved in assessing the scientific merit of the applications, but are involved in the assessment of the potential outcomes, impacts on consumers, translation of findings, collaboration and involvement of consumers in the project.

Every year Cancer Australia puts out a national call for expression of interest in involvement in the grant review process. If chosen, the consumers are provided with 2 days of training by Cancer Australia and the Cancer Council of NSW to learn about the research grants process, and go through a dummy review round to build their confidence in reviewing applications. Each grant committee is made up of three individuals nominated by the funding partner, one individual from Cancer Australia, one from NHMRC and at least one consumer representative. The scores and comments of the consumer representative are taken to be of equal weight to all other members of the grant review committee. Cancer Australia, with other funding partners has provided \$38 million for cancer research through this program.

## University of Western Australia (UWA) – Population Health

In 1998, in collaboration with the Health Consumers' Council, the School of Population Health at UWA developed a Consumer Liaison position within the department to address a lack of communication between researchers, health consumers and the community. The consumer liaison officer worked to involve consumers actively in research while also trying to change the culture around research so that consumer involvement was valued. This role included working with individual researchers on how to involve consumers in specific projects, developing organisational strategies to increase consumer involvement, and lecturing about the importance of consumer involvement in research.

As a result of this commitment to consumer involvement, a number of projects from the UWA School of Population Health have had meaningful consumer involvement in their research projects. Involvement has ranged from consumers serving on reference groups to research projects being initiated as a result of consumer experiences and concern.

In 2008, the school held a symposium on consumer and community participation in health research. This meeting 'Involving People in Research' brought together consumers, researchers and community members from across Australia to discuss ways to support further consumer and community involvement in research. The UWA School for Population Health also provides training for both consumers and researchers.

## INTERNATIONAL EXAMPLES OF CONSUMER INVOLVEMENT IN RESEARCH

### UK Quality in Dementia Research Consumer Network

The Alzheimer's Society UK awards up to £4 million per year for research into the cause, cure, care and prevention of dementia. In 1999 the Quality Research in Dementia Network was established in order to involve people with dementia and their carers in the research program. This national network was established with an initial membership of 30 and has grown to over 180 members. Members are involved in every stage of the research process setting priorities, grant evaluation, project monitoring, and disseminating project findings.

Members are provided with opportunities to engage in training in scientific principles and research methodology. This training is done face-to-face and is offered three times a year. Every member receives hard copies of all research proposals for review, and provides the first cut of applications before they go out to the scientific committees. Connecting consumer involvement to funding resources has been a successful strategy to encourage meaningful engagement. Consumers have the power to decide whether or not a project proposal should be considered for funding. Therefore researchers have an incentive to include accessible information in their proposals as well as to consider how consumers will be involved in the project.

Researchers and consumers report that the network involvement has been largely positive and useful. For example, one consumer reported "I gained insight into the work of the researchers and an appreciation of the difficulties they faced. They, in turn, gained an appreciation of what we had to offer a research project. When the results of the trial came through we were all so excited; new ways of providing training and care had been proven to work." Anecdotal reports suggest that the research process has benefited from consumer engagement. To date there has been no systematic evaluation of the effect of consumer involvement.

### 'INVOLVE'

'Involve' is a national advisory group which is funded by the National Institute for Health Research in the UK which was established to promote consumer involvement in all stages of the research process. It was established in 1996 as 'Consumers in NHS Research'. In 2001 the role of the group was expanded to include public health and social research. In 2003 the name of the group was changed to 'INVOLVE' – promoting public involvement in NHS, public health and social care research' to better fit the expanded role.

The rationale for the group is the belief that research which has consumer input is more likely to produce practical results that can be used to improve practice in health care. They advocate for an active partnership between the public and researchers in the research process. There are approximately forty members who include a mix of consumers, carers, service providers, researchers and representatives from voluntary organisations. The group meets four times a year. They advocate for consumer involvement in research as well as providing support to researchers who want to involve consumers.

The terms of reference for the group are<sup>xviii</sup>:

- To promote the empowerment of the public to become more involved in research;
- To develop and promote alliances with key groups, including the public, researchers, the Department of Health and other research funders and sponsors in order to promote greater public involvement in research;
- To monitor public involvement in research in the NHS, public health and social care;
- To encourage the evaluation of the effects of public involvement in research in the fields of NHS, social care and public health;
- To report regularly to the Department of Health on progress, and make recommendations about the development of public involvement in research.

## The Consumer Dementia Research Network

There has been very little consumer involvement in dementia research in Australia. Each of the three Dementia Collaborative Research Centres (DCRCs) has a different approach to consumer involvement. For example, the DCRC – Assessment and Better Care has a consumer panel made up of people with dementia, family carers, clinicians and service providers. This group receives information about the DCRC projects and also provides input to the DCRC on possible research areas or priorities from a consumer perspective. DCRC – Carers and Consumers has sought consumer input into specific aspects of projects during the development and roll-out phases of their research. Consumer involvement in the other DCRC is less formal.

A need for a more systematic approach to consumer involvement in dementia research has been identified. In 2008 a meeting was held at the DCRC – Assessment and Better Care to discuss the establishment of a Consumer Dementia Research Network (CDRN). This meeting included DCRC researchers, members of Alzheimer's Australia National Consumer Advisory Committee, and representatives from Alzheimer's Australia. It was agreed that a consumer network has the potential to improve the way research is prioritised, commissioned, undertaken and communicated. It was suggested that the proposed consumer network would be involved in all stages of DCRC research and would be partially supported by the DCRCs

As a result of these discussions Alzheimer's Australia established the Consumer Dementia Research Network (CDRN). The network is broadly based on the UK Quality in Dementia Research Network and has been developed with the goal of supporting people with dementia and their family carers to have an active role in research and knowledge translation while also creating a more systematic way for the DCRCs to involve consumers in their research process. A manager of the network was appointed in early May 2010. The CDRN is funded mainly through support provided by the DCRCs as part of the Australian Government's Dementia Initiative.

The CDRN is part of Alzheimer's Australia's National Quality Dementia Care Initiative (QDCI). The aim of the Initiative is to improve the quality of dementia care in Australia by facilitating the rapid adoption of research evidence into practice, and involving consumers in dementia research and knowledge translation activities. The other main component of the initiative is the National Quality Dementia Care Network (NQDCN) which aims to improve the quality of dementia care in Australia by supporting knowledge

translation projects that address significant evidence-practice gaps in dementia care. The coordination of these two projects provides an important opportunity to involve consumers at all stages of the NQDCN projects including identifying priority topics for funding. It also enables Alzheimer's Australia to require projects to plan for meaningful involvement of the consumers in project design.

## Recruitment and Membership

Recruitment for the Consumer Dementia Research Network commenced in June 2010. A number of strategies were used to recruit a diverse range of consumers with different experiences and points of views. These included:

- Utilising current dementia consumer groups to identify interested participants (National Consumer Advisory Committee, DCRC Consumer Panels);
- Advertising with relevant peak bodies (Council on the Ageing, National Seniors Australia, Consumer Health Forum, Carer's Australia, Australian Policy Online) through their membership newsletters and magazines;
- Liaising with Alzheimer's Australia's State and Territory Organisations and to identify people with dementia and family carers who have an interest in research;
- Engaging with relevant organisations that work with CALD and indigenous populations (i.e. FECCA, Migrant Resource Centres);
- Engaging with relevant service providers and community groups (ie. BUPA, Hammond Care); and
- Liaising with dementia researchers.

A list of desirable attributes for a consumer to be an effective member of the network was developed. It was not expected that any individual would have all of these characteristics, rather, they were used as a guide to recruit a variety of people with different backgrounds and strengths. These characteristics were:

### **Personal Experience with Dementia (Required)**

- People with dementia, family carers or friends of people with dementia.

### **Personal Characteristics**

- Strong interpersonal skills and an ability to work effectively within a group.
- Good verbal communication skills.
- Ability to be an active participant in the CDRN including committing to spending approximately 1 hour per week on network activities.
- A willingness to participate in training and to learn about research.

### **Knowledge and Experience**

- An interest in dementia care research and/or putting research into practice.
- Experience in participating in research studies or professional background related to dementia care and/or health research.
- Access to and willingness to use the internet/email to communicate with other members.

### **Existing Networks**

- Established networks in the community which would facilitate dissemination of research findings or other project outcomes

More than thirty-five people expressed an interest in participating in the network. Twenty-four people were selected for the consumer network based on their background and experience. The group is made up of a diverse range of people from every state and territory and comprises people from various backgrounds including CALD, Indigenous, regional/remote, gay and lesbian, and individuals with younger onset dementia. Most people in the group have had very limited or no involvement with Alzheimer's Australia previously. Many have also not been involved in consumer advocacy. They have a variety of backgrounds and have a wide range of both personal and professional experience with dementia, research and aged care. There is a mix of current family carers, former carers and people with dementia.

## Initial Functions of the Network

The initial functions of the CDRN will include involvement with the National Quality Dementia Care Network (NQDCN) and the Dementia Collaborative Research Centres (DCRCs). It is likely that involvement with the network and the DCRCs will evolve over time.

Involvement in the NQDCN may include:

- Setting priority areas in dementia care for NQDCN knowledge translation projects;
- Evaluating project proposals;
- Participating in knowledge translation projects;
- Assisting with communicating findings of knowledge translation projects to the community; and
- Advising the management of the NQDCN through representation on the Executive Committee.

Involvement with the DCRCs may include:

- Advising the DCRCs on consumer priorities for research;
- Assisting with communicating findings of research projects to the community;
- Providing information and advice to researchers on how to improve their interactions with consumers; and
- Participating in research projects.

The DCRCs will also be involved with the network through their representation on the QCDI Executive Committee.

The CDRN may also provide a consumer perspective on dementia research to other research organisations such as the NHMRC and/or government departments or committees.

## Quality Dementia Care Summit

The first meeting of the CDRN will be held over two days on the 6th and 7th September 2010 in Sydney. The first day will include background presentations, case study examples on knowledge translation and a facilitated discussion of NQDCN priorities based on areas of concern identified by CDRN. The second day will include a final discussion on the priorities, a launch of the Quality Dementia Care Initiative and a workshop between the

consumers and the heads of the three DCRCs. The two main objectives of this meeting will be to identify priority areas in dementia care to be funded by the NQDCN and also to develop a strategy for involving the CDRN with the DCRCs.

Each member of the consumer group has been asked to identify three areas of dementia care about which they are concerned. These topics have been reviewed by the NQDCN team to determine if there is a true evidence-practice gap. At the September meeting the consumer group will be provided with information about each of these topics and through facilitated discussion come to a consensus of three areas which will be priority for the first round of NQDCN funding.

The second priority for the September meeting will be to establish a mechanism by which the CDRN can be involved in the research program of the DCRCs. There will be a workshop with the consumers and the heads of the three DCRCs to discuss how the consumers can have a voice in the research agenda of the DCRCs and also how they can participate in all stages of the research process. The hope is for the DCRCs to consider the CDRN as a valuable resource that they can utilise for input into their research processes. One of the barriers to consumer involvement that has been identified by other researchers is the time and cost involved in setting up consumer involvement. Having an existing group of consumers who have an interest in research, and who are supported by Alzheimer's Australia should help to avoid some of these previous barriers.

## FUTURE DIRECTIONS AND CHALLENGES

### 1) Meaningful and continued engagement with researchers

Alzheimer's Australia is fortunate to be able to time the launch of the CDRN with the launch of a significant funding program, the NQDCN. This enables Alzheimer's Australia to engage the CDRN in all stages of the NQDCN and also to make funding of NQDCN projects contingent involvement of consumers.

The main challenge going forward will be to develop meaningful and sustainable partnerships with researchers outside of the NQDCN program. In most cases researchers have involved consumers to the extent required by their funding sources. The UK model of consumer involvement in dementia research has been possible due to its link with a significant funding source for dementia research projects. Similarly, Cancer Australia has been successful in encouraging consumer involvement in cancer research by making it a requirement for eligibility for their grants. Given that the NHMRC encourages active consumer involvement but leaves the level and type of involvement up to the individual researcher, there is little motivation to include consumers in all stages of the research process. It will be important to convince researchers of the potential benefits of involving consumers and also facilitate an easy process for researchers to consult with the CDRN. Clearly the less time and resources required to involve consumers, and the more benefits that researchers can identify, the more likely researchers will engage in consumer involvement.

The DCRCs have made a commitment to consumer involvement through their partial funding of the CDRN. It will be important to establish a systematic approach of involvement with the DCRCs. For example, in the DCRC project proposals it might be useful to include a section on how the project will engage with the consumers. In this way, a plan for meaningful consumer engagement can become a requirement for funding individual projects.

### 2) Involvement with Alzheimer's Australia Research

Alzheimer's Australia Research (AAR) is the research arm of Alzheimer's Australia, established as a separate not-for-profit company to encourage and support Australian dementia research. AAR's mission is to promote, disseminate and fund Australian dementia research into key areas such as prevention, diagnosis, treatment and care. AAR provides approximately \$600,000 a year in annual grants, scholarships, and fellowships. A key priority of the program is to support emerging Australian researchers to become involved in dementia research. AAR provides new investigator grants, doctoral scholarships, postdoctoral research fellowships and travel grants to new researchers on a competitive basis. In addition, AAR provides annual grants for research into aspects of dementia care.

Currently there is no consumer involvement in the review process for AAR grants, nor any requirement for consumer involvement in projects which are funded under this scheme. Alzheimer's Australia must work towards meaningful consumer involvement in AAR in order to be credible in their call for researchers and research institutes to increase consumer involvement. Although the available AAR funding is growing, it is small

compared with the UK Alzheimer's Society or Cancer Australia. Nonetheless, it does provide an opportunity to encourage consumer involvement in projects as well as for consumers to be involved in evaluating what type of dementia research is funded.

The role of the CDRN in AAR will be discussed at the first meeting of the CDRN. One possibility would be to follow a similar model to Cancer Australia in which consumers assess additional questions about potential outcomes, impacts on consumers, translation of findings, collaboration and involvement of consumers in the project. This would avoid burdening consumers with lengthy and sometimes technical applications, but would enable them to use their expertise to assess relevant aspects of the application. The results of discussions about AAR at the first meeting of the CDRN will be presented to the Scientific and Medical Panel of AAR and the Board of AAR for consideration. The goal will be to involve consumers in the next round of AAR funding which will be announced in February 2011.

### 3) Funding for sustained activity

Currently the CDRN is funded through contributions from the DCRCs, Wicking Trust, and Alzheimer's Australia until 2013. The funds from the DCRCs provide for the salary for the manager of the CDRN. The additional funds from Wicking Trust and Alzheimer's Australia are required for consumer travel, support, training and website design. In order for the consumer group to increase in number and in scope of activity, it will be necessary to secure additional funding in future. The current funding will only be available until the end of June 2013.

### 4) Effective Evaluation

Most initiatives which have involved consumers in health research have not been evaluated objectively. In order to secure continued funding, as well as illustrate the benefits of consumer engagement it will be key to have a thorough evaluation of the consumer network. This will also enable Alzheimer's Australia to improve on its efforts to engage consumers in research. The CDRN will be included in a broader evaluation of the Quality Dementia Care Initiative. This evaluation will include a review of process, systems and outcomes and will involve both quantitative and qualitative assessment. An evaluator will be appointed prior to the summit on the 6th of September 2010. Evaluations will enable ongoing collection of information throughout the first three years of the CDRN. The evaluator will be required to provide an interim report of the CDRN by the end of 2011. A final evaluation will be completed in 2013. Results of this evaluation will provide important information for future applications of funding, and further development of the network. It will also provide objective information on the value of consumer involvement in dementia research.



## CONCLUSIONS

There is support for greater consumer involvement in research in Australia but there has been no objective evaluation of this involvement which is often considered too difficult or costly to support. The UK Alzheimer's Society's approach to consumer involvement has a model for actively engaging consumers in dementia research. The Alzheimer's Australia Consumer Dementia Research Network has been developed from this model, and aims to enable people with dementia and their carers to have a more active role in dementia research and knowledge translation. This network represents a sharp advance on the more traditional means of involving consumers through steering committees or simply as subjects of research.

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## ALZHEIMER'S AUSTRALIA PUBLICATIONS

### Quality Dementia Care Series

1. Practice in Residential Aged Care Facilities, for all Staff
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3. Nurturing the Heart: creativity, art therapy and dementia
4. Understanding Younger Onset Dementia
5. Younger Onset Dementia, a practical guide

### Papers

1. Dementia: A Major Health Problem for Australia. September 2001
2. Quality Dementia Care, February 2003
3. Dementia Care and the Built Environment, June 2004
4. Dementia Terminology Framework. December 2004
5. Legal Planning and Dementia. April 2005
6. Dementia: Can It Be Prevented? August 2005 (superceded by paper 13)
7. Palliative Care and Dementia. February 2006
8. Decision Making in Advance: Reducing Barriers and Improving Access to Advanced Directives for People with Dementia. May 2006
9. 100 Years of Alzheimer's: Towards a World without Dementia. August 2006
10. Early Diagnosis of Dementia. March 2007
11. Consumer-Directed Care – A Way to Empower Consumers? May 2007
12. Dementia: A Major Health Problem for Indigenous People. August 2007.
13. Dementia Risk Reduction: The Evidence. September 2007
14. Dementia Risk Reduction: What do Australians know? September 2008
15. Dementia, Lesbians and Gay Men November 2009
16. Australian Dementia Research: current status, future directions? June 2008
17. Respite Care for People Living with Dementia. May 2009
18. Dementia: Facing the Epidemic. Presentation by Professor Constantine Lyketsos. September 2009
19. Dementia: Evolution or Revolution? Presentation by Glenn Rees. June 2010
20. Ethical Issues and Decision-Making in Dementia Care. Presentation by Dr Julian Hughes. June 2010
21. Towards a National Dementia Preventative Health Strategy. August 2010
22. Consumer Involvement in Dementia Research August 2010

### Reports commissioned from Access Economics

The Dementia Epidemic: Economic Impact and Positive Solutions for Australia, March 2003  
 Delaying the Onset of Alzheimer's Disease: Projections and Issues, August 2004  
 Dementia Estimates and Projections: Australian States and Territories, February 2005  
 Dementia in the Asia Pacific Region: The Epidemic is Here, September 2006  
 Dementia Prevalence and Incidence Among Australian's Who Do Not Speak English at Home, November 2006  
 Making choices: Future dementia care: projections, problems and preferences, April 2009  
 Keeping dementia front of mind: incidence and prevalence 2009-2050, August 2009  
 Caring places: planning for aged care and dementia 2010-2050. July 2010

### Other Papers

Dementia Research: A Vision for Australia September 2004  
 National Consumer Summit on Dementia Communique, October 2005  
 Mind Your Mind: A Users Guide to Dementia Risk Reduction 2006  
 Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities, November 2006  
 National Dementia Manifesto 2007-2010  
 Dementia: A Major Health Problem for Indigenous People August 2007  
 In Our Own Words, Younger Onset Dementia, February 2009  
 National Consumer Summit Younger Onset Dementia Communique, February 2009  
 Dementia: Facing the Epidemic. A vision for a world class dementia care system. September 2009

*These documents and others available on [www.alzheimers.org.au](http://www.alzheimers.org.au)*

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Visit the Alzheimer's Australia website at  
[www.alzheimers.org.au](http://www.alzheimers.org.au)  
for comprehensive information about

- dementia and care

- information, education and training

- other services offered by member organisations

Or for information and advice contact the  
National Dementia Helpline on 1800 100 500

(National Dementia Helpline is an Australian Government funded initiative)

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