

NHMRC STAKEHOLDER WORKSHOP ON THE BOOSTING DEMENTIA RESEARCH INITIATIVE 20 JUNE 2014

Panel Title: Dementia Research, Translation and Commercialisation Beyond Translational Research to Real Improvements in Care

Glenn Rees, CEO Alzheimer's Australia

Thank you for the introduction and the opportunity to speak today.

The Government's stated objectives for the Boosting Dementia Research Initiative are to prioritise and fund vital new dementia research projects and translate research to improve prevention, diagnosis, treatment and care of people living with dementia.

This are the same objectives which have driven the determined and sometimes passionate advocacy of Alzheimer's Australia for increased funding for dementia research.

We have campaigned for public investment in research efforts to develop a better understanding of the causes of dementia, and to develop new medical interventions.

We also want to see research outcomes translated into better practice in a way that improves the quality of life and the quality of care of people living with dementia, and to see consumers take a central role in research and research translation.

The \$200 million for dementia research was a cornerstone of the Alzheimer's Australia's Fight Dementia Campaign, which started in October 2011 with a march of 500 people from around Australia on Parliament House; many of them people with dementia and family carers.

Our advocacy for this funding was based on telling the stories of people with dementia and their families. Without them and their willingness to share their experience and to self advocate, we would not be meeting here today.

Let me also say that it is not an easy balance to strike for a consumer organisation which is battling to secure access to services for people with dementia to advocate and place its faith in investing in the future through research.

It is important to remember just how valuable \$200 million is in the context of improving outcomes for people with dementia. As a point of comparison, the Younger Onset Dementia Key Worker program which is providing a vital service to thousands of consumers throughout Australia costs only 10% of this amount at approximately \$23 million over five years.

We could do a great deal in services to improve the lives of a people with dementia given an additional \$200 million.

But if we are to maintain the trust of consumers in research, the sector needs to become serious about consumer involvement in research and priority setting and ensure that this investment leads to better outcomes for people living with dementia.

Consumer involvement in research has not been front of mind for researchers with, of course, notable exceptions such as the three Dementia Collaborative Research Centres led by Henry, Elizabeth and Kaarin and more recently the generous and open way that Sue Kurrle has embraced consumer involvement in the Partnership Centre on Cognitive Decline.

Alzheimer's Australia is delighted that NHMRC, the ARC and the dementia research community have the opportunity to pioneer priority driven research in the context of dementia, to build research capacity and to drive knowledge translation.

We have the belief that the success and the sustainability of the Government's bold initiative will be dependent on whether there is genuine partnership – not tokenistic consultation – with consumers including through Alzheimer's Australia.

It may seem strange that an organisation that does not have research credentials has been able to advocate, communicate and persuade those in government about the importance of investment in dementia research.

But it is this independence that ensures that we will be both the strongest supporters of dementia research and the strongest critics if we cannot see the promise of improved health and care outcomes.

We will be looking for an Institute which has five characteristics:

- Transparency in the outcomes being sought in respect of process, outputs and health care
- Independence of mind and entrepreneurial - \$10 million per year for five years is not a lot of money and the Institute will need to be entrepreneurial to survive.
- Truly collaborative in interdisciplinary collaboration and in its international networks.
- Focussed on improving care outcomes through systemic changes in the health and care system.
- Engaged with consumers

A true partnership between consumers and researchers has to begin with valuing the consumer perspective.

I hope researchers and the NHMRC will regard Alzheimer's Australia and the consumers we represent as agents of change. Again I do not think I am over stating matters by saying that without the advocacy of people with dementia and carers we would not have been successful in our call for the \$200 million investment.

We have skills in advocacy, policy, communication and networking which have delivered significant results, not just in terms of research in recent times but in the 2005 Dementia Initiative and more recently in the tackling dementia element of the 2012 Aged Care Reforms.

Consumers are practical and are keen to achieve systemic change to improve services for people with dementia. As agents of change, we have had some success.

For example, in respect of:

- Advocating for consumer directed care and the need for recognition that the achievement of person centred care will only result if there is equal partnership between health and care providers and the individual.
- In implementing with Government support the worlds first publicly funded dementia risk reduction program. Not easy to do in circumstances where some would argue the evidence is not as rigorous as it should be. But how essential is that notion of risk reduction to a more positive view of tackling dementia and its many causes as a health issue and not simply the inevitable part of ageing.
- The work we have done with a lot of support from clinicians and researchers such as Brian Draper, Jacqui Close, Len Gray, Mark Yates and others, to highlight the issues that dementia presents in the acute care environment and to start the process of prioritising change in the acute care sector.

The common element of success in all these areas has been the capacity to work with others, adopt an evidence based approach to advocacy and to engage people with dementia and family carers at every stage of the advocacy and policy process.

There are other areas where we have been equally passionate but with less success to date – the quality of residential care, the use of restraint, and early diagnosis are three that come to mind.

At a more practical level, we have seen the need to promote systematic change in care practice through the National Quality Dementia Care Initiative which brings together three elements.

First, consumers in setting priorities for improvement in dementia care based on their own experience and concerns.

Second, drawing on the experience of researchers to identify the evidence base that support practice change in these areas.

Thirdly, working in partnership with Alzheimer's organisations and service providers to develop projects that use innovative approaches to ensure that the evidence is translated into broad change in practice and outcomes for consumers on a national and sustainable scale.

Eight such projects have been implemented across a diverse range of issues including social walking programs to reduce the severity and prevalence of behavioural and psychological symptoms of dementia, an online and social media campaign to promote advance care planning; on-the-ground CPD workshops with GPs throughout Australia to improve diagnosis and management of dementia; and multi-component programs to promote dementia enabling design in aged care.

These projects are only funded if they are based on robust evidence, and have the capacity to affect change at a national level – and at an average cost of about \$250,000.

Some of these will be successful and others will fail. All are being independently evaluated. There are some early signs of success for example, in respect of GP education and our enabling environments program. However, achieving widespread improvement in practice and better outcomes for consumers will take more hard work and time.

In summary, I hope that in discussing how we prioritise the \$200 million we can keep the end game in mind: better care and support for people with dementia. In my view this will only be achieved if a true and sustainable **partnership** with consumers is developed.

Perhaps the most evil word from the point of view of consumers is the word “consultation”. It is not consultation that people with dementia and family carers want. It is involvement and engagement.

We have been able to achieve that through the Consumer Dementia Research Network which stretches across Australia and involves 20 people with dementia and

family carers. We have built it on the UK model where over time there has been respect for the part that consumers can play both in promoting the cause of research and in contributing to research.

If we are to improve dementia care through knowledge translation the approach needs to be driven not by researchers, but in partnership between consumers, providers, government and researchers.

Alzheimer's Australia will be single minded about seeking real improvements in care outcomes and for a real and substantial role for consumers in achieving that goal. I hope the CDRN will become the new Institutes consumer advisory network.