CONSUMER INVOLVEMENT IN DEMENTIA RESEARCH IN AUSTRALIA

Past, Present and Future

Jane Thompson, Kate Swaffer, Tony Ramshaw for Alzheimer’s Australia’s Consumer Dementia Research Network
The Past
PRE 2010 – the landscape of dementia research in Australia

- Some engagement with but limited true INVOLVEMENT of consumers
- Less active consumer involvement than in other fields of research e.g. cancer
- Representation on Advisory Committees e.g. Dementia Collaborative Research Centres
- Involvement of carers rather than those with lived experience of dementia
- The ‘lone’ consumer representative
The Present
2010 – 2015 Changing landscape along with international trends

• Alzheimer’s Australia, in partnership with the Dementia Collaborative Research Centres, forms the Consumer Dementia Research Network
• Modelled on UK Alzheimer’s Society Research Network
• Involvement of people with dementia as well as carers
• The ‘Networked’ consumer
CONSUMER DEMENTIA RESEARCH NETWORK

Interest Group of consumers

Core Group of up to 25 consumers committed to improving the quality of dementia care through research and knowledge translation

We all have personal experience of dementia

We have a diagnosis of dementia, or,

We care or have cared for a person close to us with dementia
CONSUMER DEMENTIA RESEARCH NETWORK

- Secretariat Alzheimer’s Australia National Office
- Face to face meetings twice per year
- Teleconferences and email
- Subcommittees share the work load
- Strategic Plan
- Formal evaluation

CONSUMER DEMENTIA RESEARCH NETWORK: Highlights

- National Quality Dementia Care Initiative
- NHMRC Partnership Centre: Dealing with Cognitive and Related Functional Decline in Older People (The Cognitive Decline Partnership Centre)
CONSUMER DEMENTIA RESEARCH NETWORK AND THE NATIONAL QUALITY DEMENTIA CARE INITIATIVE

- **Representation** on its Executive Committee
- **Setting priorities** for knowledge translation projects
- Developing project application **selection criteria**
- **Reviewing** and **selecting** projects for funding
- **Involvement in** steering committees and/or reference groups
- **Participating in** projects
- **Monitoring** progress of projects
- Assisting with **communicating** findings to the community
- Contributing to the **evaluation** of the consumer involvement in projects
DEMENTIA ENABLING ENVIRONMENTS PROJECT

Improving the standard of architectural, interior and environmental design for people with dementia
www.enablingenvironments.com.au

“A well designed garden, or an interior planned with cognitive impairment in mind can provide essential prompts, accessibility and reduce risks to support a person with dementia to maintain abilities and take part in meaningful engagement. A poorly designed environment can be at best confusing and disorienting, and at worst disabling and even dangerous for those with dementia”.

www.enablingenvironments.com.au
Promoting advance care planning to people with and without dementia
http://www.start2talk.org.au/

“Most of us would prefer not to think about becoming unwell or developing dementia, but it is important to have plans in place in case we do. Start2Talk has been developed by Alzheimer’s Australia and our partners to help all Australians start the conversations involved in planning ahead.”

—Ita Buttrose AO OBE Australian of the Year 2013, Former National President, Alzheimer's Australia

Start2Talk. Advance care planning for people with dementia
A project to help people plan ahead for medical and health care decisions
Dr Chris Shanley, Liverpool Hospital, NSW, with Alzheimer's Australia NSW
CONSUMER DEMENTIA RESEARCH NETWORK AND THE NATIONAL QUALITY DEMENTIA CARE INITIATIVE

Prioritised areas of concern

Selected projects

Called for applications

Meaningfully involved
PARTNERING WITH CONSUMERS: THE CONSUMER DEMENTIA RESEARCH NETWORK & THE NHMRC PARTNERSHIP CENTRE
Consumer Involvement in NHMRC Cognitive Decline Partnership Centre

- Consumer paid member of Management Team and Executive Committee
- Supported by sub group of Network members
- Consumer Enabling SubUnit
- Consumer members of Scientific SubCommittee
- Consumer involvement in all Activities (Projects) of the Centre
Consumer Involvement in Australian Clinical Guidelines for Dementia Project

**Planned/implemented early**
- Organising Committee – 1 consumer
- Guideline Adaptation Committee - 4 consumers
- CDRN support group

**Role Clarity**
- Why
- What
- Time
- Expectations
- TOR

**Support/Feedback**
- Peer support
- Team leaders

**Resourcing**
- Budget
- Costs
- Payment for time

**Accessibility issues**
- Language
- Special needs
- Resources

http://www.invo.org.uk/posttyperesource/before-you-start-involving-people/
Consumer Involvement in Guideline Adaptation Committee

I must say I am absolutely delighted with some of the inclusions I managed to get into the document. It is immensely rewarding and reassuring to know that consumers/carers really can influence such documents at this level. Some of the inclusions will hopefully herald some important shifts in thinking and expression.

Consumer representative

I highly value your feedback, you are an expert in this area.
Committee feedback to consumer representative

Link to the Guidelines and online feedback form.
The Future
Questions raised in formal evaluation

Do consumers have capacity for constructive input to projects and to enhance relevance?

Are consumers objective and able to assess research proposals?

What is the appropriate nature of consumer contribution?

At which stage of the research process can consumers best contribute?

What weight should be given to relevance versus quality of research in funding decisions?

How can consumer involvement be measured?
Maintaining the Network

**Enablers for success**
- Support (AA, DCRCs)
- Member commitment
- Mutual support
- Financial support
- Face to face meetings
- Open communication

**Challenges**
- Geographic separation
- Member/Secretariat staff turnover
- Time constraints
- Unpredictable workload
- Limitations of funding
- Group dynamics
The way ahead: a new landscape

Nationally

• Dementia a National Health Priority for Australia

• Boosting Dementia Research Initiative
  — Australian Government additional $200M investment over 5 years

• A National Institute for Dementia Research
  — Consumer involvement in establishing priorities for the Institute
  — Potential for significant consumer involvement in the future

Internationally

• Consumer involvement (PPI?) in all phases of research process the norm
• Need to strengthen the evidence base recognised
CONSUMER INVOLVEMENT IN ALL PHASES OF THE RESEARCH PROCESS – from knowledge generation to knowledge translation

Consumer involvement is not being participants in projects
Consumer involvement is not asking consumers to recruit participants
Consumer involvement is actively listening and responding to consumers
RESEARCH FOR US, WITH US

CDRN MEMBERS APRIL 2015