ADI2017-366: WHY GET INVOLVED IN DEMENTIA RESEARCH AS A “CONSUMER”?

PERSONAL IMPERATIVES AND POLITICAL REALITIES

JANE THOMPSON
TALK OUTLINE

• Personal motivations for my involvement in dementia research

• Consumer/public/community involvement in dementia research in Australia and politics thereof

• Successes/failures

• What is needed for future success

• What keeps me going
Australian Code for Responsible Conduct of Research states: *Appropriate consumer involvement in research should be encouraged and facilitated by research institutions and researchers.*

NHMRC encourages researchers to consider the benefits of actively involving consumers in their proposed research when they apply to NHMRC for research funding.

Statement on Consumer and Community involvement in Health and Medical Research, National Health and Medical Research Council (2016), Consumers Health Forum of Australia.
“….there have been limited examples in Australia of a comprehensive systemic approach to consumer participation (sic) in health and medical research. There have been pockets of success, generally in areas where there is a groundswell of activism around a health condition (e.g. HIV, breast cancer) or a disadvantaged community (Aboriginal health)”
CONSUMER INVOLVEMENT IN DEMENTIA RESEARCH IN AUSTRALIA

• 2010 Alzheimer’s Australia and the Dementia Collaborative Research Centres support a new Consumer Dementia Research Network

• 2010 – 2015
  • Network active in knowledge translation and research projects

• Integral involvement in NHMRC Cognitive Decline Partnership Centre
  http://sydney.edu.au/medicine/cdpc/
THE CONSUMER DEMENTIA RESEARCH NETWORK

“an innovative approach to consumer involvement within the fields of dementia research and knowledge translation”

“..an impressive list of achievements and short term impacts”

Consumers were actively and effectively involved in the development of Australia’s new clinical practice guidelines.

Appendix 1 Principles of Dignity in Care

This Guideline is underpinned by the 10 Principles of Dignity in Care. These Principles were developed by the Social Care Institute for Excellence in the UK based on consultation with consumers. People with dementia and their carers and family should expect treatment that is provided according to these principles.

<table>
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<tr>
<th>10 Principles of Dignity in Care</th>
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<tr>
<td>1. Zero tolerance of all forms of abuse.</td>
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<td>2. Support people with the same respect you would want for yourself or a member of your family.</td>
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<td>3. Treat each person as an individual by offering a personalised service.</td>
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<td>4. Enable people to maintain the maximum possible level of independence, choice and control.</td>
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<td>5. Listen and support people to express their needs and wants.</td>
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<td>6. Respect people’s privacy.</td>
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<td>7. Ensure people feel able to complain without fear of retribution.</td>
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<td>8. Engage with family members and carers as care partners.</td>
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<td>9. Assist people to maintain confidence and a positive self-esteem.</td>
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<td>10. Act to alleviate people’s loneliness and isolation.</td>
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http://www.dignityincare.org.uk/
• Working group consumers plus researchers
• Informed by other consumer guides
• Initial brief – favourable attributes
• Rounds of drafts with feedback
• Professional editor and graphic designer
CONSUMER INVOLVEMENT IN DEMENTIA RESEARCH IN AUSTRALIA PHASE 2

• 2015-16 Consumer Dementia Research Network ‘under review’; no longer supported

• 2016 Alzheimer’s Australia formed new National Dementia Consumer Network

• 2015 NHMRC National Institute for Dementia Research established
WHERE TO NEXT?

• A Framework for Public Involvement in Dementia Research in Australia

• Supported Research Network

• “Research for us, with us”
AUSTRALIAN RESOURCES
INTERNATIONAL MODELS OF EXCELLENCE

INVOLVE UK RESOURCES

• For researchers
  – How to involve people in research
  – Briefing notes for researchers
  – Plain English summaries
  – Involvement cost calculator

• For the public
  – How to get actively involved
  – Getting started
  – Finding out more
  – Jargon buster

• For both
  – User controlled research
  – Developing training and support

http://www.invo.org.uk/resource-centre/