



Alzheimer's
Australia
Living with dementia

Involving Consumers in Research

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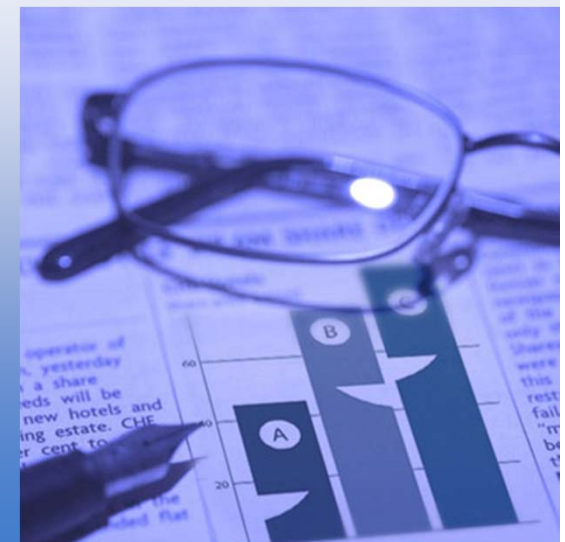
Overview

- Why Involve Consumers?
- What roles can consumers have?
- How has it been done in Australia?
- Alzheimer's Australia Consumer Research Network
 - Overview
 - Challenges
 - Success



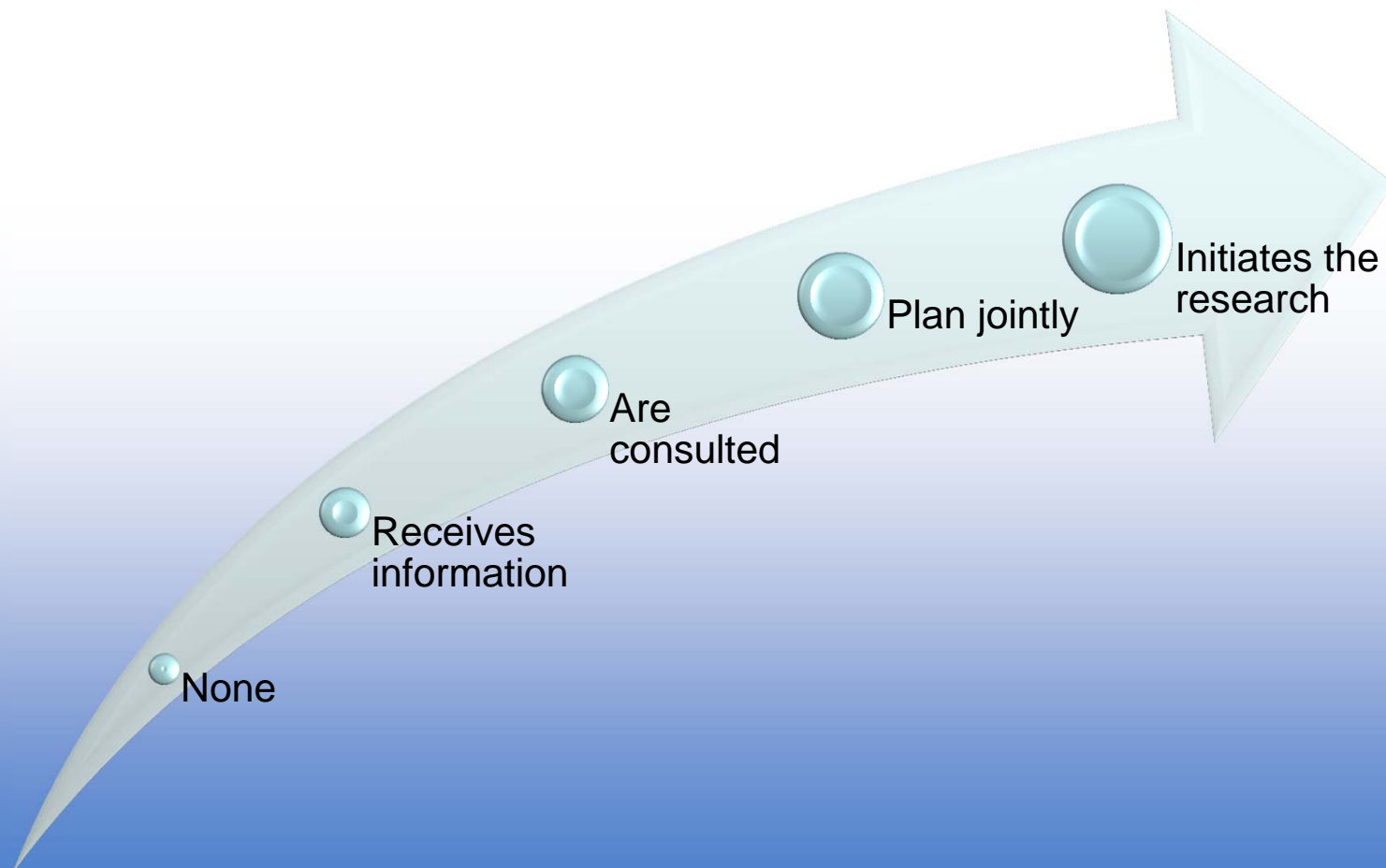
Why Involve Consumers?

- Social justice argument
- Better Quality Research
 - New Ideas
 - Innovative Approaches
 - Improved methodology
 - Greater uptake of findings
 - **Outcomes that are relevant to Consumers**



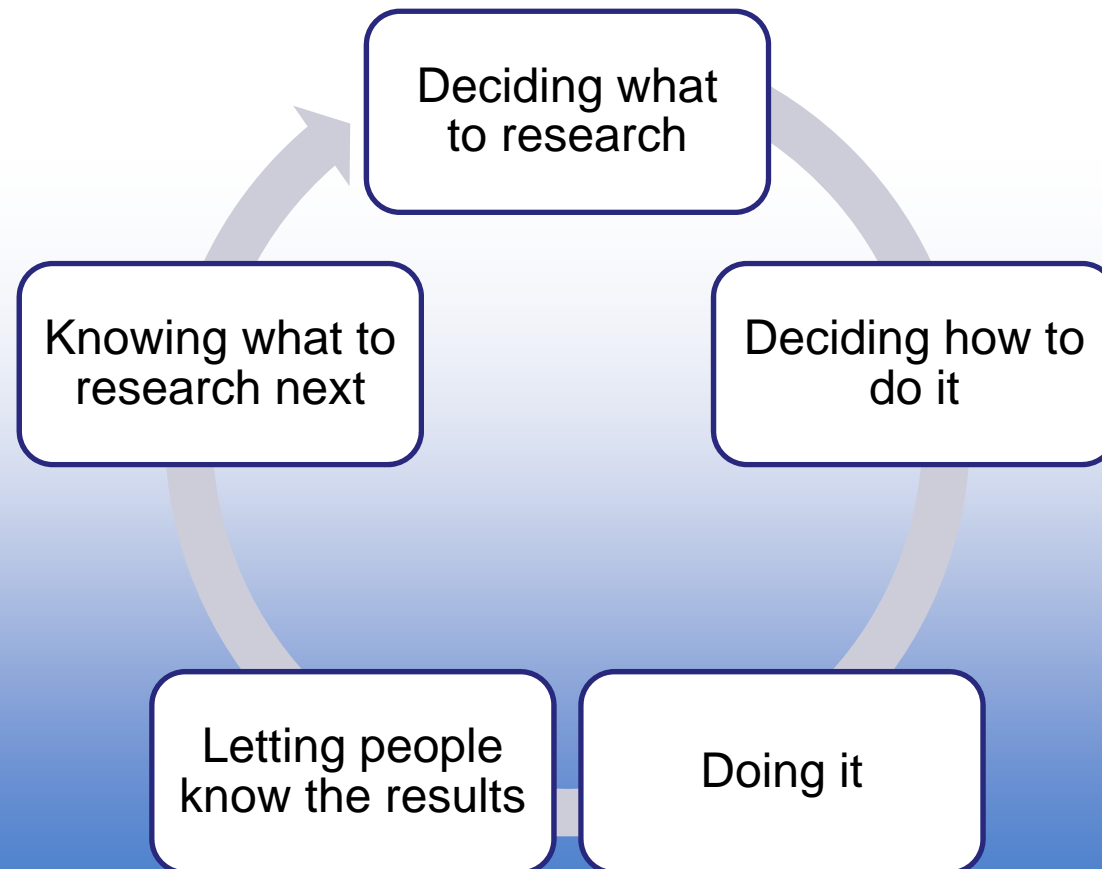


What level of involvement?





When should Consumers be involved?





Experience in Australia

- National Health and Medical Research Council (NHMRC)
 - Statement
 - Resource pack
 - Model framework
 - Statement in Australian Code for Responsible Conduct of Research
 - Researchers must encourage “appropriate consumer involvement in research”





Cancer Australia

- Cancer Australia's Collaborative Cancer Research Scheme
 - Consumer involvement is a funding requirement
 - Consumers involved in assessment of grant applications
 - Consumers given 2 days of training to learn about the grants process



University of Western Australia- School for Population Health

- Consumer Liaison position
 - Support consumers in involvement in research
 - Change the culture of research community
- Training for consumers and researchers



Quality Dementia Care Initiative

Consumer
Dementia
Research
Network*

National
Quality
Dementia
Care Network

Service
Provider
Network

***The Consumer Dementia Research Network is funded through the Dementia Collaborative Research Centres as part of the Australian Government's Dementia Initiative**



Quality Dementia Care Initiative

Objectives

1. To translate research evidence into better dementia care in Australia
2. To support consumer involvement in dementia knowledge translation and research



Overview of CDRN

- Broadly based on UK dementia network
- First meeting September 2010
- 24 members- individuals with dementia, family carers, former carers
- National- each state and territory represented
- Broad recruitment- not just AA

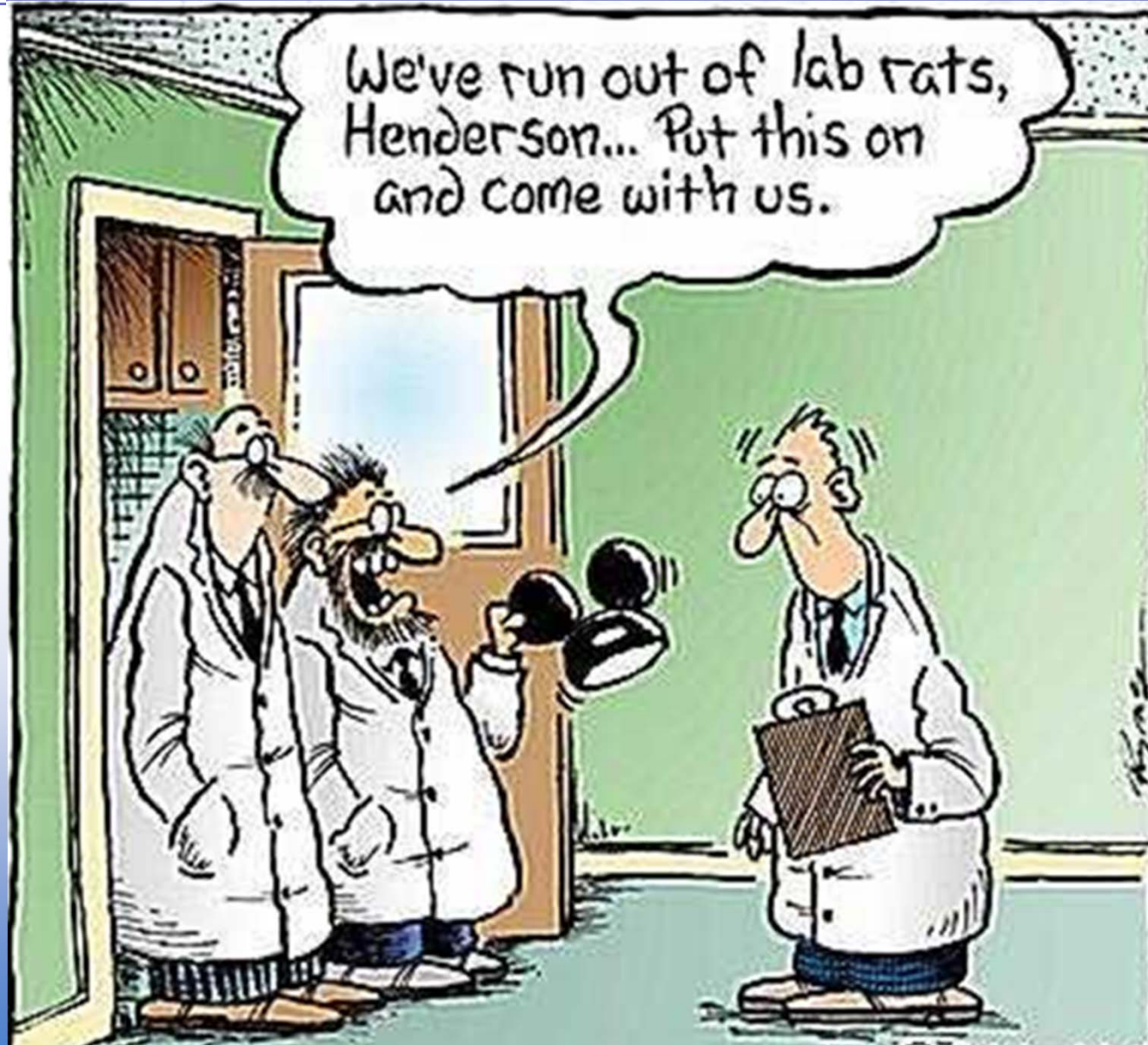
Recruitment

- **Personal Experience with Dementia**
- **Personal Characteristics (interpersonal skills, time commitment)**
- **Interest/Experience in Dementia Research**
- **Existing Networks**



Role of CDRN

- To provide a consumer perspective.
- To be a resource
- To remove barriers
- Active role in all stages of research projects (not just as research participants)
- Involvement when consumer input adds value but not as a token





National Quality
Dementia Care
Network

Alzheimer's Australia
Research

Consumer
Dementia
Research
Network

Dementia
Collaborative
Research Centres

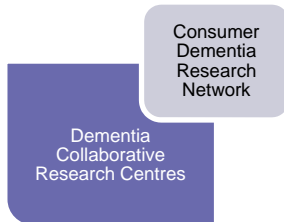
Other projects

National Quality
Dementia Care
Network

Consumer
Dementia
Research
Network

Involvement with: National Quality Dementia Care Network

- Setting Priorities for the first round of funding (September 2010)
- Evaluating Expressions of Interest (December 2010)
- Evaluating Full Project Proposals (March 2011)
- Final Funding Decision (April 2011)



Involvement with: Dementia Collaborative Research Centres

- Receiving Information
- Reviewing Project Proposals
- Correspondence & Protocol
- Coordinating Committee
- Conferences & Workshops
- Postdoctoral Selection
- Involvement in Projects
- Assistance with Recruitment
- Funding for Consumer Involvement (new)**



Alzheimer's Australia
Research

Consumer
Dementia
Research
Network

Involvement with: Alzheimer's Australia Research

- Advocate for Consumer Involvement
- AAR grants amended to include two additional questions on consumer engagement
- CDRN to assess lay summaries and the two additional questions
- One grant per year will focus on priority areas determined by CDRN



Consumer
Dementia
Research
Network

Other Projects

Involvement with: Other Projects

- Stigma Project- University of Wollongong
- Respite Feedback for PC
- Consumer Participation in health as social participation
- Couples Project
- Feedback to Dementia Study Training Centres
- Feedback on Communicating with People who have dementia- for Better Practice Seminars
- Pfizer Health Report
- National Cross Cultural Dementia Network



Challenges

- Consumers
 - Amount of work/time required
 - Lack of compensation for out of pocket expenses and time
 - Frustration at not being able to be more involved
- Researchers
 - Time required
 - Costs
 - Knowing how to do it??





Successes

- Membership
- Alzheimer's Australia Research
- Relationships with DCRCs
- Knowledge Translation projects





What Next

- ? Sustainability
- Training/Skills development
- Vision
- Broadening involvement
- Drawing on larger groups of consumers



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Thank you!

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