Involving Consumers in Research

Dr Ellen Skladzien
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?

- None
- Receives information
- Are consulted
- Plan jointly
- Initiates the research
When should Consumers be involved?

- Deciding what to research
- Knowing what to research next
- Letting people know the results
- Deciding how to do it
- Doing it
- Knowing what to research next
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
We've run out of lab rats, Henderson... Put this on and come with us.
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)
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
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
Thank you!

Ellen.Skladzien@alzheimers.org.au