Nothing about us, without us

Kate Swaffer
Co-chair, Alzheimer’s Australia
Consumer’s Dementia Research network
International Dementia Leader 2015 Award
INCLUDING CONSUMERS
Who wants change?
Who wants to change?
Equal inclusion of people with dementia as there is of care partners, in organisations, on boards and committees, and in the research.

The full cost of participation must also be covered.

Full support for disAbilities
Respect
Dementia Language Guidelines
Feedback
ALL CONSUMERS HAVE A HUMAN RIGHT UNDER LEGISLATION, TO:

• Full and equal inclusion
• A more ethical pathway of care, including rehabilitation and other non pharmacological and positive psychosocial interventions
• People with dementia being treated with the same rights as everyone else, under the Disability Discrimination Acts and UN Convention on the Rights of Persons with Disabilities
• Not to be discriminated or stigmatised
• Full citizenship
• To employment, and
• To research that does not only focus on a cure, but on improving the care of people with dementia and our families and care partners
WHAT/WHO CAN HINDER THE INCLUSION OF PWD IN RESEARCH

• Stigma and attitudes
• Gatekeepers
  • Families and care partners
  • Health Care Professionals
  • Advocacy organisations
• Ethics approval
• Prescribed Disengagement ®
  • This takes away HOPE; why bother participating
SCEPTICS COULD ASK: WHO GAINS THE MOST FROM RESEARCH?
There has been a surge in the UK in the number of people volunteering to help with medical research into dementia.

“The National Institute for Health Research, the research arm of the NHS, reported a 60% jump in people signing up in the past year. Almost 22,000 people are taking part in 100 separate studies into the degenerative brain disease.”

The Alzheimer's Society said “such volunteering was essential for developing a cure.”

JOIN DEMENTIA RESEARCH

Improving care
Finding a cure

There has been a surge of people with dementia signing up...

https://www.joindementiaresearch.nihr.ac.uk
WHY “NOTHING ABOUT, US WITHOUT US” IN RESEARCH?

Chris Roberts, from north Wales, has been taking part in a trial investigating the genetics of Alzheimer's disease.

He said: "What we then need is hope, and this is what research gives us. Taking part means I'm doing something constructive and worthwhile. I'm leaving something behind that might help others, if not myself. Any kind of research, small or large, brings with it hope that there may be a future.” (BBC, 2015)
EXAMPLES OF RESEARCH AND ADVOCACY, ABOUT US WITHOUT US

• Overcoming stigma - World Alzheimer Report 2012
  • Of 2068 UK participants, ONLY 6% were people with a diagnosis of a dementia
  • Of 277 Spanish participants, ONLY 3% were people with a diagnosis of a dementia

• People with dementia not on the Board of the NHMRC, or most Alzheimer’s organisations except Alzheimer’s NZ and ADI

• Not one person with dementia employed anywhere in the world to work on the dementia friendly communities initiatives
PARTNERING ALONGSIDE CONSUMERS

THE CONSUMER’S DEMENTIA RESEARCH NETWORK, ALZHEIMER’S AUSTRALIA, THE CDPC AND THE NHMRC PARTNERSHIP CENTRE
ALZHEIMER'S AUSTRALIA
DEMENTIA LANGUAGE
GUIDELINES, 2014

SEE THE PERSON
NOT THE DEMENTIA

Respectful language, as deemed respectful by people with dementia is imperative in research.
## PRINCIPLES OF DIGNITY IN CARE

People with dementia and their care partners and family should expect treatment that is provided according to these simple principles:

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<td>1</td>
<td>Zero tolerance of all forms of abuse.</td>
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<td>2</td>
<td>Support people with the same respect you would want for yourself or a member of your family.</td>
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<td>3</td>
<td>Treat each person as an individual by offering a personalised service.</td>
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<td>4</td>
<td>Enable people to maintain the maximum possible level of independence, choice and control.</td>
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<td>5</td>
<td>Listen and support people to express their needs and wants.</td>
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<td>6</td>
<td>Respect people’s privacy.</td>
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<td>7</td>
<td>Ensure people feel able to complain without fear of retribution.</td>
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<td>8</td>
<td>Engage with family members and carers as care partners.</td>
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<td>9</td>
<td>Assist people to maintain confidence and a positive self-esteem.</td>
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<td>10</td>
<td>Act to alleviate people’s loneliness and isolation.</td>
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CONCLUSIONS

• Consumers have been involved in research, but not as equals

• Equal consumer and care partner input is critical to ensuring research is more valid and relevant to the needs of people with dementia and our care partners and families

• Better levels of involvement will contribute to the development of more relevant, higher quality research