



Australian Government

NHMRC National Institute for Dementia Research

# DEMENTIA CARE FORUM: INVOLVING CONSUMERS IN RESEARCH TOWARDS BETTER CARE OUTCOMES COMMUNIQUE

2018

Accelerating research. Enhancing collaboration. Creating change.



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# CONTENTS

<b>CONTEXT</b>	<b>4</b>
<b>COMMUNIQUE</b>	<b>5</b>
Preamble	5
Vision for consumer and community involvement in research	5
Values	6
Purpose	6
<b>APPENDIX: DEMENTIA CARE FORUM DISCUSSION SUMMARY</b>	<b>7</b>
1. How do we ensure our care research delivers optimal outcomes for people with dementia, their carers and families?	7
2. What's working well?	7
What can be improved?	7
3. What can we introduce to provide for greater speed of translation and benefit at the "coalface"?	7
4. What are our priorities for action?	8

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## CONTEXT

The following Communique was developed at NHMRC National Institute for Dementia Research's *Dementia Care Forum 2017: Involving Consumers in Research towards Better Care Outcomes*. The Forum took place on Wednesday 18 October as part of the Dementia Australia National Conference 2017, held at the Melbourne Convention and Exhibition Centre, Melbourne. The Forum was attended by 29 participants comprising people with dementia, carers, researchers, and representatives from service providers, research organisations, peak bodies and government.

Participants worked together to answer four questions that were intended to drive conversation about how we can better involve people with dementia, their carers and families, and the wider public in dementia research. The four questions were:

1. How do we ensure our care research delivers optimal outcomes for people with dementia, their carers and families?
2. What's working well? What can be improved?
3. What can we introduce to provide for greater speed of translation and benefit at the "coalface"?
4. What are our priorities for action?

A summary of the key points from the discussion is provided in the Appendix.

On Thursday 19 October, NHMRC National Institute for Dementia Research hosted a booth at the Dementia Australia National Conference to give conference participants the opportunity to provide their input on the above four questions.

Notes from the feedback provided from the Forum and the booth were then processed to develop the following Communique. The Communique and discussion summary were then presented to forum participants at a follow-up workshop on Friday 20 October, following the conclusion of the Dementia Australia National Conference, for further refinement. There were 17 participants at the follow-up workshop and the Communique contained in this document has incorporated their verbal feedback.

The Communique is intended to articulate the vision, values, and purpose of the NHMRC National Institute for Dementia Research in creating an environment where people with dementia, their carers and families and the wider public are actively involved across all stages and types of dementia research.

## COMMUNIQUE

### Preamble

The NHMRC National Institute for Dementia Research (NNIDR) recognises that people with dementia, their carers and families, and the wider community have an invaluable contribution to make to dementia research.

The NNIDR is committed to the vision<sup>1</sup> expressed in the NHMRC/Consumers Health Forum of Australia joint *Statement on Consumer and Community Involvement in Health and Medical Research* and will promote its implementation across the dementia research sector. We are also guided by the principles of consumer and community involvement (or public involvement) in research as espoused by:

- INVOLVE UK's national advisory group established in 1996 and funded by the National Institute for Health Research to support active public involvement in the National Health Service (NHS), public health and social care research,
- Cancer Australia's *National Framework for Consumer Involvement in Cancer Control*, and
- The University of Western Australia School of Population Health and Telethon Kids Institute Consumer and Community Involvement Program – *Involving People in Research*.

In the dementia context, 'consumers' includes people with dementia, their carers and families.

Consumer and community involvement in research refers to research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. The approach and level of involvement will vary depending on the type of research being undertaken. Consumer and community involvement includes, but is not limited to, consumers and other members of the community:

- working with researchers and research funders to set research priorities,
- being members of grant application review panels,
- offering advice as members of project steering groups,
- commenting on and developing research materials,
- being a 'research buddy' or link between the researcher and the public, and
- assisting with dissemination and implementation of research findings.

We are not referring to researchers raising awareness of research, sharing knowledge or creating a dialogue with the public (often referred to as 'engagement') nor to the recruitment of patients or members of the public as participants in research ('participation'). 'Engagement', 'participation' and 'involvement' are, of course, often linked and complementary activities.

### Vision for consumer and community involvement in research

People with dementia, their carers and families, the wider community, researchers and research organisations actively working together in partnerships to achieve the best possible outcomes for Australians living with or at risk of dementia, their carers and families.

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<sup>1</sup> 'Consumers, community members, researchers and research organisations working in partnerships, to improve the health and well-being of all Australians through health and medical research.', NHMRC/CHF, *Statement on Consumer and Community Involvement in Health and Medical Research*, September 2016, p. 2.

## Values

Shared understanding, respect and commitment

## Purpose

To guide research institutions, researchers, consumers and community members in the active involvement of consumers and community members in dementia research.

### **In order to realise our vision and purpose for consumer and community involvement in research, the NNIDR will play a leadership role in creating an environment where:**

- People with dementia, their carers and families and the wider community are actively involved across all stages and types of dementia research.
- People with dementia, their carers and families and the wider community can be appropriately trained and supported to be involved in research.
- Researchers and research organisations can be trained and supported to involve people with dementia, their carers and families and the wider community in their research.
- Researchers involve people with dementia, their carers and families and the wider community respectfully.
- People with dementia, their carers and families and others from diverse communities can be involved in an appropriate, respectful and culturally safe manner.
- Funding models and mechanisms support the involvement of people with dementia, their carers and families and the wider community across all stages and types of dementia research.

### **We will action this by:**

- Working with Dementia Australia to engage with people with dementia, their carers and families and the wider community to encourage their involvement across all stages and types of dementia research. This may include:
  - developing the NNIDR Membership Network to include consumers and community as a core membership category,
  - using a variety of communication channels including social media, and other resources to better encourage the public to become involved in dementia research and to educate them about the research process and how they can be involved, and
  - finding more ways to communicate research findings to people with dementia, their carers and families and the wider community to better drive knowledge transfer and implementation.
- Working to acquire funding to provide readily available ongoing training for:
  - researchers on how to proactively involve people with dementia, their carers and families, and the wider community across all stages and types of dementia research, recognising that the type of involvement will differ for different research programs, and
  - people with dementia, their carers and families and the wider community on how to be actively involved across all stages and types of dementia research.
- Providing advice to government and funding bodies on funding guidelines to support the involvement of people with dementia, their carers and families and the wider community in dementia research.

To ensure the implementation of these actions involves people with dementia, their carers and families, the wider community, researchers and research organisations, a working group will be established to provide guidance to the NNIDR.

To be accountable to people with dementia, their carers and families, the wider community and researchers and research organisations against these actions, we will publically report on our progress annually.

## APPENDIX: DEMENTIA CARE FORUM DISCUSSION SUMMARY

### 1. How do we ensure our care research delivers optimal outcomes for people with dementia, their carers and families?

- Increase engagement between researchers and people with dementia, their carers and families and the wider community.
- Identify opportunities to improve funding and budgeting of consumer and community involvement and research implementation.
- Improve people with dementia, their carers and families and the wider community's awareness and engagement strategies for research development and involvement.
- Educate researchers about the holistic input people with dementia, their carers and families can provide from their lived experiences.

### 2. What's working well?

- Relationships between researchers and people with dementia, their carers and families and the wider community are gradually evolving and positive research experiences are beginning to occur more regularly.
- There are some measures now in place in some organisations, and some educational opportunities now available that help people with dementia, their carers and families and the wider community's education to be more informed about the contribution they can make to Australian dementia research and translation.

#### What can be improved?

- The working relationships between those people with dementia, their carers and families and other community members who are willing to be involved in research, and researchers working to improve dementia outcomes.
- The pathways for people with dementia, their carers and families and the wider community's involvement and interaction.
- Consistency and availability of educational opportunities for people with dementia, their carers and families and the wider community who would like to learn more about research methods and processes, and about the valuable roles they can play in developing, implementing and evaluating research projects.
- The funding structures for involvement, including appropriate financial compensation for various levels of involvement in research projects and funding that provides for large-scale translation and implementation of the best available research evidence.

### 3. What can we introduce to provide for greater speed of translation and benefit at the "coalface"?

- Improved education to all stakeholders involved with dementia research including researchers. This will help to drive culture change on the importance of the experiences of people living with dementia, their carers and families and the way these experiences can positively influence research outcomes.
- Improved communication strategies between people with dementia, their carers and families, service providers and researchers will help to enable people with dementia, their carers and families as drivers of knowledge transfer.
- A greater focus on implementation science within dementia research funding, which may involve greater emphasis on impact (proven capacity to work with health system partners to achieve improvements in prevention, cure and care) in the assessment process for some research projects.
- Undertaking a concerted effort to communicate research outcomes and findings to service providers to drive the application of research outcomes into everyday practice.

#### 4. What are our priorities for action?

- Design and implement consumer involvement standards, guidelines and measures (based on the NHMRC/CHF Statement for Consumer and Community Involvement in Health and Medical Research) that will provide a model for potential broader application by all Australian funding bodies.
- Build mechanisms to:
  - communicate with people with dementia, their carers and families and the wider community throughout and after the research process – this could be aided by establishing a national database for consumer and community involvement in research, and
  - embed people with dementia, their carers and families and the wider community throughout research process and standards.
- Consider and make recommendations for new funding models and mechanisms that will:
  - recognise the different requirements for knowledge transfer and research implementation, and
  - appropriately enable, recognise and support consumer and community involvement in research.
- Educate researchers and service providers about the value that people with dementia, their carers and families and the wider community can bring to research.
- Facilitate the implementation of models that demonstrate strong engagement with people with dementia, their carers and families and the wider community.
- Utilise mainstream media to increase education and research literacy of people with dementia, their carers and families and the wider community, with an aim to improve awareness and understanding of the research process.
- Create different pathways for people with dementia, their carers and families, and the wider community to be involved and interact in research to ensure there is greater representation within research.