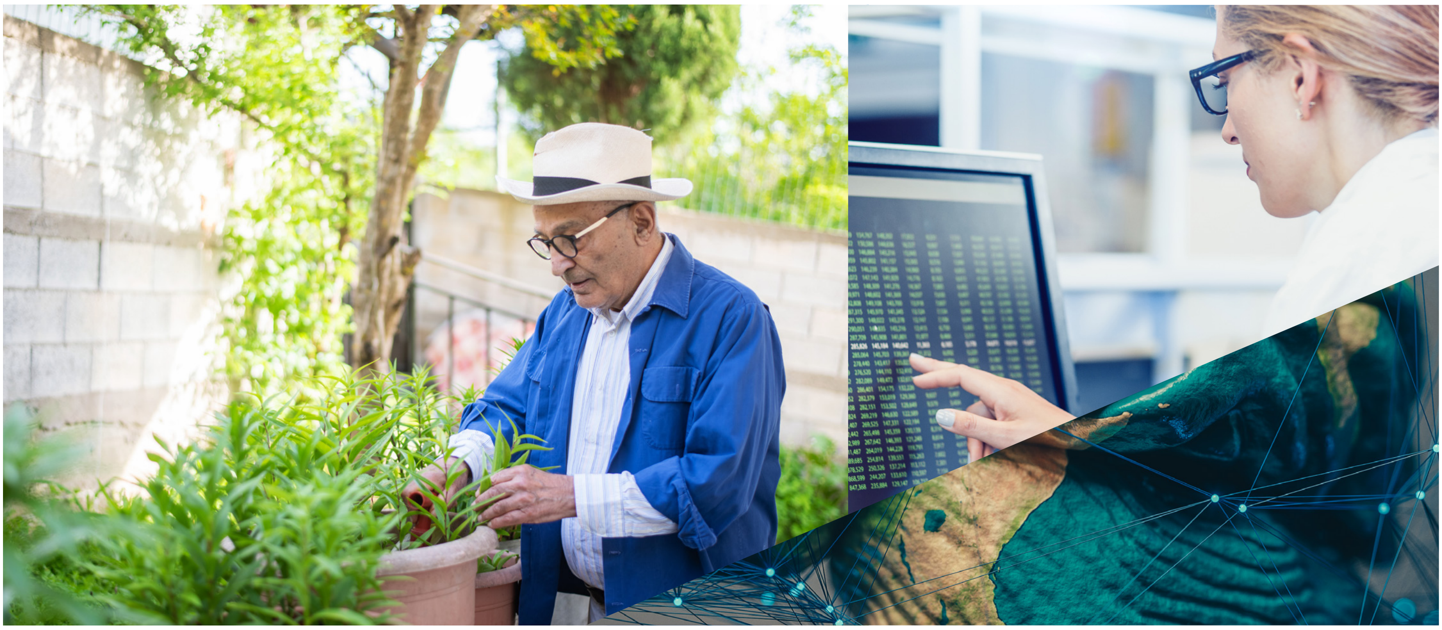
Australian Government

NHMRC National Institute for Dementia Research

BECOMING INVOLVED IN RESEARCH: A GUIDE FOR PEOPLE LIVING WITH DEMENTIA, THEIR CARE PARTNERS AND FAMILY MEMBERS

Accelerating research. Enhancing collaboration. Creating change.



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This booklet was compiled for The NHMRC National Institute of Dementia Research (NNIDR), under the guidance of its Community and Consumer Involvement Reference Group. NNIDR recognises that people with dementia, their care partners and families, and the wider community have an invaluable contribution to make to dementia research.

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INTRODUCTION

The purpose of this booklet is to facilitate meaningful involvement of people with lived experience of dementia (either as a person with a diagnosis of dementia, a care partner, or family member) in dementia research projects. Involving people with lived experience in research leads to higher-quality, more efficient research focused on what matters most to those living with dementia or caring for someone with dementia. The notes in this booklet provide some information about how you might become involved in research projects.

How to use this workbook

This booklet covers *some* of the answers to questions that people ask when they are thinking of becoming involved in dementia research. It doesn't cover everything that you will need to know because that will depend upon how much you want to get involved and on the particular research project you get involved in. Depending upon your experience, the type of involvement or the stage of the research in which you get involved, you may be offered some more training and technical information from your research team.

GETTING INVOLVED IN RESEARCH

Why dementia research is important

Dementia is the leading cause of disability in Australians over the age of 65 years and is the second-leading cause of death of all Australians (Dementia Australia, 2020). Dementia research is about discovering new evidence or knowledge that may lead to new treatments or a cure for dementia, or better care of people who are affected by dementia. It could be focused on causes of dementia, risk reduction and prevention, better ways to diagnose dementia, improving care, or enhancing quality of life for someone living with dementia or caring for someone living with dementia. Research can happen in a laboratory, health or care facility, or the community.

Potential benefits to research of your involvement:

Your value in research is your knowledge, gained through your life experiences.

Research benefits from the involvement of lived experience experts like yourself. **Involvement in research** is different from participation in a research study as a research 'subject'. It's not about filling in questionnaires or trialling a new drug. Being **'involved'** in research means that you **work alongside the research team** to help deliver research outcomes that are relevant to people who are living with dementia, their care partners and families. It means that the research is performed 'with' or 'by' people with lived experience rather than the research being 'on', 'about' or 'for' them.

Research benefits from involvement of lived experience experts in a number of ways, including:

- the important issues to people affected by a disease or condition can be identified
- real-world issues can be prioritised by researchers
- lived experience experts can help the wider community to be more informed about research outcomes
- lived experience experts can help communicate the outcomes of research to service providers and organisations and lobby for change.

The impact of public involvement on research:

Public involvement makes a positive difference to research, potentially leading to new insights, greater relevance and practical outcomes. It can also make a positive difference in the lives of the people who become involved.

> As a person with the lived experience of dementia, my participation in the *Plotting the Journey* research provided an opportunity to share my personal experiences before, during and post-diagnosis. This experience demonstrated that my input was valued, that I had a voice and motivated me to become an advisor to researchers on future committees.
>
> **John**
> a Person living with dementia

> I am very pleased to have contributed to the development of the Australian Clinical Practice Guidelines and Principles of Care for People with Dementia and to its companion guide for people with dementia and carers. It was a lot of quite intense work but with a very satisfying outcome. The input from lived experience experts ensured that the language used was appropriate and that the guidelines were underpinned by the Principles of Dignity in Care.
>
> **Jane**
> Care Partner

Potential benefits to you of involvement in research:

People who have been involved in research for many years say that at first, they didn't think that they would have anything new to contribute to research, but they knew they wanted to *"make a difference"*. People have found that the benefits of being involved in research may include having a newfound purpose and feeling valued, learning new skills or knowledge, having increased confidence or coping skills, and meeting new people and making new friends.

> As an advisor to many Social Care and Quality of Life research projects, I've realised the value of providing hope to people living with dementia, to be able to engage in more purposeful lives today and maintain their independence, confidence, interests and skills.
>
> **Glenys**
> Care Partner to a Person living with dementia

> I found caring for my husband overwhelmingly difficult and my sense at the end of it all was that it was incredibly hard — but surely it didn't need to be so difficult. I have a background in research and was motivated to support whatever research was necessary to improve the experience of dementia caring for others. I also wanted to learn as much as I could about dementia and to try and make some sense of what I and my husband had been through. I think I needed to find some meaning and purpose in my life too — which had changed dramatically and unexpectedly.
>
> **Jane**
> Care Partner

Why would you want to be involved?

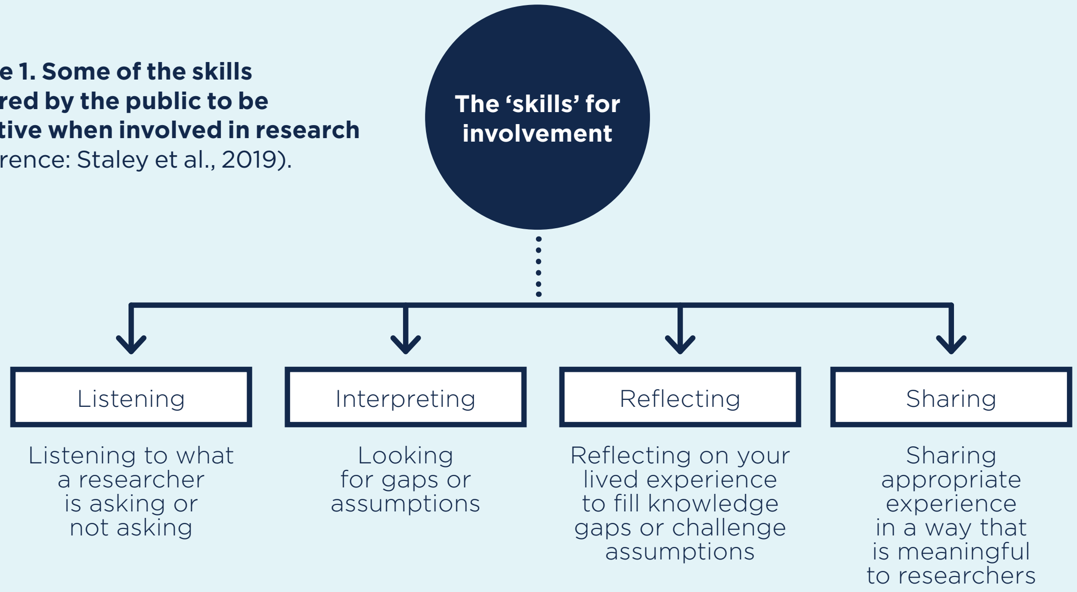
> If you feel passionate about supporting and contributing to the research necessary to improve the lives of people with dementia and carers, then I think becoming involved in research as a lived experience expert can be very satisfying. But I would also want people to know that it isn't always easy...
>
> So, I would recommend talking to others who have had some experience and perhaps partner with them on a project if an opportunity arises.
>
> **Jane**
> care partner

How can I most effectively share my knowledge to benefit research?

It is important to know how to use ‘your story’ effectively and share your knowledge in a way that benefits the researchers and the research. Lived experience experts like yourself, come with many vital skills along with their personal experiences. You can use these to contribute positively to research projects (see Figure 1).

As shown in the Figure 1 below, the skills that lived experience experts need to bring to research projects include being able to, (a) **listen** to what the researchers are aiming to do or find out, (b) **interpret** what is being said in line with your own understandings and identify if there are any gaps or misunderstandings on the part of the researchers, (c) **reflect** on your lived experiences and (d) **share** from your perspective to correct misunderstandings, fill in the gaps, or provide learning.

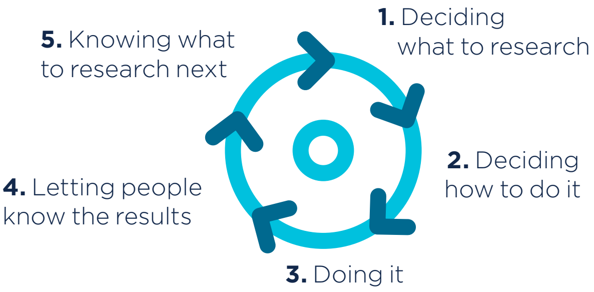
Figure 1. Some of the skills required by the public to be effective when involved in research (Reference: Staley et al., 2019).



> As an advisor to the Agents of Change research, I contributed to and influenced the MOOC (online learning) modules and provided direct feedback to numerous clinicians throughout Australia about their plans to become change agents for the betterment of people living with dementia.
>
> **John**
> a Person living with dementia

THE RESEARCH CYCLE AND WHERE AND HOW YOU MIGHT BE INVOLVED

Research usually follows a cycle as illustrated below:



1. Deciding what to research

2. Deciding how to do it

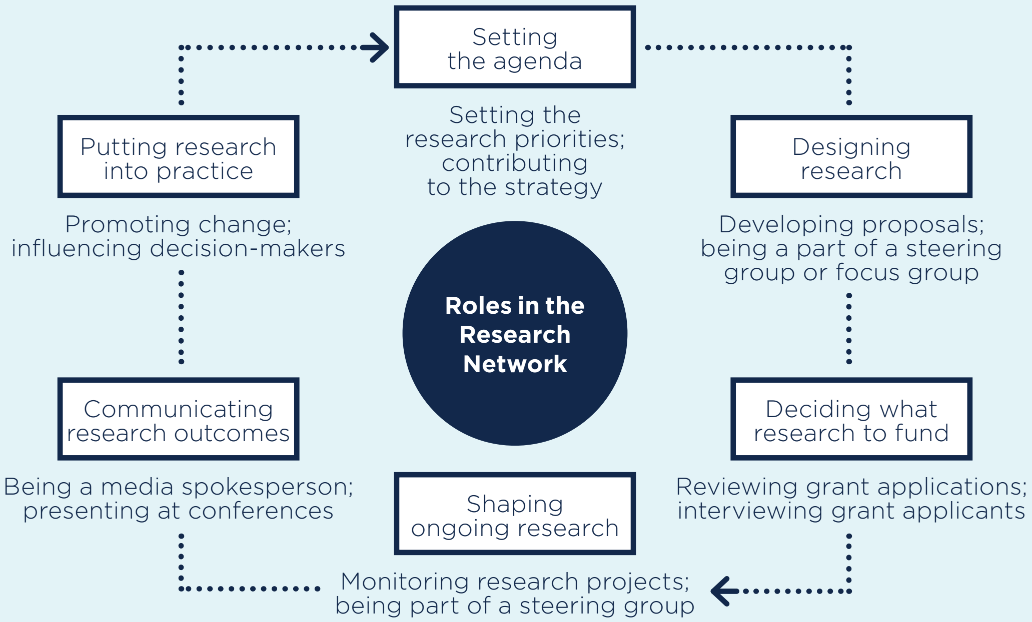
3. Doing it

4. Letting people know the results

5. Knowing what to research next

The stages of research involvement

This model of the stages of research involvement and the types of involvement at each stage comes from the Alzheimer's Society in the United Kingdom. It is based on their Research Network of lived experience experts who are trained and supported to be involved in dementia research.



Roles in the Research Network

Setting the agenda
Setting the research priorities; contributing to the strategy

Designing research
Developing proposals; being a part of a steering group or focus group

Deciding what research to fund
Reviewing grant applications; interviewing grant applicants

Shaping ongoing research
Monitoring research projects; being part of a steering group

Communicating research outcomes
Being a media spokesperson; presenting at conferences

Putting research into practice
Promoting change; influencing decision-makers

(Reference: **www.alzheimers.org.uk/blog/impact-involving-people-affected-dementia-research**).

> “Sometimes it's just about changing the colours, or changing the wording, or getting the language right. Try and be imaginative and think about the myriad of ways in which you can involve us.”
>
> **Bobby**
> a Person living with dementia

Levels of involvement at each stage

There are many different dementia-related research topics. Research may take many different forms across the research cycle (as the above diagram shows), and you can make a difference at any stage in the research cycle. Your involvement will depend on the type of research you choose, or the part of the research cycle that you get involved in.

Roles and responsibilities

Your role is an expert advisor based on your experiences as someone living with dementia or caring for and supporting someone living with dementia. Your involvement might be face-to-face with researchers, or it could be by telephone or video conference, or a combination of all of these. Your unique contributions and responsibilities will depend upon finding a research project that meets your interests and experience and being matched with a project that needs people with your lived experience.

Some examples of involvement include:

- helping to set research or research funding priorities by providing new ideas (e.g. deciding on a new intervention or program to increase quality of life)
- being members of grant application review panels (e.g. helping funders in their decisions about important and relevant research projects for funding; making sure lived experience experts are included in proposals)
- supporting researchers in their bid for funding (e.g. helping with letters of support)
- offering advice as a member of a Project Reference Panel (e.g. advising on relevance or importance of aims of the project, helping to avoid potential problems)
- commenting on and developing research materials (e.g. making sure language used is clear and respectful)
- helping researchers to make sense of data (e.g. explaining what the results of a series of focus group discussions might mean in the real world)
- helping with ethics applications (e.g. identifying potential issues, addressing needs, commenting on issues of risk and dignity)
- being a ‘research buddy’ or a link between the researcher and the public (e.g. promoting the research project or research outcomes to media, through interview, voice-over or photograph)
- assisting with communicating the results and helping to put the evidence into practice (e.g. presenting at conferences, talking to local health services, or advocating for policy change).

> **I have been involved in research as a member of Dementia Australia’s Research Foundation (DARF) Scientific Panel — reviewing biomedical and psychosocial applications from a consumer perspective; a member of the Australian Dementia Forum’s Conference Committee, advising on issues relevant to people living with dementia and making sure consumers are better catered for at the Conference, e.g. ensuring appropriate dementia friendly language is used by presenters, and ensuring the conference venue is dementia friendly…**
>
> **Ann**
> a Person living with dementia

What you should expect from your involvement

Your involvement makes a unique and valuable contribution to research and you should therefore expect to be provided with:

- clear and open communication from researchers about your role and responsibilities
- friendly and well supported opportunities to contribute your ideas during meetings, including having meetings that are not too long if you tire easily and the ability to ask questions and/or take time out when you need it
- a point of contact for you to provide ongoing feedback about involvement
- a working relationship based on mutual respect and trust
- access to any necessary training and support
- feedback about the results of the project arising from your involvement in the research, and overall project results
- an opportunity to contribute to an evaluation of how well the process of involvement worked.

Be aware that you may need to set some limits for yourself! It is important *not* to take on too much although you might be tempted to in the beginning. Research projects can be lengthy, and involvement may be taxing to you emotionally and physically.

Reward and recognition for involvement

Sometimes you may be offered payment for your involvement, this can be in the form of money or store gift cards. At the least, you should expect to be reimbursed for any expenses that you have from the research involvement, including travel, or home office expenses (e.g. telephone calls, printing from home). Be aware that some payments of money or even reimbursement of expenses may affect any Commonwealth benefit payments that you receive (e.g. health or disability or age pension). You could look online at the information on the Australian Taxation Office website or you might discuss this issue with a member of your research team.

Core principles that researchers should recognise for involving people living with dementia

These core principles are specific to working with people with dementia and were developed by the Scottish Dementia Working Group. These provide a model for researchers to strive for and what people with dementia might expect to be adhered to when researchers and people living with dementia work together and learn from each other.

1. valuing and involving people with dementia in research
2. considering lived experience as knowledge
3. ensuring physical and emotional safety
4. making research accessible, in clear and supportive language
5. researcher training to be dementia aware
6. being considerate of “dementia time” e.g. give reminders, breaks, check in regularly.

(Walsh & Griffiths, 2020)

RESEARCH AND ETHICAL RESPONSIBILITIES

Lived experience experts can expect researchers to follow high ethical standards in their research projects. There are strict guidelines and principles, which in summary mean that research projects must 'do no harm'. Ethics applications that involve research with people living with dementia are carefully produced by researchers and carefully considered by Ethics Committee Members. Therefore, it can take a long time to write and apply for, and to gain, ethical approval — many months in most cases. This might be important to consider if you join a research team from the very beginning of the project, and when you discuss your expectations and capacity for involvement with a member of your research team.

Confidentiality

Confidentiality is important for building trust in research relationships. As a contributor to the research process you will be involved in discussions and have access to information that may be sensitive and is strictly confidential. Confidentiality is particularly important for open communication and flow of information between you, the researchers, and research participants. You may be asked to sign a 'Confidentiality' or 'Non-disclosure' Agreement stating that you agree **not to share confidential material, knowledge, or information**. If you are unsure of whether something is confidential or not, you should ask your research team.

Confidentiality can only be broken in exceptional circumstances, such as when it is necessary to protect an individual's or public safety, or if directed by a court order.

How can I find out how to get involved in dementia research?

Many researchers around Australia are involving community members in their research, and you may be approached from time to time. We hope this guide helps you to make an informed decision about whether, and if so, how, to become involved in research.

Dementia Australia can provide opportunities for people living with dementia, carers of people living with dementia and former carers to share their stories and have their voices heard. Contact Dementia Australia to learn more about their Dementia Advocates Program, which was developed to strengthen and elevate the voices of people with a lived experience of dementia across Australia. On behalf of researchers, Dementia Australia may contact people who have registered through this program about opportunities for involvement in research.

www.dementia.org.au/about-us/dementia-australia/dementia-advocates-program/become-a-dementia-advocate

You may also be interested in:

- the Australian Dementia Network, which brings together Australia's leading researchers, clinicians and consumers to create a powerful network for dementia prevention, treatment and care. **www.australiandementianetwork.org.au**
- the Dementia Centre for Research Collaboration, which has toolkits, resources and advice based on the evidence generated through research. **www.dementiaresearch.org.au**

RESOURCES AND REFERENCES

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