



# Valuing the advocacy of people with dementia: moving dementia out of the shadows



Dementia Alliance International

Global Report 2021



Cover: Global Dementia Advocates Christine Bryden, Kate Swaffer, James McKillip, Kazuko Fujita and Tomofumi Tanno in Osaka, Japan.

*“Dementia used to have to be hidden away. Every time one of us stands up and speaks out about our experience we are changing society. We are changing the way we are seen. We are refusing to remain hidden behind the closed doors”.*

Respondent DAI Survey (Person with dementia, UK)

*There is a gross and systemic underestimation of the capacity of all people with dementia, even in the later stages of the condition.*

Respondent DAI Survey (Person with dementia, AU)

# About Dementia Alliance International (DAI)

DAI is the peak organisation globally representing persons with dementia and is widely accepted as the global voice of dementia. DAI has played a critical role in advocacy to have the rights of people with dementia protected under the United Nations Convention on the Rights of Persons with a Disability (UNCRPD). DAI has also played an ongoing key advocacy role in ensuring that people with dementia have an opportunity to have a say about research, services, policy, and other issues that impact on them and their care partners and families.

## Acknowledgements

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## Endorsements

The following organisations have endorsed this publication:

Alzheimer's Disease Association Singapore (now Dementia Singapore)

Dementia Australia

Alzheimer's New Zealand

Dementia Advocacy Canada

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# Introduction

In 2020 Alzheimer's Disease International (ADI) estimates that there are over 50 million people living with dementia globally, a figure set to increase to 152 million by 2050. The current annual cost of dementia is estimated at US \$1 trillion, a figure set to double by 2030 (Alzheimer's Disease International, 2020).

The significant impact of dementia has been acknowledged by countries around the world. The World Health Organization (WHO) has adopted a Global action plan on the public health response to dementia 2017 - 2025 (WHO, 2017). At least 32 countries have developed Dementia Action Plans to prepare for the increasing number of people with Dementia and to ensure they can provide the best support (Alzheimer's Disease International, 2021). At the same time, investment in research into dementia continues to increase. This work to address dementia and ensure appropriate support cannot be done alone.

People with dementia and care partners have the right to have a say in the policies, research and support that will impact their lives. It is also well established that policy, research, and services benefit from having end-users involved in planning, design, and evaluation.

In many countries, researchers and service planners are increasingly acknowledging the value of including people with lived experience, such as advocates with dementia and their care partners, in projects and in research.

At the same time, there continues to be challenges in understanding what involvement should mean, who should be involved and how their involvement will be supported.

The purpose of this publication is to outline how people with dementia and their care partners are involved in the policies, research and support that will impact their lives, reflect on the progress which has been made and to identify the next steps in ensuring that people with dementia and their care partners exert greater influence in and significantly impact public policy, service development and research.

## Types of Involvement of People with Dementia and Care Partners

There is a vast range of ways that individuals with dementia and their care partners are involved in policy, advocacy, research, and services. Below we describe some of the main types of involvement.

**Individual advocacy** refers to advocacy efforts that concentrate on issues relating to an individual person. Often families or friends take on roles as informal individual advocates. Sometimes individuals advocate for themselves (often referred to as self-advocacy) and in some cases professional advocacy organizations get involved. Individual advocacy is sometimes focused on speaking out about mistreatment, abuse, or other issues for an individual. Individual advocacy can also be to ensure that the person gets the supports and services they need, or that their wishes are listened to. It can also be an opportunity to increase community awareness or awareness within a service about the potential of people with dementia to live a full life.

For example, a family could advocate for an aged care facility to improve access to rehabilitation for a person with dementia. These individual advocacy efforts can and often do last many years, and often with little or no external support. They can also have significant positive outcomes for not only the person involved but other people who receive services from that provider/organization in future.

Sometimes people get together to share their experiences with individual advocacy and assist each-other by sharing ideas and ways to address some of the challenges people experience. For example:

*I've attended a support group weekly - We hold a "Carers Corner" where we discuss any particular problems we are dealing with - could be removal of a driver's licence, applying for a disabled parking badge, dealing with Social services or responding to doctors that don't understand. There is generally one or more people in the group who have experience of a similar situation and we share those experiences - who we contacted, who gave us good help, what we did and how we felt. This has been incredibly helpful for everyone involved.*

- Carer Partner respondent to DAI survey (UK)

**Systemic Advocacy** refers to advocacy efforts that concentrate on influencing and changing systems issues (legislation, policy, practices) in a way that will benefit people with dementia as a group. Systems advocates will encourage changes to the law, government and service policies and community attitudes. Often the peak dementia organization in each country plays a key role in systemic advocacy. People with dementia and care partners are often invited to be part of systemic advocacy. This may include participating in government processes, sharing their stories, being on Government committees, or providing advice to non-profit advocates. The amount of influence that systemic advocates have can differ greatly depending on the organization they are working with and how they are supported.

Often experiences with **individual advocacy** will lead to an individual to get involved in **systemic advocacy** with the hope that their personal experiences can lead to change and avoid other people having the same experiences. For example:

*We matter. We might have changes to our brains, but our views matter. I have had a role on Government committees and have helped with the Dementia Action Plan. I get the chance to tell people about the ways my rights have been violated. At least I have a seat at the table. I hope I can change things for the future.*

- Respondent to DAI Survey (Person with Dementia, Canada)

*Our voices are powerful, our testimony righteous. It has the impact to change hearts and minds. In Wales we changed the way services are funded, developed, and delivered. We demanded and got a rights-based model.*

- Respondent to DAI survey (Person with Dementia) UK)

*The Northwest Dementia Working Group consists of people living with dementia, their care partners, and some professionals who mentor, guide, and support. Our mission is to be a voice for people living with dementia in northwestern Ontario, and to ensure that people living with dementia are treated with respect, dignity and are afforded their human rights.*

- Respondent to DAI survey (Canada, Formal advocate for person with Dementia)

*Alzheimers New Zealand's Advisory Group consists of people with dementia and care partners. We work with Alzheimers NZ in advocating for people living with dementia to Government and other rule-making bodies; advise on Alzheimer's NZ's planning and policy positions; and generally, encourage a rights-based approach to dementia.*

- Alzheimer's New Zealand Advisory Group

**Involvement in research** is a key area where people with dementia and their care partners provide valuable input. This involvement can vary widely from being involved in setting research priorities, reviewing grant applications, providing advice on research methodology to working as a research partner on the project.

Evidence shows that involving people with lived experience leads to higher quality research which is more relevant to the end-users (Blackburn et al., 2018). It has also been suggested that this involvement increases the cost effectiveness of research (Wilson, 2015).

In some countries public involvement in research has been driven by government policy through funding requirements. For example, in the UK, the National Institute for Health Research requires researchers to develop a plan for what they refer to as "Patient and Public Involvement (PPO)", essentially outlining how they will involve end users with each funding application (Staley et al., 2013). In Australia, the Medical Research Future Fund has a specific research funding program that encourages collaboration between consumers and researchers called the "Emerging Priorities and Consumer-Driven Research initiative". Unfortunately, this level of support for involvement does not occur in all countries or across all research programs.

Public involvement in research and health priority setting in lower and middle-income countries is less developed. (Alderman et al., 2013; Essex et al., 2019). Miah (2021) and colleagues describe a targeted approach to supporting involvement of people with dementia in clinical research sites in South Asia. The outcomes of this work showed increased capacity, changes in attitude about involvement, and adaptations to the research protocols because of co-production. Despite this initial success, further work is required to support the development and engagement of involvement in dementia research and policy in these countries.

In a recent article "Active Inclusion Of People Living With Dementia In Planning For Dementia Care And Services", Breuer and colleagues (2021) found that although involving people living with dementia in service design and planning is more common in high-income countries, it remains rare in low- and middle-income countries where two-thirds of the world's people with dementia live.

Miah and colleagues (2019) conducted an analysis of research which included involvement of people with dementia in Europe. They found a range of different types of involvement across several research studies occurred in the last decade. They also found that few researchers were evaluating the impact of involvement of people with dementia on their research. People with dementia who were asked to comment on this project made several recommendations including:

- A need for a more standard approach to involvement to help people understand their role
- Consideration should be given to what support or other needs participants might have
- The need to involve people early in the research and to be involved in all stages
- Involvement should be recognized in all publications

Many researchers are working to involve people with dementia and their care partners in their projects. Some examples which were provided in the DAI survey include:

*We have two people living with dementia as full research team members. They have been involved since study conception in all phases of the project and have facilitated connections to dementia advisory and advocacy groups. I have invited them to speak at events and they have invited me to speak as well. We have been co-designing training so that wellness service providers better understand dementia and are able to engage with and support people living with dementia. It has been an incredible experience and I am lucky to have such amazing colleagues with lived experience!*<sup>1</sup>

- Respondent to DAI survey (Canada, Researcher)

*An innovation and technology project involved people living with dementia and carers in the applicant selection process, then mentoring successful applicants/innovators, part of the judging panel of shortlisted innovators, and now continuing to work alongside innovators to develop tech into prototype. All the way along the participants with lived experience were supported and provided with a person outside of the project to discuss issues/concerns/ideas with and if required to provide feedback to the innovators re how they can improve the way they work/communicate with people living with dementia.*

- Respondent to DAI survey (Australia, Non-profit staff)

Some researchers are also actively working to engage people with dementia as co-authors and partners in their research projects. For example, Swarbrik and colleagues (2019) developed the Co-researcher involvement and engagement in dementia model, which identified an approach for involving people with dementia in a deep and meaningful way across all aspects of a research project.

There are also examples of people with dementia being involved in data analysis. Dooley, (2020) described involving people with dementia in analysing recorded patient-doctor interactions within care homes. Participants were able to provide insights into how to improve communication, and to relate to their own experiences.

Frank and colleagues (2020) describe the involvement of people with dementia in organizing a scientific research meeting on care, services and supports for people with dementia. A working group was established to provide input into the agenda, speakers and recommendations which came out of the meeting.

There is also evidence to suggest that the peak organizations in the relevant country can have a key role in promoting involvement in research. For example, in the UK, the Alzheimer's Society has facilitated a Research Network since 1999. This group is now a national network of over 270 people with dementia, carers and former carers who are involved in a range of research activities. These volunteers are given

<sup>1</sup> Please note we do not have information about whether or not these research team members were paid or were involved as volunteers.

training and support to be involved. The network has been involved in all stages of the research process from agenda setting, reviewing research applications to dissemination of research. They have also been involved in advocating for involvement in research, supporting efforts to increase research funding within the UK and been involved in the development of public guidelines (Alzheimer's Society, 2018).

Similarly, in Australia, Alzheimer's Australia (now known as Dementia Australia) established a Consumer Dementia Research Network in 2010 (Skladzien, 2010). This network played a key role in promoting involvement in dementia research in Australia until it was recently disbanded, because of changes to funding arrangements. It should be noted that Dementia Australia continues to involve people with dementia in research through other mechanisms.

In New Zealand, Alzheimers NZ's Advisory Group plays an active part in the organisation's research programme. The recent project: [This is our story: A qualitative research report on living with dementia](#) (Alzheimers NZ (research by Smith, E., et.al) (2019), entailed Advisory Group involvement at all of the design, analysis and reporting phases.

**Involvement in Service Systems** is another way which people with dementia and care partners share their experiences and expertise. This could include sitting on committees for an aged care provider, providing advice to hospitals or providing input to community services on how to provide better support to people with dementia. Some services involve people with dementia or care partners in recruitment of new staff or development of new policies or procedures.

An example of this approach is a project in the UK which involved people with younger onset dementia to provide advice on community-based services. A literature review was conducted which highlighted key aspects of service provision. The people involved corroborated these findings, but also identified key priorities that needed to be addressed in the development of services. In particular, the involvement of people with dementia highlighted the need to provide access to peer-support groups for family and for the person with the diagnosis (Mayrhofer, 2018).

It has also been noted that it is important to involve people with dementia in the evaluation of services. Although at times this is deemed to be "too difficult", there are a range of strategies which can be utilized to support this level of involvement (van Baalen et al., 2011). Involving people with dementia in providing feedback on their experiences within a care setting is essential to quality improvements (Cheston, 2000) as well as safeguarding basic standards. For example, Alzheimer's NZ Advisory Group members are seeking active participation in a planned Ombudsman's project to monitor the treatment and conditions of people detained in secure dementia units. People with dementia are also engaged with auditing Alzheimer's New Zealand member services.

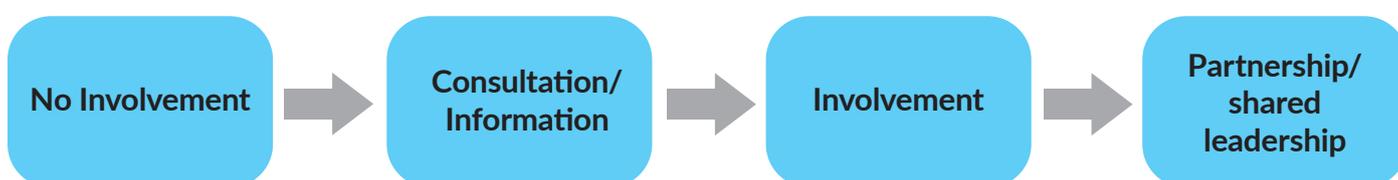
People with dementia and care partners also are often involved in providing advice and feedback on the services of their local Alzheimer's organizations. This often works best when they are involved from the planning stage to identify service gaps, as well as to audit existing services to ensure they are providing high quality supports that are needed by the dementia community. In some countries, the government requires consumer involvement in the development of clinical guidelines. People with dementia have been involved in the development of a range of different clinical guidelines. For example, Armstrong and

colleagues (2019) outline the involvement of people with dementia and care partners in the development of clinical practice guidelines on the use of Amyloid PET imaging in patients with or at risk for dementia by the American Academy of Neurology. In Australia, people with dementia and family carers contributed to the development of 'Clinical Practice Guidelines and Principles of Care for People with Dementia'

### Continuum of Involvement

Across all the different types of involvement there can be different levels of involvement. It is generally agreed that engagement can be conceptualized as a continuum ranging from no involvement to shared leadership, adapted from Arnstein's original concept of a ladder of participation (1969). At the continuum's lower end, people are involved through providing information, but they have limited input into the process. The provider, organization or system define their own agendas and then seek input. At the continuum's higher end, engagement is defined by shared responsibility, with people being active partners in making decisions and shaping policy or systems.

Figure1.1 Continuum of Involvement



Unfortunately, most of the involvement in health care and service systems has been at the level of consultation/information (Ocloo, 2016). Shared-decision making/ partnership approaches are considered best-practice but often are not achieved. Often people wanting to be involved feel that they are struggling to achieve real changes in policy or practice.

There are several notable exceptions in the dementia field, where people with dementia and care partners have had opportunities for genuine and meaningful involvement. This has included providing input into national dementia strategy plans, driving work on dementia-friendly communities as well as playing a key role in research projects and advocacy for research funding within countries.

## Why should people with dementia and their care partners be involved in policy, research, and services?

To fully understand the involvement of people with dementia and care partners, it is important to consider the rationale that is usually used for involving people in policy, advocacy, and services. These reasons can be grouped into three broad categories:

1. People with dementia have the right to have input (moral/ethical).
2. People with dementia have expertise in dementia that will lead to better outcomes (social benefit).
3. People with dementia / professionals benefit personally from involvement (personal benefit).

Involvement may be driven by a combination of these key reasons. For example, a researcher may decide to involve a person with dementia or care partner because they think they will have a better outcome from a grant application (personal benefit) but also believe that it is the right thing to do (moral/ethical reason).

### **Involvement as a right**

When considering the rights of people with dementia to have a say in services, policy, and research it is useful to examine how this relates to the disability rights movement. It is only in the last decade that Governments and policy makers have begun to understand and recognize that the symptoms of dementia are a form of disability (Shakespeare et al., 2019). The World Health Organization states that “Dementia is one of the major causes of disability and dependency among older people worldwide,” (WHO, 2019) Unfortunately, dementia policy is often still developed within a medical model.

For a very long time, people with a disability have faced stigma, discrimination and have struggled to get access to the same rights as the rest of society. The tireless work of disability advocates has led to key changes including the acceptance of the social model of disability. The social model of disability recognizes that disability is a result of the interaction between an individual’s ‘impairment’ and the social context that they live in (Oliver, 2013).

This is particularly relevant to people with dementia, as we know that the stigma and discrimination associated with dementia can have a significant impact on people with dementia. For example, an international survey completed by Alzheimer’s Disease International in 2019 found that over 85% of respondents living with dementia stated that their opinion had not been taken seriously. One respondent reported being told “your opinion no longer matters” (Alzheimer’s Disease International, 2019).

As part of this stigma, sometimes people find diagnosis is accompanied by the message is that it is time to “give up”. An example of this view comes from a paper written by Alzheimer’s New Zealand. “You’re given the impression well, go home and put your affairs in order and wait. We felt that was what was going happen to us. Go home, get your affairs in order, and that’s it.” Participant, Alzheimer’s NZ (Smith, E., et.al, 2019).

Swaffer (2014, 2016) refers to this as Prescribed Disengagement<sup>®</sup>, and many members of Dementia Alliance International repeatedly claim the experience is the same for them.

One of the key achievements of the disability rights movement was the adoption of the United Nations Convention on the Rights of Persons with a Disability (UNCRPD) in December 2006. People with disabilities were integral in the drafting and development of the UNCRPD. The overall aim of the Convention is to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” Importantly, the Convention marks a significant shift in attitudes and approaches to people with disabilities.

The Convention requires Governments to actively involve people with disabilities in disability policy development and implementation. This requirement is in line with the disability rights movement’s mantra

“Nothing About Us Without Us!” which has been used for decades to communicate the idea that no policy, service, or research should be decided without the full and direct participation of members of the groups affected by that policy (Charlton, 1998).

It should also be noted that there is also a history in the UK over the last several decades to support ‘public and patient involvement’ (PPI) in health services and research. The organization ‘Involve’ has played a key role in advocating for the right for public participation.

Globally, in the last few decades, there has been an increasing community understanding and acknowledgement about the right of people with disabilities, including those with dementia, to be involved in policy, services, research, and support.

“Listening to consumers<sup>2</sup> is the best place to start, and it is not just about choice, it is fast becoming about human rights for people with dementia.” (Swaffer & Low 2016).

### **Involvement which leads to better outcomes**

People with dementia have expertise because of their experience with dementia and the service system. Involving end users in the design of services leads to services and supports that better meet their needs (Suijkerbuijk, et al., 2019). People with dementia and care partners should be considered service user ‘experts’ who can provide advice on service development and evaluation.

In the context of research, there is a large body of work about the positive impact “public and patient involvement” within healthcare research. Hardavella and colleagues (2015) summarized the benefits of involvement as including:

- Identifying/clarifying research questions and making sure they are relevant to the need of the end user (in this case people with dementia)
- Improving the design of research studies
- Leads to more relevant research outcomes
- Can assist with recruitment
- Provides different perspectives to the research team (including assistance with interpreting findings)
- Assists with dissemination and knowledge translation.

In the context of advocacy, there is evidence that storytelling has a large impact as part of influencing public policy and public debate (Trevisan et al., 2019; Matthews and Sunderland, 2017). A key issue in this space, however, is what stories are told and how they are controlled, edited, and used by organizations.

<sup>2</sup>In this case consumers refers to people with dementia. This terminology is commonly used in Australia.

For example, a dementia organization may only want to support advocates who are calling for changes which are in line with the organizational policies or priorities of the organization. (e.g., If an organization is promoting dementia-friendly communities they may be unlikely to invite a person with dementia to speak at an event who has conflicting views on this issue). As a result, advocates can feel as if their voices are harnessed to strengthen existing advocacy but are not used to guide advocacy priorities. For this reason, it is essential that dementia organizations ensure that their policy development work is guided from the start by people with dementia, rather than just utilizing their stories when it is helpful.

### **Involvement which brings personal benefits**

There have been a range of personal benefits identified for public/patient involvement in research. These includes developing friendships and providing a more positive relationship with the condition (Ashcroft et al, 2016), feeling empowered and gaining confidence about life skills (Brett et al, 2014).

Researchers have reported that involving people with the relevant condition as led to them having better understanding and insight in their research area and developing community connections (Brett et al., 2014). Some dementia researchers have indicated that they have gained knowledge because of the lived experience of dementia, and this has changed their perspectives and provided them with motivation for future research. Similar positive experiences have been reported by staff at café's where dementia café's are being held, or journalists who have spent time with people with dementia.

Researchers can also have a personal benefit of having greater success with funding applications or research outcomes which furthers their careers. Similarly, dementia organisations may be successful in funding opportunities because of their work with advocates. It is critical that the impact of people with dementia is acknowledged, including by involving them as co-authors or through other means of public acknowledgement.

## **Examples of International Leadership in Involvement**

Below we provide a few examples from different countries about involvement of people with dementia across research, policy, and services. Please note that this is in no way exhaustive and is meant to provide examples, not a comprehensive list of involvement. We have focused on novel approaches or areas where groups or organizations have shown significant leadership or are taking innovative approaches to involving people with dementia.

### **UK- DEEP, the UK Network of Dementia Voices**

The Dementia Engagement and Empowerment Project (DEEP) was established in 2011 to map out the different groups of people with dementia who were involved in various ways. The network has evolved over the last decade and is now a network of more than 100 groups of people with dementia who want to be involved in making change across the UK. The groups share the belief that:

- The voices of people living with dementia should have the opportunity to be heard.
- People should be supported, as needed, to be involved in influencing and shaping

The involvement of DEEP members ranges from involvement in government advocacy, providing advice on specific research projects, development of community initiatives (dementia gardens, cafes, dementia-friendly communities), development of training materials, providing advice on health initiatives amongst many other projects. The support of having a national network facilitates opportunities for involvement. This networked model provides opportunities for advocates to learn from each other, provide mentorship and support ongoing social engagement.

DEEP has also developed a range of resources in partnership with people with dementia including information about rights, setting up advocacy groups and how to audit organisations. They have also produced guides for organisations about involving people with dementia. (<https://www.dementiavoices.org.uk/deep-guides/>)

### **Australia- Cognitive Decline Partnership Centre (CDPC)**

The CDPC was an Australian multidisciplinary dementia research centre that focused on translating evidence-based research to change and improve the care and quality of life of people with dementia. The CDPC brought together people with dementia and their care partners with researchers, clinicians, health care organisations, and industry partners to address the care and support of people with dementia.

The involvement of people with dementia and care partners was carefully designed from the start and was integral to the success of the Centre. People with dementia and family members were involved in all stages and at all levels of the Centre and in all the research projects funded through the Centre. The Centre employed a paid 'consumer investigator' (a care partner) who was a member of the Centre Executive Group and led a 'Consumer Enabling Sub-Unit'. This unit was focused on ensuring and supporting consumer involvement in all projects undertaken by the Centre. One of the researchers from the Centre noted: "The consumers have been enormously positive, useful and beneficial contributors to the project".

This model is notable for its approach to employing a care partner to lead 'consumer' involvement within a research centre, as well as having a clear aim to involve people in all research projects. This approach recognises both the value of involvement but also the important leadership role that people with dementia and care partners can take in supporting that involvement.

### **Ireland- Irish Dementia Working Group**

The Irish Dementia Working Group (IDWG) was set up in 2013. It is an advocacy group of people who have been diagnosed with dementia. The group is an independent campaigning voice for the lived experience with members throughout Ireland. This group is involved in a range of activities including monitoring the implementation of the Irish Dementia Strategy, advocating to politicians, raising awareness, and tackling stigma, contributing to research, presenting at conferences, and providing input into the work of Alzheimer's Society of Ireland.

This Working Group is notable for the depth and breadth of the work they have been involved in ranging across research, policy, services, and community awareness. It is also notable that the Chair of the Irish Dementia Working Group serves as a full Director on the Alzheimer's Society of Ireland Board. This is a laudable approach to ensure that the work of the Alzheimer's organization is not only advised by people with dementia, but also includes people with dementia as part of the Governance structure of the organization.

The Irish Dementia Working Group, the Alzheimer Society of Ireland and the Centre for Economic and Social Research on Dementia have developed guidelines on involving people with dementia (see Appendix 1)

### **Scottish Dementia Working Group**

The Scottish Dementia Working Group (SDWG) is a national advocacy group, led by people with dementia. They are the independent voice of people with dementia within Alzheimer Scotland, and campaign to improve services and challenge stigma.

The key priorities for the SDWG includes:

- Maintaining independence
- Local connections
- Raising awareness
- Supporting workforce development
- Member development

The SDWG has produced several key documents on involvement and support for people with dementia including:

- Post-diagnostic resource: a peer-to-peer resource for people recently diagnosed
- Dementia-friendly meeting guidelines
- Core principles for involving people with dementia in research

### **United States- Early-Stage Advisory Group**

Since 2006, the Alzheimer's Association National Early-Stage Advisory Group (ESAG) has helped bring the voice of individuals living with dementia to the national forefront. Members provide a unique perspective to the key efforts of the Association that include:

- Community awareness
- Involvement and promotion of research
- Input into public policy
- Input into Alzheimer's Association work on care/support.

### **Japan- Japan Dementia Working Group**

This group was established in 2014 and has been involved in a range of activities including supporting research on a rights-based approach to dementia-friendly communities and the development of better supports for younger onset dementia.

### **Ontario Dementia Advisory Group (ODAG)**

ODAG was formed in 2014 with the purpose of influencing policies, practices, and people to ensure that people living with dementia, are included in every decision that affects their lives. This group raises awareness, advocates to Government, and runs workshops and webinars.

### **European Dementia Working Group**

The European Working Group of People with Dementia - EWGPWD - was launched by Alzheimer Europe and its member associations in 2012. The group is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects, and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group also participates in research, advocacy and raising community awareness.

### **Alzheimers New Zealand and Alzheimers NZ Advisory Group**

People with dementia and care partners who comprise Alzheimers NZ's Advisory Group work closely with Alzheimers NZ to ensure a dementia voice in work undertaken by the organisation. The group has a particular focus on policy, has a member who is a full Board member of Alzheimers NZ, and has created its own Declaration of what people with dementia need to live well.

Alzheimers NZ takes the involvement of people living with dementia seriously. Those living with dementia pay no fees to attend the national conference and the Advisory Group members are currently engaged in planning the next one. Various members are also involved in providing advice on Alzheimers NZ education programmes, service delivery audits, research projects, as well as ongoing advocacy work.

In addition to actively promoting our Dementia Friends programme, writing blogs, and appearing in videos about living well with dementia, some members have also spoken about their experiences publicly, in such a way as to help enhance public understanding and acceptance of dementia.

### **Dementia Advocacy Canada (DAC)**

Dementia Advocacy Canada, created in 2019, is a grassroots group of people living with dementia and care partners who want to have an active and respected role in all decisions that impact their lives. They want to influence policy, inform program development, and increase access to supports and services across Canada.

### **Taiwan Dementia Advisory Group (TADA)**

TADA formally established the first Dementia Advisory Group (DAG) in the beginning of 2019. The DAG consists of 10 persons – five persons with dementia, two persons with mild cognitive impairment and three caregivers. It aims to empower people with dementia to advocate policies and related services for themselves. Currently at the idea generation stage, the DAG is building bonds and trust amongst the members and developing a plan to achieve its goals. Its current focus is on dementia-friendly facilities, transportation, problems associated with getting lost, and financial security. All the DAG members also joined the World Alzheimer's Event and are looking forward to progressing further in their journey as advocates.

# What do people say about their Involvement?

As part of this project, Dementia Alliance International conducted an international survey about the experience of people with dementia and their care partners about involvement. Professionals and Researchers were also surveyed to find out about their experience with involvement.

We had responses from 659 people in 30 different countries. It should be noted that most respondents (86%) were from high-income English-speaking countries (US, Australia, UK, New Zealand Canada) and therefore there are some limitations as to how applicable the findings are to other countries. As previously noted, involvement may look quite different in some of the lower-income countries. At the same time the results of this survey provide a starting point of evidence and information about the experience of people with dementia and their families involvement in dementia research, policy, and services.

Our survey focused on people with dementia and their families who have been involved in research to date, or who have involved people with dementia. It would be useful to collect future surveys about the views of those who have not involved people and whether they have the same level of recognition of the value of involvement.

Respondents to the survey included:

- 150 people with dementia
- 223 family members
- 108 researchers
- 95 people working with nonprofit organizations
- 72 Other professionals
- 11 advocates/legal guardians

## Why get involved:

People with dementia and care partners often spend significant time being involved in dementia research and policy. Some of our respondents were spending more than 40 hours per month being involved in research or policy. For both people with dementia and care partners the major reason for being involved was to make things better for other people in the future, and thinking it was important for people with dementia and their families to have a say.

## Why did you first get involved in providing Advice?

|  | People with dementia | Family members |
|--|----------------------|----------------|
| To make things better for other people           | 52%                  | 44%            |
| Because I thought it was important to have a say | 31%                  | 22%            |
| Because someone asked for my help                | 11%                  | 15%            |
| Other  | 6%                   | 19%            |

We also asked professionals who had involved people with dementia in their work about their experience. Most professionals recognized that involving people would achieve better outcomes including better quality research or policy and help them develop work that was more relevant to people with dementia. They also identified that it was the morally and ethically right thing to do.

### Why do you involve people with dementia?

(Please note that multiple options could be selected- which is why the total does not sum to 100%)

|   | Professionals |
|---|---------------|
| To achieve better outcomes  | 74%           |
| It is the morally right thing to do                                 | 68%           |
| Research topics that are more relevant to people with dementia      | 58%           |
| Research methods that are more appropriate for people with dementia | 49%           |
| To increase the knowledge/capacity of the researcher                | 40%           |
| Because I have done it before, and it has worked well               | 32%           |
| Because people with dementia have asked to be involved              | 28%           |
| To increase uptake of policy/research outcomes                      | 23%           |
| Because of funding opportunities                                    | 15%           |

### What helped you stay involved?

For people with dementia, 3 out of 4 respondents said that feeling valued was critical to helping them stay involved. Practical issues like costs being covered, assistance with transportation and effective communication were noted by approximately half of the respondents. Social benefits were also identified, but less frequently, including having fun, enjoying new friendships, and being mentored by other people with dementia.

For care partners and family members, feeling valued was also the most critical factor for remaining involved (65%). Social factors including enjoying new friendships was identified by half of the respondents as being important. Effective communication was also noted as important by nearly a third of participants.

### What helped you stay involved?

(Please note that multiple options could be selected- which is why the total does not sum to 100%)

|                          | People with dementia | Family members |
|--------------------------|----------------------|----------------|
| Feeling valued           | 75%                  | 65%            |
| Costs being covered      | 53%                  | 15%            |
| Effective communication  | 53%                  | 32%            |
| Enjoying new friendships | 52%                  | 45%            |
| Having fun               | 38%                  | 31%            |
| Transport support        | 36%                  | 9%             |
| Mentoring                | 36%                  | 27%            |
| Toolkits/Resources       | 19%                  | 13%            |
| Training                 | 16%                  | 23%            |
| Other                    | 6%                   | 19%            |

### When you first got involved, what would have helped you most to support your involvement?

Both people with dementia and care partners have indicated that having training about involvement would have been beneficial. The majority of both groups indicated that a toolkit that you could review in your own time would be very beneficial. They also indicated that one-on-one support and mentoring with a more experienced consumer would have been beneficial. Family members also identified respite as a support that would have been useful.

When you first got involved, what would have helped you most to support your involvement?

|   | People with dementia | Family members |
|---|----------------------|----------------|
| Toolkit that you could review in your own time (resources that tell you about involvement/research) | 55%                  | 43%            |
| Training  | 41%                  | 43%            |
| One-on-one support  | 34%                  | 23%            |
| Mentoring   | 25%                  | 48%            |
| An independent support person   | 13%                  | -              |
| Respite   | -                    | 12%            |

### Barriers to involvement

For people with dementia, the key barriers to involvement included that they felt they had a lack of opportunities, or they did not know how to get started. For example, one participant stated:

*I am passionate to be voice of dementia, but I can't find an opening. I feel like the groups won't share opportunities and is very frustrating "*

- DAI Survey Respondent (Person with Dementia, Singapore)

Some people noted frustration about the lack of communication from professionals about what impact their involvement had. They also identified practical support issues including transport and payment.

Feedback received from one member of our International Advisory Group in Canada highlighted that there is often a lack of appropriate advance notice when requesting involvement of somebody impacted by dementia? I hear stories of people who are repeatedly asked to participate at the last minute and expected to drop everything else they are doing, sometimes even when it means driving to a different municipality. The attitude is "you should be grateful that we're including you".

Lack of meaningful involvement or feeling as if involvement were purely tokenistic was identified as one of the barriers to involvement. For example:

*I have been on projects where I felt token, my opinion was not really considered. The people think they already know the answers and they just wanted me to validate what they already believed. It was a complete waste of my time*

- DAI Survey Respondent (Family member, Canada)

*Involve us from the beginning -- Not just an 'add-on' rubber stamping for kudos - We can spot 'fake' 'Being*

*patronised' from a mile away.*

- DAI survey respondent (Person with dementia, Australia)

*Researchers do not actually ask for my views. I am just a part of the data collection source, a participant not a designer or a decision maker”.*

- DAI Survey Respondent (Person with dementia, Singapore).

Family members and care partners were more likely to find that time constraints were a key barrier along with not having enough information about involvement. Often work commitments or other caring commitments made it difficult to spend the time that was required to be part of committees or research projects.

*There are unrealistic expectations. I am already balancing work, caring and somehow, I try to find time to give input or speak out about dementia. But I am using up my leave, doing unpaid work and often not even feeling like this work is valued.*

- DAI survey respondent (Person with dementia, USA)

#### Barriers to Involvement:

|  | People with dementia | Family members |
|--|----------------------|----------------|
| Not knowing how to get started               | 56%                  | 18%            |
| Lack of opportunities                        | 45%                  | 18%            |
| Lack of assistance with travel/support       | 35%                  | 14%            |
| Not having enough information                | 25%                  | 33%            |
| No communication about impact of involvement | 25%                  | 24%            |
| Not being listened to                        | 24%                  | 0%             |
| Terminology/use of acronyms                  | 22%                  | 18%            |
| Not understanding what I need to do          | 19%                  | 23%            |
| Not having the time to commit                | 17%                  | 40%            |
| Not being paid for the work I do/            | 16%                  | 40%            |
| Not having access to respite                 | 25%                  | -              |

For researchers and professionals, key barriers to involvement included not having access to people with dementia who want to be involved and the time required to involve people. Many professionals indicated that it is difficult to find funding to pay for costs related to involving people with dementia. One example of the barriers:

*I always involve people with dementia and carers but often it is difficult to find people who have the capacity, time commitment or carers who are willing to allow their involvement. Also, restrictions related to costs as frequently grants do not provide adequate reimbursement costs, and this leaves me in a difficult situation as I opt for no involvement if there is not enough reimbursement, and I can't find money to cover costs.*

- Respondent to DAI survey (Researcher, Australia)

It was also noted by some dementia-advocates that a barrier-post involvement is the lack of access to research. Often articles about dementia research are published only in peer-reviewed journals which

might be available only with paid-access. It was noted the importance of researchers providing plain English summaries of research which are then made freely available to the community.

### Barriers to involvement for Professionals

|   | Professionals |
|---|---------------|
| Not having access to people with dementia who want to be involved | 60%           |
| Time involved   | 42%           |
| Costs   | 30%           |
| Lack of assistance  | 32%           |
| Not knowing how to provide the right support                      | 23%           |
| Funding bodies not requiring involvement                          | 22%           |
| Not knowing how to get started                                    | 22%           |
| Not understanding what I need to do                               | 4%            |

### Payment for Involvement

The lack of payment and compensation for costs is a major barrier to involvement. Most people with dementia (80%) indicated that they are not being paid for any of the time they spend on involvement. 17% said that they were paid for a small amount of their time. The remaining 3% indicated that they were paid for some or most of their time. This is despite the respondents indicating they spent anywhere between 2-40 hours per month on involvement. Most respondents (52%) indicated that they wanted to be paid for the work that they do if it didn't affect their government benefits.

Similarly, most family members (79%) indicated that they were not paid for any of their time spent on involvement. 36% of carers indicated that they would want to be paid for the work if it did not affect their Government benefits. This lower number who wanted to be paid may be due to having a steady income from other employment.

Many individuals expressed a concern that other professionals were being paid for their time on committees or being involved in research but that people with dementia or care partners were expected to work for free. For example, one respondent from the survey said:

*We need to be paid so that our involvement is recognised to be of value. After all the professionals we interact with and benefit from that are always paid, mostly very well. Who else is asked to work for free or give their professional opinion for free? How can we be considered to be on equal footing or to be valued equally if our contributions are only taken when we volunteer our time. Everyone keeps saying how important it is to involve us. If it is that important than organisations need to find the money. They always cry poor- but they never seem to have trouble paying the other professionals.*

- Respondent from DAI Survey (Person with dementia, USA)

*When someone is volunteering more hours than some people are working- and they don't have any other income- this just seems unfair. The only conclusion is that we are not valued. Our time is somehow worth*

*less than the staff at our dementia organisation. This reinforces the very stigma that we are here to fight. What is the answer? If I demand to get paid- my voice will be lost. If I continue to volunteer- my voice will continue to be undervalued.*

- Respondent from DAI survey (Person with Dementia, Australia)

Given that most of the involvement is unpaid this is a significant area of concern. The challenge is to ensure that the contributions of people with dementia are valued and that there is appropriate equity. In many settings dementia advocates are being asked to provide their expertise for free ( Swaffer, 2020)Kate The idea that people with dementia's time is less valuable or that they are less deserving of being paid can be seen as yet another form of stigma.

Many individuals indicated significant concern that they were having to incur significant personal costs to fund their own involvement. For example:

*One of the barriers for me is having to travel long distances and not being adequately compensated and provided for in regard to the costs, travel, meals and hotels. I participate at [the University] in some things and it's about 8 hours of driving... sometimes we have had to stay overnight at our own expense... This is very expensive!*

- DAI Survey Respondent (Person with Dementia, USA)

Not paying people for involvement is problematic for reasons of equity but also can limit the diversity of people who are able to be involved. Those with greater wealth may be better able to provide their time on a voluntary basis. Marginalized populations often face barriers to full participation, including economic ones (Richards et al., 2018). This means that only means that involvement may come mainly from individuals from higher SES.

Some organizations or government agencies do provide payment for participation. This may be a flat hourly rate for consumer participation or may be based on the level of involvement (active participation versus leadership). These types of approaches are more commonly found in Government agencies or large research institutes. In our review, we were not aware of any dementia organization which had a specific policy regarding payment for consumer advocates. In some countries there are advocacy organisations for end-user involvement that advocate for payment for organisations (e.g. see Consumer Health Forum in Australia: [Your entitlements as a consumer representative | Consumers Health Forum of Australia \(chf.org.au\)](https://www.consumershealthforum.org.au))

## Impact of Involvement

Generally, the impact of involvement of people with dementia and their care partners has been characterized as falling into several categories including impact on:

- people involved (person with dementia/care partner)
- the researcher/professionals
- research/policy/service
- social benefit.

Responses to our survey, confirmed that the people with dementia and their care partners recognized the impact they were having.

They noted that involvement was of personal benefit to them in terms of increased opportunities for social interaction and feeling more confident and valued. They noted a benefit to the researchers/professionals as they felt that these individuals had learned important information to them. They also identified that research/services systems had changed because of their involvement.

### Impact of Involvement

|  | People with dementia | Family members |
|--|----------------------|----------------|
| Researchers/policy makers have learned from me | 70%                  | 45%            |
| Opportunities for social interaction           | 61%                  | 51%            |
| Feeling more confident or valued               | 56%                  | 57%            |
| Changes to research/policy or services         | 52%                  | 41%            |
| None   | 5%                   | 3%             |

Several people also identified that as a collective, the involvement of people with dementia is having a significant impact on society, with one respondent noting

*“Dementia used to have to be hidden away. Every time one of us stands up and speaks out about our experience we are changing society. We are changing the way we are seen. We are refusing to remain hidden behind the closed doors of an aged care warehouse”.*

- Respondent DAI Survey (Person with dementia, UK)

## Diversity

Both professionals and people with dementia raised concerns that sometimes the same people keep getting opportunities to be involved and it can be hard for new people to break in and get a chance to have a say. Some people talked about “professional advocates” who had made such a significant contribution, that organizations always looked to them to be involved in projects or committees.

There was a suggestion that researchers and organizations were looking for people who were already known to be agreeable and willing to support their agenda. There was also a concern that people involved tended to be white, upper-class individuals whose communication skills were not significantly impacted by dementia.

*I am deeply concerned that diverse groups are not included in dementia policy and outreach. Policy makers and researchers are not explicitly engaging people from CALD backgrounds, ATSI, Veterans and Homeless people in their policy agendas and research. I understand that including these cohorts in research and policy costs too much. Dementia does not just affect, white, middle class and highly educated people. It does not discriminate. Stop making this an issue which just touches a certain cross section of our societies. Get out there and link with community organizations who reach out to the diverse groups, talk to carers of diverse groups. Make an effort to reach everyone.*

-DAI Survey Respondent (Non-profit staff, Australia)

Others provided feedback that they had reached out to diverse groups and had not been able to get interest in participating in the dementia working groups or other advocacy groups. This raises a question about whether different models of involvement might be more suitable for different groups.

The concerns raised in our survey about lack of diversity and the repeated use of a small group of advocates are consistent with other work that has been done on this issue. Ocloo and Mathews (2016) identified that public and patient involvement in health care is plagued by the issues of exclusivity and tokenism. The authors note “With current involvement practice, power imbalances frequently manifest themselves in different ways, starting with who to involve. PPI often involves a narrow group of individuals, with the handpicking of just one or two ‘appropriate’ or ‘acquiescent’ patient representatives to be involved in committees or projects. Patient representatives are less commonly drawn from black and minority ethnic groups and are often middle class.” Parveen and colleagues (2018) have illustrated how diverse communities can be engaged when a targeted and culturally sensitive approach is utilized.

### **Something to change**

We asked participants about what if anything they would change about involvement if they could. Key themes which emerged included:

- Better information about research and outcomes
- More support for involvement including training
- Meaningful opportunities for involvement including involvement from the start
- Being paid for involvement
- Better communication
- Creating networks of people who are involved who can support each other.

Carers had similar suggestions but also included:

- Carers needs being taken into account and valued
- Provision of respite to support carer involvement

# Reflection on Progress to Date

Worldwide most dementia organizations were originally established to support family carers. Over the last 20 years there has been a shift in understanding and priority within dementia advocacy and research which has acknowledged the role of people with dementia. Dementia organizations have reframed themselves as being the voice for people with dementia and their families. There is increasing involvement of people with dementia as public advocates and spokespersons for the organizations over the last 20 years. (Beard, 2004; Bryden. 2015). Yet at the same time, most of the dementia organizations still have a governance structure that is largely made up of family care partners and in most cases does not include a person with dementia.

Alongside the shift in the focus of dementia organizations, there has also been significant progress across high-income countries in promoting the involvement of end-users in service development, research, and policy. In countries like Australia, Canada, New Zealand, and the UK, it has become increasingly common for people with dementia and their families to be asked to contribute to research, to be involved in health policy development, and to be involved in Government committees or advocating with the local dementia organization. This represents a significant shift since the early 2000 when it was noted by academics and advocates that the voices of people with dementia were largely hidden (Beard, 2004).

People with dementia and care partners are committing their time and energy to trying to make a difference. For many people there are multifaceted reasons for their contributions including personal benefits but also wanting to drive change and make a difference for future generations.

Gordon and McKeown (2020) powerfully communicate the rationale and impact for participation: *“For me, originally, research was an important part of my rehabilitation, getting me out of the house and engaging with others, early in 2018. Now it is an important part of what I am trying to achieve in my own small way, being involved in the development of and taking part in research. I do not do research for myself, any successes may come too late for me. I see research as a legacy I will leave for my children, grandchildren and those that come after.”*

There are encouraging examples of consumer involvement working well across research, service development and advocacy (e.g., Goeman et al., 2019). However, involvement is not always done according to this standard. As more people are asked to be involved, the quality of the involvement is not always maintained. Often people feel as if they are being involved just so that the policy maker or researcher can meet a funding or policy requirement, rather than because their expertise is valued, or will be acted upon.

In most cases people are being asked to volunteer their time, and even at times cover their own costs of involvement. In some cases, people feel as if they are not being given appropriate support or training for their involvement.

There is also a challenge that people with dementia often feel like they are only supported to be involved if they are providing feedback that is consistent with the views of the organization or researcher requesting input.

Individuals who are more critical of the status quo or who have different advocacy priorities may not be valued by the local dementia organization. Instead, dementia organizations may sometimes use the voices of people with dementia to validate and strengthen the advocacy of the organization, rather than include them to ensure the truly authentic and more diverse voices of people with dementia are heard, and their policies and programmes are meeting the needs of this group. This means that some people may feel like their voices are not being heard or considered in the policy development process. The illusion of 'having a say' or involving people with dementia when it is not genuine can be even more destructive than a total lack of involvement (Rahman, 2016).

Another key tension which has emerged as more people are involved is a question of what payment should be provided. People with dementia and care partners are often being asked to contribute their time on a voluntary basis. They are often being asked to do similar work as paid staff members (such as conduct training for health care providers, running Dementia Friends sessions, and participating on Government committees) - yet because they are doing it in the capacity of a person with lived experience, they are expected to volunteer without expectation of remuneration.

Many mental health researchers have been paying research participants appropriately for their time for many years, not just providing low value (e.g., \$30-50) voucher to cover for example, the cost of petrol for someone to attend a research focus group. One example of specific payment approaches for people with lived experience is the Western Australia government which has a payment policy. This policy was updated in 2021, to include;

- An increased payment rate from \$35 and \$70 to \$37.50 and \$75.00 per hour, with a three hour minimum payment. Wording in the Policy has been expanded to further explain this time may include pre and post meeting/event activity and reasonable out of pocket expenses;
- It was expanded to cover of out-of-pocket expenses on a case-by-case basis, to support diverse engagement;
- Retained the approach of offering payment across one engagement activity that may involve several participation types rather than across the length of a program or project;
- The offer, purchase and provision of retail vouchers has been removed from the Policy.; and
- Provided more comprehensive information regarding receiving participation payments and Centrelink, tax, and housing implications.

The work of people with dementia is sometimes not recognized appropriately. In some cases, their contributions may not even be appropriately recognized in journal articles or organizational reports. They may be referred to as "person with dementia" rather than by their name or appropriate title. Concerns have also been raised about intellectual property in relation to people with dementia when they do advocacy work for organizations (Swaffer, 2016).

Some advocates experience people questioning their status as a person with dementia. There are anecdotal reports of advocates being asked to "prove" that they do indeed have dementia, and even public statements by researchers questioning the accuracy of the diagnoses of some dementia advocates (Howard, 2017). Some advocates experience stigma and oppression because they do not meet the expectations of some in the community of what dementia looks like (Bartlett, 2014; Hu, 2017). This is a

significant issue for dementia advocates and can cause understandable stress and concern. It can be seen as another form of stigma and discrimination (Swaffer, 2018). It also can lead to people choosing to step back from public advocacy to avoid being attacked. In some cases, advocates have been so concerned by the questions, that they have released their own medical records to prove the legitimacy of their diagnosis. This can easily be seen as disability discrimination.

The power-imbalance between the individual with dementia/family member and the organization/professional who is asking for input needs to also be considered. There needs to be clear understanding about expectations from both sides, and an understanding of how any issues will be resolved. There should be an upfront and early conversation about how the organization/professional will respond if the advice/input of the person with dementia conflicts with the organization/direction of the research.

On the other side, researchers and policy makers often feel frustrated that they have difficulty sourcing people to be involved. They report that there is not sufficient guidance as to best practice of involving people with dementia. They can sometimes struggle to find the funding to support involvement. They are concerned that often the same people are put up to be involved- leading to a minority of voices, or people with certain perspectives having the loudest voices.

While researchers, NGO's, Government, and other organisations are spending significant funds to cover travel and other costs of participation, there is insufficient evaluation of impact of the involvement of people with dementia. There is often a reliance on the broader evidence around patient involvement rather than a true quantification of impact within the dementia field (Miah et al., 2019).

To improve the quality and opportunities for participation, it is essential that for any systemic involvement, there should be a measurement (even if somewhat informal) of the impact of that involvement across the key areas of personal impact, systems impact, professional impact. Documenting and publicizing the impact of involvement will help to promote increased involvement (Burton, Ogden & Cooper, 2019). In addition, regular evaluation and examination of impact will help to identify areas where involvement is being used as a tokenistic approach rather than to support genuine involvement of people with dementia.

# Where do we want to get to?

## Key Principles for Supporting Involvement

Several key themes have emerged from the research, survey responses and feedback from self-advocates:

### 1) People with dementia and care partners must be valued

Professionals should carefully plan involvement of people with dementia and care partners. This should include a careful assessment of how much time will be involved, what kind of impact is likely to occur, and how people can be supported in their involvement. In some projects it may be difficult to assess at the start of a project, but it is important to start to map out these issues and carefully communicate to both researchers and participants what is expected. It should also include being respectful about providing sufficient advance notice about opportunities for involvement.

For example, a researcher could write up a participation statement which could include:

- Who are they involving?
- What level of involvement will they have (using the continuum of involvement)?
- How much time will be required?
- What supports will be available (e.g., transport, plain English papers, funding, cost being covered)
- What impact will be having people involved make (e.g., influence the direction of the research, assist with knowledge translation, support development of a survey).
- Will evaluation be evaluated/reviewed and how? (Will there be a questionnaire at the end of the project to see what the experience was like for participants and researchers?)
- How will peoples involvement be acknowledged.

The value of involvement must be clearly articulated and publicly acknowledged where possible. For example, any journal publications and conference presentations should acknowledge the involvement of a person with dementia including as an author of the paper if appropriate. People with dementia who have been involved with projects should be encouraged to co-present at conferences or meetings.

Involvement for the purposes of achieving funding grants or validation of existing policies must be stopped. The intellectual property of people with dementia must also be respected and valued.

### 2) Diversity of advocates

Researchers, policy makers and others need to make a dedicated effort to involve people with dementia and care partners from a range of backgrounds and experiences. People from diverse cultural and economic backgrounds need to be supported to take part. For example, by purposefully seeking people from diverse background or providing reimbursement for travel or support with translation of documents.

There also needs to be a move away from engaging only with advocates who have a particular experience, or story of dementia. Instead engaging with advocates who hold different views and experiences will lead to deeper and more meaningful engagement (Brown & Jones, 2021).

There is a need to move away from a model of involvement where a handful of strong advocates provide advice on hundreds of projects, while other people struggle to get opportunities to be involved. Otherwise, there is a risk that involvement is representing only the voices of a minority of individuals, rather than organizations benefiting from the full range of experiences of dementia.

### **3) Leadership opportunities**

People with dementia and care partners should be given opportunities for leadership positions to coordinate or lead involvement. This could include paid staff positions with dementia organizations or research institutes, acting as a Chair of a research committee, or having opportunities to take part in Governance mechanisms including Boards. Providing this type of leadership opportunity will support a more genuine approach to involvement and show a true commitment to power-sharing and co-design.

### **4) Capacity Building**

People with dementia and their family members want access to better training to be advocates including self-guided training through toolkits. There are existing resources which are available, but many advocates are not aware of them- or they are not tailored to their needs. (Examples of relevant resources on how to support involvement are listed in Appendix 1). People with dementia also want opportunities for mentoring or one-on-one support. Some organizations already do this informally, but there are few established mentoring programs. People with dementia and family members can be supported to develop confidence and expertise as self-advocates. This is essential to their contributions and confidence in participating actively across all sectors.

Capacity building should also include opportunities for collaborating and connecting with other advocates. Dementia organizations should consider developing virtual networks of advocates through regular videoconferencing meetings or closed social media groups to facilitate opportunities for connection and learning outside of specific projects.

Professionals also need support to understand how to effectively involve people with dementia in research, policy, and services.

### **5) Communication**

There needs to be clear and open communication between the professional who is supporting involvement and people with dementia/care partners who are involved. This includes providing information up front about roles, responsibilities, likely impact, outcomes, and a plan for how and when communication will occur. It is also essential that there is good communication about the outcomes of the project. Special attention should be given to communication regarding grant applications where often people with dementia are left unsure as to the outcome of grant applications after having spent significant time providing input and involvement at that stage.

## **6) Support for Involvement**

People with dementia and care partners need to be provided with appropriate support for this involvement.

This includes support with practical issues such as:

- Support getting to the location (funding for transportation), making sure that it is easy to find where you are going, parking
- Support with telecommunication including for example practicing using Zoom before a meeting.
- Providing papers in plain English at least 1 week ahead of the meeting
- Allowing for written feedback or verbal feedback after the meeting.
- Support for carer involvement including respite for the person with dementia if appropriate,
- covering all out of pocket-costs.

One of the first steps in involving a person with dementia or their family should be to identify what reasonable supports they require for involvement.

## **7) Payment**

The costs associated with involvement must be included in all projects, research, and advocacy budgets. This should include an hourly rate for people with dementia and carers who are involved in the design and development of research. This payment will be a way of recognizing the significant contributions made by people with dementia and family members who bring knowledge, skills and experience that is not obtainable from the organizational employees. Reimbursement will also assist in ensuring that individuals are not out of pocket because of their participation. It should be noted that in some cases (student project, small scale advocacy work etc), there may not be a budget associated with the project. In that case it is acceptable on a short-term basis to offer opportunities for involvement in a voluntary capacity. There may also be some situations where other participants are also there on a voluntary basis (such as a voluntary Board) where payment may not be appropriate.

## **8) Evaluation of Impact**

As previously noted, it is essential that organizations commit to examining the impact of involvement within their own organization. This can lead to changes to improve the quality of involvement. For smaller projects this might not always be possible and should not be a barrier to involving people. A simple internal evaluation could be conducted at the end of the project which involves asking both the researcher and the person with dementia about their views on the impact of involvement on both the project and the individuals. Larger projects might include a more detailed approach to evaluation.

## **9) Embedding involvement within organizations**

To be effective in their involvement of people with dementia, a commitment to the value of involvement must be embedded at all levels of the organization. Where possible, this should include consideration of paid positions for advocates as well as opportunities for advocates to be part of leadership teams and Governance within organizations.

# Conclusions

Significant progress has been made over the last few decades in supporting people with dementia to have a say in policy, research, and services. This is a result of both changing cultural perspectives as well as the work of tireless advocates. There is an increasing demand for people with dementia and care partners to be involved in various projects and advocacy. While this is a positive direction, it is essential to ensure that this involvement is meaningful and leads to positive outcomes from both a systems and personal perspective. It must also be recognized that people with dementia are still having to fight to have the opportunity to be represented when dementia conferences, training, and other initiatives do not include the voice of a person with dementia.

There is significant work to be done to establish a more systematic, quality approach to involvement. There are plenty of examples of meaningful involvement which can be built upon. An essential ingredient to this success is involving people with dementia in designing the process for involvement. Unfortunately, it is still rare for people with dementia to be provided opportunities for paid leadership positions even within consumer engagement.

The stigma and discrimination faced by people with dementia is so deeply embedded in our culture, that even dementia organizations struggle to understand how they can involve people with dementia in governance and leadership roles. There is still a need to shift perceptions and understanding about the capacity of people with dementia to provide meaningful input.

There is also a need to move away from utilizing a small subset of individuals and embracing a more diverse and broader range of people with dementia to inform the work of researchers, service providers and professional advocates. Lower-income countries need to be supported in developing sustainable approaches to involvement. Dementia organizations in these countries should be mentored and supported to embed participation within their organizations.

In many countries we have achieved a significant level of involvement and contributions from people with dementia. This success, however, has led to increasing tokenistic use of people with dementia. The next stage in the development of involvement will need to focus on the quality rather than quantity of involvement. It is only by truly recognizing the value and capacity of people with dementia that we will achieve these much-needed changes.

## Appendix 1: Additional resources and practical guides on involvement

Australian Clinical Trials Alliance Consumer Involvement and Engagement Toolkit. Involvement toolkit. [clinicaltrialsalliance.org.au](http://clinicaltrialsalliance.org.au)

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15 October 2020

Kate Swaffer  
Chair, CEO & Co-founder  
Dementia Alliance International (DAI)

Dear Kate,

We are pleased to receive a copy of DAI's ***Valuing the advocacy of people with dementia***. Thank you for sharing this informative document which outlines how people with dementia can have a bigger voice, involvement and impact in public policy-making, service development and research on dementia.

***Valuing the advocacy of people with dementia*** is a timely reminder to all that, despite the progress the global dementia community has made on advocacy, there is a pressing need to focus on the quality rather than quantity of involvement, and truly recognising the value and capacity of people with dementia. We are inspired to see examples and case studies from organisations in other countries and will absorb these lessons in our work.

Aligned with DAI's vision, ADA strives to see people with dementia and their families live well with dignity, choice, and confidence to contribute to the community. Over the past few years, we ran many national campaigns in our bid to reduce the stigma associated with the condition; launched a Dementia Language Guide to inform the public on the appropriate words being used to describe the condition and the people living with it; as well as developed the Voices For Hope programme to encourage people with dementia to step up and be self-advocates.

We have made great strides. Some of the persons with dementia here are now regular speakers at webinars organised by agencies both at home and abroad, including events organised by Alzheimer's Disease International. Several of them have appeared in media engagements across print, television, radio and digital platforms. We are also heartened that, when collaborating with ADA on a wayfinding project at a local district, the Member of Parliament for the district appointed two persons with dementia as consultants.

Our work does not end there. ADA is in the midst of developing a dementia-inclusive toolkit for businesses, that will allow companies to be better-equipped to attend to customers and staff who are living with dementia.

However, there is still some way to go before we can see people with dementia influencing national policy decisions. Singapore does not have a Dementia Advisory Group yet but, for a start, ADA will be facilitating a focus group made up of people with dementia and caregivers, the aim of which is to draft a Dementia Declaration that represents the voice of all people with dementia in Singapore. We will press on.

In conclusion, ADA is pleased to endorse ***Valuing the advocacy of people with dementia.*** Congratulations on the good work done and we look forward to working closely with DAI for many years to come.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Jason Foo', with a horizontal line underneath the name.

Jason Foo  
Chief Executive Officer



Dementia  
Advocacy  
Canada

April 4, 2020

Dear Kate,

On behalf of Dementia Advocacy Canada, we would like to express our support for Dementia Alliance International's important work about recognizing and valuing the advocacy efforts of people living with dementia.

Dementia Advocacy Canada is a grassroots group of people living with dementia and family care partners who want to influence policy, inform program development, and increase access to supports and services for people impacted by dementia across Canada.

People with lived experience add tremendous value to research projects and to program and policy development. The time has come to acknowledge and fairly compensate us for our expertise and contributions.

We are grateful for the leadership of Dementia Alliance International for people living with dementia to have an active and respected role in all decisions that affect their lives and will support this work in any way that we can.

Sincerely,

Mary Beth Wighton and Lisa Poole  
Dementia Advocacy Canada Co-chairs



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**dementia.org.au**

26 November 2020

Kate Swaffer  
Chair, CEO & Co-founder  
Dementia Alliance International (DAI)

Dear Kate

**RE: *Valuing the advocacy of people with dementia***

Dementia Australia was pleased to receive a copy of DAI's *Valuing the advocacy of people with dementia*, which outlines how people with dementia can have a bigger voice, involvement and impact in public policy-making, service development and research on dementia.

The document aligns with the strategic purpose of Dementia Australia to involve people impacted by dementia and their experiences in our activities and decision-making, and to make sure we are representative of the diverse range of dementia experiences across Australia. We also aim to amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Together with our ongoing commitment to elevate the voices of people impacted by dementia, our Dementia Advocates program, and our Dementia Australia Advisory Committee, Dementia Australia has an ongoing collaboration with DAI through a formal Memorandum of Understanding, and we see all of these mechanisms as important ways through which we can contribute to the principles outlined in *Valuing the advocacy of people with dementia*.

We look forward to further collaboration with DAI.

Yours sincerely

A handwritten signature in dark blue ink, appearing to read "Maree McCabe", written over a light blue horizontal line.

Maree McCabe  
CEO Dementia Australia



20 April 2020

Alister Robertson

Vice-chair

Dementia Alliance International (DAI)

Sent via email - [robers@xtra.co.nz](mailto:robers@xtra.co.nz)

Tēnā koe Alister

Thank you for sharing a draft of the DAI document *Valuing the advocacy of people with dementia*.

As you know, Alzheimer's NZ's strategy involves people living with dementia being at the heart of everything we do. Therefore, we are strongly supportive of DAI's work over the years to bring the voice of people living with dementia to policy making globally.

*Valuing the advocacy of people with dementia* makes a valuable contribution to the policy landscape relating to people living with dementia – both in terms of the reason why the voice and experience of dementia is such a critical component within the process, and providing some great examples of what that looks like in practice. Not surprisingly, we are particularly pleased to see the examples of how the Advisory Group here in New Zealand has strengthened the work we do including our advocacy work and research activities – and most importantly the Dementia Declaration!

The work to develop a new service delivery model for local Alzheimer's organisations was also based on input from the Advisory Group who were involved throughout the development of the new core suite of Services and the standard those Services are required to meet. That model, the Alzheimer's NZ Dementia Services and Standards, is based on our strong belief that access

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Alzheimer's New Zealand Inc

to nationally consistent services that are quality assured is a fundamental human right for people living with dementia. People living with dementia are now involved in the audit process for this programme and for our Dementia Friendly Recognition Programme.

One point in relation to the document, there is no apostrophe in our name.

In summary, Alzheimers NZ is pleased to endorse this document. Please let us know if you require our organisation's logo to indicate our support.

We congratulate DAI on its work and look forward to continuing to support your activities.

Ngā manaakitanga



Catherine Hall  
Chief Executive



email: [info@infodai.org](mailto:info@infodai.org)

web: [www.infodai.org](http://www.infodai.org)

join DAI: [www.joindai.org](http://www.joindai.org)



[www.facebook.com/DementiaAllianceInternational](https://www.facebook.com/DementiaAllianceInternational)



[@DementiaAllianceInternational](https://twitter.com/DementiaAllianceInternational)