



**Australian Government**

**NHMRC National Institute for Dementia Research**

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## MEDIA RELEASE

### International survey calls for greater awareness of dementia research

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The NHMRC National Institute for Dementia Research (NNIDR) welcomes this week's release of key findings from the [world's largest Alzheimer's survey](#), which has shown that responders were overwhelmingly willing to be involved in dementia research.

Alzheimer's Disease International (ADI), in association with Banner Alzheimer's Institute (BAI), Novartis and Amgen, conducted the survey of more than 10,000 adults across ten countries. The survey found that people's willingness to become involved in dementia research was high, but that many were unaware of how to do so.

In announcing the key findings of the survey, Pierre N. Tariot, M.D., director of BAI and co-director of the Alzheimer's Prevention Initiative (API) said the results highlighted the need to raise awareness about clinical studies globally.

'Aside from funding, the greatest challenge in finding a way to treat, slow, or prevent Alzheimer's is the recruitment and retention of study participants. Scientists are making great progress in the fight against this disease, but an estimated 80 percent of studies fail to meet recruitment goals on time, which delays critically important research.'

Increasing consumer involvement in dementia research is a key area of focus in the NNIDR's current program. While there are a number of opportunities for people to participate in research studies in Australia, NNIDR is dedicated to increasing the involvement of consumers (people living with dementia, their families, and informal carers) as research contributors.

Janice Besch, NNIDR Director, underscored the importance of consumer involvement across all aspects of dementia research following the survey release.

'While the international survey is concerned with boosting clinical trial participation, the importance of broad involvement across all aspects of the research process can have important and sometimes unforeseen benefits for research, informing dementia prevention, cure and care.'

This contribution may include:

- Working with researchers and research funders to set research priorities;
- Being members of grant application review panels;
- Contributing as members of project steering groups;
- Commenting on and developing research materials;
- Being a 'research buddy' or link between the researcher and the public; and
- Helping with dissemination and implementation of research findings.

Accelerating research. Enhancing collaboration. Creating change.

NNIDR encourages people living with dementia and carers of a person living with dementia who are interested in becoming involved in dementia research to join the NNIDR Membership Network. More information can be found on [NNIDR's website](#).

For people who are interested in participating in clinical trials related to Alzheimer's disease and other forms of dementia, NNIDR suggests the following websites for further information:

- [Dementia Australia](#) has information on trials, including who to contact in order to become involved;
- [Australian Clinical Trials](#) (AusGov) has information and resources about clinical trials across a range of health conditions;
- [Australasian Consortium Of Centres For Clinical Cognitive Research](#) is a website that provides helpful information on some of the trials and sites running in Australia; and
- [StepUp for Dementia Research](#), launching later this year, is a service that allows people interested in participating in research to register on a database that matches them with relevant dementia studies

Since 2015, NNIDR has been targeting, coordinating and translating the strategic expansion of dementia research in Australia. By collaborating with researchers, involving those living with dementia in research efforts, and connecting with health professionals and policy makers, NNIDR is committed to achieving the World Dementia Council's international target – identifying a disease-modifying therapy by 2025.

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