



Introducing StepUp for Dementia Research:

An Australia-wide dementia research participation and public engagement platform

StepUp for Dementia Research is a research participation and engagement service, a “one-stop shop” that connects individuals, both with and without dementia, with researchers conducting studies into dementia prevention, diagnosis, treatment, care and cure. We make it easier for the brightest minds in research to connect with people willing to donate their time. For volunteer research participants, registration can take as little as five minutes.

In 2015, a government-funded public engagement platform called Join Dementia Research (JDR) launched in the UK. To date, JDR has attracted over 41,873 volunteers, facilitating 19,678 volunteers enrolled into over 300 studies across more than 294 locations (as of June 2019).

Leveraging the experience and knowledge of JDR, Professor Yun-Hee Jeon of the University of Sydney and her team are undertaking early implementation of StepUp for Dementia Research in New South Wales and Western Australia, ahead of nation-wide scaling later in 2019/2020. The service is being created and implemented in partnership with University College London (Professor Martin Rossor and Programmes Manager Adam Smith) and University of Exeter (Associate Professor Piers Kotting). The early implementation of the service is funded by the Commonwealth Department of Health.

Currently, there is no systematic and inclusive way in Australia for people with dementia to get involved in research. Yet each day, in doctor’s rooms and hospitals across the country, 250 people are diagnosed with dementia. This number is predicted to more than double by 2056, to 650 per day.

For researchers, recruiting participants for dementia-related studies is costly and time consuming. Delays in finding the right people can result in studies taking longer to deliver, often requiring funding extensions.

Insufficient study samples limit the effectiveness and scope of research – the difficulty researchers face when it comes to recruiting participants directly impacts their capacity for robust analysis and the generalisation of findings.

What sets StepUp for Dementia Research apart:

- We are an inclusive Australian research hub that gives everyone aged 18 and over the opportunity to participate in research
- The service is free for researchers to use; its database will be available to anyone conducting ethically approved dementia studies
- The service allows Australians to donate time (as much or as little as they want to), rather than money
- It places the value and potential of people with dementia at the centre of the solution
- Registration is simple and flexible, with a few clicks participants can sign up to be contacted and opt out at any stage

Australia’s population is ageing: the time to find better care and treatment options is now. Dementia is the leading cause of death for Australian females and the second leading cause of death for all Australians. We need to accelerate the search for a cure. This cannot happen without an efficient, effective method of connecting researchers with participants. StepUp for Dementia Research is the solution.

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