



# A dementia breakthrough, powered by you.

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THE UNIVERSITY OF  
**SYDNEY**

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# “RECRUITING STUDY PARTICIPANTS IS COSTLY, TIME CONSUMING AND CHALLENGING”

## From the public perspective

- Limited support available to facilitate a broader public engagement in dementia research
- No systematic way or one place to go to find out about dementia research
- Stigma towards dementia still very real
- Disparities in racial/ethnic minorities and those from low socioeconomic backgrounds



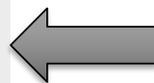
## From an institutional and researcher perspective

### *Delays in finding the right people for studies lead to:*

- investigator burnout, low morale among study team members
- funding extensions for study delivery
- study samples insufficient for robust analysis and generalisation of findings, and
- a trial to lose momentum, can be abandoned
- potentially decreasing the likelihood of a sponsor funding a particular investigator’s future research

## As a result ....

- Limiting the timeliness and effectiveness of research and evaluation
- Slowing down therapy development and derail the national goal



Fargo, et al. (2016). The crisis in recruitment for clinical trials in Alzheimer's and dementia: An action plan for solutions. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 12(11), 1113-5.

## WHAT IS STEPUP FOR DEMENTIA RESEARCH?

**An Australia-wide dementia research participation and public engagement platform**  
a “one-stop shop” that connects individuals, both with and without dementia, with researchers conducting studies into dementia prevention, diagnosis, treatment, care and cure.

### HOW DOES THIS PLATFORM WORK?

- Join via Online, Helpdesk, Post
- Anyone, over 18, with or without dementia in Australia
- Registration details: Demographics, Diagnosis/Memory issue, Medication, Health problems, Disabilities, Carer
- Volunteers can view current studies matching
- Approved dementia researchers contact matching volunteers

**It's as easy as...**



# WHAT TYPES OF DEMENTIA RESEARCH DO WE SUPPORT?

ALL TYPES OF DEMENTIA RESEARCH, for example ...



## Treatment

Looks at how to lessen or treat the effects of dementia.

## Prevention

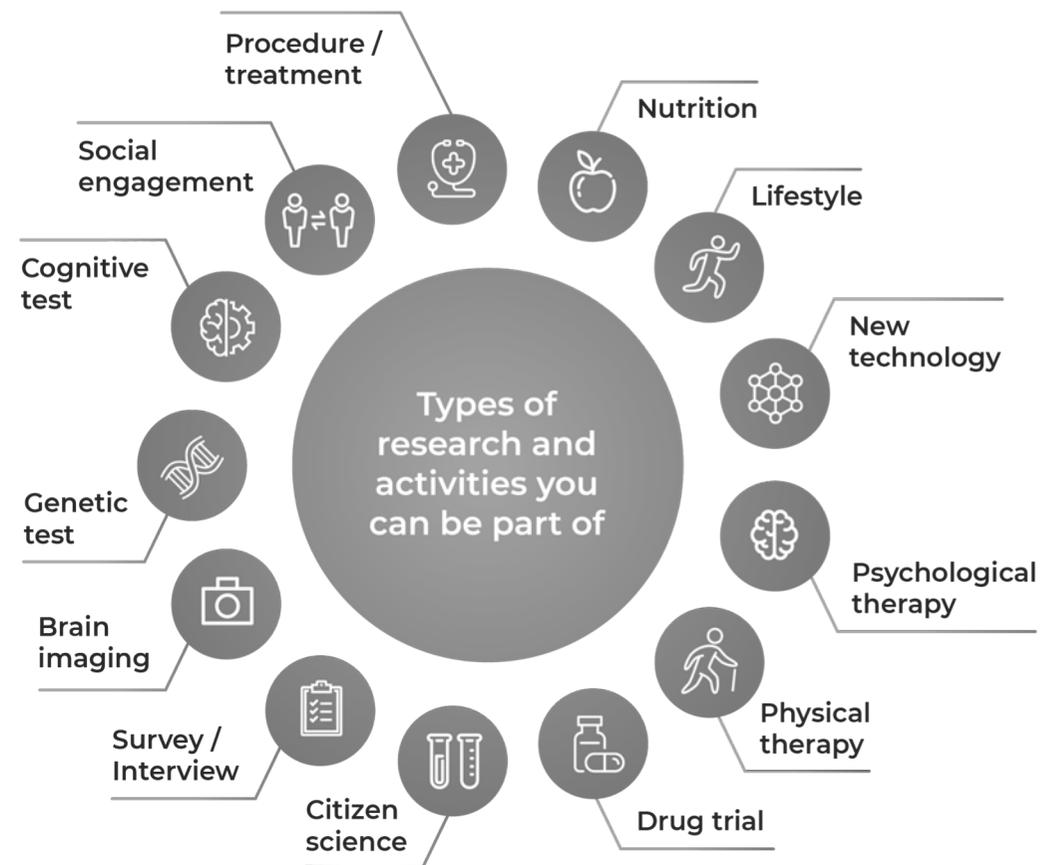
Investigates how to stop dementia from developing in the first place.

## Care

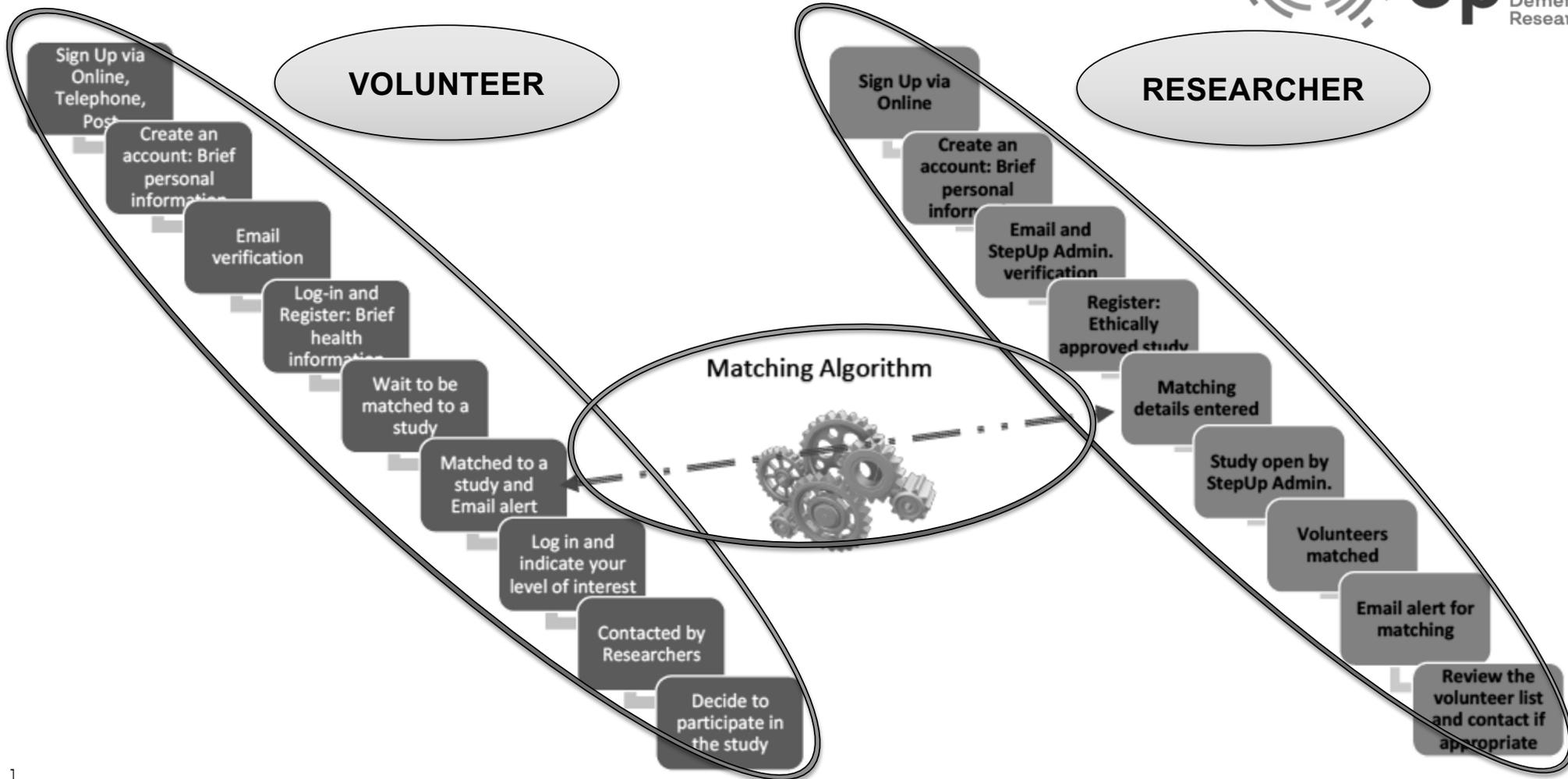
About how best to look after people living with dementia and the support people who provide care.

## Diagnosis

To find more accurate and sensitive ways of detecting dementia if it is present, as well as diagnosing the types and stage of dementia that a person has.



# WHAT IS THE PROCESS?



# WHAT IS THE PROCESS FOR RESEARCHERS?



## Researcher account

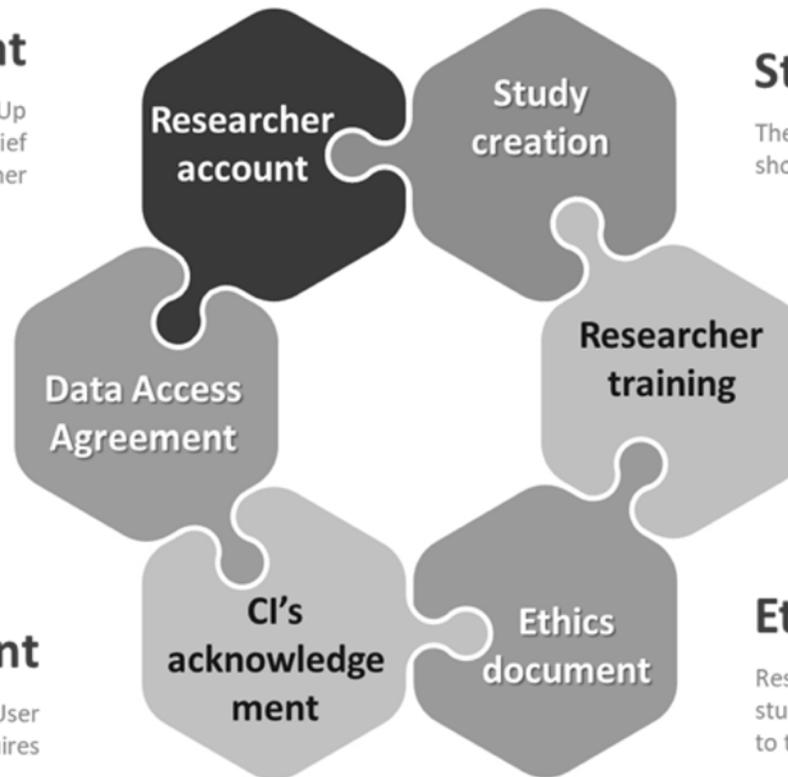
All researchers who are going to use StepUp for their study recruitment and the Chief Investigator (CI) must have a researcher account.

## Data Access Agreement

Organisational DAA must be signed by the CI's organisation. This is a one-off document. Please check the researcher FAQs for the list of organisations that have already signed the DAA.

## CI's acknowledgement

The CI must acknowledge the Account User and Confidentiality Terms. Each study requires the CI's acknowledgement.



## Study creation

The corresponding researcher for the study should submit the study creation form.

## Researcher training

Researchers must complete the researcher training prior to submitting the study creation form.

## Ethics document

Researchers must submit the ethics approval, study protocol and volunteer information sheet to the StepUp team.

# ETHICAL AND RESPONSIBLE USE OF STEPUP



<b>StepUp is a free service for researchers to use</b>	<b>Protect volunteers' privacy and confidentiality</b>	<b>Respect volunteers</b>
<ul style="list-style-type: none"> <li>• Researchers are expected to look after the database</li> <li>• Acknowledge StepUp in any publication whereby participants were recruited through StepUp</li> <li>• Researchers are encouraged to promote StepUp</li> <li>• Notify StepUp about personnel changes</li> </ul>	<ul style="list-style-type: none"> <li>• Do not download or print the volunteer's information from StepUp</li> <li>• Do not disclose any information about the volunteers' personal and/or health information</li> <li>• Do not share your account details with others</li> </ul>	<ul style="list-style-type: none"> <li>• Do not 'over contact' the volunteers matched to your study</li> <li>• Respect the volunteers' level of interest and how far they are willing to travel</li> <li>• Keep the volunteers' status up to date</li> <li>• Provide a lay summary of study findings at the conclusion of the study</li> </ul>

## PROGRESS TO DATE



### Early implementation in NSW and WA

- Volunteer site Go Live – March 2019
- Helpdesk Go Live – May 2019
- Official Launch and Researcher sign up – June 2019
- Matching – September 2019
- Further functionalities release October 2019

### National rollout 2020

### Researcher registration status

- ~60 researchers registered
- 15 study teams plan to use StepUp in 2019
- 3 Data Access Agreement received
- 11 studies looking for people living with dementia
- Researcher training in progress

### Volunteer registration status

- 670 account holders; 500 volunteers (96% via Online)
- 60% completed both mandatory non-mandatory questions
- 9% signed up by proxy and assisted by someone else
- 76% Female
- Age groups: 18-44 (7%), 45-64 (39%), 65+ (42%)
- States/Territories: NSW (44%), WA (23%), QLD (17%), VIC (7%), other (9%)
- 8% with dementia and 3% with MCI; 18% with memory concerns
- 41% with first degree family history of dementia
- Source: Media (33%), Social media & internet search (11%), Dementia organisations (20%), Health/Aged care services (4%), Events (4%), Other

### Ambassadors

- Ms Ita Buttrose
- Dame Quentin Bryce
- Ms Kate Swaffer
- Professor Graeme Samuel

### Champion Organisations

- Starts at 60
- Alzheimer's Western Australia
- Dementia Alliance International
- Global Centre of Modern Ageing
- NSW Brain Tissue Resource Centre
- Psychogeriatric Nurses' Association (PGNA)
- Multicultural Communities Council of Illawarra

# Global Collaborative: Social and Economic Impact Evaluation

## OBJECTIVES:

- To better understand different business models and governance structures and learn from each other;
- To develop common strategies and indicators to measure the impact (both economic and social returns); and
- To build sustainable models to continue

## CURRENT MEMBERS:

- **Australia: StepUp (University of Sydney) Since 2019**
- **UK: Join Dementia Research (NIHR, UCL) Since 2015/16**
- **Netherlands: Hersenonderzoek (Amsterdam UMC, VU University) Since Sep. 2017**
- **USA: Brain Health Registry (UCSF) Since 2013/14, Alzheimer's Prevention Registry (Banner Health) Since 2012, Trialmatch (Alzheimer's Association) Since 2010**



## VALUE PROPOSITIONS AND OUR AMBITIONS

- **Bringing HOPE** – contributing to finding cure, diagnosis, treatment and improving care
- **Reducing stigma**
- **Patient and public involvement in dementia research** – beyond research participation
- **Efficiency** – research recruitment, research funding
- **Eco system** – opportunity enabler
- **Cost saving** – short, medium, long term
- **Social and economic returns**

## GOALS AND AMBITIONS

- Improving research recruitment efficiency, enhancing research output, more opportunity for knowledge translation
- Bringing about sustainable and systemic change and improving society's attitude towards dementia and to empower those who are directly and indirectly affected by it
- The potential of StepUp for Dementia Research to inform and guide dementia services and research policy development, and to lead to an inclusive and integrated system.

# A CALL TO ACTION

## How can you help us?

### We would like you to consider ...

1. Signing up today as a volunteer (using personal email) and/or as a researcher (using work email)
2. Talking to your family, friends, colleagues and neighbours about StepUp and help them sign up
3. Talking to your clients/patients, research participants about StepUp and help them sign up
4. Joining the conversation   @StepUp4Dementia
5. Being a champion for your organisation – We are looking for Organisation Champions

**Together we can make a difference**



**A dementia  
breakthrough,  
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[www.stepupfordementiaresearch.org.au](http://www.stepupfordementiaresearch.org.au)

☎ 1800-7837-123