



A dementia breakthrough, powered by you.

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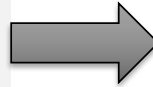
THE UNIVERSITY OF
SYDNEY

StepUp for Dementia Research is supported by funding from the Australian Government
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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

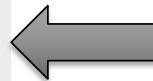


From an institutional and researcher perspective *Delays in finding the right people for studies lead to:*

- 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

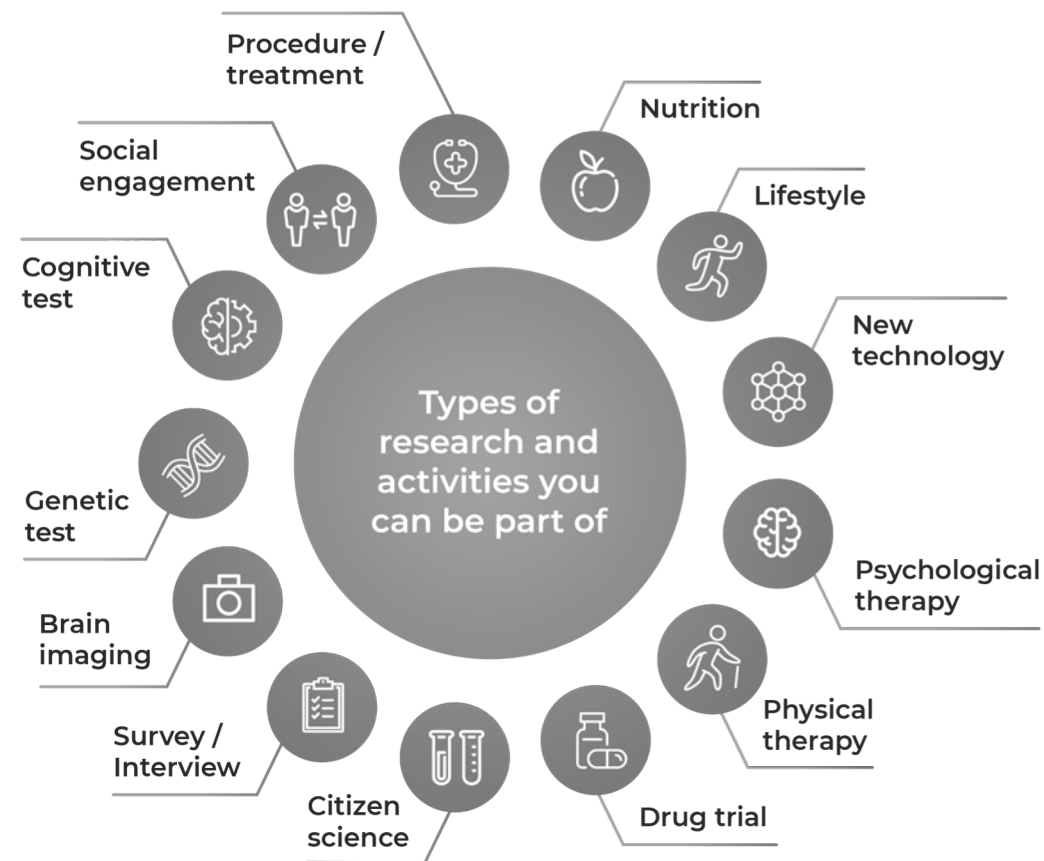
Investigates how to stop dementia from developing in the first place.

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.

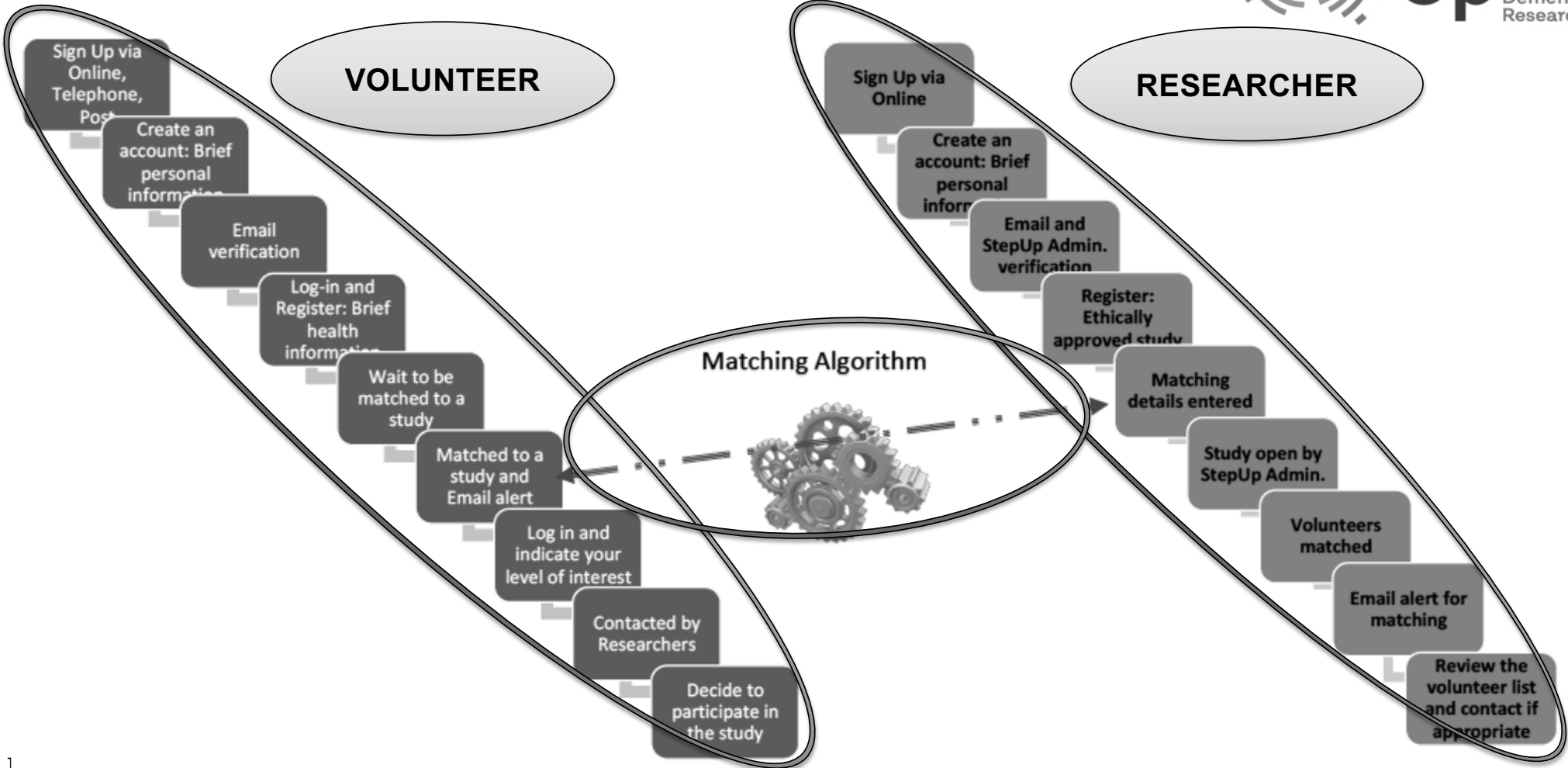


WHAT IS THE PROCESS?



VOLUNTEER

RESEARCHER



WHAT IS THE PROCESS FOR RESEARCHERS?



Researcher account

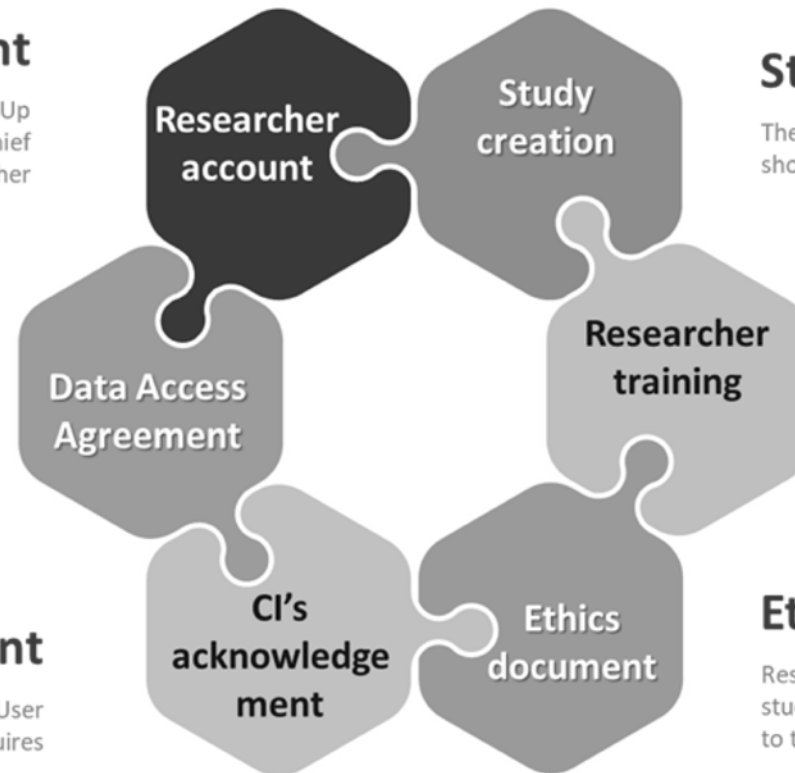
All researchers who are going to use StepUp for their study recruitment and the Chief Investigator (CI) must have a researcher account.

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



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

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,
powered by you



www.stepupfordementiaresearch.org.au

☎ 1800-7837-123