

StepUp for Research

Volunteer Information Sheet

You are being invited to be part of StepUp for Research, a service that collects information about people who are interested in taking part in dementia and ageing related research. Before you decide whether to join, it is important for you to understand what the service is and what is involved. Please take time to read the following information carefully and to decide if you wish to be part of StepUp for Research.

You are welcome to talk to others (e.g., carers, family members, and friends) about this register and also to contact StepUp for Research if there is anything that is not clear or if you would like more information. Contact details are at the bottom of this sheet.

What is StepUp for Research?

StepUp for Research is a research participation and engagement service, a “one-stop shop” that connects individuals with researchers conducting dementia and/or ageing related research studies. **StepUp for Research supports two streams of research, dementia and ageing.** Dementia research usually looks into topics associated with dementia prevention, diagnosis, care, treatment, services, policy, etc. Ageing research covers ageing and aged care related studies including health and wellbeing of older people, frailty, support, services, policy as well as issues concerning ageing and healthy societies broadly. You will be asked to select which field(s) of research (i.e., dementia research, ageing research or both) during the registration process. StepUp for Research allows people (volunteers) to provide information about themselves so that they can be matched to and contacted about relevant research studies for which they may be eligible to participate.

What are the benefits of registering?

Many people find being involved in research a rewarding experience and they enjoy the contact with research teams. Although taking part in a research study may not be of immediate benefit to you, it might help people in the future.

By signing up to use StepUp for Research, you increase your chances of being asked to consider taking part in an approved dementia and/or ageing (including aged care) related research study.

All studies using the service have been approved by a human research ethics committee. This means that they have been checked by an independent review body that ensures the research is conducted in an ethical manner and that any risks associated with participation in the research is minimised.

Please note, it is possible that there will not be any suitable studies for some volunteers at the time of registering, but new research studies are starting all the time which may be suitable.

Who can register?

Any adult (18 years old or older) who lives in Australia can sign up to use StepUp for Research.

The research studies using StepUp for Dementia Research will be looking at dementia. However, you do not have to be diagnosed with dementia to sign up. All types of people are needed for the variety of research studies- people without dementia, carers, families of people with dementia and other volunteers- having a diagnosis of dementia is not a prerequisite to volunteer. Similarly, the research studies using StepUp for Ageing Research will be looking at ageing and aged care related research. All types of people are needed for the variety of research studies- people young and old, carers, families of older people who have health concerns and/or receive care, and other volunteers.

Do I have to register?

No, it is your choice whether you sign up to use StepUp for Research or not. Whatever you decide, it will not affect the standard of healthcare you receive.

How do I register?

If you decide to register you can do it online either at www.stepupfordementiaresearch.org.au or www.stepupforageingresearch.org.au. If you cannot enter your details yourself, you can nominate a representative to support you. Your representative can be your carer, a family member or friend. Alternatively, you can sign up by phoning our helpline: 1800-STEP-123 (1800-7837-123).

What will happen if I decide to register?

As you create your account, you will be asked to consent to be contacted about your account and you will be asked to provide some personal information. This includes your name, date of birth, contact details and some basic information about your health. After you have completed registration, you will be asked to consent for the information you provide to be used to help find studies that might be a suitable match for you.

All information will be processed in accordance with the relevant privacy laws and held securely. The security of this identifiable information you provide is managed by the University of Sydney. Access to your information is controlled and monitored at all times; this and all system related policies can be found by asking a member of the StepUp for Research administration using the contact details at the bottom of this sheet.

Who will be able to see my information on StepUp for Research?

Only approved researchers, and those personnel necessary to provide the StepUp for Research services, including staff from the University of Sydney will be able to access your information*, and your information will only be accessed to allow those staff to perform their duties.

*This is the information you provide when registering and also any further optional information you choose to provide through StepUp for Research to researchers when you match to their study, as explained below in "Who will contact me about relevant research studies?"

Researcher users could be healthcare professionals or appropriately trained researchers working at universities or research institutes. All researcher users will have been fully screened and trained by StepUp for Research personnel, and will only be given access once their employer has agreed to the University of Sydney's conditions and privacy policies. These researchers will only see information on people who match to their studies' entry criteria.

Your information will not be sold.

What will happen if I want to change some of the information that I have provided?

You are free to amend your information at any time by logging into your account or by contacting us on 1800-STEP-123 (1800-7837-123).

Can researchers see my medical records?

No. You are not required to share or give access to your medical records as part of joining StepUp for Research. However, if you choose to participate in an individual study, the researchers may ask for access, and this will be discussed with you at that time.

Who will contact me about relevant research studies?

You will be contacted by a member of the research study team carrying out the research for which you have been deemed potentially suitable. When you sign up to use StepUp for Research, you will be asked how you would prefer to be contacted (for example by phone, letter or email).

When that researcher contacts you, they will talk to you about the study, its purpose, and what participation would mean to you, including benefits and any risks. They may also ask you some further questions or invite you to attend a

review to help decide your suitability.

You can choose whether or not to take part in any research study. Your choice will not affect you being on StepUp for Research or your overall care. You will always be in control.

If you do participate in a study, StepUp for Research will record which study you take part in, and this information might influence when and what other studies you are matched to in the future. For example, sometimes you may only be able to participate in one study at a time.

Will StepUp for Research contact me regarding other matters?

Yes, StepUp for Research may need to contact you from time to time regarding your account. Also, because providing a good experience and service is important, StepUp for Research would like to contact you periodically to ask for your opinion, experience and feedback. If you agree to be contacted about these things, StepUp for Research may contact you regarding polls or surveys about your experience and your participation in these is confidential and voluntary. StepUp for Research would like to keep you informed by periodically sharing the newsletter with you. Please note that you will be able to opt out of this kind of contact by changing your account settings.

What will happen if I want to withdraw from StepUp for Research?

Please note that you can decide which field(s) of research (dementia research or ageing research or both) you would be interested in participating in. You can change this information at any time.

You are also free to withdraw your information at any time without giving a reason. Please note that if a volunteer wishes to withdraw this will take precedence of those of a proxy who prefers the volunteer to remain on the service.

After you have withdrawn, your information will no longer be made available* to researchers, and you will not be contacted about any further studies. Withdrawing from StepUp for Research will not affect any existing research studies you have chosen to join.

*Identifiable data will be removed from the database. To help us understand who is using StepUp for Research we will retain and use non-identifiable data, such as your gender and age, for analysis purposes.

If you decide you no longer wish to remain on StepUp for Research, you can do so by changing your account setting or by calling the helpline at 1800-STEP-123 (1800-7837-123). If you have already been matched to a study, we request that you call the helpline so that we can alert relevant researcher user(s).

What is the process for identifying and removing the details of people who have deceased?

If StepUp for Research receives information from family or friends that a volunteer has passed away, StepUp for Research will ensure that the volunteer's information will be treated as a withdrawn account.

Also, StepUp for Research will from time-to-time check the activity of a volunteer's account to see if the volunteer has been active – either in contact with StepUp for Research directly or with researchers. Volunteers are sent annual notifications asking that they confirm their account details. If the account has been inactive for three years then StepUp for Research then the volunteer's information will be treated as a withdrawn account.

System users (helpline staff and researchers) will alert StepUp for Research administration should they discover that a volunteer is deceased. The StepUp for Research staff will remove the volunteer from StepUp for Research.

What if there is a problem?

StepUp for Research will help solve any problems you have whilst using StepUp for Research. More details are available in our Complaints Procedure, available on the website.

For technical problems, StepUp for Research encourages you to contact us at stepup.research@sydney.edu.au or by phone at 1800-7837-123.

If you are concerned about the way StepUp for Research is conducted or you wish to make a complaint to someone independent from StepUp for Research, you may contact the University of Sydney The Manager, Ethics Administration, University of Sydney at telephone: +61 2 8627 8176, email: human.ethics@sydney.edu.au, or fax: +61 2 8627 8177; please refer to project number [2018/680].

If you are unhappy with the way you have been dealt with during a research study and wish to complain formally, you must do this by contacting the actual research study team. Contact details for the research study team would have been provided by study and can also be obtained from StepUp for Research.

Who is funding StepUp for Research?

StepUp for Dementia Research was initially funded by the Commonwealth Department of Health. Both StepUp for Dementia Research and StepUp for Ageing Research are delivered by the University of Sydney.

The studies searching for volunteers using the service could have been funded through a variety of funders (e.g., through charities, government, or pharmaceutical companies). Information regarding funding or sponsorship for a study should be provided to you when you are contacted by a researcher.

Contact details

If you require further information or would like to discuss any aspect of StepUp for Research, call our helpline or contact us through email.

1800-STEP-123 (1800-7837-123)

stepup.research@sydney.edu.au

We have also published a series of documents that detail the processes followed by StepUp for Research in relation to this service. You can access these documents by contacting the helpline.

Thank you for taking the time to read this information sheet.