StepUp for Research
Privacy Statement: Volunteers/Proxies

Introduction

StepUp for Research is a service through which people register their interest in volunteering in dementia and/or ageing-related research, via **StepUp for Dementia Research** and **StepUp for Ageing Research websites**. The service matches registered volunteers to approved research studies based on a volunteer's personal and health information. StepUp for Dementia Research was initially funded by the Australian Government Department of Health involving the University of Sydney ("the University"), and the University of Exeter in the United Kingdom.

StepUp for Research will only be available to research studies that have received ethics approval by a Human Research Ethics Committee registered with the Australian Government National Health and Medical Research Council. View the NHMRC Guidelines here.

Volunteers can register through the StepUp for Dementia Research or StepUp for Ageing Research website ("the Website"), the StepUp for Research helpline ("the Helpline") and on paper-based registration forms. Volunteers can self-register or they can be registered via a proxy. The University manages the Website and the Helpline.

This privacy collection notice serves to inform volunteers and proxies as to how the University uses and discloses their personal information.

Collection

The University collects personal information:

- during the registration process;
- after registration, where additional information may be needed to match a volunteer/proxy to a study;
- as part of managing a volunteer/proxy's participation in StepUp for Research; and
- when accessing the Website and/or the Helpline.

Information collected through StepUp for Research is stored as identifiable data while a volunteer/proxy maintains an active account. For withdrawn accounts, data will be retained in a non-identifiable format to be used for data analytics and no identifiable data will be retained.

Where a volunteer/proxy does not supply all the requested information, the University may be unable to register the volunteer to participate in StepUp for Research, process a request or manage the volunteer's participation in StepUp for Research.

The University collect's personal information directly from the volunteer/proxy. We may also collect information about the volunteer from a proxy. Where a volunteer is registered by a proxy, personal information is collected about the volunteer from the proxy. An indirect collection of personal information is only done with either the express consent of the volunteer or in accordance with the law.

When a volunteer registers to participate in StepUp for Research, the University collects the following personal and sensitive information:

- their contact details;
- the details of any medical/health conditions; and

- related medications that they are taking.

Where a volunteer is registered by a proxy, the University collects the personal information of the proxy, namely, their contact details and the nature of their relationship with the volunteer. Where the proxy is acting as the authorised representative of the volunteer, the University also collects supporting documentation relating to this authorisation.

The University only collects sensitive information about the volunteer with the volunteer/authorised representative's consent unless it is otherwise required or permitted by law to do so. The sensitive information collected by the University is information about the volunteer's health.

As part of the registration process, a volunteer/proxy is asked to consent to the University disclosing their personal information to personnel from organisations that conduct research (such as, universities, research institutes, companies) for approved research studies so that the volunteer may be recruited to that study. When StepUp for Research matches a volunteer to a research study, the personal information of the volunteer/proxy is disclosed to the personnel conducting the study.

When a volunteer/proxy uses the Helpline, the University collects their username, their full name and the answers in relation to the security questions set up by the volunteer/proxy at registration.

When a volunteer/proxy is browsing the Website and wishes to access a secure area of the Website, the University collects their username and password.

Website Tracking

The Website is hosted on the cloud-based Microsoft Azure platform. The servers are located within Australia.

The University may collect a volunteer/proxy's personal information when they browse or otherwise use the Website.

Examples of information that the University collects includes

- the server and IP (Internet Protocol) address of the machine that has accessed the website;
- the dates and times of each visit to the website;
- the pages accessed and documents downloaded;
- the type of browser used; and
- sometimes, the previous site visited.

The University collects information through such mechanisms as server logs, proxy logs, web beacons and cookies.

A cookie is a package of data which a website requests be stored temporarily on a user's computer (or in memory) to identify them as a visitor to that website. Cookies may also store the following information: session (numbered key) and duration. A numbered key is a unique server-generated number used to identify the current session.

The information collected by the University is used to help improve the Website's content and performance. When a volunteer/proxy visits the secure area on the Website cookies are used for security and personalisation purposes.

A volunteer/proxy can choose to disallow cookies by changing settings on their web browser. However, disabling all cookies may affect their ability to access the secure areas of the Website.

Use and Disclosure

The University will only use or disclose your personal information

- for the purpose for which it was collected;
- for a directly related purpose;
- when it has the appropriate consent to do so; or
- as otherwise required, permitted or authorised by law.

Examples of how the University will use and disclose the personal information of volunteers/proxies include

- registering volunteers to participate in StepUp for Research;
- managing a volunteer's registration;

- liaising with a proxy in order to register a volunteer to participate in StepUp for Research and manage the volunteer's registration;
- updating volunteers and proxies about news and details relevant to StepUp for Research;
- matching volunteers with potentially relevant research studies; and
- disclosing volunteer/proxy personal information to approved studies.

The University may disclose the personal information of volunteers to the Australian Government Department of Health in accordance with the terms of the funding agreement between the University of Sydney and the Department. Where such a disclosure is made, it will only be done on the basis that the personal information is used for the purposes of collection previously detailed in this statement.

Access, Correction & Complaints

Volunteers/proxies wishing to access or amend their personal information can log-in to their www.stepupfordementiaresearch.org.au or StepUp for Ageing Research account online, or contact the Helpline on 1800 7837 123 (weekdays) or stepup.research@sydney.edu.au

For information about the StepUp for Research complaints process, see StepUp for Research Complaints Procedure or contact the Helpline on 1800 7837 123 (weekdays) or stepup.research@sydney.edu.au