

# Join Dementia Research

**Privacy Notice  
Publication Version 2  
05 July 2018**

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Join Dementia Research makes it easy for people to register their interest in dementia research, so that they can be contacted about relevant research studies. The goal is to make it possible for anyone and everyone who wants to be involved in dementia research to get the chance to do so.

Join Dementia Research is a collaborative project, funded by the Department of Health and Social Care, and coordinated by the National Institute for Health Research (NIHR) and the three national Alzheimer's charities: [Alzheimer Scotland](#), [Alzheimer's Society](#) and [Alzheimer's Research UK](#).

Our volunteers who register with Join Dementia Research provide personal information about themselves and their health, which is then shared with approved researchers looking to match volunteers to dementia research studies. We take your privacy extremely seriously, and this privacy statement sets out more detail about who is responsible for protecting your data, the information we collect, how we store and use it, and your rights.

If you have any questions or concerns, or would like us to stop holding or using your data at any time, please let us know through the details on the contact us page.

### **Introduction - protecting your privacy**

The Department of Health and Social Care ("**DHSC**") is the Data Controller for Join Dementia Research "**JDR**" under the Data Protection Act and, after 25 May 2018, the General Data Protection Regulation (EU) 2016/679 ("**Data Protection Laws**").

The Consortium of the University of Leeds and Guy's and St Thomas' NHS Foundation Trust ("**The Consortium**") is the Data Processor for Join Dementia Research. The Consortium provides the National Institute for Health Research ("**NIHR**") Clinical Research Network Coordinating Centre ("**CRNCC**") on behalf of the Department of Health and Social Care and the CRNCC is responsible for the processing of your personal data.

### **About the NIHR Clinical Research Network Coordinating Centre and JDR**

The NIHR Clinical Research Network Coordinating Centre (CRNCC) is a service provided by the Consortium, supported by a wider partnership which includes King's College London, Imperial College London, Newcastle University, University of Liverpool and PA Consulting Services Limited

The CRNCC manages the NIHR Clinical Research Network ("**CRN**") on behalf of the Department of Health and Social Care. The CRN makes it possible for patients and health professionals across England to participate in clinical research studies within the NHS. The CRN provides the infrastructure that allows high-quality clinical research funded by charities, research funders and life-sciences industry to be undertaken throughout the NHS. The CRN works with patients and the public to

make sure their needs are placed at the heart of all research, and provides opportunities for patients to gain earlier access to new and better treatments through research participation. The CRN provides practical help in identifying and recruiting patients for clinical research studies, so that researchers can be confident of completing the study on time and as planned.

The CRN supports around 5,000 clinical research studies each year.

Join Dementia Research is operated by the NIHR CRNCC on behalf of the DHSC, and is a partnership with the three national Alzheimer's charities: Alzheimer Scotland, Alzheimer's Society and Alzheimer's Research UK.

### **The information we collect**

The CRNCC collects your personal data on behalf of and as directed by the Department of Health and Social Care.

The CRNCC collects information directly and indirectly.

We collect information directly from you in a number of ways. These include via the website or web forms to collect volunteer information, from written forms posted to us, from emails and from telephone or in person conversations. When you register as a volunteer with Join Dementia Research, you consent to this information being recorded into your record on the Join Dementia Research system. This information is held securely (see below) for the purposes of matching you or the person who you are completing the form on behalf of, to opportunities to participate in and find out more about dementia research.

When you use Join Dementia Research, we use technology to collect information indirectly - such as your internet address. This is commonplace across all internet services to enable the investigation of issues such as malicious use. This information is then kept in our internet access logs. Cookies are small files of information that save and retrieve information about your visit to our site, such as how you entered our site, how you navigated through the site and what information was of interest to you. This information is collected for a number of reasons, for example, to help develop the website and associated services.

The cookies we use identify you only as a number. If you are uncomfortable about the use of cookies, you can disable them by changing the settings in the preferences or options menu in your internet browser. However, disabling cookies may affect our ability to provide services to you: if certain cookies are disabled you may not be able to access the service.

See our separate Cookies statement for more information on the cookies we use.

The only data stored in relation to navigation of the site will be:

- Navigation data – data on how you move around our site and the hyperlinks you click upon
- The IP address of your device and, if applicable, the website you originated from

- Personal information (only if you register as a Join Dementia Research volunteer) – such as your first name, last name, email address, postcode and other personal information
- Your Username and password for this system
- Your data will be stored on the Join Dementia Research website

The personal data we collect may vary depending on the nature of your interaction with CRN. However, we always protect your personal data within the terms of this Privacy Notice.

If you give us information on behalf of someone else, you confirm that the other person has appointed you to act on his/her behalf and has agreed that you can.

### **How we protect your data**

We are committed to ensuring that your information is secure. We use leading technologies and encryption software to safeguard your data, and maintain strict security standards to prevent any unauthorised access to it. However, given that transmitting information via post, by phone or over the internet cannot be completely secure, we can't guarantee the security of your data in transit.

Join Dementia Research may contain links to other websites of interest outside the CRNCC. This privacy policy only applies to our websites, systems and services, and doesn't cover other websites and services that we may link to. You should exercise caution and look at the privacy notice applicable to the website/service in question.

Join Dementia Research is hosted on the Google Cloud Platform, a cloud-based software platform which provides for 'disaster recovery processes' across its servers, which are all located within the European Economic Area (EEA). None of the data contained within Join Dementia Research will go outside the EEA. The Google Cloud Platform is accredited to ISO 27001 security standards.

We use MailChimp as our marketing automation platform, for example, to send newsletters to volunteers on a quarterly basis. Users are invited to opt in to subscribe to newsletter mailings. By consenting to this, you acknowledge that the information you provide will be transferred to MailChimp for processing in accordance with their [Privacy Policy](#) and [Terms](#). Users can opt out of receiving mailings at any time, whilst remaining opted in to the Join Dementia Research service and study alert emails.

We will disclose your personal data to third parties outside of the CRNCC only in accordance with the purposes of Join Dementia Research and its partners, to NHS researchers or other approved researchers. CRNCC administers data processing agreements on behalf of the Department of Health and Social Care with non-NHS institutions who have an interest in dementia research (such as commercial research organisations, universities and research institutes), governing their use of your data.

We will not otherwise share your data unless we have your explicit permission, or are required by law to do so. We will not sell your personal data.

We will hold the data for as long as we are providing you services and for as long as you agree to this. We will retain your data for varying amounts of time depending on the nature of your interactions with Join Dementia Research:

- We only store data that is necessary for a specific purposes
- We will not store your data for longer than is necessary
- Your data will be securely deleted when no longer needed for the purpose(s)
- It is important to note that due to the nature of healthcare research, it may be necessary to hold information for a lengthy time, including after death. You or your representative can request us to cease holding or using data (for example to contact you), or for it to be anonymised (with personal information that allows individuals to be identified removed) at any time.

### **Destruction of Data**

Data is securely destroyed when it is no longer needed or when information technology holding the data fails.

### **Who do we share your personal data with**

- Your data is shared with researchers involved in dementia research, including NHS staff and approved researchers working in commercial research organisations, or academic institutions, for the purpose of matching volunteers to opportunities in dementia research.
- Your data is also shared with our partner organisations in delivering the Join Dementia Research Registry, these being the three national Alzheimer's charities: Alzheimer Scotland, Alzheimer's Society and Alzheimer's Research UK.
- It is also accessible to approved staff within CRNCC and the wider NIHR, including the National Director for Dementia Research office, the partner JDR charities, and IT provider/s, for the purpose of administering the service.
- We also share your contact details only with our third party contracted printers who are responsible for sending out newsletters and annual update reminders to those who have registered to use the service.
- We will never share personal information with other third parties without your consent
- Navigation data is shared with trusted third parties providing analytics such as Google and Mailchimp.
- All partner organisations are either contractually obliged or have signed up to a Data Processing Agreement, which prevents them from sharing your data with other non-authorized third parties and provides for the secure disposal of this data.

## Your rights over your personal data

The Data Protection Officer for the CRNCC is:

- Name of Data Protection Officer: George Menzies
- Address: Department of Health and Social Care, 39 Victoria Street, Westminster, London, SW1H 0EU
- Email - [data\\_protection@dh.gsi.gov.uk](mailto:data_protection@dh.gsi.gov.uk)

As a data subject, you have the following rights under the Data Protection Laws:

- the right of access to personal data relating to you
- the right to correct any mistakes in your information
- the right to ask us to stop contacting you with direct marketing
- rights in relation to automated decision making
- the right to restrict or prevent your personal data being processed
- the right to have your personal data ported to another data controller (e.g. if you decide to contract with a different supplier).
- the right to erasure
- the right to withdraw consent

These rights are explained in more detail below:

<https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/>

If you wish to exercise any of your data subject rights, please contact the NIHR Service Desk in the first instance - either:

- Write to The NIHR Service Desk, Back Lane, Melbourn, Royston, SG8 6DP
- or Email: [gdpr\\_requests@nih.ac.uk](mailto:gdpr_requests@nih.ac.uk)

We will respond in a timely manner to any rights that you wish to exercise, and for Subject Access Requests (SARs) this has to be within a month of receiving your request unless the request is particularly complex.

## Contacting the Regulator

It is important that you ensure you have read this privacy notice - and if you do not think that we have processed your data in accordance with this privacy notice - you should let us know as soon as possible. Similarly, you may complain to the Information Commissioner's Office. Information about how to do this is available at [www.ico.org.uk](http://www.ico.org.uk).