

Volunteer Guide

This booklet contains everything you need to know about managing your Join Dementia Research membership, matching to studies, confidentiality and data protection. You may have read this before you signed up, but we think you will find this information useful, so here's another copy for you to keep.

Contents

1. About Join Dementia Research		4. Matching to research studies	
1.1 What is Join Dementia Research?	2	4.1 What happens after I've registered?	6
1.2 Which organisations work together on Join Dementia Research?	2	4.2 Will I definitely be contacted about participating in a study?	6
1.3 What are the benefits of registering?	2	4.3 If I match to a study, what will happen next?	6
1.4 Are the studies safe?	3		
1.5 What kind of research could I take part in?	3	5. Leaving Join Dementia Research	
2. Registering with Join Dementia Research		5.1 What will happen if I want to withdraw from Join Dementia Research?	7
2.1 Who can register?	3	5.2 What is the process for identifying and removing the details of people who pass away?	7
2.2 Do I have to register?	3		
2.3 How do I register?	4	6. Troubleshooting	
2.4 What will happen if I decide to register?	4	6.1 What if there is a problem?	8
3. Data protection and privacy		6.2 Contact details	8
3.1 Will my data be safe?	4		
3.2 Who will be able to see my information on Join Dementia Research?	5		
3.3 Who will be able to see my medical records?	5		

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1.1 What is Join Dementia Research?

Join Dementia Research is a national service which allows members of the public to register their interest in taking part in dementia research studies. The service is not a research study itself, but matches interested volunteers with researchers who are seeking participants for their studies.

Join Dementia Research enables you to provide information about yourself so you can be matched to research studies that you may be eligible to participate in. If you match to a study, the researchers can then contact you to see whether you are eligible and if you'd like to take part. You have no obligation to take part in any study on Join Dementia Research.

The goal is to make it possible for anyone who wants to be involved in dementia research to get the chance to do so.

1.2 Which organisations work together on Join Dementia Research?

Join Dementia Research is funded by the Department of Health and Social Care and delivered in partnership with the National Institute for Health Research (NIHR), Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society.

1.3 What are the benefits of registering?

By signing up to use Join Dementia Research, you increase your chances of taking part in ethically approved dementia research.

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. Some of our volunteers have told us that taking part in research gives them hope for future generations, and makes them feel like they are doing something valuable.

It is also possible that there will not be any suitable studies for some volunteers, but new research studies are starting all the time which may be looking for different volunteers.

1.4 Are the studies safe?

All studies using Join Dementia Research have been approved by a Research Ethics Committee. This means that they have been checked to make sure they protect the rights, safety and wellbeing of people involved in research.

1.5 What kind of research could I take part in?

Being part of Join Dementia Research gives you the opportunity to see which local studies match your health information and preferences. You can then choose whether or not to take part in any study you match to.

There are a number of different types of studies. For example, studies looking at prevention or new ways to diagnose the condition; drug studies trialling new treatments; or surveys aiming to improve the quality of life for people with dementia and their carers.

2.1 Who can register?

Anyone aged 18 or older, who lives in England, Scotland, Wales or Northern Ireland can sign up to Join Dementia Research.

You do not have to be diagnosed with dementia to sign up. Volunteers who do not have dementia, as well as carers or families of people with dementia are needed for some research studies.

2.2 Do I have to register?

No, it is your choice whether you sign up to Join Dementia Research or not. If you decide to sign up, you will be asked to provide your consent. This means signing a declaration to confirm you are happy for the data you submit to be accessed by the partners delivering the service as well as research teams (please see sections 3.2 and 3.3 for more details about who can access your data).

Whatever you decide, it will not affect the standard of healthcare you receive.

2.3 How do I register?

If you decide to sign up to Join Dementia Research you can do it online at joindementiaresearch.nihr.ac.uk

Alternatively you can sign up over the phone, or you can request that we send you a paper form that you can fill in and return to us by post. Our charity helplines will be happy to help (see section 6.2).

If you cannot enter your details yourself, you can nominate a representative to do this for you. Your representative can be your carer, a family member or friend. They will need to have your permission, which we may need to confirm with you. If you do not have capacity to give this consent, someone with lasting power of attorney registered for you on health and welfare grounds can do so for you.

Please note that if you are acting as a representative for someone else and have not been registered as having lasting power of attorney for them on health and welfare grounds, the volunteer will need to confirm to us that they consent to registering (by signing the form themselves or confirming over the phone).

2.4 What will happen if I decide to register?

Once you have created your account, you will be asked to provide some personal information.

This includes your name, date of birth, contact details and some basic details about your health. Before you send this information to be uploaded onto Join Dementia Research, you will be asked to consent for it to be used to help find studies that might be a suitable match for you.

3.1 Will my data be safe?

We take the security of your information seriously. The Join Dementia Research website is managed by the National Institute for Health Research Clinical Research Network Coordinating Centre (NIHR CRNCC) under a contract with the Department of Health and Social Care. All information will be processed in accordance with the Data Protection Act 2018 and General Data Protection Regulation 2016, and is held securely using a secure business enterprise Google platform. Access to information is controlled and monitored at all times as detailed in the Access Control Policy.

You can find out more about our policies on the website or by asking a member of the Join Dementia Research team (see contact details in section 6.2).

3.2 Who will be able to see my information on Join Dementia Research?

Your information is managed by a team of staff based at the National Institute for Health Research Clinical Research Network Coordinating Centre (NIHR CRNCC).

The only people who will be able to see your information are the Join Dementia Research staff at NIHR, agencies working on our behalf, approved researchers, NHS staff and the charity helpdesks.

Approved researchers may be employed by the NHS, commercial organisations or universities, pursuing activities for medical benefit. All researchers are assessed and approved on the basis that their employers are signed up to our data processing agreements and terms and conditions, and that they are working on ethically approved studies. Researchers only access your information on Join Dementia Research in relation to studies that you match to.

A list of research organisations approved to use Join Dementia Research is available on our website, at joindementiaresearch.nihr.ac.uk/help under the question 'Who can see my information in Join Dementia Research?'. Alternatively please call one of our partner charity helplines and they can request that this information is sent to you by post (see contact details in section 6.2).

3.3 Who will be able to see my medical records?

The information on Join Dementia Research is held separately from your medical records kept by your GP and/or your hospital consultant. In some cases, a researcher may also wish to view your medical records. The extra details in your medical records will help them to assess whether they should approach you to think about joining a particular study.

When signing up to Join Dementia Research, you will be asked for your permission for your medical records to be looked at. Only approved researchers and NHS staff who have been assessed in accordance with "Research in the NHS Human Resource (HR) Good Practice" will be allowed to access your medical records, and those accessing your medical records must follow the NHS Confidentiality Code of Practice and the Data Protection Act 2018. **This means that they will only view information from your medical records that is relevant to assess whether you may be suitable to be contacted about a research project,** and must keep your information secure. They will not disclose any information from your records to any unauthorised person. Unauthorised disclosure by any researcher of any information from your records is a criminal offence and may lead to their prosecution.

4.1 What happens after I've registered?

Your details will be regularly checked to see if you match to studies that are added to Join Dementia Research. If you match to a study, the research team will be notified and may get in touch with you to tell you more about the study and see if you are interested and suitable to take part.

If you have requested email alerts you will be notified by email when you match to a new study. Otherwise if you have an online account you can login at any time to find out what studies you match to and read more about them. You can indicate your interest in taking part in a study that you have matched to by ticking the relevant box. If you do not have an online account you can call our charity helplines (see contact details in section 6.2). There is no obligation to take part in any study.

If you have chosen to receive updates and newsletters from Join Dementia Research we will write to you regularly by email or post.

4.2 Will I definitely be contacted about participating in a study?

In some cases, there may not immediately be research studies that you are a suitable match for. This can be understandably disheartening for people keen to take part in research.

Registering with Join Dementia Research does not necessarily mean that there will be a study available to you straight away. However, when a suitable study does come along, researchers will be able to see that you have already registered your interest in taking part.

4.3 If I match to a study, what will happen next?

If you are matched to a study, this does not necessarily mean you are definitely eligible to take part. Researchers and NHS staff may check your medical records or talk to you to make sure you are suitable for that particular study.

If you are eligible, you will be contacted by a healthcare professional or a member of the study team carrying out the research, who will explain the study to you.

You can choose whether or not to take part in any research study and your choice will not affect you being registered with Join Dementia Research. You will always be in control. Join Dementia Research will record which studies you take part in.

5.1 What will happen if I want to withdraw from Join Dementia Research?

You are free to withdraw your information at any time without giving a reason. Your personal information will be kept in the form of an anonymous record that cannot be traced to you personally. You will not be contacted about any further studies that use Join Dementia Research. If you have participated in a research study, or have given your details separately to a research team, you may still receive their communications.

Withdrawing from Join Dementia Research will not affect any existing research studies you have chosen to join or the standard of healthcare you receive. You also have the right to full deletion of any data we hold on you, which is a more thorough process than withdrawal from Join Dementia Research.

If you decide that you no longer wish to remain on Join Dementia Research or that you want all your data deleted, you must inform the Join Dementia Research team or telephone the charity helpline numbers. Contact details are found in section 6.2.

5.2 What is the process for identifying and removing the details of people who pass away?

When registering with Join Dementia Research, all volunteers and representatives are asked to provide their consent for their information to be updated by Join Dementia Research if a person dies.

This involves NHS Digital notifying Join Dementia Research in the event of the death of a registered person. This information would be cross-checked by a senior member of the Join Dementia Research team at the National Institute for Health Research (NIHR), who will be responsible for updating the individual's record (removing personal information and pseudonymising it).

This procedure of updating and maintaining the service is in accordance with the Data Protection Act 2018 and General Data Protection Regulation 2016.

6.1 What if there is a problem?

We hope that you will have a positive experience using Join Dementia Research. However if you have a problem, please do one of the following:

- For problems relating to your clinical care, please contact your doctor.
- For problems relating to your participation in a particular research study, please contact the research team of that study. If you cannot locate details of the research team from information they have supplied you, the Join Dementia Research team can help. Please email: jdrdelivery@nihr.ac.uk or contact one of the helplines (see section 6.2).
- Any problems relating to Join Dementia Research can be addressed by using the contact details in section 6.2.

For our complaints procedure, please visit joindementiaresearch.nihr.ac.uk/policiesandprocedures or contact one of the helplines in section 6.2.

6.2 Contact details

If you require further information or would like to discuss any aspect of Join Dementia Research please call one of the Helplines:

<p>Alzheimer Scotland 0808 808 3000</p> <p>Open 24 hours a day, 7 days a week. <i>(Scotland)</i></p>	<p>Alzheimer's Research UK 0300 111 5 111</p> <p>Mon - Fri: 9am - 5pm <i>(UK wide)</i></p>	<p>Alzheimer's Society 0300 222 1122</p> <p>Mon - Wed: 9am - 8pm Thurs & Fri: 9am - 5pm Sat & Sun: 10am - 4pm <i>(England, Wales & Northern Ireland)</i></p>
<p>Calls to Alzheimer Scotland are free, calls to other Helplines cost no more than a national call from any type of phone or provider and calls are included in any free call packages on landlines and mobiles.</p>		

Alternatively, you can contact the Join Dementia Research team at manager.jdr@nihr.ac.uk

You can also visit our website at www.joindementiaresearch.nihr.ac.uk/contactus

Thank you for taking the time to read this guide.