Join dementia research

NHS

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

Delivered in partnership by

NIHR | National Institute for Health Research

Alzheimer Scotland Action on Dementia

Alzheimer's Research UK Make breakthroughs possible

Alzheimer's Society

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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?

There are a number of different types of studies on Join Dementia Research. 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 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 What will happen if I decide to register?

To register, you will need to create a Join Dementia Research account (see section 2.4).

Once you have created your account, you will then 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.

2.4 How do I register?

You can sign up to Join Dementia Research 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).

2.5 Can I register on behalf of someone else?

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. You will still need to sign the form or be ready to confirm by phone that you would like them to act as your representative.

If someone is not able to consent themselves, for example due to dementia, there are some circumstances where we may be able to take the consent of someone with power of attorney to make this decision on their behalf and give us the legal permission to hold their data.

In England and Wales, this is called a Lasting Power of Attorney (LPA), and would need to be on health and welfare grounds. In Scotland, this is called a Welfare Power of Attorney.

The same legal framework is not in force in Northern Ireland, so consent has to be given by the volunteer themselves - you cannot register on someone else's behalf in Northern Ireland.

If you hold the appropriate power of attorney for someone, and believe it would be in their best interests to volunteer for Join Dementia Research, you can sign up on their behalf. This doesn't mean that you are giving consent for them to take part in healthcare research. Each study has its own procedures and measures to ensure that the best interests of participants are protected.

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 contacting a member of the Join Dementia Research team (see section 6.2).

3.2 Who will be able to see my information?

Your information is managed by a team of staff based at the NIHR CRNCC. Only Join Dementia Research staff at NIHR or agencies working on our behalf, approved researchers, NHS staff and the charity helpdesks registered to use Join Dementia Research will be able to see your information.

We also share information with NHS Digital about volunteers approximately twice a year so that we can stop volunteers who have now died from being contacted.

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 terms and conditions, and data processing agreements; 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. Staff are only allowed to view information to assess whether you may be suitable to be contacted about a research project. They must keep your data secure and not disclose it to anyone without authorisation. Not following these rules may be a criminal offence by the member of staff and lead to them being prosecuted.

Any researchers who wish to access volunteer data on Join Dementia Research have to undergo special training and be assessed in accordance with "Research in the NHS Human Resource (HR) Good Practice". They must follow the NHS Confidentiality Code of Practice and the Data Protection Act 2018.

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 the service. 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 to identify and remove 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.

If we receive notification from a member of the volunteer's family or a researcher that an individual has died we will update the record as soon as possible. We also run checks at least twice a year to identify and remove registered volunteers from England, Wales and Scotland who have died. This involves Join Dementia Research supplying NHS Digital with a list of people who have registered, including personal information to identify them, including their name, date of birth, NHS number and address. NHS Digital then supplies Join Dementia Research with a list of those registrants who they have a record of having died.

The Join Dementia Research team then update the individual's record, so that researchers and the team do not continue to contact the volunteer. We normally remove personal information but retain a record of the volunteer's participation, using a pseudonym to protect the person's identity. We aim to undertake this cross-check with NHS Digital at least twice a year.

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

If we are not notified of a person passing away by either of these processes, their record, and that of any associated representative may be retained.

5.3 How will you keep me and my data safe if I lose capacity?

Someone may be able to consent to register on Join Dementia Research, but then as an illness like dementia progresses, may lack capacity to consent in the future or manage their account.

We will look to support people to express their wishes and make their own decisions about taking part in research for as long as they are able.

We recognise that for some people, particularly those with dementia, there may come a time when being contacted may become a burden, or be unwelcome or confusing. In these cases, we look to make it as easy as possible to suspend or delete their account.

We are happy to hear not just from the volunteer, but we also have processes where we can take a request from others including family, friends, healthcare professionals or researchers.

Unless we hear from a volunteer or someone contacting us about their best interests, we will presume that we have ongoing consent to hold a volunteer's data, even if they lose capacity.

We do not make assessments about whether someone has 'capacity' to consent to take part in research or whether taking part in a particular study is in someone's best interests. Each study team has their own agreed ethical protocol governing their study and consent process, and you can ask the researcher for more details about this when you are matched to a study.

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:

Alzheimer Scotland	Alzheimer's Research UK	Alzheimer's Society
0808 808 3000	**0300 111 5 111**	**0300 222 1122**
Open 24 hours a day, 7 days a week.	Mon - Fri: 9am - 5pm	Mon - Wed: 9am - 8pm Thurs & Fri: 9am - 5pm Sat & Sun: 10am - 4pm
(Scotland)	*(UK wide)*	*(England, Wales & Northern Ireland)*

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.

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.

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