

WELCOME TO JOIN DEMENTIA RESEARCH



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THANK YOU FOR REGISTERING

Dementia is one of the biggest challenges we face today. The number of people with Alzheimer's disease, vascular dementia, and other types of dementia, is set to double over the next 30 years.

Dementia research is particularly important because our knowledge of the different dementias currently lags behind that of other major conditions, such as cancer or heart disease.

Through research we will find ways of developing effective treatments, improving dementia care and hopefully one day beating dementia. But for research to progress we need more people like you to take part in dementia studies.

Thank you for registering with Join Dementia Research and for enabling vital dementia research.

**Martin Rossor MD FRCP FMedSci,
Professor of Clinical Neurology,
NIHR National Director for Dementia Research**

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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 service 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.

WHAT ARE THE BENEFITS OF REGISTERING?

By registering with Join Dementia Research you increase your chances of being asked to consider taking part in an ethically approved dementia research study.

Many people find being involved in research a rewarding experience and they enjoy the contact with research teams. 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 possible that there will not be any suitable studies for some volunteers, but new research studies are starting all the time. By registering with Join Dementia Research you can find out about new studies you might be able to take part in as soon as they are added.

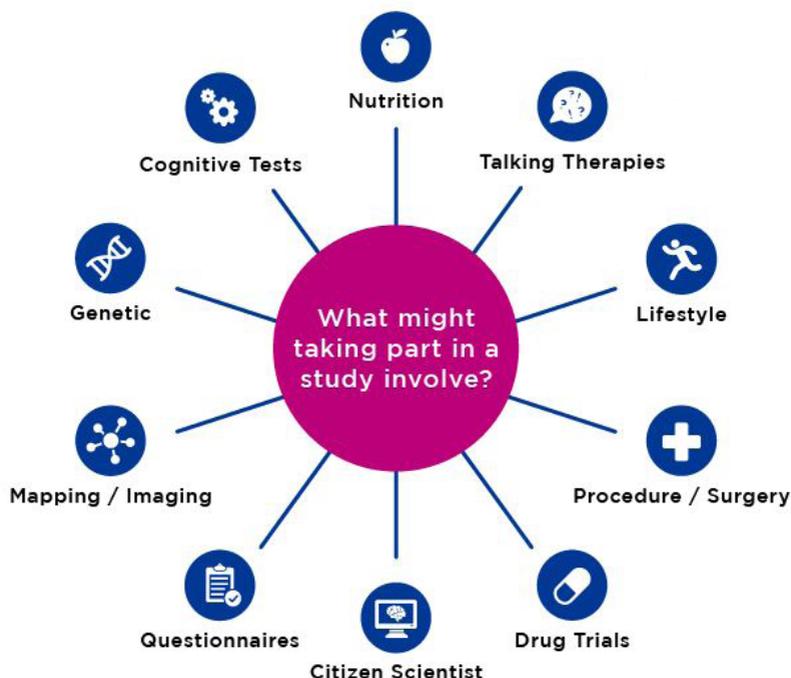


SOME RESEARCH STUDIES NEED VOLUNTEERS WITHOUT DEMENTIA AS WELL AS CARERS OR FAMILIES OF PEOPLE WITH DEMENTIA

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. Then, on a case-by-case basis, you can choose which to take part in.

There are a number of different types of studies, such as those 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.



ARE THE RESEARCH STUDIES SAFE?

All studies using Join Dementia Research will 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.

WHAT OUR RESEARCHERS SAY



"Join Dementia Research is great – it has helped us find highly motivated people all in one place.

Thanks to the people taking part in dementia research studies today, this work will translate into meaningful outcomes for people with dementia in the future."

Dr Ivan Koychev, Oxford Principal Investigator on the PREVENT Dementia study

"We were looking for 170 participants for our study but in the end more than 1,100 people took part. This tremendous response could not have been achieved without Join Dementia Research and the people willing to give up their time to take part."

Dr Sahdia Parveen, Principal Investigator of the Caregiving Hope study



"Around three-quarters of a million people currently have dementia so research into activities, care and services is just as important as trying to find a cure".

Professor Tom Dening, Professor of Dementia Research, Institute of Mental Health, University of Nottingham



WHAT HAPPENS NOW THAT I'VE REGISTERED?

- Your details will be regularly checked to see if you may 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 you can log into your account at any time to find out what studies you match to and read more about them. You can call our charity helplines if you do not have an online account.
- You can indicate your interest in taking part in a study that you have matched to by ticking the relevant box on your online account. 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.

I'VE MATCHED TO A STUDY: WHAT HAPPENS 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.

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.

Having an account with Join Dementia Research does not necessarily mean that there will be a study available to you straight away. However, more than 200 studies have been added so far, and new studies are starting all the time.

HOW CAN I IMPROVE MY CHANCES OF MATCHING TO STUDIES?

The more information you provide, the more accurately you can be matched to new studies.

You can increase your chances of being successfully matched to studies by logging into your account at www.joindementiaresearch.nihr.ac.uk and doing one of the following:

- completing the information from the additional questions on your 'Volunteer Summary' page.
- ticking the box to express your interest in studies you match to on your account.
- indicating your willingness to travel. Some areas of the country may have more dementia research taking place than others. If you are willing to travel, you may be considered to take part in studies in those areas.
- ensuring the information on your account is always up to date.

You can also call the charity helpline numbers to provide the additional information.

**VISIT THE WEBSITE
REGULARLY TO SEE
YOUR STUDY MATCHES
AND KEEP YOUR
INFORMATION
UP-TO-DATE**



HOW DO I MANAGE MY ACCOUNT AND UPDATE MY INFORMATION?

If you have an online account you can access and update your information by visiting www.joindementiaresearch.nihr.ac.uk and logging in with your unique username and password.

When you are logged in, you will see your 'Volunteer Summary' page. Here, you can update or edit your own volunteer information as well as register someone else and maintain their information for them if you have been given their consent or have Lasting Power of Attorney on health and welfare grounds.

You can also change how researchers get in touch (for example by phone, letter or email) or sign up for newsletters and updates.

If you don't have an online account, you can update your information by calling one of the helplines, run by our partner charities.

To get the most out of your Join Dementia Research account, please **log in regularly to ensure your details are up to date**. This will allow us to match you with studies more effectively. Alternatively, you can **call one of our charity helplines on the phone numbers listed on the last page of this booklet to check and update your details**.

WHAT CAN I DO ON MY ONLINE 'VOLUNTEER SUMMARY' PAGE?

- ✔ You can find the studies that match either to you, or the person you registered.
- ✔ You can read a description of each study you match to.
- ✔ You can express your interest in studies to let researchers know that you want to find out more.
- ✔ You can register a profile for someone else and manage their record for them if you have been given their consent or have Lasting Power of Attorney on health and welfare grounds.
- ✔ You can set up an alert to be informed of future studies.

www.joindementiaresearch.nihr.ac.uk

If you do not have an online account, please call one of our partner charity helplines who can make updates to your account for you or tell you about any studies you may match to.

I FORGOT MY PASSWORD. WHAT DO I DO?

Please click the 'Forgotten password/username?' link in the top right-hand corner of the homepage. You can then reset your password, by entering your username and email address. If you do not have a username or password, please call one of the charity helplines using one of the numbers on the back of this booklet.

www.joindementiaresearch.nihr.ac.uk

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 (NIHR) Clinical Research Network Coordinating Centre. Only the 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.

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 organisations approved to use Join Dementia Research is available on our website www.joindementiaresearch.nihr.ac.uk. Visit the website and click on '**Any questions?**'. The information can be found 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 this information is sent to you by post.

IS MY DATA SAFE?

We take the security of your information seriously. The Join Dementia Research website is managed by the NIHR Clinical Research Network Coordinating Centre under a contract from the Department of Health. All information will be processed in accordance with the Data Protection Act 2018 and 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 using the contact details on page 13.



WHICH ORGANISATIONS WORK TOGETHER ON JOIN DEMENTIA RESEARCH?

The service is funded by the Department of Health and Social Care and delivered in partnership with the National Institute for Health Research, Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society.

WHO WILL BE ABLE TO SEE MY MEDICAL RECORDS?

The information on Join Dementia Research is held separately from the 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 that 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.

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 then 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 please either contact the Join Dementia Research team or contact one of the charity helpline numbers:

Join Dementia Research Manager:
c/o NIHR Clinical Research Network Coordinating Centre
Minerva House, 5 Montague Close, London, SE1 9BB
email: manager.jdr@nhr.ac.uk

Alzheimer
Scotland

0808 808 3000

Open 24 hours a day,
7 days a week.

(Scotland)

Alzheimer's
Research UK

0300 111 5 111

Mon - Fri: 9am - 5pm
(UK wide)

Alzheimer's
Society

0300 222 1122

Mon - Wed: 9am - 8pm
Thurs & Fri: 9am - 5pm
Sat & Sun: 10am - 4pm

(England, Wales & Northern Ireland)

Calls to Alzheimer Scotland are free. Calls to Alzheimer's Research UK and Alzheimer's Society 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.

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 health status information to be updated by Join Dementia Research if their individual status changes (ie 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 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.

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:

- **If you have any problems relating to your clinical care, please contact your doctor.**
- If you have any 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 given you, the Join Dementia Research team can help. Please email: jdrdelivery@nihr.ac.uk.
- Any problems relating to Join Dementia Research can be addressed by by contacting the Join Dementia Research team by emailing **manager.jdr@nihr.ac.uk**. You can also call one of the helplines, who will then raise the complaint on your behalf.

Our complaints procedure can be found on our website:

www.joindementiaresearch.nihr.ac.uk/policiesandprocedures

Alternatively you can call our helplines who can request a copy be sent in the post to you:

CHANTEL & NIGEL'S STORY

Chantel and Nigel have been married for 32 years. Nigel was a bus driver for 30 years when he started to have problems with numbers and counting. This is when Chantel realised that there might be something wrong.

Nigel was diagnosed with Familial Early-Onset Alzheimer's Disease in 2009. It was on one of their visits to the hospital that their doctor asked if they would be interested in taking part in research, exploring the genetic causes of the condition.

"I can truly say that being involved in research changed our lives; we gained a better understanding of the disease and the research team were able to advise and support us all the way through. It's amazing what goes on behind the scenes. I was also able to cope better as the study

researchers helped me understand the progression of the disease and the medication options available.

It is important to be able to unite researchers with the general public, and this is what Join Dementia Research is doing. I am sure this will move the diagnosis forward for dementia and stop it. It is important we get to the bottom of why this is happening to so many younger people and to so many families."

Chantel



CONTACT DETAILS

For all general enquiries about Join Dementia Research please visit our website at:

www.joindementiaresearch.nihr.ac.uk

or if you need help, please call:

Alzheimer
Scotland

0808 808 3000

Open 24 hours a day,
7 days a week.

(Scotland)

Alzheimer's
Research UK

0300 111 5 111

Mon - Fri: 9am - 5pm
(UK wide)

Alzheimer's
Society

0300 222 1122

Mon - Wed: 9am - 8pm
Thurs & Fri: 9am - 5pm
Sat & Sun: 10am - 4pm

**(England, Wales &
Northern Ireland)**

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