

# WELCOME PACK

Thank you for  
registering



Delivered in partnership by

**NIHR** | National Institute  
for Health Research

Join Dementia Research is funded by the Department of Health and Social Care



# Welcome to Join Dementia Research

By registering, you've already taken your first step towards taking part in vital research.



Dementia is one of the biggest challenges we face today, but our knowledge currently lags behind that of other conditions such as cancer or heart disease.

It's people like you who will make a difference. By letting researchers know you're interested in taking part in studies, you can go on to help develop effective treatments, improve care, and hopefully one day beat dementia once and for all.

This booklet will help you make the most of your Join Dementia Research membership and improve your chances of matching to a study.

Thank you so much for getting involved. Together we can make a difference to the lives of everyone affected by dementia.

A handwritten signature in black ink that reads "Martin Rossor". The signature is written in a cursive, flowing style.

**Martin Rossor MD FRCP FMedSci**

Professor of Clinical Neurology  
NIHR National Director for Dementia Research

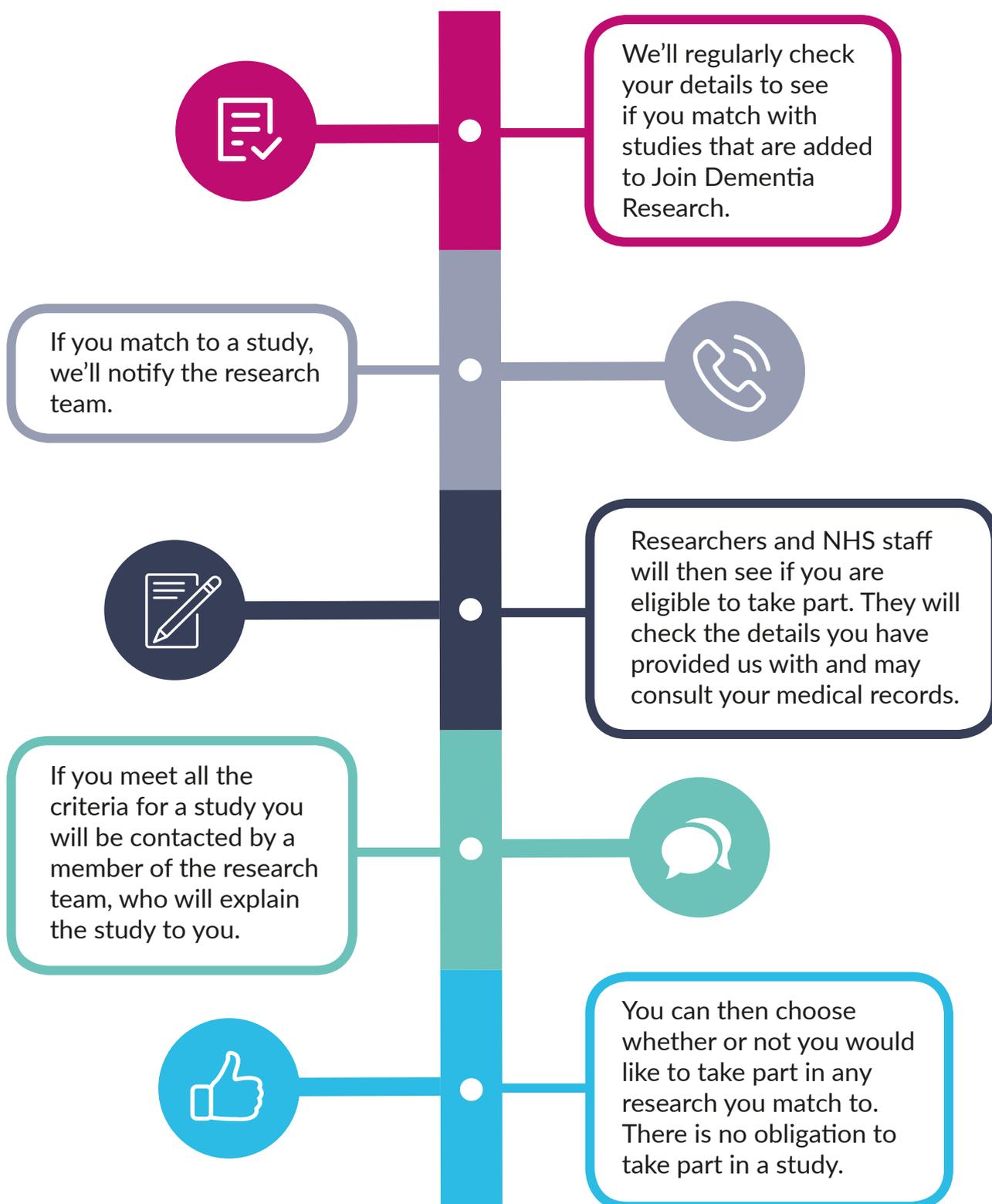
## Contents

What happens now?	3
What might a study involve?	4
How to manage your membership	5
Keeping your data safe	6
Any problems?	7
Contact us	8

## What happens now?

Now that you're registered with Join Dementia Research, researchers can find you and see that you're interested in taking part in studies.

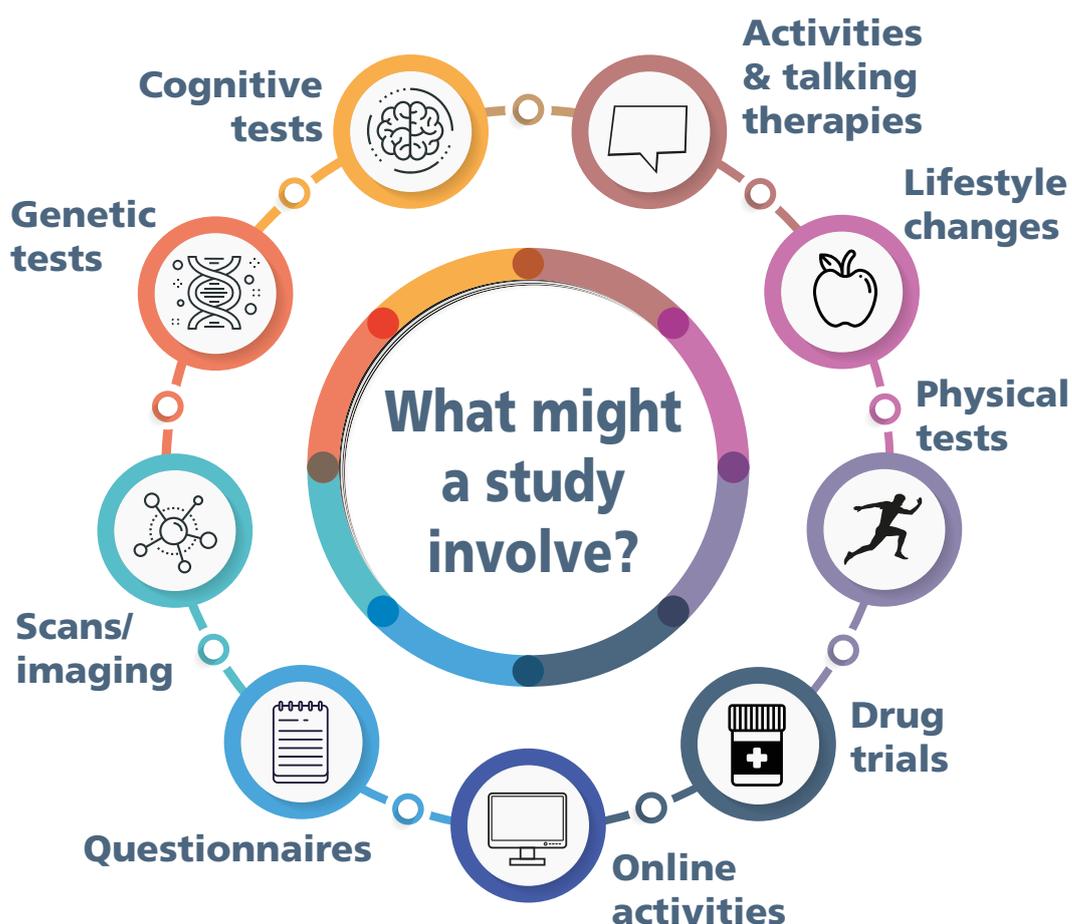
You can wait to see if you match to a study, or interact more with your account to improve your chances of matching.



# What might a study involve?

All studies on Join Dementia Research have been approved by a Research Ethics Committee. This means your rights, safety and wellbeing will always be protected if you get involved in research.

Studies cover a variety of different areas, from prevention and diagnosis to new treatments and improving the quality of life for people with dementia and their carers.



Please don't be disheartened if you don't match with any research at first. New studies are being added to Join Dementia Research all the time. When a suitable study does come along, researchers will be able to see that you have already registered your interest.

## Top tip

Improve your chances of matching to a study by keeping information such as your contact details and health information such as diagnosis and medication up to date at all times.



Login to your online account if you have one



Phone one of the charity helplines

# How to manage your membership

You can change any of your settings or information at any time.



If you have an online account, login and make changes yourself on your 'Volunteer Summary' page.



If you don't have an online account, phone one of the charity helplines, who can make any updates on your behalf.

Change whether researchers contact you by phone, letter or email.

1



2

Choose whether to receive email updates and newsletters.

Let us know about a change of address, contact details, health or medication.

3



4

Find out more about any studies you match to.

Set up alerts for future studies.

5



6

Express your interest in a study.

Indicate how far you're willing to travel.

7



## Keeping your data safe



All the personal information you have provided is managed in accordance with the Data Protection Act 2018. 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 by phoning one of the charity helplines or emailing [manager.jdr@nhr.ac.uk](mailto:manager.jdr@nhr.ac.uk).

Your personal information can only ever be seen by the people working to deliver the Join Dementia Research service.

- Join Dementia Research staff
- Approved researchers
- Some NHS staff
- Agencies working on behalf of Join Dementia Research
- Charity helplines

We never share your data with anyone who hasn't been through the relevant approval and training processes.

### Your Medical Records

The information you provide us is separate to your medical records, which are kept by your GP or hospital consultant. If researchers need information from your medical records to assess whether you are eligible for a study, they will only see information that is relevant to the study, and it is against the law for them to share this with anyone else.



For more detailed information about how we use your account information and keep it safe, please see the enclosed Volunteer Guide.

## Any problems?

**I have an online account and I've forgotten my password. What do I do?**

If you have an online account and you forget your password, click the 'Forgotten password/username?' link in the top right-hand corner of the homepage. You can then reset your password using your username and email address.

If you forget both your username and your password, please phone one of the charity helplines.

We hope that you'll enjoy being part of Join Dementia Research. However, if at any point you no longer wish to be registered, you or your loved ones can contact the charity helplines and we will remove you from the system.

Once you do this, researchers will not be able to search for you anymore. Please note that your data will be anonymised rather than deleted, unless you specifically request for it to be deleted.

**How can I remove myself from Join Dementia Research?**



If you have problems relating to your clinical care, please contact your doctor.



For problems relating to your taking part in a study, please contact the research team.



For any complaints or problems with Join Dementia Research, please email [manager.jdr@nih.ac.uk](mailto:manager.jdr@nih.ac.uk) or phone one of the charity helplines.

# Contact us



The charity helplines can help you manage your account, answer any questions, and liaise with the central Join Dementia Research team on your behalf.

## 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 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.

**[joindementiaresearch.nihr.ac.uk](http://joindementiaresearch.nihr.ac.uk)**

 [manager.jdr@nihr.ac.uk](mailto:manager.jdr@nihr.ac.uk)

 [@beatdementia](https://twitter.com/beatdementia)

 [joindementiaresearch](https://www.facebook.com/joindementiaresearch)