



# Improving lives through dementia research

An NHS service to support you and your patients



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



# THE CLOCK IS TICKING...

- 🕒 Every 3 minutes someone develops dementia in the UK
- 🕒 Over 850,000 people are currently living with the condition
- 🕒 And yet less than 6% have taken part in dementia research

We need your help to change this. It is only through research that we will find ways of developing effective treatments, improving care and hopefully one day beating dementia.

## What is Join Dementia Research?

Join Dementia Research is an online and telephone service that has been set up to support you and your patients. We are making it easier than ever before for people to participate in dementia research. The service promises to accelerate the pace of dementia research by allowing people with and without dementia to register their interest in studies, while also helping researchers find the right participants at the right time.

Anyone aged 18 or over can register and be matched to studies. This could be someone with dementia, a carer or family member signing up on their behalf, or anyone interested in dementia research.

A researcher will then be in touch when an appropriate study becomes available and volunteers can decide whether they would like to take part with no obligation. If they agree, the research team will take them, and/or their carer, through the full study consent process.

Join Dementia Research is a collaboration between the National Institute for Health Research (NIHR), Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society.

"I want to encourage people to sign-up to Join Dementia Research because dementia is likely to affect so many of us. We need to beat it and the only way to do this is to join dementia research and take part in those research programmes."

Debbie Vinsun, former nurse

"Taking part in good quality research is so important to find what really works to help the person with dementia and their carer. As a carer myself it's a comfort to know our experience is being used to improve care and treatment for others in the future."

Martin Cobley, carer for his mother with dementia

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



## Join Dementia Research can make a real difference

From our broad public consultation we know:

- Almost two thirds of people are interested in taking part in dementia research, yet less than one in five know how to find out about it. Our website guides them through a quick registration process which asks for basic demographic and health information about them or the person they're registering. Then they just need to wait for a researcher to get in touch. Charity helpdesks are also on hand to assist those who wish to register and update their account by phone.
- People's interest in different types of studies often depends on their situation, and changes over time. There are a broad range of research studies available - from clinical trials testing new medication, to attending support groups and completing surveys. Our service enables people to decide about participating in any particular study they match to on a case-by-case basis.

## People have a range of motivations for being involved, including:

- the opportunity to access new treatments
- helping future generations
- the chance to 'fight back' against their disease
- increased social inclusion, and feeling part of something valuable.

"I believe offering research opportunities is one of many positive things that we can suggest to people with dementia. Whilst it might not immediately benefit them, it can generate benefits for generations to come and many people find it a very positive experience."

Dr Jo Rodda,  
Consultant Old Age Psychiatrist

"Promoting Join Dementia Research is enabling me to meet people whose path I wouldn't have otherwise crossed, and I've met others with dementia and encouraged them to register. I also want to encourage health professionals to approach their patients to register as well."

Wendy Mitchell, diagnosed with  
young onset Alzheimer's disease

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# WE NEED YOUR HELP TO SPREAD THE WORD

We know you are at the heart of your local community, seeing patients every day. Join Dementia Research is a service you can confidently offer to patients and carers who you think will benefit from it – and the Health Research Authority has endorsed it.

Here are some hints and tips on how you can promote it to your patients:

- We have lots of materials like posters and leaflets that you can download or order for free at [tinyurl.com/joindementiaresearchmaterials](http://tinyurl.com/joindementiaresearchmaterials)
- Write to your patients and carers, giving them details on how to sign up
- Register for a Healthcare Professional's account and you'll be able to see which research studies are taking place in your area
- Hand out leaflets and application forms to anyone that's interested
- Look to include a section on your website about Join Dementia Research



## Got any questions or want to find out more?

We are always happy to help, so do get in touch if you need anything else.

- **Go online** – There is a section on our website with lots of useful information just for you. Visit [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk), click on 'For professionals' and then on 'Healthcare'.
- **Email us** – Get in touch through our website. Go to [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk) and click on 'Contact us'