

2. 'Join dementia research' Common FAQs

1. What is 'Join dementia research'?

'Join dementia research' (www.joindementiaresearch.nihr.ac.uk) is a new nationwide online and telephone service that allows people to register their interest in volunteering for dementia research studies.

2. What is the aim of the service?

'Join dementia research' promises to accelerate the pace of dementia research by allowing people with and without dementia to register their interest in studies and see what study opportunities are appropriate and available to them. This will help researchers using the service find the right participants at the right time.

3. Who is behind 'Join dementia research'?

'Join dementia research' is a collaboration between the National Institute for Health Research (NIHR), Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society, and has been funded by the Department of Health.

4. Who can sign up?

Anyone with or without dementia over the age of 18 years can register. One unique advantage of the service is that **you can sign up on behalf of someone else**, providing you are acting in their best interests. Anybody registered in the service can withdraw their information from the system at any time.

5. How can you register?

You can complete a form online at www.joindementiaresearch.nihr.ac.uk or call one of the supporting charity helplines: Alzheimer Scotland (0808 808 3000), Alzheimer's Research UK (0300 111 5 111) or Alzheimer's Society (0300 222 1122). Registration forms will also soon be available in memory services and other NHS services.

6. What was the main motivation for setting up the 'Join dementia research' service?

A recent national poll has shown that almost two thirds of the public (62%) would be willing to take part in dementia research, but more than four out of five (81%) wouldn't know how to volunteer. 'Join dementia research' is designed to overcome this barrier and give everyone the opportunity to play a

role in changing the outlook for people with dementia now and in the future. The greater the number of people who are willing to help with research, the more vital studies can get underway, helping us make progress faster to help people affected by dementia.

7. Why is dementia research so important now?

Dementia affects over 850,000 people in the UK, with 25 million of the UK population having a close friend or family member affected. Every 3.2 minutes someone in the UK develops dementia. There are numerous questions about the cause, diagnosis, treatments, and best care for which there are no clear answers yet. Our knowledge of dementia also currently lags behind that of other major diseases, such as cancer and heart disease. In order to improve the lives of people with dementia now and in the future, we need to find ways to improve the accuracy of diagnosis, to develop new preventions and treatments and to establish new care approaches. Research into dementia will help find these answers.

8. Why is this service going to be useful for improving dementia research?

This service makes it easy for researchers to find people who match their specific study requirements. As a result, it will help researchers plan their studies more effectively and deliver research more quickly and cost effectively. This will deliver improvements to people with dementia faster than ever before. It's also important for people with dementia and their friends and family to be given the opportunity to take part in research, if they choose to, and 'Join dementia research' will streamline this process.

9. What are the benefits to signing up?

'Join dementia research' provides a quick and easy way for people to **discover** dementia research opportunities, not only in their local area but also nationwide. It allows people to register their interest in taking part in research and **connect** with researchers, whose studies they may be particularly interested in taking part in. If people do decide to take part in a study, they will have the satisfaction that they have played a part in **helping to** improve dementia care and treatment for future generations.

10. Aren't there already enough people taking part in dementia research?

No. Unfortunately, the lack of access to willing volunteers can hold back critical research into the condition, with government figures showing that less than 5% of people with dementia take part in research studies. Scientists have the ideas to tackle dementia, but need people participating in research to help these ideas reach their potential. The government and charities have increased the amount of funding for dementia research, and as a result more people are needed to help participate in these new and essential studies.

11. I do not have a memory problem or dementia - can I still sign up?

Yes. We would encourage anyone who is interested to sign up. The service is primarily aimed at people with dementia, their carers and family members; however, there are a number of studies for healthy volunteers to participate in, or for those at risk.

12. Are there any studies for Alzheimer's disease?

Yes. The service welcomes people who have a diagnosis of dementia, including Alzheimer's disease, vascular dementia, Lewy body dementia, frontal dementia as well as other rarer types of dementia.

13. What's unique about the service? Is it a first-of-its kind in the country?

There is currently no single place to register your interest in studies across England, Scotland and Wales. While there are local registers, 'Join dementia research' will enable people anywhere in the nation to register their interest and to learn about studies, not only in their local area but also nationwide. This will greatly broaden access to studies, and offer people much greater choice over which research studies they want to participate in.

14. What type of information is needed to sign up?

For an initial registration, someone will need to provide basic personal and medical information about themselves or the person they are registering on behalf of. It only takes 10 minutes to sign up online. We also advise people to provide further additional information, which will make matching to a suitable study more accurate.

15. What happens after signing up?

By signing up to the service, people will be able to see studies that match to their profile. The researcher assigned to those studies will also be able to see their information. This might not always be detailed enough for more complex studies, so they may therefore undertake further checks from medical records to ensure that someone is eligible for their study, and that it is safe for that person to take part. The study's research team will then contact them, at which point they have the opportunity to ask as many questions as they like and decide if they would like to participate in those studies on a case-by-case basis.

16. If people sign up, does that mean they have to take part in research?

No. Being registered just gives someone the opportunity to see which studies match their health information and preferences. If someone is 'matched' to a study, they may be contacted by the research team if they are potentially suitable. They can then decide whether they wish to proceed or not. It's

always the volunteer's decision, and if they decide to take part in a study, they can also opt out at anytime.

17. Is it all drug studies on 'Join dementia research'? What kind of studies are on 'Join dementia research'?

The service supports a whole range of different types of research, including clinical drug trials. Current research taking place includes surveys about what works in improving quality of life for people with dementia and their carers, and exploring potential preventative strategies. A lot of research is carried out in the NHS, but some takes place in universities and research institutes, in social care services or in the private sector.

18. How many studies are on the service?

There are currently 29 studies on the service, but more are being added every week.

19. What does taking part in a study involve?

Each study is different, from the length of the study, to whether the study involves blood tests, scans etc. Some studies may require you to attend your local hospital, while for others you could take part at home. There are also many different methods for carrying out research. Studies might involve in-depth interviews, focus groups or questionnaires. Other studies might include interviews, or collecting information such as blood pressure, weight, etc.

20. The service has been trialled in certain parts of the country for a few months. What has it achieved so far?

Four NHS Trusts have piloted the service including University College London Hospital (UCLH), Barnet, Enfield and Haringey Mental Health Trust (BEH), North East London Foundation Trust (NELFT) and East London Foundation Trust (ELFT). Over 1,700 people have signed up (Date: February 3rd) to the service so far, and around 200 people are already taking part in research studies through it.

20. How can I help promote the service?

Everyone can help promote the service by spreading the word! If you are interested in helping us promoting the service, please follow us at [@beatdementia](https://twitter.com/beatdementia) and/or check our facebook page [/joindementiaresearch](https://www.facebook.com/joindementiaresearch). Healthcare professionals can order promotional materials for free; please contact us at comms.jdr@nihr.ac.uk for more information.