



Alzheimer's
Research
UK

Getting involved in dementia research



Patient Information Forum

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Introduction

This booklet gives information about what might be involved if you decide to take part in a dementia research study, and how you can volunteer. We hope this background information is helpful.

The information here does not replace advice that doctors, pharmacists, or nurses may give you. If you are worried about your health, including memory and thinking problems, you should speak with your doctor as soon as possible.

The booklet was updated in November 2021 and is due to be reviewed in November 2023. It was written by the Alzheimer's Research UK's Information Services team with input from lay and expert reviewers. Please get in touch using the contact details below if you'd like a version with references or in a different format.

If you have questions about dementia or dementia research you can contact

Dementia Research Infoline call **0300 111 5111**
email infoline@alzheimersresearchuk.org

Or write to us using the address on the back page.

The importance of volunteers for research

Dementia affects almost 1 million in the UK. It is the only condition in the top 10 causes of death without a treatment to prevent or cure the diseases that cause it. Research offers hope of future treatments and cures.

Thanks to scientific research we understand more about the brain, and the diseases that affect it, than ever before. Scientists have only been able to make this progress because of the thousands of people who volunteer to take part in dementia research studies.

We'll continue to make faster progress if more people get involved and take part.



“Research volunteers play an essential role in finding new treatments and increasing our understanding about the diseases that cause dementia. Without people taking part in research, it will be impossible to make breakthroughs happen.”

Dr Susan Kohlhaas
Director of Research, Alzheimer's Research UK

Who can get involved in dementia research?

- People with a diagnosis of dementia have an important role to play in research studies.
- People without a diagnosis of dementia can help to make up control or comparison groups in some studies, and help scientists look at what affects our risk of developing dementia over time.
- Carers of people with dementia are also needed for studies to give their opinions and insight. They can share their experience of accessing care or support, or looking after someone with dementia, and this can help shape services and inform new policies.
- People with a family history of dementia.
- Some dementia studies may focus on those over 55, but we'd encourage anyone over 18 to consider taking part in research.

Why get involved in dementia research?

People choose to take part in dementia research for a number of reasons:

- Studies can provide volunteers with an opportunity to learn more about dementia and health.
- People often feel research is something positive they can do in the face of living with a progressive condition.
- Volunteers may feel more supported as part of a research study community.
- Outcomes help advance scientific understanding, improving prevention, diagnosis and treatment options for future generations.

What types of research could I take part in?



Laboratory research

Some studies ask volunteers to give blood or skin samples, or ask for brain donation after someone has died. These samples help scientists to understand the processes that cause diseases like Alzheimer's. Taking part in these studies helps to develop new ways to diagnose and treat dementia.



Observational studies

These studies track people over time, using questionnaires, memory and thinking tests and monitoring volunteer's health, to see how lifestyle factors may affect our risk of dementia. These factors may include exercise, diet, alcohol consumption and smoking, to see how these might influence memory and thinking.

By asking volunteers to have brain scans and blood tests over time researchers can look for early 'markers' of the diseases that cause dementia. This research leads to faster and more accurate ways to diagnose dementia in the future, and helps identify ways we can reduce our risk.

The best way to find out which studies you can take part in is sign up to
Join Dementia Research

(see page17)

"After signing up to Join Dementia Research, I was selected to take part in a study looking at brain connections. I had an MRI scan, so the researchers could take several short scans of my brain. It's satisfying to know that I am, in a small way, contributing to the progress of vital dementia research."

Jude Clarke
Research volunteer



Care research

Some studies help to develop and evaluate dementia care, using questionnaires or interviews. This research aims to provide people with dementia with the best possible support and helps shape future care policies. This kind of study often involves people with dementia, their families, friends or carers.

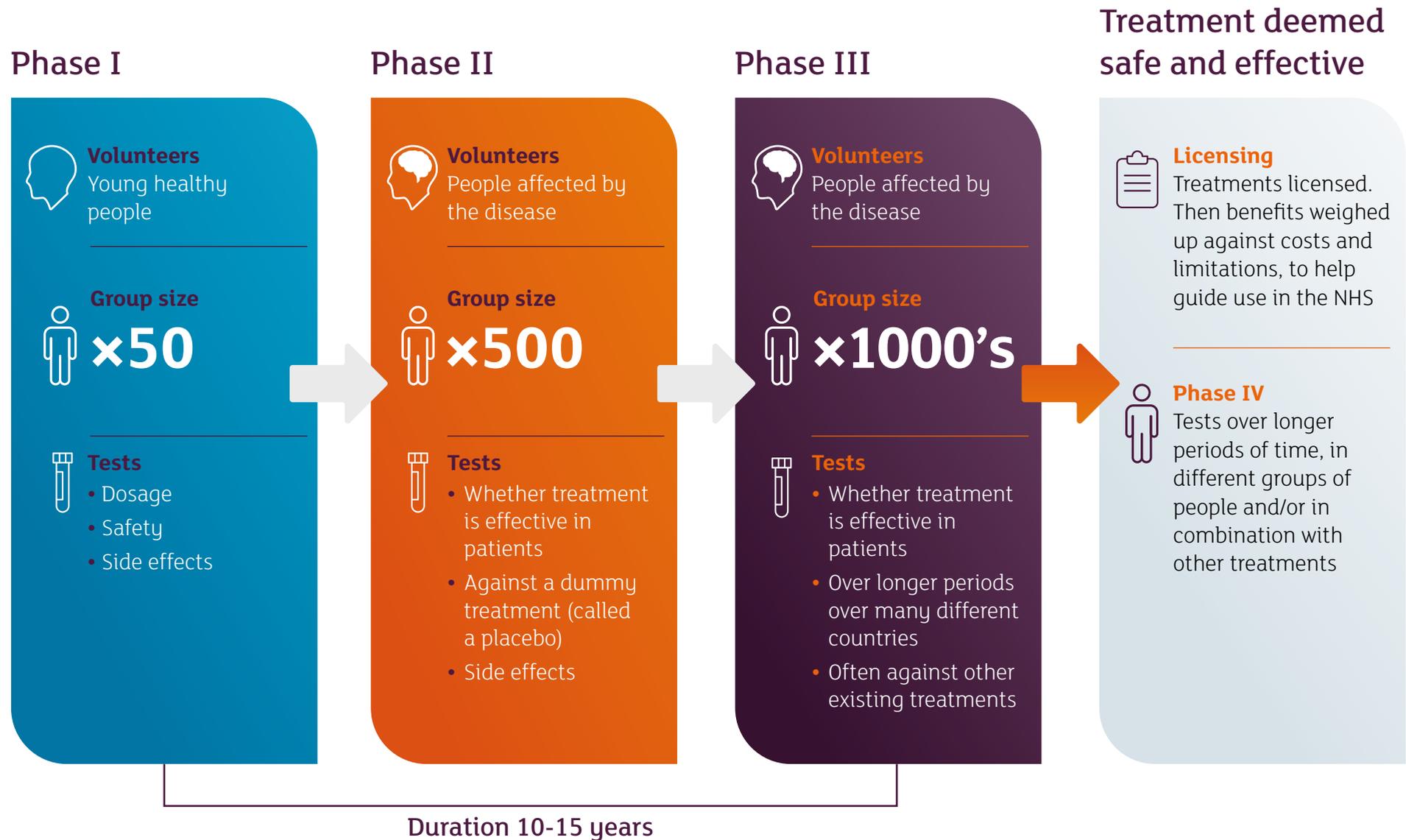


Clinical trials

A clinical trial is designed to test the benefits and safety of a treatment or therapy. This could be a new medicine or a non-drug approach like a medical device, talking therapy or exercise programme.

A range of potential new treatments for diseases like Alzheimer's and other types of dementia are now in late-stage clinical trials. Volunteers taking part in these trials will help researchers find out which new treatments will work and how they benefit people with dementia.

There are three main phases of clinical trials



If I take part in a trial will I receive the new treatment being tested?

So that scientists can test the effect of a new treatment, volunteers in clinical trials are often split into groups:

- **The experimental group** will receive the treatment being tested and have the disease that is being studied.
- **The control group** will receive a placebo (dummy treatment), or receive normal care rather than take part in an intervention.

A placebo looks identical to the treatment being researched but does not contain the active drug. This ensures that any benefit the treatment has is due to the action of the medicine, rather than the volunteers believing they are receiving an effective treatment (the so-called placebo effect). Sometimes, the effect of a new treatment may be compared to that of an existing treatment.

How are the groups decided?

In most studies, volunteers are randomly assigned to the control or experimental groups. Randomisation is important so that the groups are as similar as possible and any differences in the results are due to the treatment, not the way volunteers were chosen.



“My dad got involved with research when he had mild Alzheimer’s disease as he wanted to help future generations. We are glad we took part in research; it gave my dad a real sense of purpose at a time when he was coming to terms with his diagnosis at the relatively early age of 64.”

Hannah Willson

Alzheimer’s Research UK fundraiser who supported her father when he took part in research



Will I know which group I am in?

In clinical drug trials, it is important that volunteers don’t know whether they are receiving the treatment or the placebo. This is known as ‘blinding’. Researchers also shouldn’t know which volunteers are in the treatment and placebo groups, so they don’t treat them any differently. This is known as ‘double blinding’.

Before a new treatment can be approved for use in people, researchers must show a beneficial effect in a number of independent clinical trials. These are often run at the same time across lots of different countries.

What tests are used in research?

Volunteers in clinical trials are closely monitored before, during and after taking part in the study. By monitoring changes in health, such as brain function and symptoms over time, researchers can tell if the treatment is having an effect.

There are various ways researchers will monitor volunteers, and it is likely that they'll repeat a combination of tests during the trial. Volunteers in both the experimental and control groups will undergo these tests so that researchers can compare results to see if the treatment is effective.



Cognitive tests

In dementia research these tests are used to measure a person's ability to remember and process information. By repeating these tests over time, researchers can see whether a treatment is helping to slow down memory loss and improve brain function. Some tests also look at how well people can manage activities like eating and getting dressed to see what benefit a treatment may have on their day-to-day life.

"Taking part in research was very straightforward. Usually both my wife Trina and I were involved. Trina having had a posterior cortical atrophy (PCA) diagnosis and me taking part in the control group. It was always interesting to talk to the researchers and it certainly improves our overall understanding of PCA."



Graeme & Trina Armstrong
Research volunteers & Alzheimer's Research UK Champions
(Image Ben Quinton)



Brain scans

Brain scans allow researchers to look at physical changes in the brain caused by the diseases that cause dementia. An MRI or CT scan shows structural changes to the brain, and an EEG (brain wave test) is used to look at brain activity. Specialist scans called PET scans allow researchers to look at the build-up of proteins, like amyloid and tau, which happens in the brain in Alzheimer's disease. Volunteers taking part in a clinical trial will have regular brain scans to see if the treatment is stopping or slowing down the disease processes causing damage to the brain.



Biomarkers

Blood tests, or a procedure called a lumbar puncture, allow researchers to study markers in our blood and spinal fluid. The markers show signs of both normal or abnormal disease processes. By measuring these markers, researchers can see if a treatment is effective or not. Lumbar punctures are a standard medical procedure used for a wide range of medical purposes, and side-effects are uncommon.

Is taking part in research safe?

There are some key features of medical research that ensure the safety of volunteers and the reliability of findings. Some apply to all kinds of studies; others only apply to clinical trials.

Ethics approval

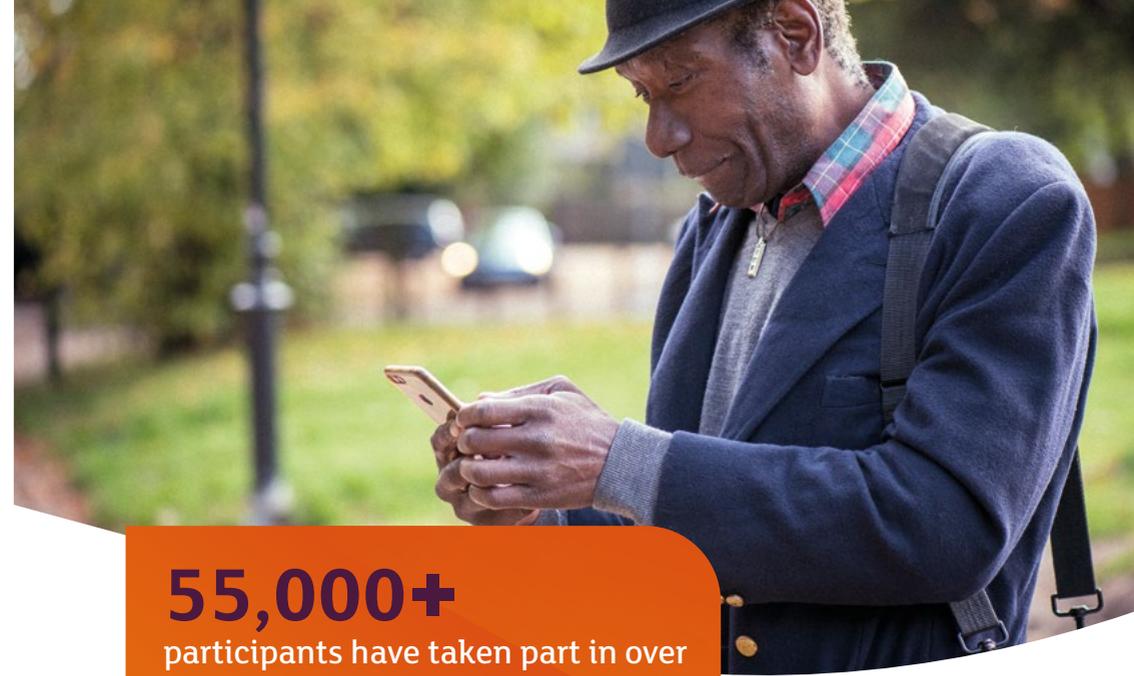
Before a study involving volunteers can start, researchers must submit a study plan to an ethics committee made up of independent scientific experts, as well as members of the public. The job of the ethics committee is to safeguard the rights, safety, dignity and wellbeing of research volunteers. A study cannot be conducted without ethical approval.

What is informed consent?

Before you agree to take part in any study, research staff must describe it to you in detail. They will tell you about the possible benefits and risks and explain your rights as a research participant. They must also answer any questions you have.

If you are happy to go ahead, you will be asked to sign a consent form stating that you understand what is involved in the study and you agree to take part. You can change your mind even after signing the form. If you do change your mind you are free to withdraw at any time without giving a reason, and without this affecting your medical care.

Every study is different. Choosing not to take part in one study doesn't prevent you from taking part in others. You decide which studies you are happy to take part in on a case-by-case basis.



55,000+
participants have taken part in over
550 studies
through Join Dementia Research

What happens if someone cannot consent?

People with dementia may not always be able to provide informed consent; this is known as 'lacking capacity'. There are strict rules about the recruitment of people to research when they are unable to make informed decisions.

Researchers may only recruit people without capacity if it is not possible to carry out the research with those who are able to consent. In these cases, a close relative or someone holding Lasting Power of Attorney on health and welfare grounds can give consent of their behalf if they believe that taking part in the study is in the person's best interest. They must be sure that the person would not refuse if they did have capacity to decide for themselves. If a volunteer who can't provide informed consent shows signs of distress or reluctance they will be withdrawn from a study.

How to get involved

Join Dementia Research is not a research study itself. It is a UK-wide service that allows you to register your interest in taking part in dementia research, matching you to studies looking for volunteers.

Signing up is easy and is the best way to find out what studies you can take part in. You just need to provide some information about yourself and your health. It is also possible to sign up for someone else if that person has expressed a wish to take part in research and consents to signing up.

Once registered you can take part in online research into dementia risk and dementia care, by doing questionnaires and memory tests via the Join Dementia Research website. If you match to a face-to-face study, a researcher may contact you to explain what is involved and ask if you'd be interested in taking part.

You have time to think about whether you would like to take part in each study before you decide; you do not have to take part in every study you are matched to. More studies are added to Join Dementia Research all the time so there are plenty of opportunities to take part across the UK. You can also withdraw from Join Dementia Research at any time.



Find out more and sign up:

Visit www.joindementiaresearch.nihr.ac.uk

Or scan the QR code here

Register over the phone, call the

Dementia Research Infoline on **0300 111 5 111**



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

There are other opportunities to take part in dementia research and research into other conditions through Be Part of Research. You can explore the opportunities available on their website at www.bepartofresearch.nihr.ac.uk



Patient and public involvement

Taking part in a research study is not the only way that people can contribute to dementia research. It is important that dementia researchers work with the public when planning their study, particularly people who have been affected by dementia, so that their work is as relevant as possible.

Alzheimer's Research UK uses Lay Research Volunteers to review grant applications from scientists who apply for charity funding. The process involves reading a selection of application summaries and completing a short review form. We ask Lay Research Volunteers to comment on whether studies are worthwhile and are addressing issues that are important for people affected and their families.

For more information about Alzheimer's Research UK's volunteer opportunities email volunteer@alzheimersresearchuk.org

Still have questions?

If you have questions about dementia or dementia research, or want to find out more about how you can get involved in studies, contact the **Dementia Research Infoline** on **0300 111 5 111** or email infoline@alzheimersresearchuk.org

The Infoline operates 9.00-5.00pm Monday to Friday. Calls cost no more than national rate calls to 01 or 02 numbers and should be included in any free call packages.

Interpreter services are available.



Research

Alzheimer's Research UK has **funded over £151 million** of research projects into dementia and the diseases that cause it.

Through the research we fund, our scientists are building a detailed picture of what happens in the brain in these diseases. This is essential for improving diagnosis and developing new treatments. Backed by our passionate supporters, and with the help of volunteers involved in research studies, we continue to support scientists who are taking us one step closer to a life-changing treatment.

Alzheimer's Research UK is the UK's leading dementia research charity dedicated to making life-changing breakthroughs in diagnosis, prevention, treatment and cure.

We provide free dementia health information, like this booklet and others. If you would like to view, download or order any of our other booklets please details below.

Contact us

0300 111 5111

infoline@alzheimersresearchuk.org

Alzheimer's Research UK
3 Riverside, Granta Park, Cambridge CB21 6AD

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**Alzheimer's
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Make
breakthroughs
possible



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