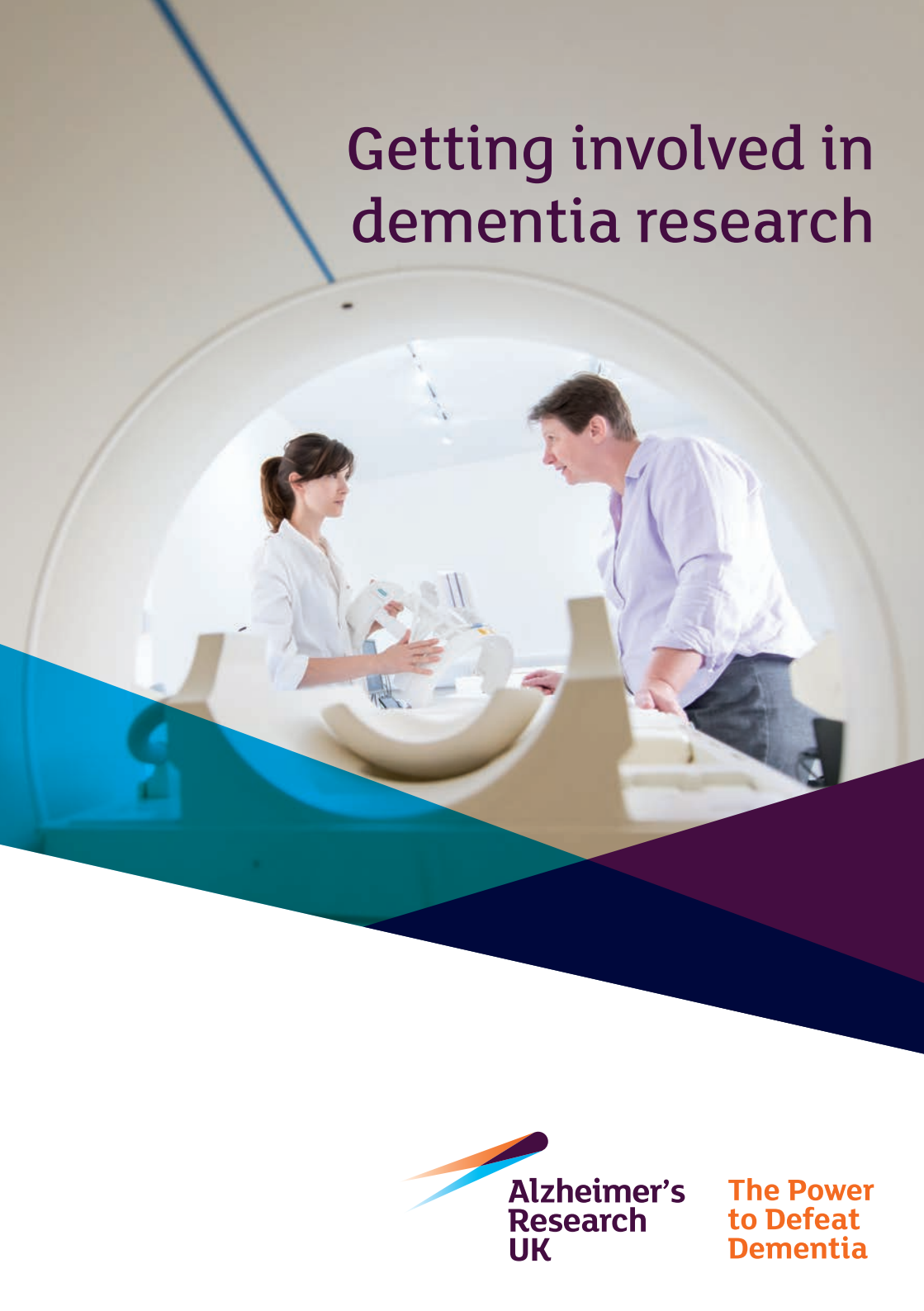


# Getting involved in dementia research



**Alzheimer's  
Research  
UK**

**The Power  
to Defeat  
Dementia**



## Introduction

This booklet aims to tell you more about what dementia research involves and how you can take part. Please contact us if you would like a version in a different format.

## Contents

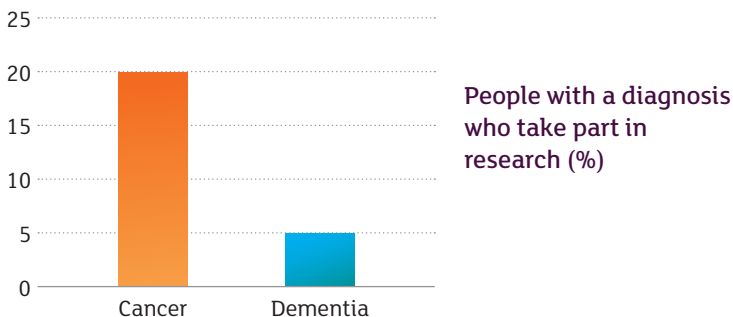
|  |    |                                |    |
|--|----|--------------------------------|----|
| The importance of volunteers for research  | 03 | Safety and reliability         | 10 |
| Who can get involved in research?          | 04 | Patient benefit and outcomes   | 14 |
| Why get involved in research?              | 05 | Get signed up                  | 15 |
| What types of research can I take part in? | 06 | Patient and public involvement | 16 |
| Clinical trials                            | 08 | Join Dementia Research         | 19 |

## The importance of volunteers for research

Dementia affects 850,000 people in the UK. There is currently no cure for dementia, and there is no sure-fire way of preventing it.

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 thanks to the thousands of people who have volunteered to take part in dementia research studies. They will only be able to make further progress if more people agree to take part.

Certain questions in dementia research can be addressed using tissue samples in laboratories, research using animals or even computer simulations. However, there are questions for which there can be no substitute for research involving people.





## Who can get involved in research?



People with a diagnosis of dementia have an important role to play in research studies.

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Healthy volunteers are frequently required to make up control or comparison groups in studies, or to complete surveys about dementia.

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Some dementia studies may focus on those over 65, but we'd encourage anyone over 18 to consider taking part in dementia research.

## Why get involved in research?

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

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**Studies can provide an opportunity to learn more about dementia and health.**

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**People with dementia may feel research is something proactive they can do in the face of a progressive condition.**

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**Studies often involve regular monitoring by doctors or dementia specialists and people can feel part of a community with other volunteers.**

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**Research will lead to outcomes that could benefit the people taking part or future generations.**

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While some people may have reservations about taking part in research or it may be impractical for them, we want to make sure that everyone has the opportunity to get involved if they wish.



**“There are never enough people involved in dementia research: we desperately need more volunteers to help take on what is the greatest medical challenge of the 21st century.”**

Prof Martin Rossor  
NIHR National Director for Dementia Research

## What types of research can I take part in?

There are lots of different kinds of research studies looking for participants. These may include:



### Laboratory research

Some studies could benefit from donated blood or skin samples. These studies help scientists understand what happens in our brains as they age, as well as the biological processes driving diseases like Alzheimer's. They are key to developing new diagnostic tools as well as targets for future treatments.



### Observational studies

Observational studies can track people over time to see which factors might contribute to a person's risk of dementia. Researchers can record aspects of people's lifestyles such as how much exercise they do, what they eat and whether they smoke, and see how this might influence their memory and thinking.

Researchers can also monitor brain scans and blood tests over time to search for early biological 'markers' of the diseases that cause dementia. This research could help to improve the accuracy and timeliness of diagnosis in the future.



### Care research

Some dementia research studies develop and evaluate care approaches to provide people with dementia with the best support possible. This kind of research could involve people with dementia, their families, friends or carers. Volunteers might be asked to answer questionnaires about quality of life and the care they have provided or received.



### Clinical trials

A clinical trial is a research study designed to test the benefits and drawbacks of an intervention. This could be a new medicine or a non-drug intervention like a surgical procedure, talking therapy or exercise programme.

After many years of hard work in the laboratory, new dementia treatments are beginning to enter clinical trials in people. Through these clinical trials, we can find out which, if any, of these treatments will work.

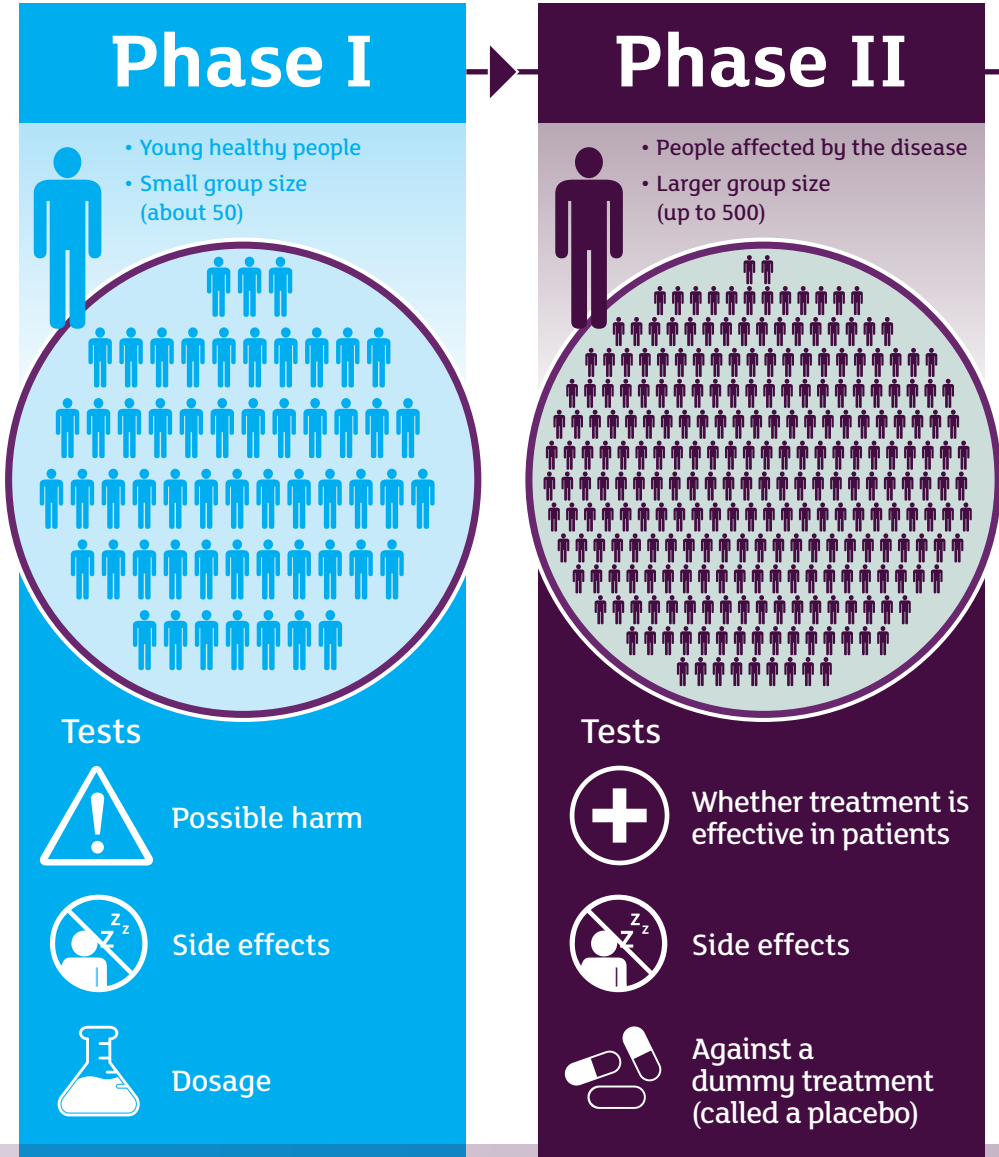


**“I used to think only people with dementia could volunteer to take part in dementia research studies. I signed up for research as a healthy volunteer and now I feel like I’m doing my part to tackle this devastating condition.”**

Susie Hewer  
Research volunteer

## Clinical trials

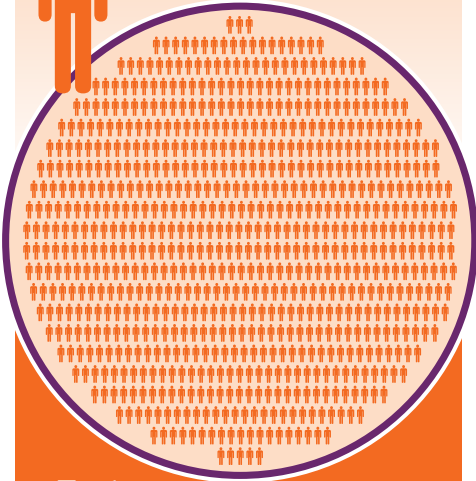
There are three main phases of clinical trials:





# Phase III

- People affected by the disease
- Larger group size (up to thousands)



## Tests



Whether treatment is effective in patients



Over longer periods over many different countries



Often against other possible existing treatments

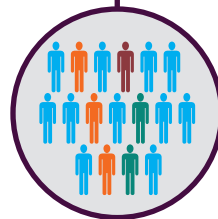


Treatment deemed safe / effective



## Licensing

Treatment licensed, and benefits weighed up by NICE against costs and limitations to help guide use in the NHS



## Phase IV

Tests over longer periods of time, in different groups of people and/ or in combination with other treatments

Ten to fifteen years later

### Safety and reliability

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

#### Ethics committee

A plan of what scientists will do must be approved by an ethics committee made up of independent scientific experts, as well as members of the public. The committee's job is to safeguard the rights, safety, dignity and wellbeing of research participants. If a research proposal is rejected, the study cannot go ahead.



### Informed consent

Some dementia studies may involve a small element of risk. Before you agree to take part, staff members must describe the study in detail, tell you about the possible benefits and risks, and explain your rights as a 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. Signing this document doesn't oblige you to go through with it and you are free to withdraw at any time without giving a reason.

### Capacity

People with dementia may not always be able to provide informed consent. There are strict rules that govern the recruitment of people to research when they lack capacity to give informed consent.

Researchers are only able to recruit people without capacity if it is not possible to carry out the research in people who are able to consent. In these cases a close relative or someone holding lasting power of attorney could provide consent on their behalf. If a participant who hasn't been able to provide informed consent shows signs of distress or resistance they will be withdrawn from the study.

### Control group

So that scientists can evaluate the effect of a treatment or study the impact of a disease, participants are often split into groups:



**The experimental group** will receive the treatment being tested or have the disease that is being studied.



**The control group** will receive a dummy treatment, or be made up of people who don't have dementia.

A dummy treatment, or placebo, looks identical to the treatment being researched but has no effect on the body. This is to ensure that any benefit the treatment has is due to the action of the medicine, rather than the participants believing they are receiving an effective treatment (the so-called placebo effect). When an existing treatment is available, the effect of a new treatment may be compared to that of the existing treatment.



### Randomisation

In some studies, participants are randomly assigned to the control group or treatment group. Randomisation is important so that the groups are as similar as possible and any observed differences are due to the treatment, not the way the participants were chosen.

### Blinding

In clinical trials, it is often important that volunteers don't know whether they are receiving the treatment or the placebo; this is known as blinding. It is also important that the researchers don't know which participants are in each group so they don't treat them any differently. This is known as double blinding.

### Replication

Before a new treatment can be considered for clinical use, researchers must repeat their findings in multiple independent studies. It is not sufficient to demonstrate an effect once; it needs to be shown to work over and over again.



**“Dementia research requires huge financial investment but, just as importantly, it needs the involvement of volunteers to work with researchers and drive promising science towards real benefit for people with dementia.”**

Dr Simon Ridley  
Director of Research, Alzheimer's Research UK

### Patient benefit and outcomes

Any medicine must show benefits in people with dementia before it's approved to treat the condition. Showing an effect on memory and thinking in the general population would not be enough. Some studies look at whether a new treatment could alter some key features of diseases like Alzheimer's, but it would not be approved unless it had also shown a real benefit for people with the condition.





## Get signed up

If you have questions about dementia research or want to find out more about how to get involved, contact our **Dementia Research Infoline** on **0300 111 5 111** or email **[infoline@alzheimersresearchuk.org](mailto: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.



**“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 Coombs

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



### Patient and public involvement

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

Alzheimer's Research UK would like to recruit Lay Research Volunteers to review grant applications from scientists planning studies involving people. The process involves reading a selection of application summaries and completing a short review form. We ask you to comment on whether studies are practical for people with dementia and are addressing issues that are important for people affected and their families.

For more information about how to become an Alzheimer's Research UK Lay Review Volunteer email

**[LRV@alzheimersresearchuk.org](mailto:LRV@alzheimersresearchuk.org)**







## Send me more information

For free information, simply complete this slip. You can drop it straight in a post box or put it in an envelope labelled with the freepost address overleaf. Alternatively, phone us on **0300 111 5555**.

### I would like to know more about

Dementia: symptoms, diagnosis, causes, prevention and care ☐

Treatments for dementia ☐

The latest dementia research ☐

Name

Address

We'd really like to keep you updated with the latest research developments, how your support is making a difference, and fundraising activities that you can get involved in. Your details are always held securely, but if you'd rather not hear from us please tick the relevant box:

No information by post ☐ No information by phone ☐

If you're happy for us to contact you by email, please enter your email address here:

If you're happy for us to contact you by SMS, please enter your mobile number here:



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Dementia**

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Freeport Plus RTSJ-ZCSB-RGCK  
Alzheimer's Research UK  
The Boulevard  
Orbital Park  
Ashford  
TN24 0GA



## Join Dementia Research

Join Dementia Research is a national service that allows you to register your interest in taking part in dementia research studies. It is delivered by the National Institute for Health Research in partnership with Alzheimer's Research UK, Alzheimer Scotland and Alzheimer's Society.

To sign up to Join Dementia Research you will need to provide information about yourself and your health. If you match to a study, researchers may contact you to see if you'd be interested in taking part. You can decide on a case-by-case basis, but whatever you decide, your details will stay in the system and you may be matched to new studies in the future. You can withdraw from Join Dementia Research at any time.

To find out more, visit **[www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)** or call the **Dementia Research Infoline** on **0300 111 5 111**.



# We are the UK's leading research charity aiming to defeat dementia.

We welcome your comments to help us produce the best information for you. You can let us know what you think about this booklet by contacting us using the details below.



## Contact us

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



## Supporter care

T: 0300 111 5555  
E: [enquiries@alzheimersresearchuk.org](mailto:enquiries@alzheimersresearchuk.org)



## Dementia Research Infoline

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[www.alzheimersresearchuk.org](http://www.alzheimersresearchuk.org)



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