

Draft content developed for Our Health

Generic research information – located under '[Living well with dementia](#)' tab

Page headers:

- What is research:
 - Understanding research
 - Types of research
 - Inclusion criteria
 - Benefits
- Benefits of getting involved in research [*expanded on above*]
- Register your interest
- National initiatives
- Frequently asked questions



What Is Research

The aim of research is to find better ways of looking after people, finding new treatments, keeping them healthy and improving their quality of life and new research cannot lead to reliable findings unless the right people join in.

As a patient, carer, family member or as a member of the public you can help research. You can participate in a study, you can give your views or you can actively get involved in shaping future research.

Every member of the public diagnosed with a dementia or Neurodegenerative Disease should have the opportunity to participate in research. These pages provides simple information for patients, family members and carers. Patients, carers, family members and the public can support research :

- As participants voluntarily taking part in research studies.
- As a member of the public working with research professionals and clinicians to help shape research and influence the research agenda.

Understanding research

There are many questions about health, illness, the approaches of care and the effects of treatment for which there are no clear answers.

Research helps:

- improve the quality of life for people living with a long-term illness
- diagnose diseases or other problems
- prevent diseases or at least reduce the number of people who get them
- cure illness, or reduce the burden of illness for individuals and families
- identify gaps in knowledge related to specific treatments or conditions
- collect people's views on how care should be provided and prioritise that research
- improve the quality of care and service provided to them; identify problems related to the treatment or service they are offered
- support family carers.

Research is important to try to understand which treatment or care method works best and when, and many people voluntarily take part in research studies. Reasons are personal; however the most common is the wish to contribute to improving services for themselves and / or those who come after them.

Types of research

In general there are three different types of research; at the centre of all studies should be an ethos of respect, dignity and confidentiality.



Qualitative & quantitative studies

In simple terms there are two approaches to carrying out research; 'qualitative research' which uses in-depth interviews, focus groups or questionnaires to collect, analyse and interpret data on what people do and say, and 'quantitative research' which uses statistical methods to count and measure outcomes from a study. They often get used together in large studies.

Observational studies

Observational studies are a different form of research. In observational studies researchers investigate what happens to groups of people. They may also include interviews with Care home residents, their families or staff members (with their consent, of course), or the collection of information like blood pressure, weight, severity of illness, medicines taken.

Trials/intervention studies

There are different types of research to get involved in. 'Trials' can test a drug's effectiveness in treating a disease, or whether certain therapies or activities are safe to use. These trials are sometimes called 'intervention studies'. This research aims to test how beneficial treatments or therapies might be for people.

- Treatments are tested on participants in strictly controlled ways to ensure safety and clear results.
- Most studies need many participants because they aim to find out what treatments are likely to be most helpful for the largest number of people.

Study phases

- **Phase 1 studies** are very small early research; they only involve a tiny number of people who try out a new drug, or a new approach to improving quality of life, such as a type of medical equipment or a "model of care". Any new drug is tested on people only if extensive laboratory work shows promising results, and the participants are monitored extremely closely for side effects.
- **Phase 2 studies** come next, if Phase 1 results are good. They're bigger, aiming to confirm whether a promising new drug or model of care actually helps, without causing unexpected events or adverse side effects. New treatments or models of care tend to be compared against the best currently available.
- **Phase 3 studies** follow next, and are much larger still. They could even involve thousands of patients over many years. This research looks at the effects of a drug or model of care over time, to assess just how beneficial the outcomes are. Phase 3 studies are also used to work out the best dose of a drug, or best method of using a new model of care. Patients are sometimes divided randomly into groups to detect small differences between the overall effects over time.

Criteria for being included in a research study

Research studies recruit many people as participants, but they have to fit the eligibility criteria in the research design of the study.

These criteria may concern the type of disease, history, age, gender, ethnicity, and so on, may need to be very specific and can sometimes be quite narrow. This is necessary because clinical research measures changes that are very precise and have to be carefully



controlled so that the research results are as clear and informative as possible. So even though you may be interested in taking part in a study, if your details do not fit these narrow criteria you would not be eligible to take part. For example, a study may be seeking men or may be seeking people who have never been smokers.

It is important to note that anyone choosing to join a study can withdraw at any time.

The '[Understanding Clinical Trials](#)' leaflet provides more information on eligibility criteria. [*add this to Leaflets section*]

More information

If you would like more information about taking part in research in a study take a look at the NIHR leaflets, 'Understanding Clinical Trials' and 'Clinical Trials: What they are and what they are not' which you can download from 'publications' in the right hand link. Information on joining all types of research can be found at [NHS Choices](#). [*Check this link is also on the Other Useful Sites section*]

Getting involved in research

There is a range of activities that patients, families, carers and members of the public are able to get involved in, with opportunity to choose what interests them.

You have the option of joining a particular study or helping to support research to ensure;

- research is done **with** members of the public, not to, about or for them, and;
- that clinical research is relevant, useful and to the benefit of the public.

Getting involved in research can include helping:

- Identify research that is important and relevant.
- Develop resident information leaflets.
- Support a research project or advisory group as a member.
- Develop accessible information and research news.
- Support and promote good research
- Inviting researchers to speak to groups.
- Including research findings in newsletters or other material.

Getting actively involved can lead to:

- More relevant research questions being asked, resulting in more useful research.
- More sensitive approaches to people who take part in studies as 'participants'.
- Helping to keep the research on track.
- Greater opportunities to share research news.
- Research done with members of the public, not to, about or for them;
- Getting involved in the research process or activity itself;
- Making sure that clinical research is relevant, useful and to the benefit of the public.



Benefits

Patients, families, carers and members of the public may benefit from being actively involved:

- By having a say in research and through sharing their experiences.
- By getting research that is important to them, and learning more about research.
- Through meeting new people – researchers, members of the public and other people from different networks.
- By gaining confidence and new skills.
- By having the chance to make a contribution.

Click here for more information on how research can benefit you [*add hyperlink to Benefits of getting involved in research' text*]



How research can benefit you

There are many benefits of participating in research. As a patient or carer you may want to participate to play a more active role in your care and treatment options, gain access to new research treatments before they are widely available, or help others by contributing to the future prevention and cure of dementia and neurodegenerative diseases.

Benefits of participating in a research study:

- you may be given a new treatment that is better for your condition
- your treatment and progress may be monitored more closely than if you were receiving the usual treatment. Of course after the trial has finished, your clinician will be better able to offer you the most appropriate and effective treatment for you
- you will obtain information and evidence that may be helpful to you in the future, as well as helping the NHS to give people the best possible standard of care

Risks of participating in a research study:

- as with any treatment, you cannot be sure of the outcome
- you may be given a new treatment that is not as effective as the standard treatment
- it is possible that you will experience unexpected side effects
- you may have to visit your place of treatment more often, or have more tests, treatments or monitoring than you would if you were receiving the standard treatment in usual care



Register your Interest

If you are interested in becoming a participant in research:

- You could ask your doctor to consider any studies that you may be eligible for;
- Search the [NHS database](#) [add hyperlink to Other Useful Sites];
- Make contact with your local [Dementia and Neurodegenerative Diseases Research Network \(DeNDRoN\) Office](#). If ... DeNDRoN will be able to talk to the Care home about how it could become a part of the 'Enabling Research In Care Homes' pilots currently happening in various places across England.

To find out more about getting involved visit the [DeNDRoN PPI homepage](#) and choose a relevant contact or click here [<http://www.dendron.nihr.ac.uk/patients-and-carers/get-involved/participate-in-a-study>]to ... [Add link]

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National initiatives

The Prime Minister in March 2012 firmly set the challenge on dementia [*retain link*] with the ambition to collaborate and drive forward major improvements in dementia care, deliver more research for patients and create dementia friendly and research minded communities by 2015.

Through the launch of the National Dementia Strategy and the work of the Ministerial Advisory Group on Dementia Research, the Department of Health (DH) hopes to deliver on this agenda across the NHS.

For further information, click here [*add hyperlink <http://www.dendron.nihr.ac.uk/patients-and-carers/national-initiatives/> to DeNDRoN national initiatives pages*]

Locally DeNDRoN Local Research Networks across the South West have been playing their part in delivering those national objectives through the DeNDRoN INTERACT Projects:

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Commissioning for Research - SW1

The NHS is changing and this has a direct effect on research and how this is delivered in both Primary and Secondary Care. This presents new challenges for research and present new challenges and opportunities to further research and ensure it features as a normal function within the NHS.

This project is looking to develop service specifications and guidance that can be used by GP commissioners to encourage Hospitals to provide to support dementia and neurodegenerative diseases research.

Involving Patients – SW2

To ensure that research is embedded into NHS care pathways in a way that suits both the service and patients it is important that both groups have a say in how this is done, ensuring it isn't all delivered according to the needs of researchers. This project is a simple, short - 'listening exercise' to engage with patients, 3rd sector organisations and normal NHS services. It is looking to gain their input and views on how DeNDRoN should asked patients about research. Seeking input on key issues around 'when, where and how' the idea of research is approached. This project will enable DeNDRoN South West to consider alternative approaches and other projects in the remainder of 2012, and will kick-start work which is already underway to improve local PPI. It will also see DeNDRoN put forward a challenge to those groups and individuals to help delivery, and ask how they collectively and individually and assist with achieving the overall ambition.

Increasing recruitment in host Trust – SW3

This aims to greatly increase Avon & Wiltshire Mental Health Partnership NHS Trusts support for recruitment to research studies. Working towards ensuring that all patients are given the opportunity to participate in current and future research studies. In the first



instance the project will focus on identifying the barriers both real and perceived, and then work with senior Trust staff to overcome the issues to improve recruitment. The project specifically targets individuals and groups within the Trust, to improve understanding of how DeNDRoN and research can support the organisation, and bring about a change in practice to improve recruitment to studies and consent lists.

Scoping & agreeing systems for complete research integration – SC1

Professor Clive Homes, Consultant Old Age Psychiatrist and DeNDRoN Research Director is working with Southern Health NHS Foundation Trust to encourage the Trust to become fully research active. This would mean systematically asking all patients if they would like to participate in current or future research and provide the opportunity for those patients to join register of interest as part of the normal process of being referred to / treated by the Trust.



Frequently asked questions

To better understand what research involves we have answered questions patients and members of the public often have.

Q. Is there any research for me to participate in?

The term “participation” is used to describe people taking part in a research study. For example: people being recruited to a research study or completing a questionnaire or participating in a focus group as part of a research study.

There are currently over 100 studies on the UK's dementia/neurodegenerative disease research [portfolio](#) [*retain hyperlink to DeNDRoN's 'About DeNDRoN' pages*], however there may not always be a suitable research study available. This can understandably be disheartening for people keen to consider possibilities for research participation. It can be difficult to accept for oneself, and sometimes even more difficult emotionally, if there is no research study suitable for a friend or relative. Sometimes, people say they are prepared to travel long distances, but that is usually not appropriate for a study.

Q. How else can I get involved in research?

Members of the public can get actively involved in research projects and in DeNDRoN's [Patient and Public Involvement groups](#).

DeNDRoN are keen to encourage more people to become actively involved in the work of the network. [For more information contact your [Local Research Network](#) [*retain hyperlink*] or DeNDRoN's National PPI Coordinator [*add hyperlink to Terry*]

Click here for more information on getting involved [*add hyperlink to the 'Get Involved' (<http://www.dendron.nihr.ac.uk/patients-and-carers/get-involved/>) page on DeNDRoN site*]

Q. Who should I contact about participating in research studies?

You can search for current studies that are open through the [UK Clinical Trials Gateway](#) [*retain hyperlink*], or contact your [Local Research Network](#). [*retain hyperlink*] A Local Research Network is a network of staff across England who have in-depth knowledge and expertise of research happening across your region. Whether you are a patient, clinician or researcher – you can get involved in clinical research. Click on your area to find out more about your network to find studies going on locally within your region, or sign up to the national register to [register your interest in research studies](#) [*keep hyperlink*] and receive information. If you are based in the South West, click here for more local information [*add hyperlink to newly proposed 'Research centres' section*].

Q. How can research benefit me?

Research is important in helping to find the best possible treatments, improving quality of life, or finding the best possible new approach to care. It is worth remembering that being in research does not in any way guarantee better health outcomes. There are potential advantages of taking part in research; for example you may receive a new treatment or be



more closely monitored. More information is available on [how research can benefit you](#) [*change hyperlink to separate page – see ‘How research can benefit you’ text*].

Q. Is there criteria for being included in a research study?

Yes, research studies often recruit many people as participants, but they have to fit the eligibility criteria in the research design of the study.

These criteria may concern the type of disease, history, age, gender, ethnicity, and so on, may need to be very specific and can sometimes be quite narrow. This is necessary because clinical research measures changes that are very precise and have to be carefully controlled so that the research results are as clear and informative as possible. So even though you may be interested in taking part in a study, if your details do not fit these narrow criteria you would not be eligible to take part. For example:

- your condition may need to be at a particular stage
- you may not be allowed to receive another treatment at the same time
- some studies seek people with certain illnesses and conditions, while others need healthy people
- some studies need people of a certain age

Q. What type of studies can I participate in?

DeNDRoN's [*add hyperlink to DeNDRoN's site*] focus is on clinical research studies in "phase 2" [*add hyperlink to Study phases text*]; investigating new treatments or models of care tend to be compared against the best currently available and "phase 3" [*add hyperlink to Study phases text*]; investigating the effects of a drug or model of care over time, to assess just how beneficial the outcomes are. Click here to find out more details about phase 1, 2, 3 studies [*add hyperlink to Study phases text*].

DeNDRoN's [*add hyperlink to DeNDRoN's site*] portfolio includes many different types of research studies such as observational, drug trials, interventions, qualitative and quantitative studies. Click here for a full explanation about the types of research [*add hyperlink to Types of research text*]

Q. What questions should I ask before I join a study?

You may need to have tests to see if you can take part. This will allow the researchers to know more about your health before the study. Your doctor will talk to you about being involved in a study and explain the possible benefits and risks. You can refer to DeNDRoN's [*add hyperlink to DeNDRoN's site*] [questions to ask the clinician](#) [*retain this link to DeNDRoN's site*] to help your discussions with your doctor or nurse.

Q. Can I leave a study at any point?

Yes, you are free to leave the study at any point without giving a reason and without it affecting the care you receive. You may decide to stop taking part in a study if your condition is getting worse or if you feel the treatment is not helping you.



If there are signs that the treatment in a trial could be unsafe, the research team or the regulators will stop the study.

If you take part in a study, you will be asked to sign a form to say that you are agreeing to take part in a study and have understood what that will involve. This is called giving your informed consent. As a patient and carer you have a right to leave the study at any point. See the [Mental Capacity Act](#) [*add this link to 'Other useful sites'*].

