

TAKING PART IN RESEARCH

A guide to understanding what is involved



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This booklet has been prepared by the Research in Ageing and Cognitive Health (**REACH**) team at Bangor University in conjunction with the Dementia Services Development Centre Wales team (**DSDC**), the Wales Dementias and Neurodegenerative Diseases Research Network (**NEURODEM Cymru**) and the National Institute for Social Care and Health Research Clinical Research Centre (**NISCHR CRC**). We hope that you find the information presented in this booklet useful in helping you to decide if you would like to take part in research.

Why do we need research?

Research provides insight into people's experiences. This can help us to improve services and support.

The REACH and DSDC teams at Bangor University carry out research projects that aim to improve the lives of older people. We ask healthy older people and people who experience physical or psychological difficulties, or mental health problems, to take part in our research projects.

Our research focuses on:

- > Promoting well-being,
- > Preventing, reducing or delaying the onset of age-related disability, and
- > Improving rehabilitation and care.



Research improves treatment and support

By better understanding people's experiences, we can help to improve health care and social care by providing more effective treatments and improving support for individuals and their relatives. We also invite people with relevant experience to contribute to advisory groups. This is where we ask for advice on developing our research plans or the running of projects.

Your involvement in our research will help to make a difference!

Why do people take part in research?

Different studies offer different types of benefits and so people decide to take part in research for various reasons. Some people choose to take part because a study might **directly benefit them** and/or because they could **help other people in the future**.

Here are some reasons why you might decide to take part in research:

> You will help to increase our knowledge. This might be about aspects of the normal process of ageing, or about a particular illness or health condition. Your contribution will help researchers to use this new information to improve the lives of older people.

> You will have access to current information that may be of interest to you.



> Your input may help to improve the support available to individuals and their families now and in the future.

> You will have contact with the research team and the chance to do something that you may find enjoyable.

Here are some comments from participants about their experiences of taking part in research:

“Each study has been quite different. Some involved a series of visits, others just one. There were tests where I had to write down answers, and others where I simply had to press keys on a keyboard...It's essential that volunteers of all kinds contribute to research which may one day result in better treatment.”

(John, a volunteer on the NEURODEM Research Participant Register)

“Invariably the research was riveting and my personal experience of caring for my husband was included.”

(A carer who has taken part in a focus group)

“I really enjoy taking part in research because it exercises and challenges my brain, I meet interesting new people...It's all good fun but with a genuinely useful purpose...My husband has taken part in several studies and has encouraged his friends to take part too. They all seem to enjoy doing it.”



(Alison, a volunteer on the NEURODEM Research Participant Register)

What does research involve?

Research involves collecting information from people (called participants) to improve our understanding about a topic. For example, the aim of a study might be to explore ways to better support individuals with a particular health condition and their family members and to improve their quality of life.

What are the main types of research study?

> **Observational studies** involve collecting information about a particular topic through questionnaires, interviews or discussions, or by asking people to carry out simple tasks.



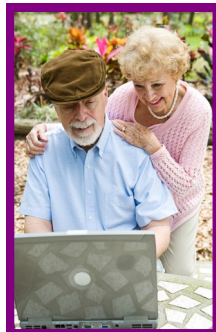
> **Intervention studies** or **randomised controlled trials** involve finding out whether or not a particular kind of treatment or activity is beneficial. Some participants might receive a new treatment or engage in a new activity while other participants carry on with their usual routine. The researcher collects information from both groups of participants, before and after the intervention, to find out if the treatment or activity was useful.



What might I be asked to do?

Researchers collect information from participants in different ways. For example, you might be asked to:

- > Fill in a **questionnaire** by choosing the answers that best match your experience.
- > Complete some **simple activities**, such as tasks that assess your memory.
- > **Talk to a researcher** about your thoughts and experiences.
- > Discuss your experiences with others in a **focus group**.
- > Receive a **new type of treatment**, such as a new therapy. You might be asked to meet with a therapist or attend group therapy to plan how best to manage a particular health condition. Together, you might identify helpful coping strategies.



When and where does research take place?

Depending on the study, you might be asked to provide information on just one occasion, or several times over weeks or months. The researcher might visit you in your home or meet you at a nearby clinic or university, at a time to suit you, or you might be asked to complete questionnaires sent to you by post.

How do I know if I can take part?

Each study requires different kinds of participants. For example, researchers might invite only people with a particular health condition, or only healthy people, or only people living in a certain area, to take part. If you are interested in taking part in a study, the researcher will ask you some questions to see if the study is suitable for you. If it is, you will be given further detailed information and time to decide whether or not you wish to take part.



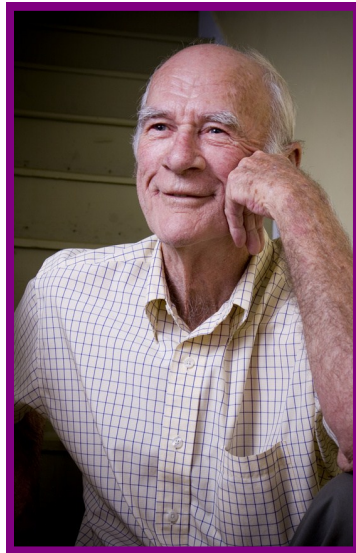
What happens at the end of a study?

The research team examines the information provided by participants and presents the findings to others. This might be by a newsletter, a report in a scientific journal and/or a presentation at a conference. Information that could lead to a participant being identified is removed so that information about the findings is anonymous. Although some studies can take several years to complete, the researchers will keep you updated on how the study is progressing.

What questions should I ask the researcher?

Before deciding to take part in research, it is important that you are aware of the purpose of the study and what is involved. You should be provided with an information sheet that includes answers to the following questions:

- > Why is the study being done?
- > Why have I been asked to take part in the study?
- > How long will the study last?
- > What will I have to do?
- > How much of my time is needed?
- > Will I need to get family, friends or a carer involved?
- > What benefits are there if I take part?
- > Who do I contact if I have a question about the study?
- > How will I hear about the findings from the study?
- > Can I claim travel expenses?
- > Who is organising the study?



Who checks that the research is conducted properly?

The study has to be approved by a research ethics committee that safeguards the rights, safety, dignity and well-being of participants. It is composed of academics, doctors, nurses, scientists, and members of the public. The committee reviews the study and considers what new knowledge and benefits it might bring.

What happens to my personal details?

Researchers must ensure that the information provided by participants is kept secure and accessible only to the team. A code (e.g. a number) is written on information provided by participants, instead of their names, to keep their identity secret. The findings are presented in anonymised form so that participants cannot be identified. Usually, only overall group findings are reported. With permission, we might quote specific comments made by participants, but without giving their names.

Who pays for research?

Our research is publicly-funded through health-related organisations, UK Research Councils, and voluntary sector organisations. Researchers apply for funds, showing how their research could benefit society, and only the best applications are funded. We train new researchers and often have doctoral and master's level students working with us. We ensure that the findings from these studies are published so as to benefit others.

What will I be told about each study?

You will be provided with an information sheet that explains what the study is about and what is involved in taking part. You should take time to discuss the study with friends and family, and ask the researcher any questions you have. If you wish to take part in the study you will be asked to sign a form. This is to show that you agree to volunteer to take part in the study and that you understand what is involved in taking part. In some studies, people with memory difficulties may be asked at the



start of the study if they would be willing to continue to take part in the study even if they lose their ability to fully understand what is involved. Sometimes, a family member (“consultee”) is nominated to advise on whether a person who cannot give consent should take part in a study.

Can I change my mind about taking part?

As a volunteer, you have the right to withdraw from a study at any time without giving a reason. If you decide to change your mind and no longer wish to take part this will not make any difference to the health care you receive. You will receive the best possible care even if you do not wish to complete the study.



How can I get involved in research?

Researchers at Bangor University need your help!

The REACH and DSDC teams at Bangor University are recruiting participants to their research studies.

For more information:

Call **01248 382356**

Email **reach@bangor.ac.uk**

Visit **<http://reach.bangor.ac.uk>**

Visit **www.bangor.ac.uk/imscar/dsdc**



NEURODEM Cymru was set up by the Welsh Assembly Government to promote high quality research. If you are interested in taking part in research, as a patient or carer, you can add your details to the NEURODEM Research Participant Register. NEURODEM will contact you about research projects in your area and you can decide whether or not to take part in any study. For more information:



Call **01248 383968** or **01248 382226**

Email **neurodem@bangor.ac.uk**

Visit **www.neurodemcymru.org**



***We hope that you have found this booklet useful
and we welcome your interest in our research.***