



# CONFIDENT CONVERSATIONS ABOUT RESEARCH

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**NHS**  
SCOTLAND  
NHS RESEARCH SCOTLAND

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NEUROPROGRESSIVE  
AND DEMENTIA

**Alzheimer  
Scotland**  
Action on Dementia



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# FOREWORD

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Henry Simmons, Chief Executive,  
Alzheimer Scotland

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Dr Tom Russ, Clinical Research Champion,  
NRS Neuroprogressive & Dementias Network

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Dr Emma Law, Manager,  
NRS Neuroprogressive & Dementias Network,  
Lead Educator, Confident Conversations Programme

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# OUTLINE OF TRAINING

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## SKILLED PRACTICE

([Promoting Excellence Framework](#) Dementia Skilled Practice Level)

- Welcome and introductions
- *Exercise One* – Rate how confident you are in talking to people about research
- *Exercise Two* – What do you think of when you hear ‘research’?
- **Session One.** Types of research
- *Exercise Three* – What are the benefits and barriers for taking part in research?
- **Session Two.** Patient and Public Involvement
- *Exercise Four* – Reflect on your learning experience

## ENHANCED PRACTICE

([Promoting Excellence Framework](#) Dementia Enhanced Practice Level)

- Introduction – you are expert in dementia
- *Exercise Five* – Successful strategies for supporting research conversations
- **Session Three.** Different types of research in more detail
- *Exercise Six* – Practical skills in talking about research
- *Exercise Seven* – When is the right time to introduce research?
- *Exercise Eight* – How will you take your learning into the workplace?

# SKILLED PRACTICE



# WELCOME & INTRODUCTIONS

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Welcome to the Confident Conversations about Research training sessions! We look forward to sharing your experience of talking to people about research and hope that you find the day interesting. All the materials you will need are in this workbook and there is space for you to take notes. There is a handy list of further resources in the back of this booklet.

## Exercise One

How confident are you in talking to people about research on a scale of 1-10?

1   2   3   4   5   6   7   8   9   10

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Not at all confident

I'm a pro!

## Exercise Two

Split into small groups of two or three people and discuss what you think of when you hear 'research'. Make some notes here so we can discuss together as a group:

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# SESSION ONE

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## What is research?

“Research” is a word that often puts people off, thinking of it as something that only special people do. Increasingly, however, the vital contribution of people with lived with experience to research is being recognised.

Taking part in research does not have to be demanding, time-consuming, or painful. At its heart, research tries to answer questions and further our understanding of the world. How it goes about this depends on the specific questions being asked, which determine the type of research carried out and the experience of taking part.

The two main types of research are **quantitative** and **qualitative**. However, many projects include elements of both - mixed methods research.

Quantitative research seeks to measure things and often involves numbers. The questions it seeks to answer usually start with 'how much' or 'how often' - for example, how many people with diabetes develop dementia? How much does having a particular genetic variant increase your risk of dementia? How often do doctors ask their patients if they have any questions during a memory clinic appointment?

Qualitative research, on the other hand, seeks to understand things and usually involves interviews or focus groups, sometimes with questions and prompts, but sometimes just a simple conversation. Qualitative researchers might be interested in: What did it feel like to be diagnosed with dementia? What makes you feel freer when you have dementia?

Both types of research – quantitative and qualitative – are complementary, and neither is better than the other. Which you use depends on what question you are trying to answer.

## What types of research are there?

The most straightforward type of research to take part in is a **questionnaire** or an **interview**. A researcher interested in some aspect of your experience will ask questions or have a conversation with you. Sometimes the researchers might ask you to participate in a focus group, which is an interview with several people simultaneously. These interviews or focus groups can be one-off, or they might invite you to participate in a series.

Another type of research is an observational study, either a **cross-sectional study** (just seeing people once) or a **cohort study**, which follows people over time to see how things change for them. The participants usually have something in common: all being born in the same year or living in the same area, for instance. In observational studies the researchers will ask questions and take physical measurements, perhaps with blood tests and scans, but will not give a treatment. They are only interested in how things change over time and, often, if there is anything particular about the participant that can predict what might happen in the future.

Another option available to people with dementia is pledging to **donate brain tissue** for research purposes after you die. In Scotland this is possible through the Alzheimer Scotland Dementia Brain Tissue Bank run jointly by the Alzheimer Scotland Dementia Research Centre at the University of Edinburgh and the NRS Neuroprogressive & Dementia Network.

A final type of research is a **clinical trial** of a new treatment or intervention, which could be administered as a tablet, an infusion through a drip, or some other kind of treatment. A trial can require a long-term commitment (often two or three years) to attend the hospital regularly for cognitive assessments, physical checks, blood tests, and, sometimes, to receive the treatment.

Most clinical trials are **placebo-controlled**, meaning the active treatment is compared to an inactive ‘sugar pill.’ You would be randomly selected to receive either the treatment or the placebo, and no one in the research team would know which you were receiving until the end of the trial. In other words, you might participate in the trial and not receive the treatment. However, this is essential to determine if the treatment works.

Some trials study brand new treatments we know little about, and some study treatments already licensed and used for other conditions that may have an effect on dementia. In the latter case, we know much more about the treatment and its safety, whereas in the case of a new treatment, less is known, so the risks are slightly greater.

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## SESSION TWO

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Research is moving away from something we do to people (who were previously referred to as research 'subjects,' being subjected to research) to something we do with people, as research participants. Indeed, many projects go further and involve people with lived experience as co-researchers, which is great fun and greatly enhances the research conducted.

### Patient and Public Involvement (PPI)

As mentioned above, researchers have often been guilty of doing research to people with dementia rather than with them. However, many research groups now involve people with lived experience of dementia and interested members of the general public at all stages of their projects. For example, someone could help guide research questions or to design a research study from the start. Some research projects are "co-produced" with people with lived experience of dementia as co-researchers on an equal footing with the "professional" researchers.

In our experience, this is a fun way to do research and leads to insights and ideas that would never have emerged doing things the traditional way. For instance, Tom was involved in a project speaking with people with dementia who were given a diagnosis remotely - either by phone or video call - during the COVID-19 lockdowns. He worked on this project with a fascinating group of individuals with lived experience of dementia. They co-produced the interview schedules we used to speak with people, read through transcripts of the interviews, identified recurring themes, and produced animated films and a podcast series about the project ("Diagnosing Dementia During COVID-19").

There can still be an element of tokenism when including people with lived experience in research studies, but their meaningful involvement is rightly becoming the norm. It remains much more prevalent in university-based research than in commercial clinical trials.

Two fantastic examples of involving people with lived experience in a meaningful way are the Partners in Research and the RICH Voices groups:

**Partners in Research** is the 'patient and public involvement' group for the Neuroprogressive and Dementia Network. The group work together to review research and research-related materials, raise awareness of dementia and neuroprogressive conditions, and co-produce future research proposals. The group is open to everyone. There is a book about dementia being written, work on increasing accessibility of academic papers, and development of new research ideas.

**RICH (Research In Care Homes) Voices** is the 'patient and public involvement' group for ENRICH Scotland. The group is open to people living or working in care homes, people with loved ones in care homes, and members of the public with an interest in this area. The group aims to review relevant research and research-related activities to increase research within care homes and find innovative ways to increase the transferability of research into practice.

Not every researcher involves people with lived experience in their research yet, but enough of us are. We would be very grateful for the valuable contribution of anyone who is interested. Our research participants tell us that they enjoy participating in research, and evidence suggests that it does you good. Everyone should give it a go!

## How to join research

### Join Dementia Research

A good way to find out about local research opportunities near you is to join a research interest register. The most important one for people with dementia is “Join Dementia Research” (JDR). Registering with JDR will link the person to studies they might be eligible for and they can opt to be contacted by the researchers to find out more.

Anyone can register with JDR (you don't have to have dementia) to take part in dementia research by visiting:

[www.joindementiaresearch.nihr.ac.uk/](http://www.joindementiaresearch.nihr.ac.uk/)



### Permission to Contact

Because the NDN doesn't just cover dementia (we also run studies in Parkinson's disease, Motor Neuron Disease, Multiple Sclerosis, and Huntington's disease), we developed our own register which is complementary to JDR. Indeed, our 'Permission to Contact' database is registered as a study on JDR so we are as joined up as we can be.

The 'Permission to Contact' (PTC) system can also be helpful for people with dementia who are interested in taking part in research as it also includes asking for permission for researchers to look at medical records to match you with the most appropriate research studies. Many clinical trials, in particular, have extensive inclusion and exclusion criteria and allowing NDN staff to look at your medical records means that they can check if you have any conditions or take any medications



that would exclude you from participating in a particular trial. This saves time and disappointment compared to finding this out at a later stage.

**Permission to Contact leaflets can be provided by your local NDN team.**

### Local NRS Neuroprogressive & Dementia Network (NDN) Contacts

The NDN have staff in every mainland territorial health board in Scotland and are a great resource for finding out more about research in general as well as what opportunities there may be for any of the people you support who may be interested. Contact details for your local team can be found at the NDN website:

[www.nrs.org.uk/dementia](http://www.nrs.org.uk/dementia)

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## Exercise Four

Reflect on what you have learned today and make some notes below. Afterwards, rate how confident you are *now* in talking about research to people on a scale of 1-10.

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How confident are you *now* in talking to people about research on a scale of 1-10?

1   2   3   4   5   6   7   8   9   10



Not at all confident

I'm a pro!

CONGRATULATIONS, YOU'VE COMPLETED THE SKILLED PRACTICE SECTION OF THE TRAINING. FOR A DIRECTORY OF HANDY MATERIALS SEE THE FURTHER RESOURCES SECTION AT THE END OF THIS WORKBOOK.

# ENHANCED PRACTICE



# SESSION THREE

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## Research examples

In this session we will discuss different types of research in more detail with examples:

- Interviews or questionnaires
- Observational studies
- Clinical trials

We will show a video about attending a Clinical Research Facility for a clinical trial which you will be able to access again on the Confident Conversations website.

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## FURTHER RESOURCES

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### Join Dementia Research

[www.joindementiaresearch.nihr.ac.uk/](http://www.joindementiaresearch.nihr.ac.uk/)



Online service where anyone can register their interest in taking part in brain health and dementia research studies. The service connects registered volunteers with researchers across the UK who are looking for people to join their studies.

### Your local NRS Neuroprogressive & Dementia Network Contacts & Permission to Contact Register

[www.nrs.org.uk/dementia](http://www.nrs.org.uk/dementia)



The Neuroprogressive and Dementia Network run studies involving lots of different brain conditions. Their permission to contact register allows researchers to view an individual's medical records to help match volunteers with the most appropriate research studies. Your local Network contacts can help with any questions you have about research and can offer advice for people looking to participate in Patient and Public Involvement (PPI) opportunities.

### Scottish Brain Tissue Bank

[www.alzscotdrc.ed.ac.uk](http://www.alzscotdrc.ed.ac.uk)



Brain tissue donated after someone has died is an incredibly generous and valuable resource which allows researchers to discover more about the diseases which cause dementia. The Scottish Brain Tissue Bank accepts donations of brain tissue from people with a diagnosis of dementia who live on mainland Scotland.

## Enrich care home network



[www.enrich.nihr.ac.uk](http://www.enrich.nihr.ac.uk)

ENRICH stands for 'Enabling Research in Care Homes'. The ENRICH network brings together care home staff, residents and their families with researchers. It provides a toolkit of resources to help care homes make the most of research; and researchers to set up and run studies effectively and collaboratively in care homes.

## Scottish Dementia Research Consortium



[www.sdrc.scot/](http://www.sdrc.scot/)

The Scottish Dementia Research Consortium (SDRC) is open to everyone who is taking part in or interested in dementia and brain health research in Scotland. Anyone from anywhere is free to join, whether they are a researcher in Scotland or not. Members of SDRC benefit from regular research activity updates, opportunities for networking with other members and invitations to exclusive members only events.

## Promoting Excellence Framework



[www.gov.scot/publications/promoting-excellence-2021-framework-health-social-services-staff-working-people-dementia-families-carers/](http://www.gov.scot/publications/promoting-excellence-2021-framework-health-social-services-staff-working-people-dementia-families-carers/)

The Promoting Excellence Framework sets out the knowledge and skills all health and social care staff should achieve in their roles in supporting people with dementia, their families and carers to maximise their rights, choices, and health and wellbeing at all stages of their own dementia journey.

## Understanding Brain Health: Preventing Dementia online course



[www.brainhealth.scot/mooc](http://www.brainhealth.scot/mooc)

This free course features interactive and flexible learning resources to introduce the very latest research topics being explored for brain health and dementia prevention.



NEUROPROGRESSIVE  
AND DEMENTIA

