PARTICIPANT INFORMATION SHEET

Study Title: Supporting carer involvement in managing dementia comorbidities

Version 1.1, dated 19-Mar-2026, IRAS: 368643

We are inviting you to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If you have any questions, please contact the research team. We will be very happy to explain anything that is not clear.

What is the purpose of the research?

The purpose of this study is to better understand how carers – or supporters – to people who are living with dementia can be best involved in the self-management of comorbid long-term health conditions in primary care. We are interested in learning about your views and experiences of working with people living with dementia and their supporters in your practice.

There is currently little knowledge about how healthcare professionals work with supporters of people living with dementia. This knowledge will help to inform strategies for working together more effectively.

Why have I been invited?

You are being invited to take part in this study because you are a healthcare professional working in Staffordshire with people living with dementia in relation to the management and self-management of comorbid long-term health conditions.

Do I have to take part?

No, taking part in this research is completely voluntary. It is up to you to decide if you want to volunteer to take part in the research or not. If you do decide to participate, you will be asked to sign and date a consent form. You will still be free to withdraw from the study at any time without giving a reason. If you choose to leave part way through, you will be offered time with a researcher afterwards if you would like to discuss your thoughts or ask questions. Please be aware that due to the nature of the focus group, it will not be possible to remove your part of the discussion after the event.

What will taking part involve?

We are inviting you to share your experiences and perspectives with a small group of other healthcare professionals during a focus group held online on MS Teams. The focus group should take approximately 60-90 minutes. The focus group will be recorded (audio and video) and transcribed through MS Teams; the recordings will be used to aid transcription and analysis only and will not be shared elsewhere.

If you are unable to attend a focus group date it may be possible to arrange an individual interview. However you choose to take part you will be asked to complete a digital consent form prior to participation.

What are the possible disadvantages, burdens and risks (if any) of taking part?

There are no risks anticipated for you taking part in this study. Your participation in this study and your responses will not be shared with your employer.

If you would like to speak with someone about your wellbeing at work, we recommend contacting the Staff Psychological Wellbeing Hub: https://staffsstokeics.org.uk/careers-education/staff-psychological-wellbeing-hub/.

What are the possible advantages or benefits (if any) of taking part?
There is no anticipated direct benefit to you of taking part in this study, but it will give you a voice in shaping recommendations and future research. We hope that the information you provide will have wider benefits to patients and the workforce by improving understanding of how self-management of long-term health conditions can be strengthened by better inclusion of supporters.

We will offer you a £20 shopping e-voucher in recognition of your time, and we will also provide you with a certificate of attendance which can be used for your revalidation if applicable.

What if something goes wrong?
If you have a concern about any aspect of this study, you can ask to speak to a member of the research team who will do their best to answer your questions.

If you remain unhappy and wish to complain formally, you can do this by contacting the research Sponsor: Research.governance@keele.ac.uk.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should follow the instructions given above.

Would my taking part in this study be confidential?
The information you provide during the research will be dealt with in the strictest confidence. The data, which identifies you, will be kept securely by the research team on a password protected research folder on the university system.

Data which would identify you will not be passed to anyone outside the research team without your express written permission. The exception to this is authorised representatives from the research Sponsor (Keele University) who may need to access data (for example for audits) to fulfil their responsibility to ensure the research is being carried out correctly, and any regulatory authority which has the legal right to access the data for the purposes of conducting an inspection, audit or enquiry. These agencies treat your personal data in confidence.

Your contributions will be linked anonymised, which means that your information will be given a pseudonym. We would like to use direct quotes, but we will ensure that your real name is not used and will avoid sharing quotes that may identify you. We will combine responses and no individual would be identifiable from the published results.

You can request for your direct quotes not be used in the study for up to two weeks following the focus group – after this time it may no longer be possible to exclude them.

Recordings of the focus groups will be used to check the accuracy of the transcriptions and to conduct early stages of the analysis. Any identifying information will be removed from the transcripts ahead of analysis.

Given the nature of the group discussion, it is not possible to guarantee anonymity. However, we will ask all attendees to keep the contents of the discussion and the participants' identities confidential.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a pseudonym instead.

Keele University is the sponsor of this research.

Keele University is responsible for looking after your information. We will not share your information related to this research project with any other organisations.

We will keep all information about you safe and secure by:

- storing this information in secure locations accessible by the research team only
- not sharing your information with other organisations
- writing our reports in a way that no-one can work out that you took part in the study

International transfers

Your data will not be shared outside the UK.

How will we use information about you after the study ends?

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will keep your study data for a maximum of 1 year. The study data will then be fully anonymised and securely archived or destroyed.

What are your choices about how your information is used?

- you can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have

- you have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- by reading our privacy notice here: https://www.keele.ac.uk/informationgovernance/informationgovernanceforthepublic
- by asking one of the research team (contact details below)
- by sending an email to Keele's Data Protection Officer at dpo@keele.ac.uk.

What will happen to the results of this research?

The data, when made anonymous, may be presented at academic conferences, or published as a project report, academic dissertation or in academic journals or book. It could also be made available to any commissioner or funder of the research. Anonymous data, which does not identify you, will be publicly shared at the end of the project and made open access. A licence will be applied to this publicly shared data. This will allow anyone else (including researchers, businesses, governments, charities, and the general public) to use the anonymised data for any purpose that they wish, providing they credit the University and research team as the original creators. No restrictions will be placed on the shared anonymised data, allowing its reuse for both commercial and non-commercial purposes.

You will be asked if you wish to leave a contact email to receive a summary of the findings within 12 months of the focus group.

Who is organising and funding the research?

This study is being led by Dr Angela Clifford and other researchers in the School of Nursing and Midwifery at Keele University. The project is funded by the North Staffordshire Medical Institute and University Hospitals of North Midlands NHS Trust Charity Fund. None of the researchers or study staff will receive any financial reward by conducting this study, other than their normal salary as an employee of Keele University.

Who has reviewed the study?

All research carried out within the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This research project has been reviewed and given a favourable ethical opinion by London - Harrow Research Ethics Committee (reference: 26/LO/0218). The study has also been reviewed by a scientific review panel on behalf of the funders.

Contact for further information about the study

If you would like to discuss this survey or have further questions at any time, please contact Dr Angela Clifford, who is the lead researcher for this project.

Telephone: +44 1782 731549
Email: a.clifford@keele.ac.uk

Thank you

Thank you for taking time to read this information sheet and for considering volunteering for this research. If you do agree to participate your consent will be sought; please see the accompanying consent form. You will then be given a copy of this information sheet and your signed consent form, to keep.