Faculty of Medicine & Health Sciences
School of Health Sciences
Room 302, B Floor, South Building
Queen's Medical Centre
Nottingham
NG7 2RD

Complex Homecare in MND (CHiMND)

PARTICIPANT INFORMATION SHEET – Key Stakeholders

Research Ethics Reference: FMHS 01-1024
Version 1.0 Date: 30.09.2024

We would like to invite you to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. One of our team will go through the information sheet with you and answer any questions you have. Please take time to read this carefully and discuss it with others if you wish. Ask us anything that is not clear.

What is the purpose of the research?

With advances in health technologies, more people with Motor Neurone Disease (MND) can now live at home supported by equipment such as ventilators and feeding tubes. This increases the demands on family carers and often requires extra support from paid homecare workers. Homecare workers play a crucial role in helping families deliver complex care at home. However, we know little about how homecare workers carry out their responsibilities, the skills required, and how they work together with family carers and other health and care professionals. The study aims to find out more about the roles and relationships of homecare workers who support people living with MND with complex care needs at home.

Why have I been invited to take part?

You have been invited to take part in this research because you have professional experience of commissioning, arranging or overseeing homecare packages, or of working with homecare workers as part of a multi-disciplinary team supporting someone with MND with complex care needs. This includes supporting someone to use equipment such as a ventilator, suction or feeding tube, or communication device. We will be recruiting up to 20 key stakeholders to take part in this study.

Do I have to take part?

It is up to you to decide if you want to take part in this research. We will describe the study and go through this information sheet with you to answer any questions you may have. If you agree to participate, we will ask you to sign a consent form and will give you a copy to keep. However, you would still be free to withdraw from the study at any time, without giving a reason, simply let the research team know.

What will happen to me if I take part?

If you agree to take part in the study, you will be asked to attend a single, online interview using a platform such as MS Teams. The interview will be arranged at a time convenient to you and will last approximately 45 minutes. You will be asked about your current or previous experience of the process of commissioning, arranging or managing homecare packages for people with MND who have complex needs and/or your experience of working with homecare workers to deliver complex care in the home. Interviews will be video and/or audio recorded with your consent. Audio recordings will be sent to an external transcribing service who have signed a confidentiality agreement with University of Nottingham.

Are there any risks in taking part?

We do not anticipate that there will be any risks involved in taking part in the study, which involves discussion of the nature and circumstances of your professional work. You will not be under pressure to answer questions or talk about topics that you prefer not to discuss. We hope you will find taking part in the study an interesting experience. However, you can stop the interview or withdraw from the study at any time.

Are there any benefits in taking part?

There will be no direct benefit to you from taking part in this research, but your contribution may help to increase understanding of the roles and responsibilities of homecare workers in providing complex care to people with MND. In future, this may lead to better care at home for people with MND and more support for family members.

Will my time be reimbursed?

There is no reimbursement for taking part in the study.

What happens to the data provided?

The research data will be stored confidentially using the research team's secure University of Nottingham MS Teams account. To help ensure your privacy, you will be assigned a study identification number (for example P01 for participant number 1), and it will be used instead of your name. We will save all interview recordings and transcripts using that study identification number so that none of the data will have your name or other individual identifiers associated with them.

Your personal data (name and contact details) will be stored confidentially in a separate file on the research team's secure University of Nottingham MS Teams account. Only the research team will have access to personal data. Personal data will be deleted as soon as possible after it is no longer needed for the study. If you give your consent, your contact details may be retained for the purpose of inviting you to participate in future research studies.

All research data and records will be stored for a minimum of 7 years after publication or public release of the work of the research. We would like your permission to use fully anonymised direct quotes from your data in research publications. We would also like your permission to use anonymised data in future studies, and to share our research data (e.g. in online databases) with other researchers in other Universities and organisations both inside and outside the European Union. This would be used for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

What will happen if I don't want to carry on with the study?

Even after you have signed the consent form, you are free to withdraw from the study at any time without giving any reason. Any personal data will be destroyed.

If you withdraw, we will no longer collect any information about you or from you, but we will keep the anonymous research data that has already been collected and stored as we are not allowed to change study records. This information may have already been used in some analyses and may still be used in the final study analyses.

Who will know that I am taking part in this research?

Data will be used for research purposes only and in accordance with the General Data Protection Regulations. Any video or audio recordings and electronic data will be anonymised with a code as detailed above. Electronic storage devices will be encrypted while transferring and saving all sensitive data generated during the research. All such data are kept on password-protected databases sitting on a restricted access computer system and any paper information (such as your consent form or contact details) would be stored safely in lockable cabinets in a swipe-card secured building and would only be accessed by the research team.

Under UK Data Protection laws, the University is the Data Controller (legally responsible for the data security), and the Principal Investigator of this study (Eleanor Wilson) is the Data Custodian (manages access to the data). You can find out more about how we use your personal information and read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx/

Designated individuals of the University of Nottingham may be given access to data for monitoring and/or audit of the study to ensure we are complying with guidelines.

Anything you say during an interview will be kept confidential, unless you reveal something of concern that may put yourself or anyone else at risk. The research team will discuss this with you and decide on a course of action. It will then be necessary to report to the appropriate persons.

What will happen to the results of the research?

The research will be published in academic journals and presented to academic colleagues and health and care professionals at research conferences and professional meetings. If you would like to receive a summary of the study findings, you will be asked to consent to your personal details being kept until after the end of the study for this purpose.

Who has reviewed this study?

All research involving people is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This research has been assessed and approved by the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee.

Who is organising and funding the research?

The research is being organised by the University of Nottingham and is funded by the Motor Neurone Disease Association (MNDA).

What if there is a problem?

If you have a concern about any aspect of this project, please speak to the researcher Nicola Turner or the Principal Investigator Eleanor Wilson, who will do their best to answer your query. The researcher should acknowledge your concern and give you an indication of how she intends to deal with it. If you remain unhappy and wish to complain formally, you can do this by contacting the FMHS Research Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen’s Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk.

Please quote ref no: FMHS xx-xxx

Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Nicola Turner
Senior Researcher
E: Nicola.turner@nottingham.ac.uk
T: 0115 8230537

Eleanor Wilson
Principal Investigator
E: Eleanor.wilson@nottingham.ac.uk
T: 0115 8231201