

The CoMMND study: Developing best multidisciplinary practice for people with Motor Neurone Disease in the UK

Participant Information Leaflet

Introduction

You are being invited 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. Please take time to read the following information carefully and discuss it with others if you wish. Please feel free to contact us if anything is unclear or if you would like more information (contact details are at the end of this leaflet). Take the time you need to decide whether or not you wish to take part.

What is the purpose of the study?

This study will help develop guidelines on how best to deliver multidisciplinary team (MDT) care in the UK to people with Motor Neurone Disease (MND). The NICE Guidelines (2016) stated that care for people with MND should be delivered by an MDT with clinic based co-ordinated care. They also indicated that the MDT should include health and social care professionals with expertise in MND. However these guidelines do not outline the optimal structure and delivery these MDT clinics. A recently completed literature review has brought together the existing evidence to inform the context and format of these clinics. The findings from this literature review along with this current study aims to develop consensus on best clinical practice in the delivery of MDT care for people with MND in the UK.

Why have I been asked to take part?

You have been asked to take part because you are either a person who has a diagnosis of MND, someone who is caring for a person with a diagnosis of MND or you are a clinician who is involved in an MDT treating people with a diagnosis of MND. We are aiming to recruit patients/carers and clinicians across the UK to take part in this study.

What will participation in the study involve?

Your participation in the study is voluntary and you can withdraw at any point. Withdrawal will not affect the treatment that you receive or your clinical position. Taking part will involve:

1. Completing three online questionnaires over a period of six weeks
2. Attending an online workshop (this is not mandatory) where we will discuss any items from the online questionnaires where consensus (agreement) has not been reached.

If you wish to withdraw then you can either contact Edward Duncan or you can simply not complete the online questionnaires when sent the email prompts. Due to the cumulative nature of information that we are collecting we will not be able to remove any previous responses prior to your withdrawal.

1. Online questionnaires

These questionnaires are a way to get agreement from study participants on what should go into the guidelines. We are using a method of reaching agreement called 'the Delphi technique'. Every two weeks for six weeks, we will send you an email asking you to go to a website to answer a questionnaire. Each of these three questionnaires will take you approximately 20 mins to complete. For each questionnaire, you can save your answers and complete it later. In each questionnaire you will be asked to vote on how strongly you think each item from a list of items should be included in the guidelines. In questionnaires 2 and 3 you can see how many participants voted each item and have a chance to change your answers from the first questionnaire. There will be no face to face communication. To take part you will need access to the internet on a computer or tablet. We will provide you with support and training to take part if you need any. You will have two weeks from when you are sent the prompt email to complete each of the three questionnaires. If you have not completed the questionnaire you will get a reminder after one week, a further reminder will be sent just before the two weeks if you have still not completed the questionnaire by then.

2. Consensus meeting

The three rounds of questionnaires will allow us to reach consensus (agreement) on the majority of the items in the questionnaire. However, in this process there are usually a number of items where an acceptable level of agreement has not been reached. The purpose of this meeting would be to get a significant number of experts to take part in an online meeting to discuss the items where consensus was not reached and to make a decision on those items at that meeting. This meeting will be attended by the research team, people with MND, carers of people with MND and clinicians involved in the MDT care of people with MND. If participants' consent, we will record the workshop

How long will I be involved in the study?

You will be involved in the study for approximately three months. For around six weeks you will be involved in the Delphi exercise and we will hold the online workshop within six weeks of completing the Delphi process.

What are the possible risks or benefits of taking part?

Your participation will help design best practice statements on MDT care for people with MND. This is designed to improve the healthcare provided to people with MND and for the healthcare that is offered to be comparable across the United Kingdom. If you have been diagnosed with MND it is unlikely that any changes in healthcare will benefit you directly but should benefit people diagnosed with MND in the future. It is unlikely that taking part in the study will cause you any harm or emotional distress, but it is possible that you may get upset if the study causes you to reflect on your own experience of healthcare that affect you or people close to you. If this is the case we would encourage to contact your GP or local MND team. Alternatively you could contact the Samaritans (**Samaritans contacts** **Tel:** 116 123 **Email:** jo@samaritans.org). You can also take a break or stop taking part whenever you want.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. In the first instance contact: Edward Duncan (Associate Professor of Applied Health Research), email: edward.duncan@stir.ac.uk. If you remain unhappy and wish to complain formally, you can do this by contacting our independent study contact Professor Jayne Donaldson at Jayne.donaldson@stir.ac.uk or Tel: 07904635881.

Taking part in this study does not affect your normal legal rights. Whether or not you do take part, you will retain the same legal rights as any other patient in the NHS (which include professional indemnity insurance for negligence).

Will the information I provide be kept confidential?

Yes. All information collected about you will be kept strictly confidential. We will not hold any paper records containing and of your personal information, name, email address etc. The information that you provide to register your interest in the study will be kept secure on the University Server as well as being kept in a University hosted secure survey space which only the research team have access to. Computerised data will be kept on a password protected computer and only those involved in the research will be permitted access to any of the files or data. Any information that you provide will be seen by the research team only. When the results of the study are written up, individuals who have taken part will not be identifiable in any way.

Who is doing this study?

The research is being carried out by a group of experienced researchers and clinicians from The Chief Scientist Office funded Nursing, Midwifery and Allied Health Professions Research Unit, University of Stirling and NHS Ayrshire and Arran. The study is funded by the Gordon Aikman Scholarship Scheme.

Who has reviewed this study?

This study has been reviewed by the University of Stirling, General University Ethics Panel (GUEP).

Can I contact a member of the research team for further information?

If you have any further questions about the study at any stage, please feel free to contact:

Chief Investigator: Dr Edward Duncan

Email: edward.duncan@stir.ac.uk

Tel: 01786 466286

Thank you for reading this and considering taking part in this study.

The University of Stirling is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Stirling will keep identifiable information about you for 10 years from the last publication from the study or 10 years from when the data was last accessed.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Edward Duncan on the details above.