Participant information sheet

Exploring the views of healthcare professionals regarding non-invasive ventilation in patients with motor neuron disease: a qualitative focus group study.

We are a team of researchers from the University of Sheffield and Sheffield Teaching Hospitals NHS Trust. We would like to invite you to take part in a research study. Before you decide if you would like to take part in this study, it is important that you understand the aim of the study and what it would involve. This information sheet will describe what the aim of the study is and what it will involve if you decide to take part. If you are interested in taking part, please read the following information. If after reading this information sheet you have any questions, please contact the research assistant using the contact details at the bottom of this page.

Study summary

This study will contribute to the third work package of a wider project which aims to identify the best ways of providing non-invasive ventilation (NIV) services to people with motor neuron disease (MND). The project aims to use this information to develop evidence-based recommendations/resources to improve clinical practice in order to ensure that patients get the best service possible and therefore, gain maximum benefit from NIV. This project is funded by the National Institute for Health Research (NIHR) and is supported by the MND Association. The first work package involved a systematic review which identified factors associated with optimal NIV use. The second work package involved carrying out two surveys which explored the role of MND care centres, respiratory professionals and the community team in supporting and delivering NIV to people with MND. The aim of the third work package is to explore the views of healthcare professionals on the earlier research findings from work packages 1 and 2 and will help determine how best to translate this knowledge into improved clinical practice. Work package 4 will use these findings to develop a series of recommendations/resources to help improve the way in which NIV is delivered.

Why am I being invited?

We are inviting healthcare professionals who recommend, support and/or deliver respiratory care and NIV to people with MND in hospitals, hospices and at patient's homes. We are also inviting other stakeholders from third-party organisations (e.g., representatives from the MND Association).

What will the study involve?

Participation will involve attending one focus group with other healthcare professionals and representatives from the MND Association. The discussion will be facilitated by a member of the research team. It will consist of approximately 8-10 people, will be audio-recorded and will last approximately 2 hours. We will briefly present our

research findings from the earlier phases (from the systematic review and surveys explained above).

You will then be asked to give your views on the findings and think about them in relation to your own professional practice and experience. We will then explore the group's views on the implications of these findings and what could, or should, be done to translate these findings into improved clinical practice.

Do I have to take part?

No, taking part in this study is completely voluntary and you can withdraw your participation at any time before and during the focus group. . If you choose to withdraw after the focus group has started, information already collected from you will still be used. You are welcome to ask the researchers if you have any questions before deciding to take part.

What are the benefits and disadvantages of taking part?

We cannot promise that this study will benefit you. However, you will be given the opportunity to hear about our earlier findings and be able to share your views on them. You will also be given the opportunity to provide ideas on how best to translate these findings into improved clinical practice. We hope to use these findings to develop resources to help improve clinical practice to ensure that patients get the best service possible. This can have potential positive implications for patient survival and quality of life.

We expect there to be minimal burdens involved in taking part in the study. You will have to give up some of your time to attend the focus group. However, reasonable out-of-pocket travel expenses (e.g. a 2nd class rail ticket to your nearest venue) will be reimbursed and you are able to leave and withdraw at any time during the focus group.

How will you use my information and will it be kept confidential?

Sheffield Teaching Hospitals NHS Foundation Trust is the sponsor for this study based in the United Kingdom but will not have access to personal identifiable information. The University of Sheffield 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 they are responsible for looking after your information and using it properly.

The University of Sheffield will collect information from you for this research study in accordance with our instructions. You will be asked to indicate whether you would like to keep your contract details on file for future contact about the wider study. If you agree to future contact, the University of Sheffield will keep your name and contact details confidential and will not pass this information to Sheffield Teaching Hospitals NHS Foundation Trust. The University of Sheffield will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. The

University of Sheffield will keep identifiable information about you for up to 2 years after the study has finished.

All of the information that we will collect will be kept confidential. Only members of the research team and a trusted transcriber will have access to the information. All research data will be stored in a folder on the University's secure X: drive. Data will only be accessed on the University of Sheffield computers which are password protected. The forms used to collect demographic information and the consent forms will be scanned and uploaded onto the secure X: drive and the paper copies will be destroyed. These documents will be stored separately to the transcriptions. The field notes taken during the focus groups will be typed up and/or scanned and anonymised, and the paper copies will be destroyed. The focus groups will be audio-recorded. The audio-recordings will be transcribed verbatim and anonymised. Your responses may be used in reports of the research. However, your responses will be anonymised using simple coding such as by profession (e.g. respiratory professional 1, 2, 3 or community professional 1, 2, 3 etc.). The research team will use their discretion when reporting the results. If a response is identifiable then pseudonyms will be used to omit identifiers e.g. place of work or names of colleagues. A list of the codes will be kept alongside identifiable information until analysis is complete. Following this, the list will be destroyed. The transcripts will be read alongside listening to the audio-recordings before the audio-recordings are destroyed.

Anonymous data will be retained for 10 years after the final publication is complete. Anonymous data will also be made available for other approved research. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you such as insurance.

Certain individuals from Sheffield Teaching Hospitals NHS Foundation Trust and regulatory organisations may look at the research records to check the accuracy of the research study. Sheffield Teaching Hospitals NHS Foundation Trust will only receive information without any identifying information.

If any issues are identified by the research team, these will be reported to the chief investigator and co-investigators. If judged to be a serious risk to patient safety and we are able to identify the site, we will report the information to the senior clinician in charge of the unit but we will not identify the person who said it to maintain their anonymity.

What happens if I have a complaint?
Any complaints should be addressed to the chief investigator of the study, Professor Christopher McDermott in the first instance:

Professor Christopher McDermott
Sheffield Institute for Translational Neuroscience
University of Sheffield
385a Glossop Road
Sheffield
S10 2HQ

Email: c.j.mcdermott@sheffield.ac.uk

If complaints cannot be resolved, then you can contact the sponsor of the study:

Clinical Research and Innovation Office
Sheffield Teaching Hospitals NHS Foundation Trust
D49, D Floor, Royal Hallamshire Hospital
Glossop Road
Sheffield
S10 2JF

Telephone: 0114 226 5938

Who is organising and funding the study?
The programme of research is funded by a NIHR Programme Grant for Research for Patient Benefit (RfPB). The study is organised by the University of Sheffield.

Who has reviewed the study?
The study has received approval from the University of Sheffield.

Timescale
This part of the research project is expected to take place for approximately 5 months starting in May/June 2019.

Further information
Please ask the research team:

Research assistant: Lucy Musson
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