



MND Register
CARE-MND

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We would like to invite you to participate in the Scottish MND Register.

The purpose is twofold:

1. To record basic information about the diagnosis and care journey of people with MND. This is necessary to improve the quality and timeliness of care provision.
2. To offer people living with MND the opportunity to participate in research, including clinical trials to test potential new drugs.

Research and audit findings from the register have already resulted in some changes to practice and have helped local care teams deliver higher standards of care (eg. more timely interventions to improve quality of life, an increase in the number of specialist care team members). Ongoing audit through the register means we can ensure continuous measurement and improvement of care provision for people living with MND.

It is important to emphasise that volunteering to be on the Register does not in any way influence your routine care. Similarly you can be on the register and not participate in any research studies. You do not need to give any reasons for your decisions. There is no obligation whatsoever to participate in research. If you do agree to receive research information, it is important to note that some research projects can be undertaken at your home, without the need to travel.

Please read the information sheet carefully and do contact us if you have any questions. Once you are satisfied that your questions have been answered please complete the form with the relevant option ticked, along with the consent form. If you would like more time to consider your involvement, or to ask further questions, please take your time, and return the form in the enclosed envelope.

The Register is part of the **Clinical Audit Research Evaluation-MND (CARE-MND)** project which is based at Edinburgh University (www.care-mnd.org.uk).

Thank you for your consideration.

Yours faithfully,

Shuna Colville
Research Project Manager

Suvankar Pal
Consultant Neurologist

Siddharthan Chandran
Consultant Neurologist



MND Register - Participant information sheet

What is the purpose of the Register?

The purpose of the Register is to improve quality and equity of care across Scotland and to enable research and clinical trials. The register was established in response to many approaches from patients and health care professionals enquiring about standards of care and crucially a strong desire to participate in research studies and clinical trials. A national register is the standard and best method of ensuring these clinical and research needs are met. Scotland is also ideally placed to be a leader in this area due to the infrastructural strengths of NHS Scotland and the network of dedicated MND Clinical Specialists.

Why have I been approached?

The clinical care teams approach all people who have been diagnosed with motor neurone disease. If you require any further information we would be happy to answer your questions, our contact details are at the end of the document.

Do I have to take part?

No, and if you choose not to be included in the register this will not have any influence on your clinical management. You are also free to withdraw from the Register at any time without providing a reason.

What do I have to do?

You need to read this information sheet carefully and ask any questions that you feel you need to (our contact details are below). When you are satisfied that your questions have been answered you can complete the consent form and information form and return them in the envelope provided.

Are there any risks or disadvantages of taking part?

There are no risks or disadvantages to being included in the Register.

What are the possible benefits of taking part?

You will receive information about research projects as they arise. You can then decide whether or not to participate in any of them. There are no financial benefits to being on the Register.

Will my taking part in the Register be kept confidential?

Your medical records will be viewed by the research team to classify diagnosis and to research quality of care. All data / records are anonymised by a unique study number. Personal or identifiable data will never be disclosed to anyone outside the core research team based at the University of Edinburgh. All details will be kept securely on an NHS approved system within Edinburgh University and situated at the Western General Hospital, Edinburgh. If you agree, your GP would be informed of your consent to being on the Register. If you agree, we can tell you about future research studies including clinical trials that you may be interested in taking part in.

What if there are any clinically relevant findings from the research project?

If any clinically relevant findings become apparent as a result of this research (for example something that can be treated and has so far gone unnoticed, or there are questions about your diagnosis) this will be fed back to your clinical care team for them to action if relevant.

Do other researchers access my identifiable information?

Some studies may include completion of anonymised questionnaires ie no identifiable data is involved. Other studies may involve face to face interviews or tests which do require the external researcher to know who you are. Even here it is important to highlight that no identifiable information will ever be in the public domain or provided to third parties. Nonetheless to ensure that you are in control at all times of whether you participate in research we have put in place the following process.

External researchers will **not** approach you directly.

- All requests to use the Register to identify potential research participants are first evaluated by the Register Management Committee comprising Professor Siddharthan Chandran, Dr Suvankar Pal and Shuna Colville to ensure that the research is appropriate and ethically approved.

- If deemed suitable study information (project invitation letters and information sheets) will then be sent by the MND Research team to potential participants who have already indicated that they wish to receive information about future studies.

Confidential details are not released by the MND research team to other researchers without your permission.

What happens to the results of the Register?

The results of individual research projects will be presented at academic meetings and published in academic medical journals. This will always (see above) be anonymised. In other words your personal details will never be identifiable. A summary of the results, when available, will be published in the quarterly MND Scotland publication, Aware. If you would like to receive a summary of the results please let us know by contacting us (address supplied below).

Who is organising the research?

The Register is organised by a team of researchers based in Scotland and is part of the **Clinical Audit Research Evaluation-MND (CARE-MND)** project. The research does not involve medical or pharmaceutical companies. The researchers are not paid to recruit patients into the Register.

Who has reviewed the study?

The study has been reviewed by Scotland A Research Ethics Committee and externally peer reviewed by MND Scotland's research panel.

What if there is a problem?

All core research staff are covered by NHS contracts and the NHS public liability insurance. We do not anticipate any problems with this study but if you do have a complaint, please report this using the standard NHS Lothian Complaints Procedure (0131 558 3681).

Is there anyone I can speak to about this study who can offer me independent advice?

If you have any questions needing independent advice, please contact: Dr Peter Connick (Consultant Neurologist), 0131-465-9500, email: pconnick@exseed.ed.ac.uk

Contact for further Information:

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