



THE UNIVERSITY of EDINBURGH



Rowling CARE

Participate and shape future research in Neurological conditions in Scotland

1. Introduction

As a carer/relative of someone with a neurodegenerative condition you are being invited to consider giving your consent to be part of Rowling CARE (Clinical, Audit, Research, Evaluation). Rowling CARE is a research database and registry for those interested in taking part in future research studies (involving carers/relatives), and helping to shape research studies and improve care. Before you decide if you'd like to be involved it is important for you to understand why we have this database and what consenting to be part of it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for reading this.

2. What is the purpose of Rowling CARE?

Rowling CARE is an electronic record of routinely collected medical data (healthcare data) from people with neurological conditions. This allows us to conduct research, identify research projects that are relevant to individuals, and to identify people who can help shape future research. Such a collection of data is called a registry. As part of Rowling Care we would also like to invite carers/relatives to register so that their views and experiences can be included, and relevant opportunities for carers/relative research are made available to you.

Rowling CARE has been developed in response to requests by our attendees at the Rowling Clinic, people with neurological conditions throughout Scotland and clinicians to increase the opportunities for active involvement in research. It offers carers/relatives the the option to contribute in the following ways:

- **The opportunity to hear directly about research opportunities**
Participating in research requires awareness about the projects that are relevant to you, together with access to the information needed to make an informed choice. **Rowling CARE allows you to tell us whether you would like to hear directly from us about research projects that you may be eligible to participate in.**
- **The opportunity to shape future research**
Our researchers design and lead world-class clinical research. However, the people best placed to tell us how to do even better research are our patients and their carers/relatives. **Rowling CARE allows you to tell us whether you would like to help shape the design and implementation of our next generation of research projects.**



3. Why have I been invited to take part in Rowling CARE?

Rowling CARE is available to people living in Scotland who are a carer/relative for someone who meets at least one of the following criteria:

- A person living in Scotland with or under investigation for, a neurodegenerative condition such as Motor Neurone Disease, Multiple Sclerosis, Parkinson 's disease, Young onset Dementia (or any other neurodegenerative condition not listed)
OR.
- A person who attends or has a booked appointment to attend at The Anne Rowling Regenerative Neurology Clinic

4. Do I have to take part?

No, and if you choose not to join Rowling CARE this will not have any influence on the clinical care of the person you know with, or under investigation for, a neurodegenerative condition. You are also free to withdraw from the register at any time without providing a reason.

5. What will happen if I take part in Rowling CARE?

Participants are asked to provide consent for the use of their anonymised data in the following ways:

Using and sharing of data for research

- Use of non-identifiable data for research (by the Rowling CARE research team)
- Sharing of non-identifiable data with other researchers for research purposes.

Direct contact about participation in research activities

- Contact about research studies that may be of interest
- Contact to assist in the design and implementation of future research projects
- Contact to invite membership of focus or consultation groups

Participants can select whether they wish to receive direct contact about participation in research activities.

Your level of involvement (responses to the options above) is entirely voluntary and is at your discretion. You can change your mind at any time – if you would like to be more or less involved, or removed from Rowling CARE – all you need to do is to contact us at the address below.

6. What are the possible benefits of taking part?

Rowling CARE offers the opportunity to contribute to research, learn about research projects that you may wish to participate in, and/or to get involved with the design and management of research projects.

7. What are the possible risks or disadvantages of taking part?

We take every possible measure to ensure data security, including compliance with all standards that apply to data held in NHS Scotland. We comply with all audits to ensure data governance is adhered to. No identifiable data (e.g. your name, contact details or date of birth) is released to researchers out with the small core team.



8. What if there is a problem?

If you have a concern about any aspect of this study please contact Mrs. Dawn Lyle (contact details below) who will do her best to answer your questions. In the unlikely event that you wish to take the complaint further the normal National Health Service complaints mechanisms will still be available to you (if appropriate).

9. What happens when the study is finished?

Rowling CARE is an ongoing project that will continue for the foreseeable future.

10. Will my data be kept confidential?

All the information we collect during the course of the research will be kept **confidential**. Where we have consent, the University of Edinburgh/NHS will collect information about you for research and audit purposes. We will not provide any identifying information about you. We will use this information in line with current General Data Protection Regulation (GDPR).

Details that could identify you will only ever be seen by our core clinical research team; no identifiable information will ever be shared with other researchers out with the core team. To ensure that the study is being run correctly we may be audited and so will also ask your consent for responsible representatives from the Sponsor (University of Edinburgh) and NHS Lothian to access the data collected in Rowling CARE.

11. What will happen to the results of the study?

Results from Rowling CARE research will be written up as scientific papers and published at specialist conferences and meetings. **You will not be identifiable in any published results.** We will also provide updates on research facilitated by Rowling CARE through the Anne Rowling Clinic website and newsletter.

12. Who is organising Rowling CARE and why?

Rowling CARE has been organised by the Anne Rowling Regenerative Neurology Clinic and is sustainably funded internally.

13. Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. A favourable ethical opinion has been obtained from Scotland A REC. NHS management approval has also been obtained.

If you have any further questions about Rowling CARE, please contact:

Dawn Lyle (Rowling CARE), The Anne Rowling Regenerative Neurology Clinic, 49 Little France Crescent, Edinburgh, EH16 4SB. Tel: 0131-465-9517. Email: anne.rowling.clinic@ed.ac.uk

If you would like to discuss Rowling CARE with someone independent of the study please contact:

Please contact: Dr Peter Foley, Consultant Neurologist, The Anne Rowling Clinic, 49 Little France Crescent, Edinburgh, EH16 4SB; Tel: 0131 465 9517.

If you wish to make a complaint about Rowling CARE please contact NHS Lothian:

NHS Lothian Complaints Team: 2nd Floor, Waverley Gate, 2-4 Waterloo Place, Edinburgh, EH1 3EG, Tel: 0131 465 5708, Email: craft@nhslothian.scot.nhs.uk

