

How to get involved

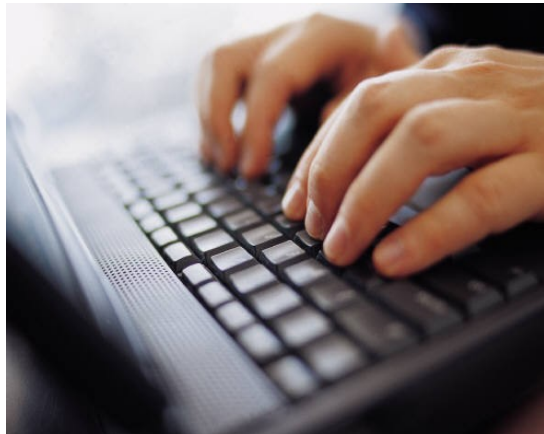
Clinicians

If you wish to encourage your patients to sign up to the register, please contact us at the address / telephone number provided and we will be happy to give you details of the case register protocol. We will provide patient and carer information leaflets about the case register and permission slips for you to pass/send to your patients.

Researchers

If you are considering recruiting cases from the NEURODEM Cymru Research Case Register we advise you to write this into your protocols for ethical approval. To identify potential participants from the case register, please contact us for a patient identification form in order to investigate this process. All requests for patient information/ identification will be reviewed by the executive management team, to ensure the required approvals are in place.

Please do not hesitate to contact us



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Research Case Register

Clinician and Researcher Information sheet



www.neurodemcymru.org

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Welcome to NEURODEM Cymru

NEURODEM Cymru is one of the nine Thematic Research and Development networks for health and social care in Wales, which aims to encourage and facilitate high quality clinical trials and research studies for patients with all stages and types of dementia, or with neurodegenerative diseases such as Parkinson's disease. NEURODEM Cymru is a vital part of the new research and development infrastructure funded by the Welsh Assembly Government known as Clinical Research Collaboration Cymru (CRC Cymru).

Patient and Carer Case Register

For new treatments to be developed, patients and their carers and relatives need to be kept informed and offered opportunities to take part in research and clinical trials.

It is often difficult and time consuming for clinicians and researchers to identify suitable patients for a range of clinical trials and other studies. For this reason we are working closely with a number of clinics and inviting patients with dementia or other neurodegenerative diseases to join the NEURODEM Cymru Research Case Register which will serve as a clinical research resource.

How can the NEURODEM Cymru Case Register help clinicians/ researchers?

Staff working on the NEURODEM case register can help you with the following:

- Raising patient awareness and promoting a research culture in your clinics.
- Signing patients up to the case register.
- Identification of suitable patients from the case register for your academic research studies, collaborative research studies or for any NEURODEM Cymru studies/trials that you wish to participate in.
- Facilitating new research collaborations between clinicians in different areas.
- NEURODEM / CRC Cymru will do all the day-to-day management of the case register on your behalf.
- Additionally, we will send out annual newsletters to all clinicians, patients and carers involved.

What happens to my patients if they sign up for the register?

When we become aware that one of your patients has signed a case register consent form to state that they are happy to be contacted about research, we will send you a copy of this for your records. We will keep a record of the dates and names of the trials/studies discussed with each patient in order to avoid overloading individuals with repeated requests.

Data protection, consistency, and confidentiality.

All data we collect will be stored securely on a password protected database with restricted access to a few NEURODEM/ CRC Cymru staff. We will maintain consistency of consent and data by re-contacting patients periodically to check that they or their relatives still wish to be on the register. All data collected will be kept completely confidential and will be handled in accordance with the Data Protection Act 1998.

An essential part of the register is the processing of data in an anonymised manner to ensure that nobody other than the authorized staff of NEURODEM/ CRC Cymru can trace back the identity. Before the data is entered on to the database, the patient is given a unique register number. No details which could identify the patient are saved on the database.

