

The **MND Register of England, Wales and Northern Ireland** is the first comprehensive source of information collected by healthcare professionals about people with MND.

We have received approval under section 251 of the NHS Act 2006 to allow authorised healthcare professionals to collect patient data without seeking consent from each patient to help us understand more about MND. Under this exemption your data will be collected at your local MND clinic unless you choose to opt out.

Why are you collecting my data?

- To count how many people currently have the disease as this is unknown
- Establish where people with MND live, to help improve care in those areas
- Collect detailed information to detect changes in rates of MND over time
- Identify best practice and improve patient care and outcomes

What data is collected?

Your name, gender, date of birth, diagnosis, postcode, care and treatment you receive are collected from your medical records by a trained healthcare professional at your local MND clinic. A full list of the data we collect can be found here <https://mndregister.ac.uk/about>.

What happens to my data and how is it protected?

A trained healthcare professional at your local MND clinic transfers your data via secure coded NHS email to the MND Register team. Your data is then stored on a secure platform at King's College London accessed by two members of the MND Register team for data cleaning, analysis and is used for research purposes. Some of your identifiable data (name, DOB, NHS number, gender and postcode) in the MND Register database are used to link to other healthcare information held by NHS Digital, NHS Wales Informatics Service and the Office for National Statistics. This enables us to look at care and access to services patients receive across England and Wales. We may also receive requests from other MND researchers who wish to obtain a copy of your de-identified data (data that does not identify who you are) to learn more about MND. This will include researchers outside the UK who would receive your data in an anonymised format and would be unable to identify you. For more information please view our privacy notice <https://mndregister.ac.uk/about>.

What if I do not want to have my data included?

If you wish to be excluded from the MND Register please contact the MND Register team by email mndregsiter@kcl.ac.uk / emma.harper@ndcn.ox.ac.uk or by telephone 0207 848 5258. Opting out does not impact your treatment or the standard of care you receive.

The MND register is run by King's College London and Oxford University and supported by the below funders and a family trust that wishes to remain anonymous.

