

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

Why are you collecting my data?

- To count how many people currently have the disease as this remains 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?

Only your de-identified data (data that does not identify who you are) will be collected from your medical records by a trained professional at your local MND clinic and entered into a database. De-identified data includes your gender, year of birth, diagnosis, postcode district and any care and treatment you receive.

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.

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 policy <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 mndregister@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.

