MND Register Opt-out

I no longer want my data to be collected as part of the MND Register.

If you **do not wish** your data to be included in the MND Register you can **opt-out.** If you opt-out of us collecting your data, this opt-out will remain in place unless you change your mind.

Why is the MND Register important?

The MND Register is the first national resource collecting information about people living with motor neuron disease (MND) across England, Wales and Northern Ireland. MND affects around 5,000 people in the UK at any one time, yet there is no single source of information about who is affected, where they live, or how their care is delivered. By collecting this data, we can better understand how many people are diagnosed each year, how MND progresses, and how care can be improved. The Register supports vital research into the causes of MND and helps ensure healthcare services are planned around real patient needs. Every person's data makes a difference. For more information regarding our output and impact please visit https://mndregister.ac.uk/.

Does opting out affect my care and treatment?

Opting out will not affect the standard of care or treatment you receive in any way.

What happens to my data once I opt-out?

Once you opt-out any data collected and stored associated with your person will be deleted from the UK MND Register database both from KCL and Oxford University.

Please bear in mind that **if you choose to opt-out**, any data already collected and included in existing datasets outside of the UK MND Register cannot be removed or erased. This includes anonymised data that has already been shared with researchers or linked with other databases.

Some de-identified clinical information (where details that could directly identify you, such as your name, NHS number, or date of birth, are removed or replaced with a code to protect your privacy) may still be submitted as part of mandatory national audit requirements. However, the MND Register will no longer be able to identify you, link new information to your records, or use your data for any future research.

How can I opt-out?

If you wish to opt-out, you can contact the MND Register team using the contact information below.

Email: mndregister@kcl.ac.uk