UK Myotonic Dystrophy Patient Registry

What is a patient registry?

- Patient registries are databases containing information about individuals who are affected by a specific condition or genetic mutation.

Why do we need a registry for Myotonic Dystrophy?

- Finding enough people with Myotonic Dystrophy for clinical trials and research studies can take years, which can delay the testing of potential therapies.
- Patient registries enable people to be identified and contacted more easily.

Why should I register?

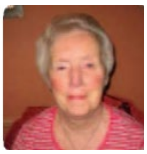
- Registering may open up opportunities to take part in **clinical trials** and **research studies**.
- The information you provide can help in the development of **care standards**, to help improve the care that yourself and others receive.
- The information can be used to allow doctors and researchers to understand more about **how myotonic dystrophy progresses** over time.
- The registry supports **specific research questions** that doctors and scientists may have about myotonic dystrophy.
- The registry provides a link to the **research community** (patients can receive newsletters, study results, updates on standards of care etc.)

The registry has supported over **27** research enquiries which includes helping get people involved with clinical trials, research studies and surveys from patient organisations.

Who can register?

- Anyone in the UK with a diagnosis of Myotonic Dystrophy (young people under 16 years of age must be registered by their parent/guardian).





Data Protection

- To view the data protection steps in place to protect your data please see: https://www.dm-registry.org.uk/general_information/data_protection/index.en.html for further information.

How do I register?

- To register please visit: https://www.dm-registry.org.uk/ and click 'Register now'. Alternatively if you scan this QR code by opening up the camera on your smartphone and hovering over this – it will take you to the registry homepage directly. If you have any questions please contact the registry curator and manager Helen Walker, at myotonicdystrophyregistry@ncl.ac.uk or the registry PI, Dr Marini-Bettolo at Chiara.Marini-Bettolo@ncl.ac.uk