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 you 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