

Who should register?

This registry is for patients living in the United Kingdom who are affected by Myotonic Dystrophy (DM1, Curschmann-Steinert or DM2, Proximal myotonic myopathy 'PROMM').



How do I register?

You can register online and create an account so that you can view and update your information at any time.

Register at www.dm-registry.org.uk

What if I change my mind?

Participation is completely optional, and you can withdraw at any point. Please contact: myotonicdystrophyregistry@newcastle.ac.uk if you have any questions about participating



For more information about the UK Myotonic Dystrophy Patient Registry please visit www.dm-registry.org.uk



SCAN ME
visit registry website



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The UK Myotonic Dystrophy Patient Registry: For patients living with Myotonic Dystrophy in the United Kingdom



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Thanks and acknowledgement to our funders:

What is the UK Myotonic Dystrophy Patient Registry?

Patient registries are databases containing information about individuals who are affected by a specific disease. The UK Myotonic Dystrophy (DM) Patient Registry is a patient-initiated, clinically supported national platform, collecting data from myotonic dystrophy patients. Established in May 2012, the registry is run by the John Walton Muscular Dystrophy Research Centre at Newcastle University.

How will my data be used?

Healthcare professionals and pharmaceutical companies conducting clinical trials in the UK can seek assistance from the UK Myotonic Dystrophy Patient Registry to identify individuals who may qualify for participation in a specific study. Additionally, the registry's data may be utilized to support scientific research aimed at enhancing understanding of Myotonic Dystrophy. Personal identifiable information, however, will never be disclosed.



Why should I join the registry?

Registering via our secure online website allows you to:

- Share information on your symptoms, trial preferences, access to care and support
- Answer questionnaires on our improved registries platform
- Nominate your neuromuscular consultant or other care providers to add important clinical data
- Receive information about clinical trials you might be able to participate in
- Provide essential information to support DM research

What information do we collect?

We collect personal information, including name, address, date of birth, NHS number, and the healthcare facility where you or your child receive treatment. Additionally, we gather details about genetic diagnosis, motor abilities, wheelchair usage, medications, and preferences regarding participation in research.

Is my data safe?

The details you provide about yourself or your child on the registry's online platform are securely stored on a GDPR-compliant server and kept strictly confidential. Access to this information is restricted to authorized members of the registry team.

Additionally, the registry operates under the oversight of an ethics committee and a Steering Committee, which includes researchers, healthcare professionals, and patient representatives. These committees ensure that all research collaborations adhere to strict ethical and regulatory standards.

Can I have more information about the registry?

Yes, please scan the QR code, or type in the address below to fill out a form and we'll send you more details.



www.bit.ly/UKDMREGINFO