Resource Summary Report

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Neuromuscular disease outcome measures

RRID:SCR_006267
Type: Tool

Proper Citation

Neuromuscular disease outcome measures (RRID:SCR_006267)

Resource Information

URL: http://www.researchrom.com/

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Description: ROM is an on-line Registry of Outcome Measures and associated tools designed to give guidance, information and assistance to international collaborative teams of reviewers undertaking the crucial task of choosing the right outcome measures (OMs) for neuromuscular disease trials and studies. It is also hoped that the Registry will reduce duplication of effort in this area. Outcome measures are the tests that investigators perform to decide whether a treatment being tested in a clinical trial is having any effect. These can come in many different forms from assessing how far a patient can walk in six minutes to looking at changes in their muscle through a biopsy and using the right outcome measure is a vital step in making sure a trial can really prove whether or not a treatment works. The searchable Registry contains information about OMs, such as a description, details of validation, availability, contact details for providers, and references to related documents including manuals and training videos. Review teams can record OMs by category as being considered for a specific study or trial and benefit from seeing the OM choices being considered by other review teams. A manual gives advice on how to assess and select OMs. Information contained in ROM may also prove useful to doctors, clinicians, physiotherapists, industry and other organizations with an interest in OMs relevant to NMD research.

Abbreviations: ROM

Synonyms: TREAT-NMD: Registry of Outcome Measures, TreatNMD Outcome Measure Registry, Registry of Outcome Measures

Resource Type: data or information resource, database

Keywords: assessment, spinal muscular atrophy assessment, duchennes muscular dystrophy assessment

Resource Name: Neuromuscular disease outcome measures

Resource ID: SCR_006267

Alternate IDs: nif-0000-06700

Record Creation Time: 20220129T080235+0000

Record Last Update: 20260729T044132+0000

Ratings and Alerts

No rating or validation information has been found for Neuromuscular disease outcome measures.

No alerts have been found for Neuromuscular disease outcome measures.

Data and Source Information

Source: SciCrunch Registry

Usage and Citation Metrics

We found 3 mentions in open access literature.

Listed below are recent publications. The full list is available at T1D .

de Groot IJ, et al. (2013) 184th ENMC International Workshop: pain and fatigue in neuromuscular disorders: 20-22 May 2011, Naarden, The Netherlands. Neuromuscular disorders : NMD, 23(12), 1028.

Mercuri E, et al. (2011) Choosing the right clinical outcome measure: from the patient to the statistician and back. Neuromuscular disorders : NMD, 21(1), 16.

Thompson R, et al. (2009) Patient Registries and Trial Readiness in Myotonic Dystrophy--TREAT-NMD/Marigold International Workshop Report. Neuromuscular disorders : NMD, 19(12), 860.