



AUTHORSHIP POLICY

This document describes the guidelines for the publication of work generated using any of the data stored on the EURO-NMD Registry. It applies to all individuals requesting to use and wishing to publish any form of publication based on data that have been provided to the EURO-NMD Registry, including (but not limited to) manuscripts, abstracts, posters and presentations.

This policy does not apply to site-specific data and, as such, contributing hospitals are free to publish their own data at any time with acknowledgement of the EURO-NMD Registry as per section below.

Acknowledgement

The EURO-NMD Registry should be acknowledged in any form of publication using data provided by the EURO-NMD Registry using the following wording:

This study makes use of data provided through the EURO-NMD Registry, which received funding from the European Union's Health Programme (2014-2020) under grant agreement No. 947598. The EURO-NMD Registry is an initiative of the European Reference Network (ERN) for Rare Neuromuscular Diseases (EURO-NMD), funded by the European Commission under the EU4Health programme and coordinated by Assistance Publique - Hôpitaux de Paris (AP-HP).

In recognition of the effort that data contributors made in collecting and providing the data to the Registry, it is also a requirement to acknowledge contributions to the data collection. Where possible, publications based on data held by the Registry will include a list of local site Principal Investigators (PIs) from hospitals participating in Registry, as part of a study collaborators list if they have not been involved as co-author.

Authorship criteria

Authorship on scientific publications emerging from registry data may be required when investigators associated with contributing hospitals make substantial contributions to a published study. Authorship credit should be based on the International Committee of Medical Journal Editors (ICMJE, <http://www.icmje.org/>)

The ICMJE currently recommends the following criteria for authorship credit:





1. Significant involvement in study conception/design, data collection, or data analysis/interpretation;
2. Involvement in drafting or revising manuscript;
3. Approval of final version of manuscript for publication; and
4. Responsibility for accuracy and integrity of all aspects of research.

Authorship may be granted to at least one representative from centres that have contributed data to the Registry within the period covered in a proposed study, this may be done through a group authorship, e.g. the “EURO-NMD registry investigator group”. The EURO-NMD unit lead will be invited to participate and/or to nominate a member of their team to be part of the writing committee for that paper and therefore qualify for co-authorship. To ensure co-authorship status, everyone who agrees to participate on the writing committee must make valuable contributions to the study consistent with ICMJE authorship guidelines. Centre designated co-authors who are unable to meet the obligations of authorship will be named in the Acknowledgement.

Typically, one or two potential authors would be selected per centre, but the number of selected authors will depend on the size of the study and the number of centres. When necessary, the criteria for defining the number of co-authors per centre will be the number of included patients; e.g. if a centre is among the five centres with the largest numbers of cases in the study or contributes 10% or more of the cases. In special cases, only centres that contributed data for substantial numbers of patients meeting the eligibility criteria for a study will be solicited to join the Writing Committee.

The sequence of listing of the co-authors will follow the number of included patients in the publication per site; otherwise, authorship ranking will be based on the value and extent of contribution to the manuscript. If the number of authors is restricted by a journal, authorship may be attributed to the “EURO-NMD Registry” with authors names explicitly identified anywhere else in the text of the article as the members of the writing group for the article.

For studies which had been proposed by investigators from participating hospitals, two co-authorships will be accepted from the investigating centre which submitted the data request. The principal investigators should be appointed as the first author. Only active investigators (minimum 50 complete documented entries) may submit data requests for projects intended for publication.

If hospitals wish to publish comparisons of local hospital data with the Registry published data (including data published in the Registry annual report) then the EURO-NMD Registry must be acknowledged in the appropriate way as described above.

Investigators who uniquely use data published on the EURO-NMD website may do this without co-authorship with centres investigators as long as they reference correctly the EURO-NMD Registry website.

