

Appendix 7: Publication & Authorship Policy

Public reference copy of Appendix 7 to the EURO-NMD Registry Data Sharing Agreement as amended by Amendment No. 2. The executed Agreement remains authoritative.

This Policy establishes the rules governing publications, presentations, abstracts, posters, manuscripts, and other dissemination activities arising from the use of Registry Data.

It applies to all individuals and organisations that access or use Registry Data and intend to publish, present, or otherwise disseminate Results derived from such data.

The objectives of this Policy are to:

- ensure appropriate acknowledgement of the EURO-NMD Registry and participating HCPs;
- promote transparency, fairness, and scientific integrity in the attribution of authorship;
- encourage collaboration among contributing investigators and institutions; and
- ensure that publications arising from Registry Data are conducted in accordance with internationally recognised standards of scientific authorship and good research practice

This Policy does not apply to data held exclusively by an individual HCP outside the Registry. Contributing HCPs remain free to analyse and publish their own local data, provided that any use of Registry Data is conducted in accordance with this Policy and that the EURO-NMD Registry is appropriately acknowledged where applicable.

1. Acknowledgement of the Registry

The EURO-NMD Registry shall be acknowledged in any publication, presentation, abstract, poster, manuscript, or other dissemination activity arising from the use of Registry Data using the following acknowledgement statement:

This study makes use of data provided through the EURO-NMD Registry, an initiative of the European Reference Network for Rare Neuromuscular Diseases (ERN EURO-NMD). The Registry was established with support from European Union funding programmes.

In recognition of the contribution made by participating HCPs to the collection and maintenance of Registry Data, publications should, where appropriate, acknowledge the contributing institutions and investigators. Where contributors do not meet the criteria for authorship, they may be recognised as collaborators or acknowledged in accordance with the publication requirements and journal policies.

2. Authorship criteria

Authorship of scientific publications arising from Registry Data shall be determined in accordance with the recommendations of the International Committee of Medical Journal Editors (ICMJE).

To qualify for authorship, an individual must satisfy all of the following criteria:

- (i) substantial contributions to the conception or design of the work, or to the acquisition, analysis, or interpretation of data;

- (ii) drafting the work or critically revising it for important intellectual content;
- (iii) final approval of the version to be published; and
- (iv) agreement to be accountable for all aspects of the work and to ensure that questions relating to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

3. Eligibility

- Authorship may be granted to at least one representative from centres that contributed data to the Registry within the period covered by a given study.
- Only active investigators (defined as having submitted at least 50 complete patient entries) are eligible to submit data access requests for projects intended for publication and to be considered for authorship on publications arising from Registry projects, provided they also meet ICMJE criteria.
- All investigators from contributing HCPs, whether ERN Members, Affiliated Partners, or non-ERN centres that have acceded to the Registry, shall be entitled to the same authorship opportunities, provided they meet the ICMJE criteria and the conditions set out in this Policy.

4. Writing Committee and Authorship Attribution

Unit leads from contributing centres will be invited to participate and/or to nominate a team member to join the Writing Committee.

To qualify for co-authorship, nominated individuals must contribute meaningfully in accordance with ICMJE criteria. Those who do not meet the criteria will be acknowledged as collaborators.

Typically, one or two potential authors may be selected per centre, depending on the size of the study and the number of centres involved. Where needed, the number of authors per centre will be weighted according to contribution; e.g. centres in the top five for patient numbers or contributing $\geq 10\%$ or study cases.

In some cases, only centres that contributed data meeting the eligibility criteria for a study will be solicited to join the Writing Committee.

Authorship order will reflect both intellectual contribution and, where relevant, the scale of data contributed. ICMJE criteria always take precedence.

When journals impose limits on the number of authors, group authorship under “EURO-NMD Registry Writing Committee” may be used, with individual names listed elsewhere in the manuscript or supplementary materials.

5. Studies Initiated by Contributing HCPs

For studies initiated by investigators from participating HCPs, up to two authorships may be allocated to the lead centre, with the PI typically listed as the first author. Additional contributors from the same centre may be listed in the collaborator section or acknowledged, unless they have played a significant role in study design, analysis, or manuscript drafting, in which case they may be considered for additional authorship in line with ICMJE criteria.

6. Use of Published Registry Data and Publication of own data

HCPs may publish comparisons of their local hospital data with published Registry data (including data published in the Registry's annual report), provided the Registry is properly acknowledged.

Investigators who solely use data already published on the EURO-NMD website may do so without involving centre investigators as co-authors, provided proper citation is given.