



International Niemann-Pick Disease Registry Publication Policy

Purpose

This document outlines the process of acknowledging contributors to the INPDR for publications in accordance to the International Committee of Medical Journal Editors (ICMJE) guidelines. This guidance is applicable to all publications generated by INPDR data, including peer-reviewed manuscripts, abstracts, posters and oral presentations at scientific or medical meeting. This Publication Policy applies to all involved in the production of any INPDR publications, including INPDR partners. All INPDR publications will be the output of a Publication Project (PP). Centres contributing significant data to the INPDR must be part of a PP.

Selection and Order of Authors

The main intention of all authors should be to produce a publication that meets the highest standards of scientific research. Authors must confirm their adherence to the INPDR Publication Policy in writing by signing an Authorship Agreement Form (Appendix 1) prior to the PP commencing. The selection of authors should be outlined at the start of any PP. The INPDR Scientific Advisory Committee will review and approve PP authors before work commences. In certain circumstances where additional expertise is required, additional authors may be recruited to an ongoing PP.

Author selection and order, including first, last and corresponding author, should be agreed by all participants via i) a face-to-face meeting (where convenient), ii) a PP kick-off teleconference or iii) email. Factors to be considered when determining author selection and order include (but not limited to): contribution of data to the INPDR, conception or design of PP, analysis or interpretation of data, speciality of author to meet PP requirements, geographic representation of author and contribution of time and effort to PP. The author order may be modified during the PP to reflect actual author contribution. In instances where author order is in dispute, the first and last author will lead discussions and make the final decision.

International Niemann-Pick Disease Registry

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INPDR is a registered charity in England and Wales: 1175311.



Applicants submitting an PP can be from any background, including (but not limited to) members of the INPDR, clinicians, researchers, patient advocates, members of industry and regulators. All authors must be able to commit to the PP. If an author is unable to meet PP commitments or timelines, the author must notify the first and last author who will work with the author to remedy the situation. Where an author is unable to commit to a PP after work has commenced, they may be asked to renounce their involvement in the PP.

Statement of Guidelines

Authorship of all publications within the scope of this guidance will be determined according to the principles set forth in the “Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals” (ICMJE Recommendations), as may be established by the ICJME. In addition, editorial rules and disclosure requirements from a journal where a publication is proposed to be published should also be taken into account.

The ICMJE Recommendations outline the ethical principles and best practices in conducting and reporting medical research and provide recommendations on the editing and writing of medical research to allow for accurate, clear, reproducible and unbiased medical research publications. A summary of the ICMJE Recommendations are as follows:

- Authorship based on meeting the following four criteria: 1) Substantial contribution towards the conception or design of the work; or the acquisition, analysis or interpretation of data; 2) Drafting the work or revising it critically for important intellectual content; 3) Final approval of the publication; 4) Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.
- Obtaining funding, collecting data or general supervision of a research group is not sufficient for authorship
- Individuals within a large, multi-centre group should be identified as having direct responsibility for the work
- The order of authorship on the by-line should be a joint decision between all co-authors. Authors should be prepared to explain the author order.
- All contributors who do not meeting authorship criteria should be listed in the acknowledgements. A contributor is an individual who has contributed any data used in the PP.
- Authors must disclose any known conflicts of interest that could influence their views or actions, whether in relation to a sponsor or any other third party, in line with journal requirements.
- The sources of funding for the publication work must be stated in the publication.

Where possible, all PPs will be submitted for presentation in high impact forums (international meetings, symposiums, conferences, workshops, patient and public involvement events, etc). For article publications, high impact, peer reviewed, Open Access journals will be targeted.



Unpublished Data

In certain circumstances, principal investigators (PI) who contribute data into the INPDR may delay use of data for PPs. Reasons for delaying access include principal investigators requiring a period of exclusive access for PI-led research where the data is being gathered and analysed for a non-INPDR research project (also known as First Rights). A PI can apply a temporary embargo to their data, including specific data fields, specific patients or all data associated with the PI. Any data that is subject to a temporary embargo will not be included in an PP until the temporary embargo has been lifted. The duration and nature of the temporary embargo will be negotiated between the PI and the INPDR via the SAC.

Publication Project procedure

1. Proposals for Publication Projects are submitted using the INPDR Publication Project (PP) form.
2. Once the complete PP form has been submitted, the INPDR Registry Management Team (RMT) will complete a feasibility assessment to ensure the PP can be supported by both the INPDR and the requestor.
3. Feasible PPs are escalated to the INPDR SAC who will review the PP to ensure the purpose of the PP aligns with the INPDR. The SAC may designate specific SAC members to review a PP if it falls within their area of expertise.
4. When a PP is approved, the PP will be formally established and a PP Working Group will be convened.
5. All PP authors will complete and sign the INPDR Authorship Agreement Form (Appendix 1.)
6. PP work will begin.
7. The PP Working Group and a member of the SAC who approved the PP will review and approve all publications prior to submission.
8. The corresponding author will coordinate the publication submission and notify co-authors of the publication submission status.
9. Once a publication has been accepted, a copy of the published manuscript will be shared to all co-authors and with INPDR Registry Management Team.

Appendix 1. Authorship Agreement Form

INPDR Authorship Agreement Form

<<DATE>>

This statement acknowledges that each undersigned author will make a substantial contribution to the manuscript and is willing to take public responsibility for its contents. Author(s) attest that all persons designated as authors qualify for authorship and all those who qualify are listed. The corresponding author takes responsibility for the integrity of the work as a whole, from inception to published article. The JNP follows the latest definition provided by the Uniform



Requirements for Manuscripts Submitted to Biomedical Journals (<http://www.icmje.org>): "Authorship credit should be based on 1) substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; 2) drafting the article or revising it critically for important intellectual content; and 3) final approval of the version to be published. Authors should meet conditions 1, 2, and 3." All others who contributed to the work but are not authors (if any) are named in the acknowledgements section of the manuscript.

Order of authorship	Name of Author	Institution Affiliation	Email address	Degree	Title
First					
Second					
Third					
Fourth					
Fifth					
Sixth					

* *Corresponding Author*

