



## Data Access Request Form

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Name of applicant undertaking data access request	
Email address	
Organisation of the applicant	
Is this a draft for discussion, or a complete proposal for approval?	
List of co-applicants / Project team including job title and affiliations	
Date of application	

Title of project	
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**International Niemann-Pick Disease Registry**

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+44 (0)191 415 0693 | [info@inpdr.org](mailto:info@inpdr.org) | Registered company in England and Wales: 10646129.  
INPDR is a registered charity in England and Wales: 1175311.

Aims of the project	
Method to be used (analysis plan and statistical methods) – indicating variables to be used (including outcome measures, co-variates)	
Study synopsis, including expected outcomes	
Key references	

Please highlight all data points (or questionnaire instruments) required for analysis (please use the attached excel spreadsheet to complete)		
If you are requesting any additional Data items to be collected by the INPDR please specify the population, the question and the timeframe over which you would like it to be collected as well as the rationale		
	<i>*you are recommended to speak with the Registry Management Team with regard to any requests for the INPDR to collect additional data</i>	

Would data generated from this request form part of a larger body of work? If so, please explain.	
Specify the extent to which any required ethical approvals are already in place, or yet to be obtained.	



Indicate titles, reference numbers and expiry dates if known.	
Identify any risks	
How will identified risks be managed?	
Please state any requests regarding data quality in the collection or cleaning prior to the delivery of this data. <b><i>The INPDR may not be able to accommodate these requests but this will be considered as part of wider data quality considerations in the processing of your application.</i></b>	

Time-frame of project	
What is the expected output format of this request? (Aggregated data extract, report, chart, presentation etc)	
Would the output of this request be considered for publication?	
Are all the required resources available for the project?	

Are there any supporting documents to be submitted for this request? Please list each document.	
Please declare any conflicts of interest (relating to any members of the study)	



team) including commercial relationships or funding	
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Please ensure that any support documentation is provided with this form

**Applicant declaration**

I declare that the above information is true and an accurate reflection of the work required for this request.

Name	
Date	
Signature	

**Scientific Advisory Committee review**

- The SAC agrees that this is a suitable project for the above applicant to undertake and therefore recommend the request be approved
- The SAC agrees that this is a suitable project requiring minor changes (please see comments) and therefore recommend the request be approved once the changes have been verified by the INPDR Registry Management Team.
- The SAC agrees that this project application requires major changes (please see comments) and recommends the request be rejected in its current form. The request can be revised by the applicant and resubmitted for further SAC review.
- The SAC agrees that this is not a suitable project due to major concerns (please see comments) and recommends the request to be rejected

Name	
Role	
Date	



**Board of Trustees Application outcome**

Approval with no change required	
Approval with minor change	
Significant revisions - resubmission required	
Approval not recommended due to serious objection	

**Board of Trustees declaration**

We authorize the above data request and for INPDR data extraction activities to begin.

Name	
Date	
Signature	

