

Terms of Reference
Project Management Committee
International Niemann-Pick Disease Registry (INPDR)



The Project Management committee (PMC) will monitor the objectives and outcomes of the International Niemann-Pick Disease Registry (INPDR) project to ensure delivery as planned, in due time and in budget.

To grant proper implementation of the partners respective rights and obligations in accordance with the contractual framework of the INPDR project and the Grant Agreement.

To assess risks which may impair progress towards the project objectives and suggest strategies to minimise risks whenever possible.

To review all requests by Research Partners to assess operational feasibility and priority for access, taking into consideration any recommendations made by the Scientific Advisory Committee (SAC).

The PMC meetings are chaired by the Project Leader. Up to 2 co-opted members can be nominated at the discretion of the Project Leader if they have expertise that will add value to the execution of the project. The Project manager shall provide administrative support to the meetings.

A minimum of 4 members are required and a maximum of 12. Members can be those involved in the project or can be nominated individuals. The quorum should represent a mix of scientists, clinicians, patient representatives and biochemists. Nominated individuals can be suggested by an existing member of the PMC and there should be a majority decision over the inclusion of the investigator.

The PMC shall meet via teleconference quarterly and at least annually face to face.

All decisions of the Committee will be circulated to all project members via the minutes.

Declaration of Acceptance by Project Management Committee member:

Please sign below to confirm your acceptance of the SAC terms of reference

Name:..... Date:

Signature: