

Terms of Reference  
Scientific Advisory Committee  
International Niemann-Pick Disease Registry (INPDR)



**1. Accountability**

The INPDR Scientific Advisory Committee (SAC) is accountable to The Executive Agency for Health and Consumers (EAHC) for the duration of the project (3 years to September 2016) and to the Project Management Committee.

**2. Scope and Duties**

The INPDR SAC will provide timely scientific, technical and clinical advice as well as provide impartial peer review of proposals for scientific excellence and recommendations for access to the INPDR. The SAC in partnership with the INPDR project management committee (PMC) will require evidence of national and local approvals before access is granted to the registry, and will review all potential studies for operational feasibility, determine priority, and have the final decision over fees and logistics.

The SAC will report to the PMC, who will provide support as necessary.  
All members serve on the SAC on a volunteer basis and will not be paid to sit on the committee.

**3. Membership**

At each meeting, Committee Members shall be required to declare any actual or potential conflict of interests, including involvement with other organisations and commercial interests relevant to current activities of the Committee. The coordinator and Chief Investigator will decide whether this outside interest requires the member to be excluded from the current activity.

The SAC should have a minimum of 10 members but not exceed 20.

Members of the SAC include associate partners and collaborative partners, and can also be recruited through targeted nomination. Members are identified from a broad array of sources such as health professional and scientific societies and should be nominated by one or more members of the SAC/PMC.

**4. Frequency of Meetings**

The SAC shall meet at least on an annual basis with interim teleconferences as required.

Meeting attendance is by invitation only. If the invitee cannot attend a representative can be nominated to attend. Members receive the agenda, briefing material and presentations in advance of the meeting with administrative support provided by the project manager.

**Declaration of Acceptance by Scientific Advisory Committee member:**

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

Name:..... Date: .....

Signature: .....