



TREAT-NMD Project Ethics Council (PEC) Terms of Reference

- The PEC is a high-level advisory group offering advice and guidance on the ethics and governance issues arising within TREAT-NMD.
- Although it will be the responsibility of individual partners to keep well informed about the ethical regulations relevant to their own area of expertise within TREAT-NMD, the PEC will be responsive to specific requests for advice, clarification and information from TREAT-NMD Partners.
- It will be the responsibility of the PEC to ensure that ethical practices are adhered to within TREAT-NMD Partners by monitoring the activities of the Governing Board who will have oversight of network activities.
- Where appropriate the PEC, in conjunction with project partners, and any relevant external agencies will contribute to maintaining researchers' awareness of ethical issues.
- The PEC will contribute towards a project ethics and governance policy and advise on, and where appropriate contribute to, the ethics training of project partners.
- Communication will be maintained between PEC members by a members' only distribution list. Communication with the wider TREAT-NMD community will be via common e-mail distribution list and via the project web-site.
- Training for PEC members will be initiated from expertise within the PEC membership.
- Reporting responsibilities are to the Governing Board in the form of minutes of each PEC meeting and the minimum of one annual report.
- Privacy and confidentiality – it is agreed that in the interests of openness the business of the PEC may be openly discussed outside of the PEC group unless explicit agreement has been reached that an item or issue is confidential. Minutes of the meetings will be copied to the Governing Board, and may be available for wider disclosure on request.
- Public statements, oral and written presentations on behalf of the PEC – it should be presumed that public statements regarding PEC activities are made in the spirit of corporate representation and such statements must be clearly distinguished from any statements made in a personal capacity.