Ethics at the edge of translation: the work of the TREAT-NMD Project Ethics Council

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Project Ethics Council – ‘the PEC’

The PEC (pronounced pek) was instituted to examine and advise on ethical issues arising out of translational research in neuromuscular disorders and particularly, the work of TREAT-NMD. The PEC is a voluntary multidisciplinary group.

Operational aspects

Specific questions and answers

The PEC works in three different ways. Firstly, it provides a publicly available question and answers forum where anyone with an ethical query concerning neuromuscular disorders can submit their question. Questions are debated by the PEC members who compile a summary answer and make this publicly available on the PEC’s website.

Logistics

The PEC meets twice a year face to face to discuss on-going issues. All other business is carried out online.

Each question received is sent out to members and debated via email. The PEC chairperson and co-ordinator then pull together the different aspects of the debate into a summary answer. The answer is sent back to the original questioner and published online.

Conclusions

The PEC has been an effective mechanism for dealing with day-to-day ethical questions which arise out of cutting edge translational research. In addition it is a helpful conduit for making transparent issues which are the subject of rumour, speculation or misunderstanding.

http://www.treat-nmd.eu/resources/ethics/social-ethical-research/