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Date deposited: 8th February 2013

Version of file: Author

Peer Review Status: Unknown

Citation for item:

McCormack P, Woods S. [Ethics at the edge of translation: the work of the TREAT-NMD Project Ethics Council](#). In: *TREAT-NMD International*. 2011, Geneva, Switzerland: TREAT-NMD.

Further information on publisher website:

www.treat-nmd-conference.org/

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

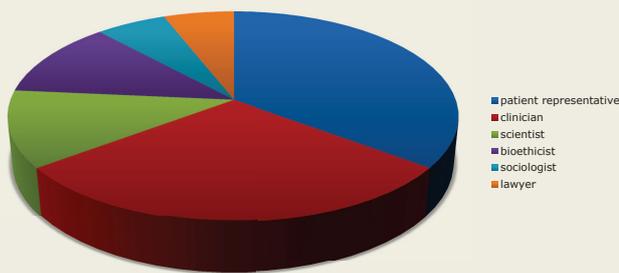
Pauline McCormack, Simon Woods - Policy, Ethics & Life Science (PEALS), Newcastle University on behalf of the TREAT-NMD Project Ethics Council
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PEC panel debate at 'Bringing Down the Barriers' conference 2009

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.

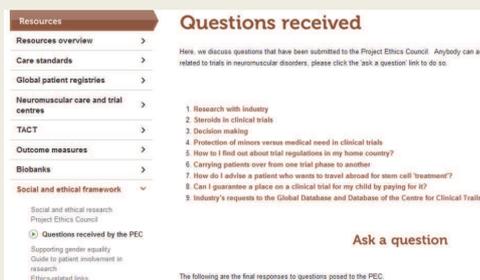


Membership of the PEC by role

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.



PEC Q&A webpage

PEC Members

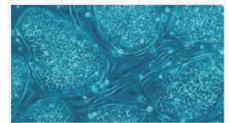
Annemieke Aartsma-Rus; Alessandra Ferlini; Lynn Hagger; Agnes Herczegfalvi; Emma Heslop; Joseph Irwin; Janbernd Kirschner; Pauline McCormack (co-ordinator); Patrick Moeschon; Francesco Muntoni; Marie-christine Ouillade; Jes Rahbek; Christop Rehmann-Sutter; Francois Roulaud; Thomas Sejersen; Elizabeth Vroom (vice-chair); Simon Woods (chair)

Broad issues of interest

Secondly, the Council works on broad issues of interest which arise through the development of care and therapies for neuromuscular disorders and brings these issues to the attention of groups concerned. After discussing the ethics of trials of therapies on single patients, the PEC contributed to a publication "the risks of therapeutic misconception and individual patient (n=1) 'trials' in rare diseases such as Duchenne dystrophy". In the case of stem cell tourism the PEC provided an online resource "Hope versus hype" for education and awareness raising for patients, scientists and clinicians.

Hope versus hype: an online guide

In recent years the hype surrounding stem cells and the hope they might bring to patients with incurable diseases has grown at an alarming rate. We need to remember that stem cell treatments which make claims that are not based on valid science and good clinical practice can be unethical and potentially harmful.



Clinics providing such stem cell "therapies" and claiming to cure or improve the health of people with neuromuscular disorders (NMDs) without providing scientific proof of these claims, only encourage false hope in patients. Clinics which charge

PEC online resource on stem cell tourism

Day-to-day ethical problems

Thirdly, the PEC or a sub-group of members will work in private with any TREAT-NMD partner who has a sensitive or confidential ethical problem with a view to identifying and resolving the significant issues.

PEC Membership

1. Interested volunteers from TREAT-NMD partner organisations
2. Invited members – also volunteers – who are co-opted for their specialist knowledge

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.