

CONDITIONS OF NON-FINANCIAL RESEARCH SUPPORT

DEFINITIONS

Applicant:	A person applying for non-financial support
CRB:	Criminal Records Bureau
Ethics Committee:	the Ethics Committee of the Host Institution
Grant Period:	the period of time for which non-financial support is granted pursuant to these Conditions or as otherwise agreed by T-A in writing
Host Institution:	The University, NHS trust or other body at which research supported by T-A will be carried out and where the PI is employed
Intellectual Property Rights:	any patents, rights to inventions, registered designs, copyright and related rights, database rights, design rights, topography rights, trade marks, service marks, trade names and domain names, trade secrets, rights in unpatented know-how, rights of confidence and any other intellectual or industrial property rights of any nature including all applications (or rights to apply) for, and renewals or extensions of such rights and all similar or equivalent rights or forms of protection which subsist or will subsist now or in the future in any part of the world
PI:	The principal investigator
Publication:	Every publication, communication, presentation, poster, broadcast or any other material relating to the research supported by T-A, including recruitment advertisements for staff employed on projects supported by T-A
Subjects:	Members of T-A who volunteer for research studies
T-A:	Tourettes Action
TARN:	Tourettes Action Research Network

1. The Application

1. 1 Support can take the form of a grant of money or help in kind (e.g. access to people with TS, participation in TARN) or both. For conditions regarding financial support, see 'Conditions of financial research support'.
1. 2 All applications for non-financial support must include an explanation of how they meet T-A's research aims as set out in the Research Support Policy Statement.
1. 3 T-A will keep confidential information about the application for support (except insofar as is necessary to process the application) and pre-publication information about the research findings.
1. 4 Applications for non-financial support are considered and decided by a triage assessment from T-A's Honorary Medical Director, the Chief Executive and the Research Manager. The triage's decision will be final as regards the awarding of non-financial support.
1. 5 All awards of non-financial support are made on the understanding that the Applicant will at all times comply with these Conditions. Failure to so comply will entitle T-A to terminate the support forthwith.
- 1.6 Any significant deviations in the research protocol from those stated in the submitted research proposal must be reported immediately to T-A's Research Manager to determine whether the non-financial support may continue.

2. Support

Access to adult members

2. 1 Access to adult members of T-A for the purpose of research (for B.Sc., M.Sc., PhD and higher levels) will be considered at the sole discretion of T-A provided that the researcher submits the following to T-A:
 - the CV of the PI;
 - a copy of the Ethics Committee's approval of the study;
 - a copy of the full Ethics Committee application
 - evidence of clear CRB checks taken within the past 3 years, from all research staff who will have contact with children and/or vulnerable adults and
 - a copy of the project proposal together with evidence of support from the Host Institution.
2. 2 T-A will protect the identity and whereabouts of T-A's members. T-A will not pay for any mail-out or prepare any questionnaire letters for the researcher.
2. 3 If the research study constitutes a questionnaire which is to be sent out to T-A's members, T-A reserves the right to review and approve the questions in advance, before any members are contacted on the researcher's behalf. The questionnaire must be accompanied by an introduction letter and a letter of consent.
2. 4 T-A reserves the right to deny researchers access to members if the criteria listed above are not met and subject to overall assessment. Further, research proposals will be subject to

prioritisation based on how well they meet the aims of T-A's research strategy and how original they are compared to other ongoing projects supported by T-A.

- 2.5 If the research study requires meeting the members, the invitation for the meetings must go through T-A, unless members themselves decide to contact the PI through the research recruitment advert on T-A's website. As with all non-financial support given by T-A, meeting with members will only be allowed after all the criteria stated above are met.
- 2.6 T-A requires the researchers to adhere to the highest standards of integrity and good scientific practice.
- 2.7 T-A requires the researchers to fully explain the purpose, aims and conditions of their research study to their subjects prior to the initiation of the study. Further, T-A requires the researcher to inform the research subjects' of their rights in accordance with the WMA Declaration of Helsinki 2008.
- 2.8 The PI and Host Institution must each comply at all times with any relevant requirements of the Data Protection Act 1998 (as amended).

Access to young members

- 2.9 T-A provides access to its members who are children at its sole discretion, provided that the Host Institution has a child protection policy and that all researchers and staff who are in contact with the children have been granted satisfactory and appropriate current CRB clearance.

3. Recognition and acknowledgement of support by T-A

- 3.1 All Publications must acknowledge T-A's support.

4. Confidentiality agreement

- 4.1 Depending on the nature of the study and T-A's involvement in the study, the PI may be required to sign a confidentiality agreement as provided by T-A.

5. Liability

- 5.1 Nothing in these Conditions shall exclude or restrict the liability of any party for:
 - death or personal injury caused by its negligence;
 - fraudulent misrepresentation; and
 - any limitation or exclusion prohibited by law.
- 5.2 Whilst T-A may provide access to its members under these Conditions, the Applicant and Host Institution expressly acknowledge and agree that T-A shall have no liability whether in contract, tort (including negligence or otherwise) for the acts or omissions of any such member. The Applicant and the Host Institution further acknowledge that, but for the exclusion in this clause 5.2, T-A would not be willing to provide access to its members to the Applicant or Host Institution.
- 5.3 Without prejudice to clauses 5.1 and 5.2, T-A shall not be liable to the Host Institution for any loss of profit, loss of sales, loss of business, third party claims, loss of goodwill or

reputation (in each case whether direct or indirect) or indirect or consequential loss suffered by the Host Institution arising under or in connection with these Conditions.

- 5.4 The Host Institution shall indemnify, keep indemnified and hold harmless T-A against any liability, fine, penalty, action, claim, demand, loss, award, cost or expense (including legal and other professional fees) which arise from:
- alleged infringement by the Host Institution or its employees or agents of any third party Intellectual Property Rights; and/or
 - any failure by the Host Institution or its employees or agents to comply with any applicable data protection laws.

6. Termination

- 6.1 T-A reserves the right, in its absolute discretion and without any liability, to withdraw non-financial support including, without limitation, access to its members at any time on giving the Applicant and/or Host Institution written notice to that effect.

- 6.2 At termination, the Applicant must:
- ensure that the project is brought to an orderly conclusion;
 - ensure that records are archived in a form that they can be readily accessed by T-A; and
 - submit a full report to T-A on the conclusions of the research to which the support related.

5. Third Party Rights

- 5.1 A person who is not a party to the agreement incorporating these Conditions cannot enforce or enjoy the benefit of any of these Conditions under the Contracts (Rights of Third Parties) Act 1999.

6. Governing law and jurisdiction

- 6.1 These Conditions and any disputes arising under them (including non-contractual disputes) shall be governed by and interpreted in accordance with English law. The Host Institution and the Applicant irrevocably submit to the jurisdiction of the English courts to settle any disputes in association with these Conditions.