



Research Advisory Committee (RAC)

Terms of Reference

Action for A-T's Research Advisory Committee (RAC) volunteer their time to provide independent scientific advice in ensuring that the charity invests its funds as wisely as possible and in line with the charity's mission and strategy.

The committee will be asked to advise the board of trustees and the Chief Executive of the charity on its research strategy, to make recommendations as to which research grants the charity should support and to recommend change and development as appropriate. Members of the committee will be selected to ensure a broad range of inputs from clinicians and researchers in areas relating to A-T but will not all be active researchers in the field of A-T in order to minimise bias and conflicts of interest. There will also be lay representation on the committee.

This document sets out the role and membership of the committee.

Role of members

Research investment

- To maintain an overview of A-T research and related fields being undertaken and to identify and make recommendations on the most appropriate areas for research investment.
- To maintain an overview of research projects previously funded by the charity, including areas and research spend.
- To make recommendations on existing research processes in which the charity makes decisions on which applications to fund.

Research strategy

- To provide advice on the charity's research strategy and to recommend changes as appropriate.

Communication

- To be a point of contact to provide advice on Action for A-T's response to press articles, assist staff in interpreting scientific findings and research project data.

Integrity

- To assess all research investment processes undertaken by the charity and the research institutions funded, against the highest standards of ethical and research best practice.
- To support the AMRC's position statement on the use of animals in research.

Peer review

- External and internal reviews are used for deciding the scientific quality of research applications.

- Applications will be assessed by a minimum of two external experts with appropriate experience/expertise relating to the application. External reviewers provide a written report and score on the research application. Their anonymised feedback is then passed onto the applicant and they are given an opportunity to respond to the feedback. The RAC are then given the external reviews and applicants response to this feedback to review.
- The RAC is Action for A-T's internal peer review committee.
- Lay members on the committee do not judge the science of research projects. They assess the importance and impact of the project from a patient representative perspective. They look at what the potential benefit of a proposed research project is for a person affected by A-T and their family.

Conflict of Interests

- To work within the charity's conflicts of interest policy. All members must declare any interests which may potentially cause a conflict in the course of fulfilling their duties and responsibilities as a committee member.
- To maintain strict confidentiality ensuring all verbal or written information shared is kept within the RAC.
- Members of the Committee, other than the Chair, a trustee or patient representative, are eligible to apply for funding but he/she must be absent from the meeting room whilst the application is being discussed. He/she would not be shown the external review scores.

Independence

- The Chair of the RAC is also a trustee on the board of the charity. He will not have the opportunity to provide comments, score or vote at the RAC meeting.

Meetings

- The RAC will meet once a year (unless agreed otherwise).
- Members are required to declare at the beginning of every meeting if they have a conflict of interest with any agenda item.
- Action for A-T staff or trustees may attend a meeting but will not be involved in the committee's decision process.

Membership

- The Chair and members of the RAC will be co-opted onto the committee by the charity's Board of trustees for a three-year term. This term may be renewed.

Reimbursement

- All members of the committee will be reimbursed for any reasonable travel costs and any other pre-authorised expenses incurred in the role.