



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 we invest our funds as wisely as possible and in line with the charity's mission.

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 generally be active researchers in the field of A-T in order to minimise bias and conflicts of interest. There will be lay representation on the committee; the charity supports public and patient engagement in its research processes.

Introduction

Action for A-T is committed to ensuring the research we fund adds the greatest possible value to the overall research activity in the field of A-T. We will continue to develop our research strategy for research investment, taking into account the global research effort and scientific advice. 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 processes for calling research applications, to evaluate external peer review feedback and the process in which the charity makes decisions on which applications to fund.

Research strategy

- To provide advice on the charity's research strategy, keep under review the achievement by the charity of its agreed research strategy and to recommend changes as appropriate.

Communication

- To recommend approaches of effectively communicating to the donors and supporters of the charity in a 'user friendly' manner.
- 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 and expertise relating to the application. Once external reviewers have provided a written report on the research application, their feedback is passed onto the RAC to assist in assessment of the applications.
- The RAC is Action for A-T's internal peer review committee, made up of independent experts, who on behalf of the charity, assess applications and make recommendations for funding to the board of trustees.
- 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.
- Action for A-T have a research partnership with Sparks, a leading UK children's medical research charity. One A-T grant round is funded through Sparks annually on behalf of Action for A-T. The Sparks peer review process is used for this grant round. In order not to duplicate efforts, research projects partnered through Sparks will not require peer review from the RAC.

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 reports.

Independence

- To ensure grants are allocated on an impartial basis, the chair of the RAC who is also a trustee on the board of the charity will only vote once in the research grant review process.
- The Chair has been chosen on the basis of his skills and ability to chair meetings. The Chair is also a trustee and must only vote on whether applications should be funded once; at the committee meeting. He will not have the opportunity to vote at the trustee meeting as voting twice unbalances the nature by which funding decisions are made.

Working

Meetings

- The RAC will meet once a year (unless agreed otherwise).
- In addition one teleconference meeting may be held to discuss projects funded by the charity and any other items. Members may need to be contacted in-between meetings to ask for specific advice.
- 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 be in attendance at a meeting but will not be involved in the committee's decision process on research applications.

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 for a second three-year term.

Reimbursement

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