

College of Experts Membership

Terms of reference and role

1. Introduction

- Action for A-T fund medical research to speed up the process of identifying a cure for Ataxia Telangiectasia (A-T) or treatments that delay or prevent the disabling effects of the condition.
- The College of Experts (COE) is formed of scientific experts from areas relating to A-T and of people affected by A-T with lived experience of the condition.
- The COE makes recommendations for all research project funding.

2. Purpose

- The COE scientific members and lay reviewers provide advice to Action for A-T as
 to whether research grant applications merit charity funding and is in line with the
 charity's strategy.
- The COE is expected to ensure its recommendations have a direct benefit to people affected by A-T and make effective use of charitable funds.
- Action for A-T may co-opt additional COE members for grant applications which lie outside the remit of the existing members or where the number of conflicts with existing members would preclude obtaining sufficient scientific reviews.
- COE members have a duty to bring an independent judgement when reviewing grant applications and, on all issues, considered at grant assessment committee meetings. On appointment, they must comply with these Terms of reference, and act in good faith and in the best interests of the charity.
- It is a requirement of the Association of Medical Research Charities (AMRC) that the names of grant assessment members are shared. Therefore, the names of COE scientific members and a link to their details on their institution webpage will be present on the charity website.

3. Period for application review and committee meeting

- Dates for the periods in which members are asked to review applications or attend in person/virtual online meetings will be requested at least four months in advance.
- The agenda for a meeting, all applications, external reviews and other supporting documents will be available at least three weeks in advance.
- At committee review meetings, a primary COE scientific member will be nominated to present an overview of the external reviews and grant applications. A secondary COE member will provide additional comments prior to opening the application to discussion by attendees. Attending COE members will be requested to score each application at the end of discussions.
- Recommendations for funding are based on the combined mean score for each application (from lay and scientific members).
- In the absence of the Chair or Deputy Chair, an alternate Chair will be elected for the meeting.
- Meetings will have minutes and notes taken.

4. Role of Chair

The Chair has responsibility for:

- Encouraging high standards
- Ensuring all members attending committee meetings have the opportunity to be heard and no view is ignored.
- Ensure any conflict of interest is declared and action taken to mitigate the impact of this whilst evaluating applications

5. Role of Lay members

- The Lay members help the COE scientific members assess applications from the point of view of people affected by A-T.
- Lay reviewers do not need to have any specific understanding of scientific methodology or concepts and are only expected to read the lay section of applications.

6. Role of Scientific members

• Scientific members will be nominated to review specific grant applications and present a summary at the grant committee meeting. Scientific members are expected to take an active role in discussions on each application.

7. Conflicts of Interest

- When asked to review a grant application, COE members need to consider whether there are any potential conflicts of interest and if so inform us as soon as possible.
- Before each meeting, or when asked to review an application, the Research Manager and Committee Chair will ask members to declare conflicts of interest.
- Where a conflict of interest exists, a COE member will not take part in the review process of the application, will not receive the scientific or lay reviews, and will leave the meeting during any discussion relating to the application.
- If the Chair has a conflict of interest regarding an identified application, they will leave the meeting whilst that application is being discussed.
- The minutes of the meeting will record decisions about conflicts of interest and any withdrawals for applications.

An absolute conflict of interest, where the individual should decline to comment is when the COE member is:

- a close friend or related to the principal applicant(s) or co-applicant(s)
- directly involved in the work the applicants propose to carry out
- located at the same department as the principal applicant(s), co-applicant(s) or collaborator(s) in the proposed research team for the project
- working closely with the principal applicant(s) or co-applicant(s) (for example as a co-author or PhD supervisor) or has done so within the last five years

8. Confidentiality

- The COE reviews, discussions, scores and decision making are confidential to allow free and transparent expression of opinions. COE members must agree to treat as confidential all correspondence and documents sent by Action for A-T both in electronic and printed format.
- Grant applications, external review, applicants' response to reviews and meeting minutes must not be disseminated outside of the review process.
- Action for A-T will not use comments provided by COE members for any purpose other than is necessary for the review / funding process and will not disclose them to any person except as is required for the review / funding process or as is required under the <u>General Data and Protection Regulation</u> (GPDR) (or any other law or regulation to which Action for A-T is or may become subject).

9. Expenses

- All reasonable travel and subsistence costs incurred by the COE members to attend meetings will be reimbursed.
- The charity does not allow reimbursement for first or business class travel.