

Terms of Reference of the Research Committee of Cure Parkinson's (CP)

A. Purpose of this Document

The Trustees of CP are hugely grateful to the members of the CP's Research Committee ("RC") for their commitment, knowledge and expertise when volunteering their time for service on the committee.

This document sets out terms of reference for RC members.

B. AMRC membership

CP is a member of the Association of Medical Research Charities ("AMRC") and complies with AMRC requirements and guidance, including those relating to research strategy, conflicts of interest, research evaluation (described by the AMRC as "peer review") and animal research.

C. Documents defining the role of the RC

The following documents define the role of RC and its members,

- This document;
- CP's [Research Strategy](#) defining CP's funding scope;
- CP's [Information for Applicants for Grant Funding](#) describing CP's processes for grant applications and the evaluation thereof (such evaluation described by the AMRC as "peer review");
- CP's [Conflict of Interest Policy](#) covering members of the RC (such a committee described by the AMRC as "scientific advisory panel") and [peer reviewers];
- The [RC membership list](#) providing the names and short biographies of the current members of the RC pursuant to AMRC requirements of accountability.

The contents of these documents are treated as incorporated into these Terms of Reference. RC members are provided copies by CP upon request. All the documents (apart from these Terms of Reference) are available on CP's website.

D. Research Strategy & Criteria for Funding

The RC considers applications for funding in the light of CP's agreed [Research Strategy](#) and the further criteria and process set out in CP's [Information for Applicants for Grant Funding](#).

E. The Research Evaluation Process of the RC (including written peer review)

The RC evaluates research following the process set out CP's [Information for Applicants for Grant Funding](#)

F. Relationship and communication between RC and Trustees

The RC exists to evaluate and provide recommendations to the Trustees of projects for funding by CP. Following the process set out in CP's [Information for Applicants for Grant Funding](#) the RC communicates with the Trustees as follows:

1. The minutes and recommendations from the relevant RC meeting are shared with the Trustees in advance of the Board meeting at which the Trustees consider relevant funding decisions.
2. In addition, the Trustees receive at that time (i) an overview summary by CP executive, (ii) a brief summary by the Chair of the RC of the RC's decision and reasoning provided, and (iii) the relevant excerpts of the project summary substantially as provided by the applicant.
3. Further, the Chair of the RC may be invited to attend the relevant part of the Board meeting in which the Trustees consider the application for funding, in person or remotely by audio or video link.

G. Attendance at RC meetings

RC meetings may be attended by:

1. Members of the RC;
2. Members of the CP research team, one or more of whom act as secretary of the RC in order to:
 - a. record draft minutes and recommendations of each meeting for the Chair, and
 - b. otherwise support the Chair with administration of RC business and the project application process;
3. CP's CEO and Director of Fundraising & Marketing; and
4. Up to two Trustees.

Only RC members (category 1 above) may speak and vote at RC meetings. All other attendees (categories 2, 3 and 4 above) may only attend as observers, without any right to vote. They may only speak at RC meetings with prior permission of the Chair.

On occasion, with the prior consent of the Chair, other observers may be invited to attend RC meetings to understand the meeting process as well as the diligence and rigour with which they are conducted.

H. Commercial and lay reviews

As indicated in CP's [Information for Applicants for Grant Funding](#), a commercial and or lay review may be sought (for the benefit of the RC or Trustees) by CP staff at their own instigation or at the request of the Chair of the RC or the Trustees. The reviewer may be a member or members of the RC, CP staff, CP Trustees or a suitably qualified individual approved by CP's CEO under conditions of confidentiality.

I. Membership of the RC

Pursuant to AMRC guidance, it is important that membership of the RC is independent of the charity's staff and Trustees, so that the RC can exercise independent decision-making on scientific matters, without influence from CP staff or Trustees.

1. Membership of the RC is honorary and voluntary. The members of the RC (including its Chair, as described below) are not paid, but CP may reimburse expenses reasonably incurred for the sole purposes of the work for the RC. Typically, these constitute reasonable travel expenses.

2. RC members either (a) must have specific expertise relevant to the scientific work of the RC (e.g. neuroscience, clinical trial practice and/or clinical neurology) or (b) be people living with Parkinson's with a high level of knowledge and understanding of the science behind the condition or a pharmaceutical, regulatory and/or biotechnology background. It is important that the combined membership of the RC have a sufficient range of expertise to be able to make informed recommendations to the Trustees.
3. The quorum for any meeting of the RC shall be [7] members, in person or in teleconference, at least [5] of which are described under 2(a) above.
4. All members of the RC can vote at each meeting.
5. An individual is invited to become a member of the RC under the following procedure:
 - a. Under the guidance of the Chair, taking account of the skillsets of existing RC members and the desirability for a wide range and balance of expertise, experience, location, age, gender and ethnicity, potential new RC members may sought by:
 - public advertisement (typically on CP's website and AMRC's listings);
 - recommendation from existing and former RC members; and
 - recommendation from members of CP's executive team.
 - b. The RC typically reviews the applications and recommendations and selects one or more candidates for recommendation to membership. Where necessary, further details and/or CV may be sought for any particular candidates. The recommendation(s) is/are submitted to the CP Trustees for approval, following which an invitation to join the RC is extended by its Chair.
 - c. If an advertisement or call for recommendations produces a large number of candidates, CP's executive team may identify a shortlist of suitable candidates for consideration by the RC (and, to ensure transparency, the full list of candidates is also shared with the RC). At least the members of the shortlist are then considered for membership as above, along with any other candidate on the full list who is identified by any RC member.
6. Membership of the RC is for three years, renewable for one further three-year term. After stepping down from membership the RC, a person cannot become a member again for another year.
7. RC members are expected to attend all four meetings per year in person or by zoom, although, 1-2 meetings in person are requested. If absence is unavoidable, written comments in advance of meetings are expected.
8. Members of the RC may resign their membership at any time.
9. In the event of repeated unjustified absence or otherwise as a result of unreasonable behaviour on behalf of a relevant RC member, the other members of the RC may vote to require the Chair to serve notice on the relevant member to terminate his/her membership.

10. Significant discussion and action points from each RC meeting shall be recorded in official minutes, to be approved by the RC and signed by the Chair. Such minutes may be shared in draft with the Trustees at the Trustee Board meeting next following the relevant RC meeting.

J. Chair of the Research Committee

The Chair is a member of the RC and is responsible for ensuring that applications for funding are evaluated to the highest standards with due process and in keeping with AMRC guidance.

1. The position of Chair is honorary and voluntary.
2. Although the Chair should have relevant neurological experience, to maximise independence the Chair should not be a current researcher in Parkinson's disease.
3. The Chair is appointed by CP's Trustees at their discretion, typically by way of approval of a recommendation from the RC. The RC shall make such a single recommendation upon request from the Trustees. The RC's recommendation may be an existing RC member or an external candidate.
4. The Chair assumes the role for a three-year period, renewable for one further three-year term.
5. During the period of tenure, the Chair may not apply to CP for funding.
6. Occasionally, a Vice-Chair may be elected for limited purposes, as described in the next section.

K. Conflicts and Funding Applications from RC Members

All members of the RC must sign CP's [Conflict of Interest Policy](#) upon their appointment to the RC, upon any renewal of membership after three years, and upon any re-appointment to the RC. Each member of the RC will also be reminded of the terms of the policy, and the provisions below, and asked to re-sign the policy annually.

The existence of any conflicting interests is the first standing item at RC meetings and must be declared to the RC.

Neither the Chair of the RC, nor any CP Trustee or nor any member of staff may apply for funding.

However, members of the RC (other than the Chair) may apply to CP for funding, either as a sole or joint applicant, provided that any member of the RC applying for funding will be excluded from all discussion of the application during RC meetings and is required to leave the meeting room for the duration of the discussion.

Should the Chair declare a potential conflict on an application (e.g. institutional, co-authorship, personal or professional relationship), the RC shall decide whether there is an actual conflict. If there is an actual conflict, the Chair shall leave the meeting room for the specific discussion of that application, and the RC shall appoint a Vice-Chair, with no conflict, to act as Chair for that specific discussion. The decision shall be recorded in the RC

minutes.

L. Funded research projects and reporting to the RC

The following provisions apply after projects have received approval by CP Trustees and work has commenced.

1. Grant holders provide a progress report to CP at least every six months during a project and within three months of project completion. Such reports are made available to the RC prior to the next relevant RC meeting.
2. Comments upon the progress (or otherwise) of the project are sought from the RC at that meeting, so that CP staff and Trustees can ensure that each project duly proceeds in the light of the original application.
3. If the progress report is not clear, the RC and/or its Chair will assist CP to formulate queries for CP to put to the Principal Investigator of the project.

M. Research Strategy Review

Every five years, CP evaluates its research strategy to fulfil its aim to cure Parkinson's. This review shall involve at least five members of CP staff and, at the invitation of CP, at least five external advisers, whether or not RC members. Such external advisers shall have specific expertise relevant to the objectives of CP (e.g. neuroscience, clinical trial practice and/or clinical neurology). In addition, the review shall involve, at the invitation of CP, several people living with Parkinson's with a high level of knowledge and understanding of the science behind the condition or a pharmaceutical, regulatory and/or biotechnology background.

A research strategy review took place in March 2019. CP publishes its [Research Strategy](#) on its website, setting out CP's priorities for the research it funds. The next research strategy review will take place in/by early 2024.