

Terms of Reference of the PSPA Research Committee October 2020



Background and responsibility

1. PSPA is the only UK charity supporting people living with PSP & CBD. We provide information and support to enable people to live the best life they can. We campaign to improve accurate diagnosis and better care, and fund ground-breaking research to help turn our vision of a world without PSP & CBD into a reality.
2. The Research Committee takes delegated responsibility on behalf of the Board of Trustees for the research strategy, its delivery and all funding streams.
3. The Research Committee ensures there is a framework for accountability, and that the charity is working within appropriate legal and ethical boundaries, to fund research of the highest quality, and of greatest benefit to people with PSP and CBD.
4. The Research Committee must adhere to the recommendations of the AMRC for the management of research.

Composition

5. The Research Committee will consist of at least eight (8) members including the Chair. Membership will include the Chair and a minimum one (1) Trustee, at least four (4) members who should provide the committee with broad representation from all health disciplines and research areas within the PSP and CBD specialty and one (1) lay member.
6. The members of the Committee shall be appointed by the Board of Trustees.
7. The members of the Committee may serve for a term of not more than 3 years, renewable once by the Board of Trustees.
8. In the absence of the Chair, the Research Committee will nominate an interim Chair.
9. The Research Manager shall act as Secretary to the Research Committee but shall not be a voting member of it. He/she will be entitled to attend any Committee meeting not designated a private meeting by the Chair of the Committee.

Proceedings

10. The Research Committee shall meet least 2 times a year.
11. Unless otherwise determined by the Board of Trustees a quorum shall consist of four (3) members of the Committee including at least one (1) Trustee.
12. Any Trustee may attend a meeting of the Research Committee including those not members of the Committee.
13. The Research Manager, and other members of staff as required by the Chair of the Committee, shall be in attendance at Committee meetings.
14. Individuals, with a specific expertise, may be co-opted onto the Committee, be invited to attend meetings, or asked to submit papers as required, at the request of the Chair.

Reporting

15. The Research Committee shall report back to the Board of Trustees at least twice a year

16. The Committee will provide minutes of all its meetings for review at the meetings of the Board of Trustees.

Main Duties

17. To support the Research Strategy of PSPA by:

- identifying new opportunities or areas of research most important to the charitable goals of PSPA
- aligning patient-centred research strategies with other funders working in the field
- raising research priorities on the UK research agenda, identify potential funding or research partners, to stimulate research in thematic priority areas
- advising on opportunities for periodic calls for proposals in priority areas, exploring potential funding partnerships with individuals, companies or organisations with common interests.

18. To support research management by:

- recommending to the Board of Trustees the proportion of funds to be allocated annually to different funding streams according to strategic objectives and variations in overall research funds available
- ensuring that all research supported by PSPA is conducted to the to the highest levels of integrity, clarity and good management by working with the PSPA Research Manager and following the Association of Medical Research Charities (AMRC) guidance on the management of research
- enabling the development and maintenance of a set of objectives to evaluate grant applications
- ensuring a clear application peer review process is followed under the guidance of the Research Manager
- ensuring an adequate system of grant management, including internal control, is implemented and maintained to safeguard all assets and liabilities
- ensuring consistency in decision-making and grant management across all grant funding streams.

19. To encourage greater patient engagement and participation in research and clinical trials

- identifying guidance for patients and researchers on taking part in clinical trials and research studies
- identifying opportunities for research engagement
- identifying links to published research.

20. To support research communication by:

- identifying objectives to assess and communicate the impact of research, and how the charity will support researchers beyond the award of the grant
- engaging support from existing and new stakeholders, including individuals and funding partners
- ensuring the effective communication of research progress and achievements.

Confidentiality and Conflicts of Interest

21. All documents, materials and associated information made available to committee members must be treated as strictly confidential and shall not be shared, disclosed to, or discussed with any other parties, and no personal use shall be made of any information, documents or materials.

22. To ensure openness and fairness any potential conflicts of interest with the business of the Committee must be declared immediately to the Research Manager at the PSPA.

23. A Committee Member cannot take part in the recommendation of an application for which they have a personal or institutional interest in the research that is being undertaken which may inappropriately influence or bias judgement.

24. To ensure openness and fairness, all members must declare any conflict of interest with the Research Manager, before the meeting.

25. A Conflict of Interest applies if a Committee Member fits any of the following criteria:

- is approached by an applicant for technical advice on an application, he or she may provide advice, but must report this to the Chair and Research Manager. They may subsequently be asked by the chair to absent themselves from a discussion of the application concerned.
- is a named party on a grant application, either as PI, co-applicant, collaborator, or Head of Department
- has a close personal or familial relationship with any of the named parties on a grant application
- is employed at the same Research Institute as the lead applicant or a co-applicant of the grant application
- is seen as a direct competitor of the applicant (e.g. they are funded or applying for funding on a similar project to the proposal under discussion) or have collaborated or published with the proposal applicant within the past three years, or work in the same institution, should declare an interest and may be asked to withdraw from the meeting for that application, or may be allowed to stay, but not vote on the application.

26. Any conflicted member will be excluded from the discussion on that issue for which they are in conflict, and will be asked to leave the room.

27. If the Chairman of the Committee has a conflict then another member will be asked to take on his role during the discussion of the business related to the said conflict.

28. The Chairman and Research Manager reserve the right to advise a Member not to attend a meeting.

29. All conflicts will be recorded in the minutes of the meeting which will act as the conflict register.

Resolution conflicts of interest

30. The Charity recognises that the majority of conflicts or potential conflicts will relate to a particular issue and as such will not present any long term restrictions on an individual's ability to work sit on the Committee.

31. In a small number of cases, major conflicts of interest may arise which compromise a member's ability to continue in their position on the Committee. Where such a situation arises the matter will be taken to the Board of Trustees by the Committee Chair and the Research Manager.

32. All members will sign an acceptance of the terms of reference, confidentiality and conflicts of interest form (Appendix 1).

Appendix 1: Confidentiality and conflicts of interest form

1) General

1.1 The purpose of this document is to minimise the potential for conflicts of interest arising and to protect the charity and those who work for it from any perception, real or otherwise, that the external interests and affiliations of its committee members might interfere with their ability to work towards the furtherance of the charity's.

2) Declaration of interest

2.1 Any persons covered by this policy, as defined in paragraph 1a), must declare any disclosable external interest on their appointment to the charity, and annually thereafter. A register of interests will be kept up to date by the charity.

2.2 Interests which should be disclosed by such individuals include:

Equity interests (if worth £20,000 or more, or more than 1% of the total issued capital) in enterprises with involvement in pharmaceuticals, healthcare, biotech or related areas, or in any other enterprise that may have a real or perceived interest in the work of the charity. Third party investments (e.g. ISAs) should be held exempt from this.

Consultancies and other external appointments (paid and unpaid).

2.3 Committee members (including trustees) should also adhere to the spirit of this document and declare any other interests which they feel may be a source of conflict, or which might be perceived to conflict, with the interests of the charity. This includes interests held by the members' spouse or children.

3) Resolution conflicts of interest (to be read in conjunction with clauses 30 and 31 of the Terms of Reference)

3.1 The Charity recognises that the majority of conflicts or potential conflicts will relate to a particular issue and as such will not present any long-term restrictions on an individual's ability to work for the charity or to sit on its committees.

3.2 In a small number of cases, major conflicts of interest may arise which compromise an individual's ability to continue in their position within the charity. Where such a situation relates to a member of committee, the matter will be discussed by the Chair of the committee together with a committee staff member or secretary. In cases where agreement cannot be reached through this means, the case will be referred to the Committee as a whole, whose decision should be taken as final.

3.3 Members of committees are expected to declare any potential conflicts of interest relating to individual funding decisions to the Chair and Research Manager before the meeting wherein they will be discussed, or during the meeting as soon as the existence of a conflict becomes apparent.

3.4 In cases where an individual is uncertain as to whether a conflict of interest exists or not, they should report this to the Chair and Research Manager who shall discuss the matter with the individual as necessary and decide on a course of action.

3.5 If an individual is concerned about a possible conflict of interest involving another member of the Committee, then he or she should raise the matter with the Chair and Research Manager.

As a member of the PSPA Research Committee, I agree to follow the rules set out in this document:

Name:

Signature:

Date: