

Cohort Studies Council – Terms of Reference

Introduction

1. The Cohort Studies Council, or Council, is an advisory group established by Parkinson's UK (the Charity).
2. These Terms of Reference will be reviewed periodically by the Charity, but no change to them shall govern an individual member unless and until agreed by that member by written agreement.
3. The Charity has adopted a strategy for the period 2015-2019, with the three principal themes of Better Treatments and a Cure, Better Services, and Taking Control. In pursuit of the first theme the Director of Research is charged with developing and implementing a subordinate Research Strategy to include all activities spanning from scientific investigation into causes and mechanisms of Parkinson's disease, through to clinical studies of potential new treatments and clinical research into improvement of non-pharmacological treatments.

Purpose & Responsibilities

4. The role of the Council is to advise the Charity's management (specifically the Chief Executive and the Director of Research) on all aspects of the Charity's funding of research involving longitudinal studies of disease progression in Parkinson's (also referred to herein as "cohort studies").
5. Individual Council members may from time to time be invited to participate in other related activities for the Charity but are under no obligation to accept these supplemental roles.

Key tasks & responsibilities

Council collectively:

6. Develop a strategic view of the field of natural history of disease studies in Parkinson's, including international activity;
7. Identify important questions for the field that can be answered through cohort studies over the next decade;

8. Develop and recommend a strategy for cohort studies for Parkinson's UK, to include where appropriate collaboration with partners outside of the UK, and from other fields of medicine and technology;
9. Identify and propose opportunities for cooperation, collaboration and cost savings amongst existing and proposed studies;
10. Make recommendation on funding of specific research proposals in the area of cohort studies (Advisory Members only, as defined below).

Individual members:

11. Use reasonable care and skill along with personal skills and experience to all issues considered by the Council;
12. Bring independent and impartial judgment to all issues considered by the Council;
13. Contribute views on the broader issues and "big picture" not restricted to an individual's area of special expertise;
14. Provide advice objectively and in the best interests of Parkinson's UK and people affected by Parkinson's;
15. Avoid conflicts of interest and declare and appropriately manage any conflicts should they arise;
16. Maintain confidentiality about the Council's work where necessary.

Membership

17. The Council shall consist of between eight and twenty members, each of whom shall be invited by the Charity, normally by letter from the Director of Research.
18. Meetings will also be attended by a limited number of staff and other representatives of the Charity, at the discretion of the Charity.
19. The Council has two classes of member:
 - Regular Members are selected for reason of their direct supervision of, or close involvement with, major cohort studies in Parkinson's currently active in the UK. Regular members are offered membership on a yearly basis.
 - Advisory Members are selected for their special expertise in the design and conduct of cohort studies in the area of chronic neurological disorders or

other relevant expertise, but are not directly involved in studies in the field of Parkinson's. Advisory members will be offered terms of between two and four years, as indicated in the letter of invitation.

20. One of the Advisory Members will appointed as Chair of the Council by letter from the Director of Research.
21. Advisory Membership may be renewed for one or more additional terms upon mutual agreement of the member and the Charity, provided that the combined terms shall not exceed six consecutive years. Exceptionally, the Charity may agree a further short extension.
22. Notwithstanding such term, the Charity may terminate membership of a member at any time without requirement for advance notice.
23. A member may resign at any time without requirement for advance notice by providing notice in writing to the Charity.

Meetings

24. It is expected that the Council shall meet between one and three times a year.
25. Council meetings shall normally be of not more than four hours' duration and shall take place in the United Kingdom. Efficiency of travel plans for members shall be a strong consideration in planning of the meetings.
26. Meeting agendas shall be developed by the Charity in consultation with the Chair.
27. Regular and Advisory Members normally consider and discuss together all matters before the Council.
28. Advisory Members and selected representatives of the Charity may also meet in closed session (that is, in the absence of the Regular Members) when individual project proposals must be prioritised and recommended for funding. When meeting in closed session, the Advisory Members are the peer review panel for cohort studies for Parkinson's UK.
29. Notice of each meeting and supporting papers shall wherever possible be circulated to all Council members by the Charity at least seven days prior to the meeting and should include an agenda and confirmation of date, time and venue.
30. Written minutes of Council meetings shall be prepared by the Charity and circulated to all Council members within one week of the meeting concerned. Members shall

be invited to provide their comments on such summaries, normally within two weeks of the meeting concerned.

Reporting

31. The minutes of each Council meeting shall be made available to the Chief Executive and Director of Research and as soon as practicable and submitted to the Board of Trustees or its duly delegated representatives for information.
32. The Council shall be entitled to receive the final approved minutes and supporting papers of meetings for information.

Cohort Studies Council – Role Description

QUALITIES, SKILLS AND EXPERIENCE

Essential

- Expert knowledge of aspects of research and development in the field of cohort studies in Parkinson's and other chronic neurodegenerative diseases, and related specialties such as genetics, epidemiology, and management and analysis of 'big data';
- Commitment to the aims and values of Parkinson's UK;
- Ability to work effectively as a member of a team while contributing an independent perspective;
- Willingness to devote the necessary time and effort;
- Commitment to the seven Nolan Principles of public life: selflessness, integrity, objectivity, accountability, openness, honesty and leadership (appendix A).

Practicalities

1. Support is provided by the Charity, for such matters as assistance with travel arrangements, meeting logistics, circulation of meeting papers and general queries.
2. Meetings will be held in the United Kingdom and the efficiency of travel plans for members shall be a strong consideration in planning of the meetings.
3. The Council is expected to meet between one and three times a year and during normal business hours. Members are expected to adequately prepare for, attend and contribute to all Council meetings and participate in additional tasks and meetings as required by the Council.
4. The expected time commitment is the equivalent of between 2 and 4 days per year.

Expenses

5. The Charity does not offer remuneration for membership on the Council. However all reasonable travel and other direct costs incurred by members in the completion of their duties as Council members shall be reimbursed by the Charity in accordance with its Volunteer Expense Policy.
6. The Charity's policy does not allow for reimbursement of first or business class travel.

Conflicts of interest

7. Members may not gain materially or financially from membership of the Council unless specifically authorised to do so.
8. Members have a duty to act in the best interests of the Charity as a whole, and not as a representative of any group – considering what is best for Parkinson's UK and its present and future beneficiaries.
9. Members have a duty to avoid conflicts of interest (unless authorised to do so) where their personal or professional interests conflict with those of the Charity.
10. Where a potential or actual conflict arises members must declare this to the Director of Research at the earliest opportunity. In such case the Charity may decide that a member declaring a conflict on a topic shall either not participate in discussion and advice on that topic, or be included in the discussion with an open declaration of the conflict in the Council.
11. A failure to declare of conflict of interest may result in the termination an individual's membership of the Council.
12. An individual who is concerned about another's potential or actual conflicts of interest should raise the issues with the Chair (in private, if possible); this includes issues concerning Parkinson's UK staff. Conflicts of interest may arise from:
 - close links with, or interest in, a particular institution from which a grant or other funding proposal is being considered (eg employment or academic collaborations)
 - a commercial or pecuniary interest (eg where a member or an organisation with which an individual is involved may benefit financially, directly or indirectly, from a decision made)
 - a non-pecuniary interest where a member has other interests that might be thought to influence them, either wittingly or unwittingly
 - personal or family interest with regard to both pecuniary (eg from connections with bodies which have a direct financial interest, or from being a business partner, or being employed by a person with such an interest) and non-pecuniary (eg any benefit or favour 'in kind' including arising from membership of clubs or other organisations) interests
13. An absolute conflict of interest, where the individual should decline to comment, is when the Advisory member is:

- a close friend or related to the applicant(s)
 - directly involved in the work the applicant proposes to carry out
 - located at the same department as the applicant(s), co-applicant(s) or project partner(s)
 - working closely with the applicant(s) (for example as a co-author or PhD supervisor) or has done so within the last five years
14. Where a conflict of interest exists the Advisory member will not take part in the review process, under certain circumstances will not receive any of the paperwork and will leave the room during any discussion relating to the application.

Confidentiality

1. Members may be asked to review in the course of their duties confidential information not yet disclosed into the public domain.
2. 'Confidential Information' means any information contained in documents supplied by the Charity that are clearly marked "Confidential", and that does not fall within the exclusions in paragraph 11 below.
3. Confidential information should be used solely for the purpose of Council business.
4. Council members will not, without written consent from both Parkinson's UK either disclose Confidential Information to any third party or use Confidential Information for any purpose other than that described in paragraph 9 above. For the purposes of this paragraph, third party means any party other than a Parkinson's UK employee or a fellow Council member.
5. It is understood that the foregoing restrictions on use and disclosure shall not apply to information which:
 - was in the public domain or which subsequently becomes part of the public domain by publication or otherwise, except by your wrongful act
 - was in your possession and was not acquired directly or indirectly from Parkinson's UK
 - was received by you from a third party who did not acquire the same directly or indirectly from Parkinson's UK and who did not require you to hold the same in confidence.
6. A failure to respect the confidentiality of the Council may result in the termination an individual's membership of the Council.

Publicity

7. The Charity may publish the names, professional affiliations and other information of Council members on its websites and in its other publications. The Charity undertakes to make such publication only with the written approval of the member of both the principle of such publication and the specific information on the member. A member may withhold such approval and may discontinue a previous approval at any time by written notification to the Charity.

Agreement

I agree to serve as a member of the Cohort Studies Council of Parkinson's UK, in accordance with the Terms of Reference and Role Description described above, having received a letter of invitation specifying my term of membership.

Name:

Signature:

Date:

Appendix A

The seven principles of public life (Nolan principles)¹

Selflessness

Holders of public office should act solely in terms of the public interest. They should not do so in order to gain financial or other benefits for themselves, their family, or their friends.

Integrity

Holders of public office should not place themselves under any financial or other obligation to outside individuals or organisations that might seek to influence them in the performance of their official duties.

Objectivity

In carrying out public business, including making public appointments, awarding contracts, or recommending individuals for rewards and benefits, holders of public office should make choices on merit.

Accountability

Holders of public office are accountable for their decisions and actions to the public and must submit themselves to whatever scrutiny is appropriate to their office.

Openness

Holders of public office should be as open as possible about all the decisions and actions that they take. They should give reasons for their decisions and restrict information only when the wider public interest clearly demands.

Honesty

Holders of public office have a duty to declare any private interests relating to their public duties and to take steps to resolve any conflicts arising in a way that protects the public interest.

Leadership

Holders of public office should promote and support these principles by leadership and example.

¹ First Report of the Committee on Standards in Public Life, Cm 2850-I (London: The Stationary Office, October 2001).