

FIGHTING INFLAMMATORY BOWEL DISEASE **TOGETHER**

Terms of Reference Research Strategy and Funding Committee Crohns and Colitis UK

Background and responsibility

- Crohns and Colitis UK is a national charity leading the battle against Crohns Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD). By working with all those affected, Crohns and Colitis UK ("the Charity") aims to achieve a better quality of life, improve services and support, and through advances in research ultimately find a cure.
- 2. The Research Strategy and Funding Committee ("RSFC") Committee ("the Committee") takes delegated responsibility on behalf of the Board of Trustees for the research strategy, its delivery and all funding streams.
- 3. The RSFC 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 IBD.
- 4. Crohn's and Colitis UK seeks to build on its position as the UK's foremost medical research charity dedicated to IBD. Supporting research to advance our understanding, uncover the causes, reduce the social and psychological impact on patients and their families, develop better care and treatments and, ultimately, to find a cure for IBD.

Composition

- 5. The RSF Committee will consist of at least twelve (12) members. Membership will include at a minimum two (2) Trustees, one (1) of the Clinical Advisers to the Trustees, Chair of the Medical Research Awards Panel (1), Chair of the Living with IBD Awards Panel (1), one (1) paediatric IBD health professional (from any discipline) and one (1) lay member. Other members should provide the committee with broad representation from all health disciplines within the IBD specialty
- 6. The members of the Committee shall be appointed by the Board.

- 7. The members of the Committee may serve for a term of not more than 3 years, renewable once by the Board.
- 8. The lead trustee for research will chair the RSF Committee and his/her term will be dependent on their term of office as a trustee lead. In their absence, the Director of Policy, Public Affairs and Research will nominate an interim Chair.
- 9. The Director of Policy, Public Affairs and Research shall act as Secretary to the RSF 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 RSF Committee shall meet least 2 times a year
- 11. Unless otherwise determined by the Board a quorum shall consist of six (6) members of the Committee including at least one (1) Trustee.
- 12. Any trustee may attend a meeting of the RS&F Committee including those not members of the Committee.
- 13. The Director of Policy, Public Affairs & Research, 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 RSF Committee shall report back to the Board 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 Crohns and Colitis UK by:

• identifying new opportunities or areas of research most important to the charitable goals of Crohn's and Colitis UK

- aligning patient-centred research strategies with other funders working in the field of IBD
- raising IBD 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 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 each funding stream, directing limited funds towards areas of high priorities, according to strategic objectives and variations in overall research funds available
- ensuring that all research supported by Crohn's and Colitis UK is conducted to the relevant national and European legal standards and to the highest levels of integrity, clarity and good management
- enabling the development and maintenance of a set of objectives to evaluate grant applications
- managing the application peer review process through delegation to the Medical Research and Living with IBD Research Award Panels then considering their recommendations
- 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 on IBD

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 Director of Research, Policy and Public Affairs at the Crohns and Colitis UK.
- 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 Director of Research, Policy and Public Affairs, before the meeting.
- 25. A Conflict of Interest applies if a Committee Member fits any of the following criteria:
 - 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 coapplicant of the grant 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 Director of Research, Policy and Public Affairs 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.
- 30. All members will sign an acceptance of the terms of reference, confidentiality and conflicts of interest form (Appendix 1).

Resolution conflicts of interest

- 31. 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.
- 32. 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 by the Committee Chair and the Director of Research, Policy and Public Affairs.

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