



Supporting families affected by chronic granulomatous disorder

## Research Advisory Panel Code of Practice and Conflict of Interest Policy

### Background

A primary objective of the CGD Society (CGDS) is to fund medical and scientific research aimed at understanding, treating and curing chronic granulomatous disorder (CGD). When allocating charitable funds for research, the overriding consideration of the CGDS is the potential benefit for those with CGD.

The CGDS relies heavily on, and is greatly appreciative of, the goodwill and willingness of those members of the medical and scientific community who generously give their time to act as advisors and participate in the CGDS peer review processes.

The CGDS aims to ensure that it receives expert and appropriate advice in research matters and that it sets an appropriate research strategy that enables the CGDS to meet its primary objectives. It also aims to ensure that research proposals are assessed objectively, impartially and in accordance with the guidelines set out by the [Association of Medical Research Charities](#) (AMRC), of which the CGDS is a member. Advice from and review by an appropriately constituted body is seen as an essential element of this process.

As part of its commitment to impartiality and the integrity of the peer review and advisory processes, the CGDS has set down this Code of Practice and Conflict of Interest Policy for the members of the Research Advisory Panel. The purpose of this policy is to protect and preserve the integrity of both the peer review processes and advisors.

### Code of Practice

#### 1. Introduction

1.1 The purpose of this Code of Practice is to provide guidance focused on the operation of the CGDS Research Advisory Panel (the Panel) and to guide day-to-day practice.

1.2 The Panel must at all times:

- Observe the highest standards of propriety involving impartiality, integrity and objectivity within the context of 'The 7 principles of public life' set out by the Committee on Standards in Public Life (see Appendix A)

- Comply fully with the provisions of the Freedom of Information Act 2000
- Be accountable to the Board of Trustees and members of the CGDS.

## 2. The role and remit of the Panel

2.1 The terms of reference of the Panel are:

- To advise the CGDS Board of Trustees on the overall strategy for research and identify and notify the Chair of the Advisory Panel of any research opportunities and gaps
- To advise the CGDS Board of Trustees on the best mechanisms to achieve the research objectives
- To assist the CGDS Board of Trustees in monitoring the research strategy and assessing the effectiveness and impact of the CGDS research spend
- To assist the CGDS in exploring opportunities for leverage of research funds and for developing research partnerships
- To judge the quality and help produce a ranking to the CGDS Board of Trustees for applications received within the various research funding schemes.

2.2 Panel members should ensure that they understand fully the terms of their appointment and their duties and responsibilities.

2.3 Panel members have a duty to bring an independent judgement to bear on all issues considered by the Panel. On appointment they must undertake to comply at all times with this Code of Practice and act in good faith and at all times in the best interests of the CGDS.

2.4 The arrangements for appointing Panel members normally make it possible to remove an individual Panel member from office if he or she fails to perform the duties required of a Panel member to the standards expected.

2.5 Unless specifically stated otherwise, Panel members are appointed as individuals to fulfil the role of the committee, not as representatives of their particular profession, employer or interest group, and have a duty to act in the interests of the CGDS. Where members declare an organisation's views rather than a personal view, they should make that clear at the time of declaring that view.

2.6 A member's role on the Panel should not be circumscribed by the expertise or perspective he or she was asked to bring to the committee. Members should regard themselves as free to question and comment on the information provided or the views expressed by any of the other members, notwithstanding that the views or information do not relate to their own area of expertise. If members believe the committee's method of working is not rigorous or thorough enough, they have the right to ask that any remaining concerns they have be put on the record.

2.7 All members should regard it as part of their role to:

- Examine and challenge, if necessary, the assumptions on which scientific advice is formulated and ask for explanations of any scientific terms and concepts which are not clear
- Ensure that the committee has the opportunity to consider contrary scientific views and, where appropriate, the concerns and values of stakeholders before a decision is

- taken
- Share in the general responsibility to consider the wider relevance of their decisions to the field of CGD research.

2.8 Panel members will be expected to review individual applications. Guidance for the assessment of research proposals is given in Appendix B.

### **3. The role of the Chair of the Panel**

3.1 The Chair has particular responsibility for ensuring that the Panel is an effective and accountable decision-making body and for providing effective strategic leadership in matters such as:

- Effective execution of Panel decisions
- Encouraging high standards of propriety
- Representing the views of the Panel to the Board of Trustees.

3.2 The Chair should ensure that all new members of the Panel are properly briefed on the terms of their appointment and on their duties, rights and responsibilities.

3.3 The Chair should ensure that the Panel meets at least once a year, or as appropriate with CGDS grant-giving activities, and that minutes of meetings accurately record decisions taken and, where appropriate, the views of individual Panel members and any conflicts of interest are declared.

3.4 The Chair has responsibility for:

- The operation and output of the Panel, including assessing the workload and ensuring that the volume of work does not compromise the rigour of the discussion
- Ensuring that every member of the Panel has the opportunity to be heard and that no view is ignored or overlooked, using, where appropriate, a structured process which ensures that all views are captured and explored
- Ensuring that the full range of scientific opinion, including unorthodox and contrary scientific views, are appropriately taken into account
- Ensuring that any significant diversity of opinion among Panel members is fully explored and discussed and if it cannot be reconciled is accurately reflected in the minutes
- Ensuring that CGDS staff accurately document the Panel's proceedings so that there is a clear audit trail showing how the Panel reached its decisions
- Authorising actions affecting the Panel's business outside the normal meeting cycle
- Ensuring that the Panel acts in accordance with this Code of Practice.

3.5 The Chair of the Panel is precluded from applying to the CGDS for research funding for the duration of his or her term of office.

### **4. Working practices**

#### **4.1 Procedures for arriving at conclusions**

4.1.1 The Panel (and individual members) should ensure that it is comfortable with the mechanisms by which it reaches funding decisions or agrees its view.

4.1.2 Whatever mechanism is used to reach decisions, it is essential that the minutes of the meeting clearly set out the result of the discussion.

4.1.3 In reaching its funding decisions, the CGDS seeks to apply peer review of the highest international standards and to engage the appropriate additional expertise in the assessment of applications and the evaluation of funded research programmes.

## **4.2 Dealing with dissenting views**

4.2.1 When offering scientific advice, members should be clear about whether or not they are expected to reach a consensus on particular issues. The Panel should not seek unanimity at the risk of failing to recognise different views on a subject.

## **4.3 Minutes**

4.3.1 Minutes will be prepared as soon as possible after the meeting, subject to initial amendment/approval by the Chair.

4.3.2 Minutes should show clearly how the Panel reached its decisions. The minutes should accurately reflect the proceedings of the Panel, and any significant diversity of opinion among the Panel members should be accurately reflected.

4.3.3 The minutes of the Panel are confidential and will not be circulated outside the CGDS. All funding decisions are made public on the CGDS website and in publications.

## **5. Conflicts of interest**

5.1 Panel members are expected to declare any potential conflicts of interest relating to individual funding decisions to the CGDS before the meeting wherein they will be discussed, or during the meeting as soon as the existence of a conflict becomes apparent. Such conflicts of interest may include:

- The individual concerned is the sole applicant on the funding proposal
- The individual is a joint applicant on the funding proposal
- A relative of the individual is the sole or a joint applicant on the funding proposal
- An applicant on the funding proposal is a business partner of the individual
- An applicant on the funding proposal is a member or employee of the same institution as the individual.

In any of the circumstances above an individual will be automatically excluded from participation in a funding decision. He or she should absent himself or herself from the meeting while the proposal concerned is being discussed. He or she will not receive the application itself or any related papers, including the referee reports.

5.2 A register of interests will be kept up to date, and members should declare new interests as they arise to the CGDS.

5.3 In certain situations, an individual may be excluded from discussion of a proposal at the discretion of the Chair. Examples of such situations include:

- The individual concerned can be seen as a direct competitor of the applicant; i.e. the individual is currently being funded or is currently applying for funding on a project of a similar nature to the proposal under discussion
- The individual has acted as an external referee or on a funding panel/committee in respect of the proposal under discussion at a time when the proposal was being discussed by another funding body
- The individual has collaborated or published with the proposal applicant within the past three years
- The individual is aware of any other issue that might reasonably be expected to give rise to, or give rise to the perception of, a conflict of interest. In any of these cases, the particular situation will be discussed by the Panel Chair and the CGDS, who will decide on one of the following options:
  - The individual is allowed to participate fully in the funding decision.
  - The individual is allowed to discuss and vote on the proposal but may not present the proposal to the Panel.
  - The individual may comment on the proposal but not take part in any funding decisions.
  - The individual absents himself or herself from the meeting while the proposal is being discussed.

## 6. Confidentiality

6.1 Applications, reviews and the identity of reviewers are strictly confidential and should be kept secure and not discussed with or disseminated to others outside the Panel and the CGDS.

6.2 The Chair and Panel members should not discuss committee deliberations or reviewers' comments with applicants unless specifically directed by the Panel Chair. This should apply to funded grants as well as those that have been rejected.

6.3 The following are strictly confidential:

- Decision-making and Panel discussions (including the reasons for decisions to fund or not to fund)
- The contents of papers and correspondence relating to applications for funds, funding policy and site visits if applicable.

6.4 Panel committee members and referees also have a right to expect that their comments will be treated in confidence, by both the charities staff and other members of the Panel. For that reason:

- Papers must be kept secure and not disseminated to anyone
- Applications must not be discussed with anyone else (including colleagues based at the members' host institutions, and referees) without prior permission from the Trust
- No aspect of the deliberations or recommendations regarding any application should be discussed with applicants unless authorised by the Panel Chair. Feedback will be provided as appropriate by CGDS staff. Panel members should refuse any requests for information or for an explanation of how a particular decision was reached. All such requests must be referred to CGDS staff.

6.5 Applicants may seek advice from CGDS staff before applications are submitted. However, a clear condition of applying for a CGDS grant is that applicants should not approach the Chair or other Panel members, either before or after the decision on the application. If applicants approach members of the Panel, CGDS staff must be informed of the incident.

6.6 Any requests for further feedback, beyond that initially sent with the decision letter, and any complaints about the review process should be directed to and handled by CGDS staff.

6.7 The CGDS will only release anonymous Panel comments to applicants. The CGDS will not release Panel members' names in connection with any specific comments that are released under the Data Protection Act 1998 or the Freedom of Information Act 2000 without first obtaining permission to do so.

6.8 A list of Panel members is publicly available on the CGDS website.

## **7. Communication of decisions**

7.1 Only the Chief Executive, or those members of staff authorised to act on his or her behalf, may communicate decisions taken either by the Panel or the Board of Trustees.

## **8. Review**

8.1 This Code of Practice will be reviewed by the CGDS at least every three years.

*Dated June 2015*

## Appendix A

### The 7 principles of public life (Nolan principles)

#### **Selflessness**

Holders of public office should act solely in terms of the public interest.

#### **Integrity**

Holders of public office must avoid placing themselves under any obligation to people or organisations that might try inappropriately to influence them in their work. They should not act or take decisions in order to gain financial or other material benefits for themselves, their family, or their friends. They must declare and resolve any interests and relationships.

#### **Objectivity**

Holders of public office must act and take decisions impartially, fairly and on merit, using the best evidence and without discrimination or bias.

#### **Accountability**

Holders of public office are accountable to the public for their decisions and actions and must admit themselves to the scrutiny necessary to ensure this.

#### **Openness**

Holders of public office should act and take decisions in an open and transparent manner. Information should not be withheld from the public unless there are clear and lawful reasons for so doing.

#### **Honesty**

Holders of public office should be truthful.

#### **Leadership**

Holders of public office should exhibit these principles in their own behaviour. They should actively promote and robustly support the principles and be willing to challenge poor behaviour wherever it occurs.

Committee of Standards on Public Life (1995).

## Appendix B

### Assessment of research proposals by the Panel

The Panel should also consider the following points:

#### Importance

- Is the research likely to yield results that would be of immediate importance for people with CGD?
- Is there an important 'window of opportunity' (e.g. the chance to introduce a new clinical advancement)?
- How persuasive is the case for replicating the results or extending them to another system?
- Do the proposals effectively address needs or strategies identified by the CGDS?
- Has past work been exploited effectively?

#### Research plans

- How innovative are the general plans or specific methods, or is this a tried and tested approach? Where approaches are judged to have a high risk of failure, is this balanced by the benefits that success might bring?
- Taking into account any technical comments raised by the referees, how feasible is the proposed approach? Is this likely to be the most effective way of tackling the problem?
- Are there realistic approaches to the translation of research findings into improved practice in other fields and disciplines, whether more applied or fundamental?
- Are there realistic approaches to commercial development of any intellectual property arising from the research?
- Where relevant, are plans for organising research and fostering links to add value both realistic and likely to deliver higher quality or more productive science?

#### Justification of resources requested

- Has the applicant clearly set out the reasons for requesting the level of staffing and overall resources? Is this level adequate for the work described?
- Taking into account the expected benefits of the work proposed and the level of resources requested, do the proposals promise good value for money?

#### Ethics and research governance

- Is the proposed work ethically acceptable?
- Are there any ethical issues that merit separate consideration?
- If the research involves human participants (whether patients or healthy volunteers) or records, does the applicant have or plan to obtain appropriate ethical clearance from the relevant research ethics committee?
- Is the outcome of the proposed research likely to have ethical implications in the future?
- Could the proposed research work be carried out using approaches or techniques that avoid the use of animals?
- Has the applicant fully justified the use of animals and the proposed species?
- Is the number of animals appropriate?
- Are there any other concerns about the use of animals in this proposal?