

HEALTHCARE RESEARCH GOVERNANCE OVERVIEW

1 INTRODUCTION

The MND Association's vision is a world free of MND.

A published [Research Strategy](#) highlights the mechanisms through which research funding programmes will be developed 2018-2021, to deliver significant and measurable advances in understanding and treating the disease. To ensure the excellence of the research funded by the MND Association, applications for funding of research projects are evaluated by peer review.

Peer review is carried out by a committee of experts, the Healthcare Research Advisory Panel (HRAP). HRAP members are appointed by the Board of Trustees on the recommendation of the director of research development. The director of research development may consult the HRAP and the wider MND healthcare community on suitable candidates.

The purpose of this document is to inform applicants and members of the HRAP about relevant MND Association policies and procedures in relation to research funding.

2 GENERAL CONSIDERATIONS

The Panel has no responsibility for decisions concerning the size of the research budget. This is fixed annually by the Board of Trustees, which has ultimate responsibility for the allocation of funds.

2.1 The HRAP is responsible for the assessment and rating of applications for research funding. The HRAP makes a recommendation to the Board of Trustees of the MND Association, based upon its considerations. The Board of Trustees is responsible for the allocation of funding and for making the formal offer of a grant to applicants.

2.2 **Research Practice**

The research institute where the grant is awarded is responsible for the research practice of each research grant. It is responsible for ensuring that the necessary legal and regulatory requirements are met by the grant holder and approvals obtained before the commencement of the research grant and during the full research grant period. The research institute must have in place formal procedures for the handling of allegations of misconduct.

2.3 Confidentiality

By agreeing to become a member of the HRAP, an individual undertakes not to use or disclose any information obtained in the course of their membership for any purpose other than considering the relevant research or application under review, without the written consent of the Association. The Association will seek the consent of any concerned party prior to providing such written consent. This clause does not apply to any information already in the public domain prior to its disclosure via the HRAP. No copies shall be made of any information obtained via the HRAP and any documents (including electronic copies) obtained via the panel, shall be returned to the Association upon request. The supply of any information to panel members by the Association does not create any licence, title or interest in respect of any intellectual property rights. Panel members must not discuss with applicants or reviewers any information relating to the review of a specific application, or offer opinions on the chances of success or failure. All requests for information on an application or a reviewer report should be referred to staff in the Association responsible for research grants management.

Applications involving industrial partners may contain confidential and commercially sensitive information. In order to make such information available to members of the HRAP, to assist in the evaluation process of applications, the director of research development may sign a Confidentiality Agreement on behalf of the MND Association. Panel members must hold such information in strict confidence and not make use of the information other than for the purposes of evaluating a funding application.

Under freedom of information legislation, applicants have access to their own application files. Therefore, all written material used to evaluate an application may be made available to the applicants. The identity of the reviewers will not be revealed to the applicants.

2.4 Conflict of Interest

The Association must make every effort to ensure that its decisions are fair and objective and are also seen to be so. No panel member with a conflict of interest may participate in the review of an application.

Guidelines for disclosing conflicts of interest include panel members who:

- Are from the same immediate institution (same department/unit) as the applicant, and who interact with the applicant in the course of their duties at the institution.
- Have collaborated, published or been a co-applicant with the applicant, within the last five years.
- Have been a student or supervisor of the applicant within the last five years.
- Are a close personal friend or relative of the applicant.
- Have had long-standing scientific or personal differences with the applicant.
- Are in a position to gain or lose financially from the outcome of the application (eg hold stock in a company of an industry partner or a competitor).
- For some other reason feel that they cannot provide an objective review of the application.

Panel members must declare a conflict of interest in advance of reviewing an application. The director of research development is responsible for resolving areas of uncertainty.

The staff of the Association are subject to the same conflict of interest guidelines as regular panel members.

All panel members must agree to abide by the above confidentiality clause (paragraph 2.3) and the guidelines for declaring conflicts of interest (paragraph 2.4) when they join the panel. Members are asked to sign a form of agreement on appointment to the panel.

3 ROLE OF PANEL MEMBERS

3.1 HRAP Members

All panel members will review each application received for consideration and will be asked to provide confidential, constructive comments, when possible, to feedback to applicants.

3.2 Trustee Member of the HRAP

- MND Association trustee members of HRAP are trustees of the Association who have a demonstrated interest in health and science, but who are not currently active in the field of MND research. The trustee members provide a mechanism for public accountability and transparency of the peer review process, ensuring Association funding is in accordance with its strategic objectives. They also ensure the panel considers the relevance of the proposed research to people affected by MND and the likelihood of tangible benefits arising from the funding.

The duties of a trustee member include:

- Ensuring that the proposed research has a clear focus for people affected by MND.
- Commenting on the standard of lay abstracts, specifically the extent to which the intent and importance of the proposed research is well explained and written in language clear to members of the Association staff and the general public.
- Providing feedback on the general working of the panel such as the quality of work reviewed by the panel, the structure of the (online) discussions, the objective nature of the discussions and any other general comments.

Following the HRAP discussions, which may take place online or by teleconference, trustee members will provide assurance to the full Board of Trustees that all funding discussions and recommendations were conducted according to 'due process'.

4 REPORTS ON GRANT PROGRESS

4.1 Grantees must submit to the Association:

4.1.1 **Annual progress reports:** required within **four weeks** of the anniversary of the start date, using the Association's annual report form. A detailed report covering the whole year is required for review by members of HRAP. A short summary in language intelligible to the lay reader should also be submitted for possible use in Association publications.

4.1.2 **Interim reports:** if the project is funded through the Association major donor scheme, the grantee will be required to provide brief 6-monthly reports of no more than two pages. These reports are subject to review by the director of research development, not by the HRAP.

- 4.1.3 **Final report:** required within **six weeks** of the end of the project using the Association's final report form. A detailed final report covering the whole project is required for review by members of HRAP. A summary should also be provided in language intelligible to the lay reader. Grantees must avoid the use of jargon and technical language and should pitch the summary at the level of a science feature in a broadsheet newspaper.

This may be used in Association publications.

- 4.1.4 The final instalment of the grant will be paid after receipt and approval, by independent referees, of the final report. Payment may be delayed further if reports are not submitted on time and/or if clarification is required.

5 HRAP PROCESS FOR REVIEW OF REPORTS

- 5.1 Panel members who are reviewing annual/final reports should be familiar with the main objectives of the project and the applicant's experience.
- 5.2 A copy of the annual or final report will be forwarded to three panel members (including one trustee), along with the original application and past reports. They should review the work carried out to date, the likelihood of the project achieving its goals and highlight any problems of which the Association should be aware.

Panel members are asked to provide feedback via email. These comments will be passed on anonymously to the applicant, who has the chance to respond, if required.

6 PUBLICITY, REPORTING AND PRESENTATIONS

- 6.1 Grantees are expected to liaise with the MND Association Research Development Team when using the Association logo and images, presenting work funded by the Association and/or talking to the media about their MND Association funded work.
- 6.2 **Open Access**
Grantees in receipt of awards from 2011 onwards are mandated to make their peer reviewed papers, directly arising from their grant, available through open access. These research papers should be available within the Europe PubMed Central (Europe PMC) repository as soon as possible but within six months of publication of the paper (grant conditions section 17).

For more information please see the [Open Access Research](#) pages of our website.