



HEALTHCARE RESEARCH GOVERNANCE OVERVIEW

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1 INTRODUCTION

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

A published [Research Strategy](#) highlights the activities through which our research funding programmes seek to deliver significant and measurable advances in understanding and treating the disease. To ensure the quality and relevance 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 the Healthcare Research Advisory Panel (HRAP) comprising healthcare researchers, clinicians and patient/carer representatives. 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.

HRAP is responsible for the assessment and rating of applications for research funding. HRAP makes a recommendation to the Board of Trustees of the MND Association, based upon its considerations. The Board of Trustees is responsible for setting annual budgets and the formal offer of new research grants.

2.1 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.

2.2 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 destroyed/deleted or 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 about an application or a reviewer report should be referred to the Association's Research Grants Team.

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.

Applicants have the right to request access to all information held about themselves and their application. Therefore, 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.

2.3 Conflict of Interest

The Association will make every effort to ensure that its decisions are fair and objective and are also seen to be so. HRAP members must declare any potential conflict of interest. If a conflict of interest is deemed to exist, then the panel member will not 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 any other reason feel that they cannot provide an objective review of the application.

All 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 2.2) and the guidelines for declaring conflicts of interest (paragraph 2.3) when they join the panel. Members are asked to sign a form of agreement on appointment to the panel.

3 OUTLINE OF PROCESS FOR REVIEWING GRANT APPLICATIONS

Funding opportunities and deadlines for the submission of applications are published on the Association website and may also be advertised by email and other social media, on external websites, in specialist journals and on grants databases

Research workers who are considering submitting an application are encouraged to read the guidelines and grant conditions on our [website](#). Please contact the research grants team with any queries.

3.1 Summary Applications

The first stage in the application process is the submission of an outline of the proposed research – the summary application. Summary applications should be submitted online via the MND Association website at www.mndassociation.org.

A decision will be made as to whether summary applications are sufficiently relevant to MND (ie ALS, PLS and PMA) and/or Kennedy's disease (SBMA) and whether the project aims fit with one or more of aims outlined in published MND Association Research Strategy by:

- Seeking to address knowledge gaps in clinical/healthcare provision, including support for carers and families. Although not necessary, please refer to relevant themes that may have been identified through the [PSP on Palliative and End of Life Care](#) or the [NICE Guideline: Assessment and Management of MND](#)
- Building on studies already incorporated within the [MND Clinical Studies Group](#) portfolio
- Evaluating emerging pharmacological and non-pharmacological interventions in clinical trials
- Incorporating new evidence into clinical practice.

Summaries that are deemed unsuitable (this includes overseas applications that do not meet the overseas criteria) will not be considered by the summary review process outlined below. Applicants will be advised of this within two weeks of the deadline for receipt of summary applications.

Summary applications will be sent to three members of the HRAP for evaluation. Material arriving after the deadline date for summary applications will not normally be considered, unless it relates to the outcome of related applications submitted by the applicant or the appointment status of the applicant.

The criteria used for the initial review of summary applications are weighted as follows and scored using an agreed template based on categorical descriptors.

The Five Criteria and their Weights in the Overall Score of Summary Applications:

Institution and Applicant		
Experience and ability of the applicant and co-applicants	15%	25%
Project is a good fit with existing work and established methods in the applicant's department/institution	10%	
Project		
Overall aims, novelty, timeliness and relevance	30%	75%
Feasibility of achieving the work given the outline workplan within the cost and timescales of the proposed Project Grant/PhD Studentship	25%	
Potential to improve understanding of MND and/or inform clinical management	20%	
		100%

In each application round a cut-off score will be set (denoted **X** below). Typically this has been 50%, but may be set higher if the number and quality of received applications is correspondingly high.

A single decision is required of each of the three panel members at this stage:

Yes – suitable for consideration as a full application when the total score is **>X%**

No – not suitable for consideration as a full application when the total score is **<X%**

Panel members are asked to provide constructive comments on the proposal which can be fed back to the applicants, using the same categories as the rating criteria. Panel members are also asked to provide clarification if their scores are at odds with their comments eg a score above **X%** with comments that suggest a full application should not be invited or vice versa.

The applicants will be notified of the decision within six weeks of the deadline for receipt of summaries. Any comments from the initial review stage are fed back to the applicant.

- If the majority vote is **yes**, a full application is invited with notification of the deadline date.
- If the majority vote is **no**, a letter is sent to the applicant informing them that a full application is not being requested.

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3.2 Full Applications

All full applications received by the appropriate deadline date are entered into the competition. Material arriving after the deadline date will only be considered if it relates to the acceptance for publication of previously submitted manuscripts, the outcome of other applications submitted by the applicant or the appointment status of the applicant.

3.2.1 External review

Within three weeks of the submission deadline, the director of research/research grants manager will:

- Assign external reviewers to whom the application will be sent for written reviews, aiming for three written reviews per application.
- Provisionally assign the application to a panel member as internal reviewer, who will lead the review of the application at the panel meeting.

These assignments may take into consideration any suggestions made by the applicants for external reviewers but are not bound by them. Internal and external reviewers receive full copies of the applications assigned to them.

The HRAP chair and director of research development may suggest that additional members be co-opted to the panel for a certain competition, or to assist in the review of one or more specific applications, if it is felt that appropriate specific expertise is lacking among the regular panel members.

External reviewers will be asked to rate the applications according to the table below. (For more details on factors on the assessment, please see paragraph 2.2.)

Should be supported as research of high quality and timeliness. Links closely with the MND Association Research Strategy, with potential to make a significant contribution to future clinical management.	6	<input type="checkbox"/>
	5	<input type="checkbox"/>
	4	<input type="checkbox"/>
Links to the MND Association Research Strategy and is worthy of support in principle. Would add to understanding of clinical management but which is considered lower priority and significance than above.	3	<input type="checkbox"/>
	2	<input type="checkbox"/>
Reject: Does not link to the MND Association research strategy OR methodology is not sufficient to deliver meaningful evidence/outcomes	1	<input type="checkbox"/>
	0	<input type="checkbox"/>

They will also be asked to consider and provide written comments on the applicant's productivity, experience and training, the research proposed, the environment in which it will be conducted and the training environment (where this is applicable). Reviewers will also be asked if there are any specific concerns or questions that they feel should be clarified prior to the application being considered by the HRAP. Applicants will be given the opportunity to respond, time permitting.

Each panel member receives a copy of all the applications to be discussed at least two weeks before the meeting (unless there is a conflict of interest) and has access to all the relevant external reviewer reports. After the meeting the panel's funding recommendations are communicated as soon as possible for consideration by the Board of Trustees.

Applicants are informed of the results of the competition in three stages:

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- An initial email will be sent as soon as possible informing the applicant of the decision on their application. This enables unsuccessful applicants to consider applying for funding elsewhere.
- Applicants will receive a copy of the anonymous referees' reports, together with feedback from the panel discussion (where appropriate).
- Once funding has been approved by the Board of Trustees, successful applicants are sent a grant offer letter, together with supporting documents (including: *Terms and Conditions*; *Acceptance Form*; *Activation form*; *Payment and Reporting Guidelines*). Negotiation may be required prior to the grant being formalised.

In the course of discussion at a HRAP meeting, some applications may be flagged for special attention (for example because of funding overlap, eligibility, ethics, consent,) and may be held as 'pending'. The applicant will be notified by the director of research development or research grants manager if further information is required. The additional information may be discussed with the panel chair and/or reviewers if necessary, prior to a final decision regarding recommendation for funding.

4. THE ASSESSMENT OF AN APPLICATION

The objectives of the MND Association healthcare research programme are to fund research aimed at increasing treatment options and improving clinical/healthcare practice, to support not only people living with MND but also caregivers and families.

Evidence of originality, clear thinking and the potential for high quality and/or high impact publications is sought in preference to elaborations on existing knowledge, lack of focus or large numbers of low impact papers.

4.1 The Internal Reviewer Report

- 4.1.1 The internal review should briefly outline the aim(s) and description of the project, the purpose of the proposal, the hypothesis to be tested or question to be addressed, the objectives to be achieved, the approach proposed, the progress made in this general area by the applicants and other researchers to date.
- 4.1.2 This is followed by an assessment of the application (see section 2.2). It should be clear and concise, using objective language. The reviewer should state his/her opinions with justification. The review should also include comment on the external reviews, pointing out areas of agreement and disagreement. This might have to be done very shortly before the meeting, as not all external reviewer reports will be available at the time the review is initially written. It is not necessary to repeat the statements of the external reviewers, but if the panel member disagrees with them, reasons for doing so should be clearly stated.
- 4.1.3 The review should contain an assessment of the strengths and weaknesses, the originality and potential impact of the research described in the application, the appropriateness of the research plan, the past productivity of the applicants and the suitability of the research environment. The most useful reviews are those which

provide constructive advice to the applicant, enabling him/her to improve the quality and efficiency of the proposed research.

4.1.4 The review should include comments on the budget requested and a formal recommendation which is consistent with the scientific recommendations. If budget cuts are recommended, there should be clear and detailed reasons for the cuts.

4.1.5 If necessary, the reviewer may comment on such factors as the ethical acceptability of the research. It should be noted that the MND Association does not require copies of ethical approvals *per se* at the application stage. The Association may wish to ensure that certain details have been considered by the relevant ethics committee, or that appropriate licences/permissions have been obtained. If a grant is awarded, the MND Association may withhold funding until it is certain that such issues have been resolved.

4.2 Factors in the Assessment

The following questions are among those which should be considered. It is understood that reviewers and the panel may weigh these questions differently from one application to another.

The Applicant's Productivity, Experience and Training:

- How appropriate is the training or track record of the applicant(s) to the research proposed?
- How important and original is the recent productivity of the applicant(s)?
- How confident are you that the applicant(s) can do the work proposed?

The Proposed Research:

- How important and/or original are the questions to be addressed, and how clearly are they formulated?
- Will the study provide significant new knowledge with the potential to inform clinical/healthcare practice?
- How well will the proposed methodology address the questions? How appropriate are the methods to be applied and the proposed analyses of data? How will the applicant implement new methods which are to be introduced? Have the applicants anticipated difficulties in their approach and considered contingencies or alternatives?
- Is the rationale for the proposal grounded in a critical review of pertinent literature?
- Depending on the type of research, does the applicant have a plan for the dissemination of the findings so that they can be eventually translated into benefit for people with MND?

The Research Environment:

- Are the facilities and personnel available that are required to do the work?
- Is the applicant able to commit the amount of time that is required to do the research well?

- Are appropriate collaborations in place?

The Training Environment (where applicable)

- Are facilities and personnel available to provide a sound research training?
- Is the applicant able to commit the amount of time that is required to deliver training and supervision?
- Are appropriate student supervisory systems in place?
- What is the track record in student supervision?

5 THE PANEL REVIEW PROCESS

It is expected that the HRAP will work in a more consistent manner if members follow defined procedures.

- 5.1 Any panel member with a conflict of interest with a particular application will leave the room before that application is discussed. They will not have received any paperwork related to that application and a record of the discussion will be omitted from their copy of the minutes. If this applies to the chair of the panel, they will appoint a delegate as chair in their absence.
- 5.2 All panel members should be familiar with the main objectives of the project and the applicant's experience, as well as with the external reviewer reports. Internal reviewers therefore need only briefly summarise these during their five to six minute presentation of an application.
- 5.3 At the panel meeting, the assessment of each application begins with the internal reviewer announcing an initial rating of **A, B or C**, based on the 'scoring and rating research grants criteria' (see below). If the internal reviewer's rating is **C**, then the panel is given the option of not discussing the application further. If any panel member objects, the application must be discussed. If an application is not discussed, the applicant will receive a copy of the internal and external reviews, but there will be no other feedback. C rated applications are not scored. Typically, this process streamlines the panel meetings and allows panel members to devote more time to discuss competitive applications.
- 5.4 For applications that pass this first stage, discussion proceeds with the internal reviewer presenting his/her assessment of the application, describing the strengths and weaknesses of the proposal (see paragraph 5.2 Factors in the Assessment) and addressing the comments of the external reviewers. The director of research development may wish to comment further on issues that have already been raised or may wish to raise additional issues as appropriate.
- 5.5 The chair leads discussion of the proposal by all panel members. In addition to points raised by the internal reviewer, views expressed in the external reviewer reports must also be taken into account. The research grants manager or director of research development may introduce points not adequately addressed by the internal reviewer.

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- 5.6 Special concerns of eligibility, ethics, overlapping sources of funds, or other points are discussed. If necessary, such concerns should be flagged for MND Association staff to address should the proposal be funded.
- 5.7 Any concerns regarding the timescale or budget for the proposal should also be discussed and recommendations for changes should be noted.
- 5.8 If required, the director of research/research grants manager may read back their notes capturing the key elements of the discussion, which should be considered when rating the application.
- 5.9 Following the discussion, the chair seeks a ‘suggested consensus rating’ from the internal reviewer. This may be a revision of their initial rating based on the panel discussion, if they see fit. All panel members including the internal reviewer and trustees, but excluding MND Association staff, are then invited to agree or disagree with this suggested consensus rating.
- 3.10 Once all applications have been reviewed, if the panel feels that any application(s) has been treated inconsistently, re-review of one or a small number of applications is permitted. Any panel member with a conflict of interest must again leave the room. Following this additional discussion, a consensus rating is suggested by the internal reviewer and other panel members asked to agree or disagree.
- 5.11 The panel does not review the overall ratings of all applications at the end of the meeting, as individuals with conflicts of interest would inevitably be present during such a process.
- 5.12 When all applications have been discussed, each scoring member of the panel is invited to score all applications with a suggested consensus rating of **A or B**. This is done in writing and in confidence. The final rating assigned to the proposal is the average of these confidential numeric scores. Panel members do not score those applications where there is a conflict of interest.

A scoring system will be used as follows	Rating	Scoring					
		Not fundable		Recommended for funding			
				Low → High			
Appropriate for support	A			3	4	5	6
Possible for support	B	1	2	3	4		
Declined	C	Not scored					

Note that the A and B applications are both considered in the process, but the C applications have already been rejected.

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Only applications rated 'A' and 'B3' or higher are eligible for a recommendation for funding by the panel. Applications rated below 'B3' may be flawed in some respect, such that they are not considered to be of high enough priority, do not meet standards or fit with the research strategy and would require significant rewriting to be considered acceptable.

- 5.13 At the end of the meeting the **mean** score for each application will be calculated to two decimal places and applications ranked in order of priority.
- 5.14 From the scores, a ranked list of projects is produced suitable for presentation by the director of research development to the Board of Trustees for funding decisions.
- 5.15 An essential component of any panel meeting is a final review of the panel's effectiveness and functioning, along with a discussion of policy issues that may have arisen in the course of its deliberations. Panel members should therefore plan to stay for the entire meeting and make travel arrangements accordingly. Guidance on the probable length of the meeting will be provided in advance.

6 THE RATING

The rating given to an application reflects the evaluation of many factors. The Association does not provide rigid guidelines since no two applications are identical.

On occasion, if an application contains sections of varying quality and part(s) is(are) regarded as particularly compelling, the panel may prefer to base its rating on the parts regarded more favourably and recommend reducing the requested duration and/or funding of a project accordingly. It may also happen that a proposal is particularly exciting but feasibility of the entire body of work depends on a positive outcome to an initial experiment. In such a case, the panel may recommend funding to enable the applicant to obtain 'pilot' data that can then be used to support a subsequent follow-up proposal.

In deciding on the rating, panel members should use the full scale. The rating should not be influenced by such factors as overlapping funds, eligibility or issues of ethics which do not have scientific relevance. These should be discussed *after* the application has been rated. If the panel agrees, the concerns should be flagged for attention by MND Association staff.

7 BUDGET CONSIDERATIONS

An important part of the review process is to seek justification of resources and consequent budget requirements to fund a project. The appropriate budget is very much a matter for judgement by the panel. Some areas of research are more expensive than others. The panel may recommend funds for only the part(s) of the proposed research which are regarded more highly than others.

Discussion on justification of resources may be influenced not only by the perceived costs of the work proposed, but also by the judgements of the rate at which the panel feels the applicant should be able to progress. The latter may correlate with

the rating value. Thus, an application rated as merely good is not likely to be given the same latitude in terms of requested resources as one regarded as excellent.

Each budget item must be justified. If a budget is not adequately justified or explained in order to assess the request appropriately, the panel may request a follow-up by MND Association staff. If the proposal is approved for funding, funds will not be released until the budget justification concerns are resolved.

For equipment requests built into grant applications, recommended budgets should be justified item by item. Recommendation of only a global amount without itemised justification is not acceptable.

Consideration of the budget should follow this sequence:

7.1 Research Staff

Research staff should be determined by the actual needs for the techniques and work required for the research, as well as by the speed at which the panel considers the work could proceed. Applications for less than two years must include a named researcher who has the relevant expertise.

7.2 Materials, Supplies, Services and Travel

The panel may wish to consider the detail of costs in the above heading. MND Association grant awards may not be used for indirect costs, eg library access, heat and light, office furniture, regular telephone rates etc. Some applications request an amount for what may seem to be indirect costs or 'overheads'. These will need to be justified in terms of their direct contribution to the research, eg a cost of a mobile phone or stationery only used for the project.

7.3 Equipment

Equipment costs may be requested for identified items required to do the research. Cost quotations should be provided for equipment or service contracts greater than £10,000. The panel may receive proposals requesting equipment and/or maintenance alone.

All such costs should be rated according to the quality of the science the equipment is to support and the necessity for the equipment. Reviews should include comments on the proposed uses and need for the equipment and/or maintenance, the appropriateness of the equipment and/or maintenance requested, and the availability of similar equipment or services to the applicant's laboratory.

7.4 Overlaps with other Funding Sources

The panel is asked to review the requested resources in grant applications irrespective of other sources of funds received or applied for, ie they should *not* reduce recommended budgets to take into account potential overlap. However, if there is evidence of overlap with other actual or potential sources of funds, the application should be flagged by the panel. This information will be followed up by MND Association staff, with further consultation with panel members as required and adjustments made as appropriate. A summary and description of overlap for any grants held or applied for by the applicant should be included on the application form

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8 ROLE OF PANEL MEMBERS

8.1 HRAP Members

Unless they have a conflict of interest, 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.

8.2 Trustee Members of HRAP

MND Association trustee members of HRAP are trustees of the Association who have a demonstrated interest in healthcare research and/or practice. The trustees help to ensure that 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 on people affected by MND, with clearly stated outcomes for improving treatment and/or clinical management.
- Providing feedback on the general working of the panel such as the quality of work reviewed by the panel, the structure of the discussions, the objective nature of the discussions and any other general comments.
- Providing assurance to the full Board of Trustees that all funding discussions and recommendations were conducted according to 'due process'.

9 REPORTS ON GRANT PROGRESS

9.1 Grantees must submit to the Association:

9.1.1 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.

9.1.2 Interim reports: if the project is funded through the Association's major donor scheme, the grantee may 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

9.1.3 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.

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

10 HRAP PROCESS FOR REVIEW OF REPORTS

10.1 Panel members who are reviewing annual/final reports should be familiar with the main objectives of the project and the applicant's experience.

10.2 A copy of the annual or final report will be forwarded to two panel members (along with the original application and past reports if required). 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.

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