



Action for M.E. research funding assessment process

Introduction

This process has been developed to provide clarity, transparency and a clear governance framework for key stakeholders which includes researchers, universities, donors, Action for M.E. supporting members and other people affected by M.E.

As part of our Research Strategy 2014-2016, we highlighted the value we place on the engagement and involvement of people with M.E. and this revised process seeks to build this in as an inherent part of decision-making about research projects that we do and don't fund.

Action for M.E. is not a member of the Association of Medical Research Charities (AMRC) as our current policy is not to fund medical research projects involving animals. Action for M.E.'s policy on animal use can only be changed with full consultation with our supporting members. We don't feel this is necessary at this time.

While we do not meet this criterion to be an AMRC member, we are working towards achieving the remaining elements of the AMRC¹ five principles of peer review:

Accountability: Charities are open and transparent about their peer review procedures and publish details, including the names of the members of scientific advisory committees or other decision making bodies.

Balance: Scientific advisory committees reflect a fair balance of experience and scientific disciplines.

Independent decision making: The scientific advisory committee is independent of the charity's administrative staff and trustees.

Rotation of scientific advisers: Scientific advisory committee members have a fixed term of office and do not have tenure.

Impartiality: Scientific advisory committees include a significant number of non-beneficiaries. There is a conflict of interest policy and potential beneficiaries are not present when decisions are made.

¹ Association of Medical Research Charities, Principles of Peer Review (March 2014)

Stage one: Triage

All applications will undergo an initial stage triage by the CEO to ensure that applications meet two key criteria:

- Has the application form been completed fully and correctly?
- Does the application fall within the scope of the research call or if outside a call, the parameters of Action for M.E.'s Research Strategy?

If an application does not meet the above criteria, applicants will be notified within 10 working days after the closing date. Applicants will be able to reapply in subsequent calls.

Stage two: External peer review

All applications will be subjected to external peer review. The minimum requirement for all applications is one external peer review but in most circumstances, at least two will be sought. Where there are significant differences with scoring between two peer reviews, a third review will be sought.

Applicants will be asked to nominate two external peer reviewers at the time of application. Applicants are advised to refer to the Governance and Code of Conduct (Appendix III) when nominating reviewers and ensure that any nominated reviewers are made aware of their nomination.

In some circumstances, if suggested by reviewers and agreed by the Chair of the Scientific Advisory Panel, applicants will be given feedback to enable minor amendments or points of clarification to be made within five working days.

Stage three: Voice Committee

The Committee is made up of people with M.E., and clinicians, allied health professionals and primary care physicians all of whom are not currently active in research. The CEO will support the Committee and attend meetings but in a secretariat capacity only.

Members are selected in accordance with a person specification (Appendix I) following application and interview (may be done via phone/skype) by the Chair of the Scientific Advisory Panel and the CEO. Members are appointed for a term of two years' and can serve for up to six years consecutively. All Committee Members are required to work in accordance with the Governance and Code of Conduct (see Appendix III).

Voice members will be provided with a lay case for support (contained as part of the full application and written using guidance available as part of the application process) from all submissions six weeks in advance of a meeting. Lay cases should be written using non-technical language and aim to provide sufficient insight for the non-specialist to enable an understanding of the research proposal. Members may also have access to the full submission, should they wish to.

Voice members will be asked to consider three key criteria:

- Given the priorities laid out in Action for M.E.'s research strategy what potential is there for the research to lead to clinical/patient benefit or further research outcomes?
- Are there any issues of practicality for specific projects (e.g. demand on participants etc.)?
- From a patient/clinician perspective, what are the strengths/weaknesses of this project?

A meeting will be held (this may be a combination of physical meeting and remote via conference call) where the Committee will aim to reach a consensus view and scoring based on consideration of the above questions. See Appendix 4 for the scoring criteria. A brief report will be prepared for the Scientific Advisory Panel outlining the view/s on each application.

The Committee may ask views of the Scientific Advisory Panel which may inform its recommendation. While the primary focus of the Voice Committee is not the science *per se*, lay stakeholders may have valuable contributions and/or questions about the suitability or relevance of the research. Where this is the case, Voice may ask the Scientific Advisory Panel to consider specific questions in making their recommendation.

Stage four: Scientific Advisory Panel

The Panel is made up of researchers with a proven track record in their field and ideally with a specialism or interest within the M.E./CFS field. The CEO will support the Committee and attend meetings but in a secretariat capacity.

Members are selected in accordance with a person specification (Appendix II) following application and interview (may be done via phone/skype) by the Chair of the Scientific Advisory Panel and the CEO. The Chair of the Scientific Advisory Panel is appointed by the Chair of Action for M.E. Research Panel and the CEO. If a trustee meets the person specification and is selected to join the Panel, they will not hold the right to vote or participate in the discussion in stage five.

Members are appointed for a term of two years' and can serve for up to six years consecutively. All Committee Members are required to work to a Code of Conduct (see Appendix III).

Each application will have a nominated member from the Panel, nominated in advance, who will present the application, in light of the peer reviewer's comments, at a Scientific Advisory Panel Meeting. This meeting will usually take place immediately after the Voice Committee meeting.

After each application is presented and discussed, members will be given anonymised copies of the full applications and peer reviews and asked to score each application. The CEO will collate the scores and will determine an average score for each project and rank them in order of score at the end of the meeting. Only applications with an average score of 3.75 (out of six) or higher will be considered;

the remainder will be discarded and feedback will be provided to applicants who will be able to reapply in subsequent calls.

Stage five: Award decision-making

The scores from both the Voice Committee and the Scientific Advisory Panel will be combined for the shortlisted applications. A vote with supporting members and donors in the last research appeal will be undertaken on shortlisted applications to identify their top priority. The shortlisted applications and outcome of the vote will be presented by the Panel Chair to the Board of Trustees for a final decision to be made in conjunction with the funding available at that time.

Appendix I: Voice Committee person specification

The Voice Committee member role is a voluntary role and no reimbursement will be made for time and participation. However, reasonable expenses will be reimbursed. Voice Committee members should:

- have a keen interest in research, health and/or consumer-related issues
- be willing and able to commit the time required to take part in Voice activities and prepare appropriately, including the careful reading of relevant material provided four weeks in advance of the meeting. We anticipate one meeting per year
- be willing to travel to meetings usually in Bristol or London²
- demonstrate a balanced, broad view of understanding relating to M.E./CFS and the experiences of people with it
- have the ability to understand the concerns of people with M.E., their families and carers
- consider the research requirements and implications for all patients with M.E./CFS (and associated illnesses, where appropriate), without having a pre-set agenda
- have a keen interest in critical evaluation and be able to look at a situation as objectively as possible and from many viewpoints, not purely from one's own
- be willing to challenge and be challenged and to take an active part in meetings whilst also allowing others to play a part
- hold experience from one or more of the following (preferred but not essential):
 - research
 - health care
 - science communication
 - sciences
 - education
 - charitable funding
 - work in voluntary committees
- be able to listen to, read, assimilate information and analyse evidence that is sometimes complex
- demonstrate tact and discretion and uphold confidentiality.

² We recognise that some people will not be able to travel due to M.E. Discussion with a number of other research charities highlights that physical meetings work well. We accept that not everyone will be able to travel all of the time and therefore attendance and availability may be sporadic; where it aids accessibility teleconferencing will be possible

Appendix 2: Scientific Advisory Panel person specification

The Scientific Advisory Panel member role is a voluntary role and no reimbursement will be made for time and participation. However, reasonable expenses will be reimbursed.

Scientific Advisory Panel members will be a scientist or researcher (including clinicians with research experience) and should:

- have proven research experience in their own field, and ideally in the M.E./CFS field, including published papers in peer reviewed journals
- have experience of reading and reviewing written documents and experience of assimilating a large volume of written information.
- have good communication and team-working skills, including the ability to listen and take part in constructive debate, to present views succinctly and to respect views expressed by others.
- have an understanding of the impact of research in practice
- have an active interest in remaining current in relation to M.E./CFS research developments
- be willing and able to commit the time required to take part in the Scientific Advisory Panel activities and prepare appropriately, including the careful reading of relevant material provided four weeks in advance of the meeting. We anticipate one meeting per year
- consider the research requirements and implications for all patients with M.E./CFS (and associated illnesses, where appropriate), without having a pre-set agenda
- have a keen interest in critical evaluation and be able to look at a situation objectively and from many viewpoints, not purely from one's own
- have a demonstrable understanding of what constitutes a conflict of interest and commitment to minimising their occurrence
- be willing to travel to meetings usually in Bristol or London
- uphold confidentiality.

Appendix III: Governance and code of conduct³

1. Voice Committee remit

- 1.1 To scrutinise, from a stakeholder (patient and clinician) perspective, applications for research funding.
- 1.2 To advise, as a result of this scrutiny, the Scientific Advisory Panel and Board of Trustees on the importance and relevance to stakeholders of applications for research funding.

2. Voice Committee membership

- 2.1 Chair: To be appointed. This person will be required to have experience of facilitating discussions and managing meetings.
- 2.2 The committee comprises up to 9 members as follows:
 - Lay: 5 members
 - Clinician: 4 members
 - There must be a minimum of three people, at least one lay member and one clinician, participating in the meeting for it to be quorate.
- 2.3 Voice Committee members are recruited through a process of open competition instigated by the Chief Executive.
- 2.4 Voice Committee members are appointed for an initial term of office of two years, and may be invited to extend this for an additional 2 terms (maximum term of 6 years).

3. Scientific Advisory Panel remit

- 3.1 To scrutinise, from a researcher/scientist perspective, applications for research funding.
- 3.2 To advise, as a result of this scrutiny, the Board of Trustees on the scientific quality, value to the research field and potential benefit of applications for research funding.

4. Scientific Advisory Panel membership

- 4.1 The Panel will be made up of at least five research/science experts who have proven expertise, including published articles in peer reviewed journals. There must be a minimum of three people participating in the meeting for it to be quorate.
- 4.2 Scientific Advisory Panel members will ordinarily be recruited through a process of open competition instigated by the Chief Executive. However, to ensure a

³ With thanks to Arthritis UK for giving Action for M.E. permission to use and adapt their Code of Conduct

balanced membership that brings a high level of expertise, insight and experience, individuals can be co-opted on to the Panel.

- 4.3 Scientific Advisory Panel are appointed for an initial term of office of two years, and may be invited to extend this for an additional 2 terms (maximum term of 6 years).

5. Voice Committee, Scientific Advisory Panel and peer reviewer code of conduct

- 5.1 The Committee and Panel have a duty to ensure that grant assessment is carried out as impartially and objectively as possible. Where specific views or interests in a specific research area are held, these should be declared at the beginning of the process to ensure transparency and aid objectivity.
- 5.2 Individual grant applications and the results of the committee discussions are strictly confidential and should not be discussed or disseminated to others outside the Committee or Panel. All paperwork and electronic material should be kept secure and, where relevant, left for the Chief Executive to destroy after the meeting, shredded or permanently deleted from any computer or other electronic storage device.
- 5.3 Committee and Panel members should not discuss committee deliberations or the peer review process directly with applicants.
- 5.4 When Committee or Panel members are connected with an application that in any way presents a conflict of interest, they should alert Chief Executive prior to the meeting, and absent themselves from the meeting room while the application is being discussed.
- 5.5 If Action for M.E. has reason to believe that a member of a Committee or Panel has breached this code of conduct, they may be asked to resign in order to ensure the impartiality of the review process.

6. Voice Committee and Scientific Advisory Panel rights and responsibilities

- 6.1 Members with a particular expertise have a responsibility to make the Committee or Panel aware of the full range of opinions within their discipline.
- 6.2 Members should be free to question and comment on the information or the views expressed by any other Committee or Panel member, even if these are outside their own area of expertise. If members have concerns about the Committee's or Panel's method of working, they have the right to ask that these are put on record.
- 6.3 Unless otherwise specifically stated, members are appointed as individuals with a specific expertise to fulfil the work of the committee, not as representatives of a particular profession or interest group, and they have a duty to act in the interests

of Action for M.E. Members should make it clear when they declare an organisation's views rather than a personal view.

- 6.4 All members should regard it as part of their role to ask the applicant, via the CEO, for explanations of any scientific terms or concepts which are not clear.
- 6.5 All members should attempt to review all applications that have been allocated to them prior to the Committee or Panel meeting. If any member is unable to review all or some of their allocated applications, the CEO must be informed as early as possible in the process, and certainly by two weeks after issue of the applications.
- 6.6 All members must notify the CEO of their review outcomes by the date set at the beginning of the review period. This is typically 5-6 weeks after issue of the applications.
- 6.7 Unless the CEO has been advised otherwise (see 5), all members must contribute to the initial review process and advise the CEO of the outcomes of their review, regardless of ability to attend the relevant meeting.
- 6.8 All members are expected to be actively involved in this defined process. Employment commitments and personal circumstances may make this difficult for some members. Action for M.E. acknowledges this, as well as the voluntary nature of the committee. However, any member failing to actively participate in two consecutive meetings will be deemed to have resigned from the committee and a replacement will be sought. Members are able to take a break for up to 12 months from the Committee if personal circumstances necessitate without the requirement of re-application and interview.

Appendix IV: Scoring of applications and final funding decision-making

1. Peer review scoring

- 1.1 Peer reviewers are asked to comment on:
- scientific merit and major concerns
 - resources and feasibility
 - potential overlaps with existing research
 - importance to M.E.
 - potential patient benefit and impact
 - value for money.

- 1.2 Peer reviewers provide an overall score (1 – 6) taking into account:
- quality of science
 - significance to M.E.
 - feasibility and likelihood of successful outcome.

- 1.3 The scoring scale is as follows:

6	Excellent – definitely fundable
5	Good – fundable
4	Good potential – possibly fundable
3	Some merits – probably not fundable
2	Poor – not fundable
1	Extremely poor – definitely not fundable

- 1.4 Anonymised feedback from peer reviewers will be provided for all applicants subjected to the peer review process.

2. Voice Committee scoring

- 2.1 Voice Committee members are asked to comment on:
- relevance and importance of the research to people with M.E., clinicians and other key stakeholders
 - relevance of the research in relation to Action for M.E.'s strategic goals
 - the potential for the research to lead to clinical benefit
 - any potential practical issues or concerns.
- 2.2 Members will be asked to individually and then collectively provide an overall score (using the table in 1.3) taking into account:
- relevance
 - importance
 - potential benefit.

3. Scientific Advisory Panel scoring

3.2 Members will be asked to individually and then collectively provide an overall score (using the table in 1.3) taking into account:

- Quality of science
- Significance, relevance and importance to M.E.
- Potential benefit
- Feasibility and likely success

4. Final funding decision

4.1 An average score will be identified for each application. Any scoring below 3.75 (out of 6) will not be considered for funding and will not be put forward for the supporting member/donor vote.

4.2 The Board of Trustees will consider the scoring, the outcome of the vote and make the final decision in respect of funding. The Board's decision is final.

5. Version control

Version Number	Implementation Date	Author	Comments
1	16.5.14	SC	Board approval 14.5.14 – new procedure
2	03.02.15	SC	Research Panel approval – co-opting for SAP