



## **Society for Mucopolysaccharide Diseases**

### **Policy No. 8C**

### **TERMS & CONDITIONS OF MEDICAL RESEARCH GRANTS**

#### **1. Policy statement**

1.1 The Society for Mucopolysaccharide Diseases (MPS Society) expects the highest standards of integrity to be adhered to by the charity. To facilitate this process the MPS Society has drawn up these terms and conditions constituting good research practice.

1.2 The MPS Society funds a wide range of disease specific research including basic, applied, clinical and psychosocial. The MPS Society provides funds in a variety of different ways from small pump priming grants to substantial level of funds for programmes of research. The majority of MPS Society funded research is carried out in institutions where the MPS Society itself is not the employer and where the MPS Society looks to the host institution to implement good research practice.

1.3 The research institutions in receipt of MPS Society funding are expected to make researchers and others aware of the MPS Society's terms and conditions and ensure compliance with them.

#### **2. Introduction**

2.1 The MPS Society can only fund research that falls within its charitable objectives. These objectives focus on research closely related to the Mucopolysaccharide and related lysosomal storage diseases.

2.2 Charity law imposes certain obligations and restrictions on the use of charitable funds for research, for example, a requirement to disseminate useful research findings and a restriction on funding research for the purpose of commercial or private gain. Institutions should be aware of these conditions when in receipt of funding from the MPS Society.

2.3 The MPS Society cannot be prescriptive about individual approaches taken by researchers to solve particular research problems. However, the MPS Society expects institutions to ensure that an adequate structure exists to promote and promulgate good research practice, emphasising integrity and rigour in research, and creating a culture in which the following general principles can be understood and observed.

2.4 Researchers are also reminded that they are accountable to the MPS Society for their use of MPS Society funds and should ensure that any charitable funds received are used for the purpose agreed.

2.5 The MPS Society also expects that host institutions have in place formal written procedures for the handling of allegations of research misconduct. Useful models for such procedures can be found in the Wellcome Trust '*Statement on the Handling of Allegations of Research Misconduct*' and MRC's '*Policy and Procedure for Inquiring into Allegations of Research Misconduct*'. The MPS Society believes it essential that both 'whistleblowers' and the 'accused' are adequately protected when research misconduct is investigated.

### **3. Application process**

3.1 The MPS Society expects that the principles of these terms and conditions apply both to the grant application process and the carrying out of the subsequent research. In addition, researchers applying for funding from the MPS Society should:

- Not make the same application to several charities/medical research funder at the same time unless each charity/medical research funder is made aware.

3.2 The MPS Society uses peer review in the allocation of grants and support for research. Apart from the peer review process, the MPS Society normally seeks supplementary comments from external referees.

### **4. Research grant management**

#### **4.1 Lead Investigator**

The lead investigator undertaking the research must be either employed by a UK institution or form part of collaboration with a UK institution in which they intend to undertake the project. Unless applied for in the application, the salary of the lead investigator must be guaranteed by the institution during the term of the grant. It is essential that the lead investigator(s) should be actively engaged in the project and should not be substituted without MPS Society consent.

#### **4.2 Grant-funded staff**

The grant holding institution concerned must employ any individual paid from an MPS Society grant as one of the grant holding institution's employees for the duration of the grant. The MPS Society does not accept any liability for such staff.

#### **4.3 Start of the project**

It is the intention that when funds are available the grant awards are approved by the end of December. A 'start date' for the project must be specified in writing to the MPS Society within six months of the approval of a grant. The start date will be the date on which the first person is appointed or, where no staff are involved, the date when the first purchases are made in direct relation to the project. A form for notification of the actual start date will be enclosed with the acceptance forms for the grant. If that start date is deferred beyond six months, the MPS Society reserves the right to withdraw the grant without liability to the grant applicant.

#### **4.4 Reimbursing research costs**

Claims for reimbursement of research costs which have been agreed shall be covered by the grant should be submitted quarterly in arrears by the host institution's finance officer. Claims should detail expenditure and quote the grant number. Single expenditures (or aggregate purchases of the same nature) over £500 must be identified individually.

#### **4.5 Salaries**

Support for salaries must state the grade and basic salary requested with separate amounts for superannuation, national insurance and if appropriate London Weighting. Annual increments and allowances for inflation, in terms of cost of living, should be included. The MPS Society will sympathetically consider nationally agreed pay awards as far as it is able to do so but formal agreement must be obtained in each case. The MPS Society does not normally meet any other salary increases such as merit awards, promotions or salary enhancements nor additional costs arising from appointments made at a higher level than was specified in the grant application.

Advertisements recruiting staff for the MPS Society funded projects must acknowledge the support of the MPS Society.

#### **4.6 Expenses**

An expenses allowance may be applied for to cover research consumables such as reagents, materials, animal feed, etc. The amount requested should be reasonable, fully justified with allowances for increases in cost due to inflation being taken into account. In line with other medical research charities, the MPS Society does not

provide funds for administrative expenses or institutional overheads or expenses for attending scientific meetings.

#### **4.7 Equipment**

If equipment is required specifically for the project, detailed justification must be provided. If approval is given, the equipment remains the property of the MPS Society, but the grant holder is responsible for all costs of installation, maintenance, repairs, insurance etc. The equipment may not be transferred to another institution or research team without the MPS Society's permission. Permission will normally be given if that equipment continues to be dedicated to research into mucopolysaccharide and related lysosomal diseases and that no extra cost falls to the MPS Society. Estimation of equipment expenditure should include projected inflationary costs at the point of perceived purchase. If, at the conclusion of the project, the grant holder wishes to acquire the equipment, (s)he may apply to the MPS Society otherwise, title shall remain vested in MPS Society.

#### **4.8 Move to another UK institution**

If the grant holder is an individual and wishes to move to another institution within the UK, the MPS Society must first be informed and approval obtained before the transfer of the grant.

### **5. Monitoring Procedures**

#### **5.1 Annual reports**

Grant holders must provide the MPS Society with an annual progress report halfway throughout the period of the grant, for scrutiny by the Board of Trustees of MPS Society. A summary of no more than 250 words in lay terms is also required for publication on the MPS Society's website. Failure to submit the interim report by the date specified by the MPS Society may jeopardise the continuation of the award.

#### **5.2 Presentations**

Grant holders may be requested to attend conferences arranged by the MPS Society to present a poster or speak on the progress of their research. (Maximum of twice yearly)

#### **5.3 Site visits**

Site visits will be made by mutual agreement.

#### **5.4 Final reports**

Within six months of the end of the project, grant holders must submit 15 copies of a full report, for scrutiny by the Board of Trustees and for inclusion in the MPS Society's library. In addition, grant holders must submit two copies of all papers, in press or published, as a result of the project and a 250 word summary of their findings in lay terms for publication on the MPS Society's website. Failure to submit a final report by the date specified by the MPS Society will debar the lead investigator from holding a further MPS Society award.

#### **5.5 Safeguarding**

Where research involves direct work with patients, institutions need to provide the Society with their safeguarding procedures and any other relevant information as requested.

Intellectual property in any reports, presentations or publications (in any form of medium) shall belong to MPS Society and it shall grant a non-exclusive, royalty free licence to the grant holder to use the same for the purposes of fulfilling the terms and conditions of grant, for the grant recipient or its host institution's own internal learning or for any other charitable purpose authorised in writing from time to time by MPS Society. Any such intellectual property shall not be used by the grant recipient or any other person for commercial purposes.

### **6. Recognition and acknowledgement for support by the MPS Society**

All publications, communications and broadcasts relating to the work supported by the MPS Society must be approved in advance and acknowledge the MPS Society's support. This includes recruitment and advertisements for staff employed on projects supported by the MPS Society. Please consult with the MPS Society's Communications & Information Manager in regards to brand guidelines.

## **7. Publicity and dissemination of information**

The MPS Society research grants are financed by donations from people with MPS, their carers and members of the public. They welcome information about research success, which can influence future donations. If publication of the results of a research project funded by the MPS Society is likely to attract favourable publicity, it would be helpful if grant holders would inform the Group Chief Executive of the MPS Society so that press releases could be advantageously planned. Grant holders should do everything they can to support the aims of the MPS Society and increase understanding of mucopolysaccharide and related lysosomal diseases.

## **8. Scientific integrity**

8.1 In the rare event of scientific fraud occurring, the MPS Society wishes to make it clear that it is the responsibility of the employing authority to investigate this.

8.2 If a case of scientific fraud is suspected in the course of the research then the MPS Society should be notified and kept informed of further developments. At the initial stages of the enquiry the MPS Society will suspend the grant. If fraud is proven the MPS Society will terminate the grant immediately.

8.3 Researchers should be honest in respect of their own actions in research and in their responses to the actions of other researchers. This applies to the whole range of research work, including experimental design, generating and analysing data, applying for funding, publishing results, and acknowledging the direct and indirect contribution of colleagues, collaborators and staff.

8.4 Researchers are also accountable to the MPS Society, their profession, the institutes where the research is taking place, the staff and students involved and, in particular, the MPS Society who are funding the research. Researchers are expected to understand and apply the following principles:

- Plagiarism, deception or the fabrication or falsification of results should be regarded as a serious disciplinary offence
- Researchers are encouraged to report cases of suspected misconduct and to do so in a responsible and appropriate manner.
- Researchers should declare and manage any real or potential conflicts of interest, both financial and professional.

8.5 These might include:

- Where the researchers have an existing or potential financial interest in the outcome of the research;
- Where there is a public or private practice benefit significantly dependent upon the outcome of the research;
- Where the researcher's professional or personal gain arising from the research may be more than might be usual for research.

## **9. Openness**

9.1 Whilst recognising the need for scientists to protect their own research interests, the MPS Society encourages researchers to be as open as possible in discussing their work with other scientists and with the public. The aim in disseminating MPS Society funded research is to increase knowledge and understanding of the subject matter of the research for the benefit of the public as a whole. Its purpose should not be primarily to seek publicity or gain for the researcher, the research institution or the funder but to promote wider understanding of the subject matter.

9.2 Once results have been published, the MPS Society expects researchers to make available relevant data and materials to other researchers, with approval from MPS Society, provided that this is consistent with any ethics approvals and consents, which cover the data and materials and any intellectual property rights in them.

9.3 Researchers should be especially careful when discussing work that is not complete or has not been published, particularly if it has not undergone peer review.

9.4 The MPS Society accepts no responsibility for the accuracy or validity of any research undertaken or the results thereof.

## **10. Guidance from professional bodies**

Where available, the MPS Society expects researchers to observe the standards or research practice set out in guidelines published by scientific and learned societies, and other relevant professional bodies.

All researchers should be aware of the legal requirements which regulate their work.

## **11. Leadership and co-operation**

Heads of institutions and their senior colleagues should ensure that a research climate of mutual co-operation is created in which all the members of a research team are encouraged to develop their skills and in which the open exchange of ideas is fostered.

## **12. Supervision**

12.1 Institutions should ensure that appropriate direction of research and supervision of researchers is provided. Training in supervisory skills should be provided where appropriate.

12.2 A code of practice on the responsibilities of supervisors should be available indicating, for example, the frequency of contact, responsibilities regarding scrutiny or primary data, and the broader development needs of the research trainees.

12.3 The need should be stressed for supervisors to supervise all stages of the research process, including outlining or drawing up a hypothesis, preparing applications for funding, protocol design, data recording and data analysis.

## **13. Training**

13.1 Institutions should have in place systems which allow students and new researchers to understand and adopt best practice as quickly as possible.

13.2 All researchers should undertake appropriate training, for example, in:

- Research design
- Regulatory and ethics approvals and consents
- Equipment use
- Confidentiality
- Data management
- Record keeping
- Data protection
- Home Office training to gain licences when using animals in medical research
- Management of intellectual property
- Involvement of patients and consumers
- NHS research governance requirements
- Conduct of clinical trials

## **14. Primary data/samples/equipment**

14.1 There should be clarity at the outset of the research programme and the ownership and use of, where relevant, the following agreed with the MPS Society:

- Data and samples used or created in the course of the research; and
- The results of the research
- Patient questionnaires
- Equipment paid for by the MPS Society

14.2 Researchers should keep clear and accurate records of the procedures followed and the approvals granted during the research process, including records of the interim results obtained as well as the final research outcomes. This is necessary not only as a means of demonstrating proper research practice, but also in case questions are subsequently asked about either the conduct of the research or the results obtained.

14.3 Data generated in the course of research should be kept securely in a paper or electronic format, in adherence to data protection law from time to time, including UK GDPR and Data Protection Act 2018. The MPS Society considers a minimum of ten years to be an appropriate period to maintain research records. However, research based on clinical samples or relating to public health might require longer storage to allow for long-term follow-up to occur.

14.4 Back-up of records should always be kept for data stored on a computer.

14.5 Institutions should have guidelines setting out responsibilities and procedures for the storage and disposal of data and samples (including compliance with the requirements of any ethics committee).

14.6 Researchers should report any changes in the direction of research funded by the MPS Society to the Group Chief Executive and to any other relevant body. It would be expected that any change in the direction of the research will be discussed with the MPS Society prior to its implementation.

## **15. Ethical practice**

### **15.1 Research involving human participants**

Approval from the appropriate research ethics committees is required for all research funded by the MPS Society that involves human participants or human biological samples.

The MPS Society expects the relevant regulatory approval to be in place before funding is allocated to a researcher and reminds researchers that, where appropriate, the following bodies should be contacted and/or consulted:

- Local Research Ethics Committees (LREC)
- Multi-centre Research Ethics Committees (MREC)
- The host institutions' own Research Ethics Committee and those of collaborators.

The MPS Society also reminds researchers of the importance of regulatory approval from bodies such as:

- Human Fertilisation and Embryology Authority
- Gene Therapy Advisory Committee

The MPS Society recommends that researchers also contact:

- Any relevant professional or scientific body

And in some cases it may be appropriate to seek the views of the MPS Society's members.

Researchers should ensure the confidentiality of personal information relating to the participants in research, and that the research fulfils any legal requirements such as those of UK GDPR and Data Protection Act 2018.

### **15.2 Research involving animals**

The MPS Society requires that research involving animals should have approval of the following (through appropriate bodies):

- Ethical review process
- Home Office licences for the institution, the investigator and the project

Researchers should consider, at an early stage in the design of any research involving animals, the opportunities for reduction, replacement and refinement of animal involvement.

## **16. Dissemination/publication practice**

16.1 The MPS Society understands that researchers must have academic freedom and would not wish to discourage publication or dissemination of research or research findings.

16.2 The MPS Society encourages the publication of and dissemination of high quality research but believes that researchers must do this responsibly and with an awareness of the consequences of dissemination in the wider media.

16.3 Every effort should be made to inform the MPS Society of any potential publication or dissemination of the research findings in advance of any such publication. This will enable the MPS Society to have adequate time and accurate information to plan their own public relations. This can be especially important in respect of raising funds for further research.

16.4 Researchers supported by the MPS Society should take into account the following guidance when publishing or disseminating research at conferences or on websites:

- The MPS Society should be notified in advance when research might be published, publicised or disseminated
- Researchers should make every effort to make sure research is peer reviewed prior to it being published, publicised or disseminated. If research is placed in the public domain before peer review has been undertaken the researcher and research institution must make this clear in any publicity
- The MPS Society must be acknowledged in any publication or publicity. Please consult with the MPS Society's Communications & Information Manager in regards to brand guidelines.
- Results of research should be published in an appropriate form, usually as papers in referred journals
- Anyone listed as an author on a paper should accept responsibility for ensuring that he/she is familiar with the contents of the paper and can identify his/her contribution to it. The practice of honorary authorship is unacceptable.
- The contributions of formal collaborators and all others who directly assist or indirectly support the research should be properly acknowledged

## **17. Patient aspects/consumer involvement**

Researchers should consider and be aware of the active involvement of patients and consumer groups in research and the dissemination of research findings. It is important that researchers consider the impact any publication of research findings may have on patients with Mucopolysaccharide and related lysosomal storage diseases, those involved in the research and consumer groups.

## **18. Intellectual property**

18.1 It is a condition of the grant that researchers must inform the MPS Society of any intellectual property rights that may arise or arise from the research that it has funded. Although it is usual for the host institution to own the intellectual property arising from the results of the research the MPS Society has funded, it is important to remember that the intellectual property rights could not have been generated without the financial support for research activity provided by the MPS Society.

18.2 The grant recipient (or any person in whom intellectual property in the results of any research undertaken vests) shall grant to MPS Society (and any member of its group) an exclusive (subject to clause 18.4), royalty free, perpetual licence to use such intellectual property for its own purposes, including but not exclusively its own internal learning and development.

18.3 The MPS Society funds research for charitable public benefit and not for commercial or private gain. The purpose of the research is to educate the reader in relation to its subject matter, to promote and enhance good medical practice, to impart useful knowledge, and improvement in treatment or care of patients or in treating or preventing disease.

18.4 No rights to any intellectual property arising from research funded/part funded by the MPS Society may be sold, used or otherwise transferred to a third party without the written agreement of the MPS Society. An agreement for sharing of any revenue resulting from intellectual property generated through the project must be negotiated in advance of any commercialisation.

The latest version of this policy document dated 16.08.2024 is available to all employees of the MPS Society on the corporate intranet.

This policy document was approved under the Society's policy approval process on a version controlled basis.

Name of GCEO: Bob Stevens

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<b><i>Document History</i></b>			
<i>Version</i>	<i>Author</i>	<i>Date</i>	<i>Changes</i>
1.0	<i>C. Lavery</i>	<i>Sept 2011</i>	<i>First version</i>
2.0	<i>Tom Kenny &amp; Solicitors</i>	<i>19.07.2021</i>	<i>Complete review / update of IP</i>
3.0	<i>Fiona Stewart &amp; Derralynn Hughes</i>	<i>March - August 2024</i>	<i>Reviewed – Additional wording in section 18.4</i>