

Improving Quality of Life Grants

2026

TERMS AND CONDITIONS OF IMPROVING QUALITY OF LIFE GRANTS

1. MDUK REMIT

- 1.1. Muscular Dystrophy UK (MDUK) is a charity that connects a community of more than 110,000 people living with one of over 60 muscle wasting and weakening conditions, and all the people around them. So everyone can get the healthcare, support and treatments needed to feel good, mentally and physically. We fund groundbreaking research to understand the different conditions better and to lead us to new treatments.
- 1.2. The remit of Muscular Dystrophy UK (which refers to the charitable company legally known as the Muscular Dystrophy Group of Great Britain and Northern Ireland) is to increase understanding of muscular dystrophy and other muscle wasting conditions, and to support people with these conditions. This includes funding scientific and clinical research into understanding the causes and identifying potential management and treatment strategies, supporting clinical infrastructure relevant to muscle wasting conditions.
- 1.3. MDUK takes all necessary steps to ensure that the work it funds is innovative and does not unnecessarily duplicate world-wide research.
- 1.4. Research grants must be aligned to the current Research Strategy.

2. CONDITIONS OF GRANT

- 2.1. Improving Quality of Life grants are available for a period of up to one year. Funds awarded under this grant scheme can be for any type of research that fits the remit of the call.
- 2.2. The Principal Investigator must hold a contract, which extends beyond the termination of the grant, at a UK-based Institution (“the Institution”) approved by MDUK.
- 2.3. The grant must be used by the Institution only for the purposes of the award.
- 2.4. For projects falling within the scope of the Research Governance Framework for Health and Social Care MDUK is **not** the Research ‘Sponsor’. The Institution in which the research takes place must either accept responsibility as the Research Sponsor or put in place arrangements with a third party such as a local NHS Trust to be the Research Sponsor.

- 2.5. For projects falling within the scope of the UK Policy Framework for Health and Social Care Research the Principal Investigator must accept the responsibilities of Chief Investigator as set out under the policy framework (<https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/>).
- 2.6. The Principal Investigator (Chief Investigator) and any other lead investigators involved in clinical trials involving medicines, must be authorised health professionals as defined in the Medicines for Human Use (Clinical Trials) Regulations 2004, and any subsequent revisions (<http://www.legislation.gov.uk/uksi/2004/1031/contents/made>).
- 2.7. The Institution must accept full responsibility for the management, monitoring and control of all research work funded under this MDUK grant and all those staff (permanent, temporary and students) employed in, or involved in, any research funded as a result of this grant. This includes, but not exclusively, the requirements of all regulatory authorities governing the use of research on human subjects, or radioactive isotopes, pathogenic organisms, genetically manipulated organisms (GMOs), toxic and hazardous substances.
- 2.8. The Institution shall be responsible for maintaining appropriate policies of insurance covering professional indemnity, public liability and employer's liability insurance and it shall provide evidence of such cover to MDUK upon request. The Institution shall carry out appropriate Disclosure and Barring Service checks, or equivalent, on individuals whom it engages to provide the Services to the extent this is a statutory requirement relating to the Services under this agreement.
- 2.9. Any serious incident occurring in the course of a research project that has potential to harm the reputation of the charity should be reported to MDUK within 15 days. MDUK must be informed about and kept up to date with the investigation of any such events.
- 2.10. The project must have prior approval of the applicant's Head of Department and, where appropriate, the relevant local ethics committee. A project should not be activated without approval of the relevant ethics committee, even where such permission is not required for the start of the project. In the circumstances where this might delay the project the award holder should contact the MDUK research team in order to determine whether there is flexibility on this point.
- 2.11. Unless otherwise stated, all correspondence regarding the grant should be to our research team at Researchgrants@muscular dystrophyuk.org
- 2.12. The following must be completed before the start date of the grant:**
 - 2.12.1. Upon receipt of an award letter applicants should visit their online portal at <https://mduk.smartsimpleuk.com> and **accept the offer within one month of the**

award. If acceptance of the offer is delayed for any reason the applicant should contact MDUK's research team

- 2.12.2. The Institution must accept and agree to abide by MDUK's Terms and Conditions and any additional stipulations made at the time of award. A signed, scanned copy of the Terms and Conditions must be uploaded to the Grant Activation Form; this is found on the Principal Investigator's MDUK online grant record (<https://mduk.smartsimpleuk.com>). The Institution must obtain from all individuals subsequently funded as a result of the application the equivalent undertakings as required from the applicants when signing the application form.
- 2.12.3. The Grant Activation Form must be completed by the Principal Investigator on their online grant record – signed, scanned copies of the Grant Activation Form and the Terms and Conditions must also be sent by email to the Research Officer at researchgrants@muscular dystrophyuk.org. The Research Officer will confirm the activation of the grant. **The Grant Activation Form must be completed *prior* to the start date of the grant and no monies will be backdated if this form is not received in time.** By completing this form confirmation is being given that the project is about to start. The financial commitment for MDUK commences on the confirmed start date of the grant.
- 2.13. The project must begin within six calendar months of the date of the award letter. Written approval from MDUK is required for extension beyond this period and must be requested in advance. MDUK reserves the right to withdraw funding if it deems the start of a grant to be unnecessarily delayed beyond six months from its award date.
- 2.14. Any actual, potential or foreseen significant deviations in research protocol from those stated in the grant application must be reported immediately to the Research Officer of MDUK so that MDUK can determine whether the grant may proceed. In such circumstances it may be necessary for the Principal Investigator to provide a status report and for the grant to be reviewed by members of MDUK's Medical Research Committee. If deviation is not seen to be scientifically warranted or in line with the original application MDUK may withdraw the grant. Further supporting documents may be requested by MDUK. Failure of MDUK to respond within 20 working days of the initial notification or provision of further supporting documents, whichever is the later date, will be deemed to be approval.
- 2.15. Any actual, potential or foreseen significant delays of the research, of one month or more, for example, but not limited to, from sickness, maternity leave or staff turnover must be reported immediately to the Research Officer of MDUK. In such cases, MDUK expects to be kept up to date with progress on the delays.

- 2.16. The project must terminate within the time period specified at the time of the original award. Requests for extensions will only be considered on a no-cost basis. All requests must be submitted in writing (by email) a minimum of 30 days in advance of the start of the extension. No-cost extensions may be granted at the discretion of the Research Team but where there are concerns about progress of the project MDUK's Medical Research Committee may review the grant.
- 2.17. Should any Principal Investigator move to another Institution during the tenure of the grant, the grant may not move with them unless MDUK agrees to such a move. MDUK will not pay any additional costs as a result of such a move. In these circumstances the Principal Investigator must notify MDUK of their intention to move the grant and a letter must be issued by the Principal Investigator's new institution accepting responsibility for the grant. Should any Co-Investigators move to another institution during the tenure of the grant, MDUK will not pay any additional costs as the result of such a move. The Principal Investigator must notify MDUK of any such move and whether this will have material impact on the delivery of the project.
- 2.18. Should the Principal Investigator become unable to continue managing the grant for any reason, MDUK must be notified immediately by the Principal Investigator and/or the Co-Investigator(s) and/or the Institution. MDUK expects the Co-Investigator(s) and/or Institution to seek an alternative Principal Investigator for the grant and to be consulted as part of this process. Any changes in Principal Investigator must be agreed with MDUK in advance and MDUK reserves the right to terminate the grant if an appropriate plan is not put in place.
- 2.19. MDUK reserves the right to change the terms and conditions in accordance with changes to its own processes, legislation changes and/or Association of Medical Research Charities (AMRC) guidelines, at which point the new terms and conditions will apply both to new and existing grants.
- 2.20. MDUK reserves the right, without notice, to terminate the grant in the event of serious irregularities or non-performance of the grant or for other material breach of these terms and conditions. In such a case, MDUK will reimburse the Institution for expenditure properly incurred under the award up to the termination date, but will not be responsible for any administrative or overhead costs imposed by an Institution.
- 2.21. MDUK does not provide financial support for research projects conducted at overseas institutions except in exceptional circumstances.

3. FINANCE

- 3.1. MDUK is reliant on voluntary sources of funding, and therefore is subject to the continued availability of necessary funds.
- 3.2. MDUK also reserves the right to terminate the grant, with three calendar months' notice, should financial restraints require it to do so.
- 3.3. The Charity expects grant holders to begin the recruitment process in good time so that there can be assurance they have made every effort to have a candidate in place by the specified start date for their grant. If a grant is delayed, MDUK must be kept abreast of the situation and the efforts being made to recruit (see also clauses 2.12 to 2.16).
- 3.4. All payments made by MDUK are made to the Institution.
- 3.5. Grants may be for salaries (apart from Principal Investigator) of part-time or full-time workers, costs of laboratory consumable materials and equipment depending on the grant stream (£30k or £10k) and as specified in the award letter. It is assumed that ordinary equipment, facilities and materials are available in the laboratory in which the work is undertaken. **Under no circumstances will the Charity agree to meet administrative or other overheads imposed by a University or other Institution.**
- 3.6. Invoices for recurrent expenses should be for 3-month periods of the grant (referred to here as the "claim period") and should be submitted in arrears. **Invoices must be submitted to MDUK within three calendar months of the end of the claim period. Any outstanding amounts not claimed within three calendar months of the end of the claim period, will not be available unless a written request is received no less than 30 days prior to the end of the three-month period.**
- 3.7. Invoices should be raised via MDUK's online system, Smart Simple. MDUK will not accept any finance or service charges imposed in respect of this arrangement, nor will it enter into any other method of reimbursement. Invoices should be accompanied by a breakdown of the consumables costs being claimed and should be clear enough to allow MDUK staff to determine (a) whether the cost is an allowable cost and (b) that the item has been ordered within the period of the invoice.
- 3.8. Costs must relate only to those applied for in the application and allowed in the award letter. **The following costs are not allowed** unless specifically covered by the award and detailed in the grant application;
 - 3.8.1. Travel costs are excluded unless they are an integral part of the project.
 - 3.8.2. Costs of attending scientific meetings or society membership.

- 3.8.3. Computer equipment unless integral to the project (for example, bioinformatics projects).
- 3.8.4. Data storage costs unless integral to the project
- 3.8.5. Equipment costs unless integral to the project. We expect laboratories to provide and maintain equipment for general use and only under specific circumstances where specialist equipment is required will we consider providing funding.
- 3.8.6. We do not provide equipment maintenance costs.
- 3.8.7. Publication costs.
- 3.9. Costs must relate to the period stated on the invoice. Data entered on Smart Simple must reflect the information on the relevant invoice.
- 3.10. Credit notes must relate directly to only one invoice and to the period covered by that invoice.
- 3.11. In the circumstances that MDUK queries invoices we expect every effort to be made to notify the Institution's credit control team.
- 3.12. The final claim must be submitted to MDUK within six calendar months of the end of the grant. Any outstanding invoices not submitted within six calendar months of the end of the grant, will not be paid.
- 3.13. The final claim will not be paid until a satisfactory End of Project Report has been submitted. MDUK reserves the right to withhold payment of the final invoice if this report is not submitted by the Principal Investigator within two calendar months of the grant end date.
- 3.14. Nationally awarded salary increases will only be allowed if they have been provided for in the grant application and subsequent award. Reasonable allowance for such increases whether known, pending or anticipated must be included in the grant application.
- 3.15. Supplementary grants will not be considered in the circumstance where the applicant has failed to identify the appropriate costs in their application.
- 3.16. If at completion, the project runs under-budget, any excess monies awarded shall belong to MDUK and will not be made available for any other purposes.
- 3.17. Requests for virements between headings must be made in writing (by email) to MDUK at least 30 days in advance and may require the approval of the Chair of the Medical Research Committee. Any decision made in this respect is non-negotiable.

- 3.18. MDUK accepts no responsibility for expenses incurred over and above the amounts awarded.
- 3.19. The grant-holders, the Institution and the researchers working on the grant must not accept (and must not have accepted) any third-party funding for the grant, without the prior written consent of MDUK.

4. AUDIT

- 4.1. MDUK reserves the right to audit the finance of a grant at any time, either itself or using a third party, and the Institution shall provide such breakdowns, receipts, supplementary evidence and reasonable assistance as MDUK may require for this to be effected.
- 4.2. Principal Investigators are required to have in place formal purchasing procedures that ensure only valid grant expenditure is charged.
- 4.3. The grant may be cancelled if such procedures are found not to be in place.

5. EMPLOYMENT OF STAFF

- 5.1. MDUK does not act as an employer or accept any responsibility for staff employed on the grant.
- 5.2. Where posts are funded by MDUK in full or in part, the post-holder must spend their time providing the services/performing the research specified in this contract.
- 5.3. Employer's contributions in respect of National Insurance (including industrial injuries) and Superannuation will be reimbursed by MDUK to the appropriate employing authority, but responsibility for these arrangements lies entirely with the Principal Investigator. Responsibility for complying with the statutory requirements in respect of these matters lies with the Institution.
- 5.4. All liability in respect of maternity benefits, sick leave, redundancy, health and safety lies with the Institution.
- 5.5. MDUK must be informed of every member of staff employed on the grant. MDUK should be notified immediately of any changes to these details, including changes to the contracted hours, and be kept up to date with any relevant developments, for example in the recruitment process. Permission must be sought if the grant needs to be frozen or if there is to be a change of end date as a result of changes of staff.

- 5.6. If changing staff is likely to have financial implications on the grant, including but not limited to movement between headings, any such change must be requested in writing (by email), in advance to MDUK. Additional funds for employment of staff at a different level will not be provided by MDUK.
- 5.7. A CV Form for each staff member employed on the grant must be submitted by the Principal Investigator to MDUK once their identity is known. These are available from the online Grant Activation Form on the Principal Investigator's MDUK online grant record (<https://mduk.smartsimpleuk.com>).
- 5.8. The Institution must ensure that all permanent and temporary staff and students employed in or involved in the research receive training appropriate to their duties, in accordance with the regulations set down under Control of Substances Hazardous to Health (COSHH), Advisory Committee on Dangerous Pathogens (ACDP) and Advisory Committee on Genetic Modification (ACGM) guidelines (as updated), the Health and Safety at Work Act and regulations, and any other regulatory requirements as may apply from time to time.

6. ANTI-BULLYING AND HARRASSMENT POLICY

- 6.1. MDUK expects all people involved in its research to treat each other with dignity and respect and bullying and harassment of any kind, in any context, unacceptable.
- 6.2. MDUK may terminate the grant, or require that investigators are removed from the project, if either the Principal Investigator or the Co-Investigator(s) have had an allegation of bullying or harassment upheld against them, or where there is an ongoing formal disciplinary investigation. In such cases, the Institution must contact MDUK's Director of Research and Innovation.
- 6.3. It is the Institution's responsibility to:
 - 6.3.1. Adopt a formal policy that clearly sets out the standards of behaviour it expects from staff and the procedure for making and responding to complaints, including a first point of contact.
 - 6.3.2. Require that any sub-grantee or sub-contractor have an equivalent policy in place.
 - 6.3.3. Follow MDUK's procedures about notifying the Charity of misconduct on our active grants. Where a decision is made to investigate formally an allegation of bullying or harassment against an individual named on an active grant, the Institution must inform us when a decision to investigate formally is made.

- 6.3.4. Investigate allegations of bullying and harassment in an impartial, fair and timely manner, ensuring the rights of employees involved are protected, and appropriate action is taken. If the Institution is advised by the Principal Investigator, or any other named individual(s) on the grant, that a disciplinary procedure is warranted, MDUK expects the Institution to complete the disciplinary procedure such that a formal finding can be reached.
- 6.3.5. Ensure no agreements are entered into which prevent the Institution from telling MDUK of investigation findings.

7. FUNDRAISING

- 7.1. The Principal Investigator and Co-Investigator(s) will assist with any reasonable request to assist the MDUK fundraising strategy for this project, potentially including but not confined to:
 - 7.1.1. MDUK may deliver a public fundraising campaign for funding of the project grant. Staff employed on the project grant may be expected to attend fundraising events to meet key donors or speak at events
 - 7.1.2. requests for further information/clarification on project detail or budget breakdown for use in preparing a case for support;
 - 7.1.3. acknowledging significant donors' contributions if required by MDUK;
 - 7.1.4. disseminating information to donors, for example by hosting site visits at no cost to MDUK (other than transportation and costs associated with relationship development) or attending meetings with the donor off-site where they will be asked to meet key guests and speak to a lay audience.
- 7.2. Principal Investigators will make space available (for example in laboratories, clinics or at open days) for MDUK patient materials, information and/ or banners if appropriate. These are available upon request from MDUK.
- 7.3. Site visits may be arranged with reasonable notice by MDUK.
- 7.4. As trusts/donors/lay panel members may be involved in funding of grants, it may be requested that such individuals visit the Institution with prior arrangement.

8. EQUIPMENT

- 8.1. MDUK will only consider funding for specific items of equipment that are essential to the project and could not reasonably be expected to already exist within the research setting. Equipment for general laboratory use will not be funded by the charity.
- 8.2. Medical or Scientific equipment solely for use in medical research, diagnosis or treatment should be zero rated for VAT (general-purpose goods, even though used for scientific research, bear VAT).
- 8.3. MDUK-funded equipment must not be removed from the original location or modified without permission from MDUK.
- 8.4. At the end of the project the Principal Investigator must contact MDUK Director of Research and Innovation to tell them what the plans are for future use of any equipment having an original value of £2,000 or over, which has been purchased with MDUK's funds. MDUK reserves the right to suggest alternative use of such equipment, if deemed appropriate.
- 8.5. Any loss resulting from payments made for equipment in advance of delivery will be entirely the responsibility of the Institution.
- 8.6. The Institution is responsible for ensuring that any equipment, provided by this grant, has adequate insurance cover. If the equipment is damaged or destroyed, the Institution will be required to repair or replace it.
- 8.7. The Institution is responsible for maintenance of the equipment during its useful lifespan.
- 8.8. Should the Principal Investigator move to another Institution during the tenure of this grant, MDUK reserves the right to require that the equipment be transferred with them after discussion, as necessary, with the Institutions concerned. If the Principal Investigator moves to another Institution within three years of the termination of a grant and wishes to take the equipment with them, MDUK reserves the right to require that the equipment be transferred after discussion, if necessary, with the Institutions concerned.

9. RESEARCH MONITORING AND INVESTIGATIONS

- 9.1. The Principal Investigator is required to complete an annual progress report. Subsequent funding will not be awarded until receipt of this report and approval of this report by MDUK's Medical Research Committee. Interim meetings with the Principal Investigator and Co-Investigator(s) may be requested to provide an update on the research.

- 9.2. On termination of the grant, the Principal Investigator is required to complete an End of Project Report which is to be received by MDUK within two calendar months of the end of the grant period. Failure to submit will result in the final payment being withheld until submission of the report and may affect future grant applications.
- 9.3. Where volunteers are involved in research the Principal Investigator and Co-investigator(s) are required within the bounds of relevant ethical framework to provide feedback to the volunteers at appropriate intervals during and after their research; this should be evidenced in the annual progress report.
- 9.4. MDUK has a duty to its donors and supporters to provide evidence of the outcomes and impact of the research it has funded. Therefore, the Principal Investigator is required to complete on an annual basis submission of outputs and impact data through ResearchFish and to respond in a timely manner to any requests for clarification, corrections or otherwise of that submission. ResearchFish submissions should only include information that is relevant to MDUK-funded grants. The Principal Investigator will be required to provide follow-up information on the research after completion of the project as and when requested by MDUK.
- 9.5. As part of its obligations as a member of the Association of Medical Research Charities (AMRC), MDUK is required to provide them with annual details of grants awarded. Therefore, we reserve the right to submit information including the grant reference number, grant title, start and end dates, award amount, co-funding information (where relevant), host institution, principal investigator name, award abstract, grant type and information on animal use. This information may also be shared in other data analyses unless marked as confidential.
- 9.6. The Principal Investigator shall allow an individual authorised by MDUK to inspect and observe the performance of the work of the grant at all reasonable times with reasonable prior notice.
- 9.7. MDUK shall ensure that any person it authorises to carry out an inspection, monitoring or investigation shall not interfere with or disrupt the performance of the grant, shall have proper regard for the nature of the grant and shall comply with MDUK's obligations of confidentiality.

10. EXTERNAL COMMUNICATIONS

- 10.1. The Institution, the Principal Investigator and/or the researcher working on the grant should disseminate any outcomes of the project to as wide and as suitable a public audience as possible, as soon as possible after completion of the project or publication of any papers, subject to the rest of this section. Principal Investigators are

encouraged to disseminate negative outcomes of their research, as well as positive outcomes.

- 10.2. The Institution, the Principal Investigator or any staff employed on the grant should inform MDUK before contacting the media about any aspect of the grant, giving MDUK the opportunity to see and approve the communication before its distribution. If a publication is likely to generate media interest, MDUK requires prior notification, and will work with the Principal Investigator to plan an appropriate external communications approach to the wider media and stakeholders. Where appropriate, MDUK should be given the opportunity to submit a comment and/or a case study to the media as part of any coverage being placed.
- 10.3. All media enquiries received by the Institution relating to the grant should be discussed in advance between the Institution and MDUK to decide the most appropriate form of response.
- 10.4. MDUK should be acknowledged as the funder of the grant in all relevant external communications for the duration of the grant. When acknowledging MDUK the full charity name (Muscular Dystrophy UK) should be used. Our current logo should be used on posters and on presentation slides wherever possible. The Research team at MDUK will supply you with a high-resolution logo suitable for print and/or digital media as required.
- 10.5. Any scientific publication resulting from all or part of the work funded by MDUK must bear due acknowledgement to MDUK, quoting our grant reference. An electronic version must be sent to the Research Officer of MDUK before publication.
- 10.6. Any scientific papers submitted for publication, resulting from all or part of the work funded by MDUK should be sent to MDUK by the Principal Investigator two weeks prior to publication where possible, but at the latest, as soon as the paper is accepted for publication. This is to allow time to prepare communications and if necessary a statement, on an embargoed basis, for stakeholders, supporters and/or the media should it be deemed appropriate.
- 10.7. The grant-holder is expected to continue to alert MDUK of any publications arising as a result of this award after the grant is completed.

11. PATIENT AND PUBLIC INVOLVEMENT AND ENGAGEMENT

- 11.1. The Principal Investigator and any other relevant staff working on the project will be expected to participate in at least one MDUK event during the course of the grant. This may involve giving a presentation or presenting a poster.

- 11.2. The host institution is expected to have appropriate policies and practices that support the involvement of people with lived experience and the public in research, and their engagement with the project.
- 11.3. Where possible/appropriate Principal Investigators should include patients in the design of the research, in particular for clinical studies.
- 11.4. The Principal Investigator and any other relevant staff working on the project will be expected to participate in events that enable them to disseminate information about their work to a lay audience.

12. COMPLAINTS

- 12.1. The Principal Investigator shall make known to MDUK any formal complaints relating to the grant within 14 days of the receipt of the complaint. The Principal Investigator will outline the action that has been taken to address the complaint.
- 12.2. Within 28 days of receipt of the complaint, the Principal Investigator will confirm that the complainant is satisfied with the outcome, or inform MDUK of the further action to be taken.

13. TERMINATION

- 13.1. In the event that premature termination of the grant is being considered, MDUK must be included in any discussions prior to a decision being made.
- 13.2. In the event of termination, written notification must be given to MDUK immediately, outlining the reasons. This letter must be signed by the Principal Investigator and their Head of Department (or Dean of Research if the Head of Department is involved in the project).
- 13.3. MDUK will provide a letter to confirm closure of the grant upon submission of the final claim.
- 13.4. An end of project report must be completed within two calendar months and the final claim is to be submitted within six calendar months of notice of discontinuation.
- 13.5. The Institution will be reimbursed for expenditure properly incurred or reasonably committed up to the termination date.

14. DATA PROTECTION

- 14.1. MDUK requires that all grants comply with current data protection laws and regulations and any subsequent changes. The host institution is expected to have appropriate policies and training in place to ensure that the MDUK-funded staff and Principal Investigators are aware of, and compliant with, the law.
- 14.2. The use of patient health and medical information is subject to compliance with applicable data privacy laws. The Principal Investigator, therefore, agrees to take all reasonable steps to protect the confidentiality of any patient health and medical information to which they have access and to comply with any and all Applicable Laws relating to data privacy.
- 14.3. The provisions of this clause shall survive termination of this contract.

15. REMOVAL OF HUMAN TISSUE

- 15.1. Principal Investigators should note that MDUK expects that any procedure undertaken during the course of their projects that involves the removal of human tissue at post-mortem examination (Human Tissue Act 1961), or other tissue at other times, for example biopsies, will be carried out in accordance with the guidance issued by the Health Department/local Health authority.
- 15.2. It is the responsibility of the Principal Investigator to check whether ethical approval is required and obtain said ethical approval before the project starts.

16. HUMAN VOLUNTEERS

- 16.1. **Where human volunteers are to be involved in the research, Principal Investigator and Co-Investigator(s) must obtain relevant ethical approval before the project starts.**
- 16.2. Informed consent of every volunteer must be obtained in writing (by email) before their participation in the work commences.
- 16.3. Research involving individual patient data where the patient's consent will not be obtained is regulated by Section 60 of the Health and Social Care Act 2001, subsequently National Health Service (Consequential Provisions) Act 2006 and requires additional procedures which must be adhered to.

- 16.4. Award holders and Institutions have absolute responsibility for ensuring that investigations being undertaken at any site do not take place without the explicit approval of the appropriate authority in advance.
- 16.5. Although MDUK is not the Research Sponsor, any serious incident or serious adverse event (SEA) arising in the course of a research project must be reported to MDUK within 15 days, and statutory rules regarding notification to appropriate ethics committees must be followed. The research must be suspended until the ethics committee has reached a conclusion as to whether this research may continue and MDUK must be informed about and kept up to date with the investigation of any such event(s).
- 16.6. Where studies are carried out in an NHS Trust, the Trust has a duty of care to its patients. MDUK does not accept liability for any failure in the Trust's duty of care, or any negligence on the part of its employees.

17. RESEARCH CONDUCT AND INTEGRITY

- 17.1. MDUK expects that the researchers it funds maintain the highest standard of integrity. The Institution must have formal written procedures for the investigation of allegations of scientific misconduct.
- 17.2. It is a condition of funding that the Institution can produce evidence of a procedure for dealing with scientific fraud if requested. In the rare event of scientific fraud or other scientific irregularities occurring, they are the responsibility of the Institution.
- 17.3. The Institution must ensure that all funded work is at all times adequately supervised, monitored and evaluated.
- 17.4. The Institution is required to have in place procedures for governing good research practice, and for investigating and reporting unacceptable research conduct, which meet the requirements set out in the [Concordat to Support Research Integrity](#) and the [UKRI Research Integrity policy](#).
- 17.5. The Institution must report to MDUK:
 - 17.5.1. any investigations (and their outcomes) into research misconduct associated with the grant at the stage that it is decided to undertake an informal inquiry;
 - 17.5.2. on request, information on:
 - 17.5.2.1. its management of research integrity and ethics as described at [UKRI Research Integrity policy](#);
 - 17.5.2.2. details of any retractions or withdrawal of submissions/publications;

17.5.2.3. any allegations, proven or not, of any cases of fraud.

- 17.6. MDUK reserves the right to withdraw funding if allegations of research misconduct associated with the grant are upheld following investigation by the institution or relevant authority.

18. INTELLECTUAL PROPERTY AND OTHER RIGHTS

- 18.1. MDUK is under obligation to ensure that any results of its funded research (whether in whole or part) are applied for the benefit of the public. In some circumstances, this obligation may be best achieved through the protection of intellectual property and commercial exploitation. MDUK therefore requires the Institution to develop and implement strategies and procedures for the identification, protection, management and exploitation of MDUK-funded intellectual property. These shall be disseminated in clear guidelines to all staff and students working on the grant.
- 18.2. The Institution is required to ensure that all persons in receipt of MDUK funding or working on a MDUK-funded activity (including employees, students, visiting staff and subcontractors) are employed or retained on terms that vest in the Institution all MDUK-funded intellectual property and that they are aware of, and accept, the procedures.
- 18.3. The Institution and Principal Investigator and Co-Investigator(s) should notify MDUK promptly, before publication or other disclosure, in writing (by email) when any potential intellectual property, any results that appear to be suitable for commercial exploitation, including for patents, arises from the grant. They should take reasonable steps to ensure that such intellectual property is protected and not published or otherwise disclosed publicly prior to protection. Although this may mean delaying scientific publication for a reasonable period in order to file patents on inventions of potential commercial relevance before disclosure, any delays in publication should be minimised.
- 18.4. All intellectual property created or acquired out of the Project belongs to the Institution. However, no intellectual property, created or acquired, as a direct result of MDUK funding may be discussed prior to commercial exploitation or exploited commercially without the prior written consent of MDUK. Consent will not be unreasonably withheld, and MDUK will only refuse an Institution's request where it considers that the proposed commercial exploitation would run counter to its interests and charitable objectives. In the event that MDUK does not provide a response to the Institution's request for consent within 60 days, the Institution will automatically have the right to proceed with such commercial exploitation. Exploitation includes the use for any commercial purpose or any license, sales, assignment, materials transfer or

any transfer of rights. For the avoidance of doubt prior written consent shall not be required in respect of materials transfer to research institutions for academic research use. The Institution is not required to seek MDUK's consent in assigning Intellectual Property to its technology transfer company, subject to clause 26.10 being upheld.

- 18.5. The Principal Investigator must advise MDUK in writing (by email) of the nature of any proposed exploitation, identifying partners and proposed sharing of royalties. Any commercial benefit will be shared between the Institution and MDUK in such proportion as may be equitable, taking into account their respective contribution to the Intellectual Property. If a third party is used in this process then the Institution/Principal Investigator must provide details of the proposed third party to MDUK and obtain MDUK's prior written approval.
- 18.6. MDUK will assess on a case-by-case basis the proposed exploitation plan from the Institution. The terms of exploitation will then be set out in a separate agreement between the Institution and MDUK.
- 18.7. If the Institution chooses not to exploit or protect any intellectual property, or fails to do so to MDUK's reasonable satisfaction, MDUK shall have the right, but not a duty, to protect and exploit such intellectual property. If MDUK decides to exercise these rights, the Institution shall procure that its employees, students and any third parties acting on its behalf agree to co-operate fully and to carry out all acts required to assist MDUK in such protection and exploitation. Any commercial benefit will be shared between the Institution and MDUK in such proportion as may be equitable, taking into account their respective contribution to the Intellectual Property.
- 18.8. The Institution, Principal Investigators and Co-investigator(s) should inform the charity of any pre-existing arrangements of which they are aware, and which could lead to a breach of MDUK's standard terms and conditions with respect to this Intellectual Property and Other Rights section. The Institution should ensure that no consultancies, third party restrictions or arrangements which might impact on this MDUK-funded grant are entered into in relation to any MDUK-funded person or activity without prior agreement of the Charity. MDUK-funded investigators or individuals involved in a MDUK-funded project should not use materials or compounds (other than those obtained commercially), on terms which would place restrictions on intellectual property or publication of the results. Institutions shall use all reasonable endeavours to ensure 'reach through rights' have not been granted on any Charity-funded intellectual property in favour of commercial organisations providing materials or compounds to Charity-funded individuals for research purposes. However, MDUK recognises that companies providing materials may often require co-ownership of, or exclusive rights to any intellectual property arising from use of that material, and that this requirement is often non-negotiable. Where intellectual property arises from research linked indirectly to the use of material provided under such agreement, the

provider should be offered a time-limited opportunity to take out a revenue generating licence. In each of these two cases, MDUK requires notification prior to signing such an agreement.

- 18.9. The Institution will provide detailed accounts of Royalty Income and relative costs as required from time to time by MDUK, and in any case not less than once a year. Where the Institution bears the risk and cost of applying for patents, it will be entitled to recover its direct costs as a first charge upon the Royalty Income.
- 18.10. As a condition of granting consent, MDUK will require the Institution to accept the standard revenue and equity sharing terms of the charity; these will be based on a negotiated percentage of the net income.
- 18.11. MDUK expects that the Institution shall not, to the best of its knowledge, enter into arrangements which are inconsistent with the terms of this agreement. To the best of their knowledge and using their reasonable endeavours, the Principal Investigator and Co-Investigator(s), along with the Institution, will not enter any such arrangements in the future without the previous consent of MDUK, not to be unreasonably withheld or denied.

19. EQUAL OPPORTUNITIES STATEMENT

- 19.1. MDUK aims to be an equal opportunities employer. The Organisation treats all people with whom it comes into contact with the same respect regardless of age, disability, political belief, race, religion, sex or sexual orientation. It endeavours to provide its services to all that need them and strives to ensure its services meet their individual needs.
- 19.2. The Institution must have an Equal Opportunities statement or policy for equality, diversity and inclusion and provide a copy to MDUK on request.

Acceptance of Terms and Conditions

The Head of department, principal applicant and administrative authority are required to sign this form to confirm acceptance of the Terms and Conditions as published by Muscular Dystrophy UK. The standard Terms and Conditions may be modified by specific stipulations made at the time of award. These will be highlighted in the Award Letter sent to the Principal Investigator. **Please refer to the Award Letter prior to signing this document.** Please sign and upload a scanned copy of these Terms and Conditions to the online Grant Activation Form (accessed by the PI on their online grant record).

Grant reference number:

Head of Department

I confirm that I have read the Terms and Conditions as published by Muscular Dystrophy UK and agree to abide by them. I understand that the terms and conditions may change throughout the duration of the grant and I would be required to sign my agreement to the new Terms and Conditions. Failure to do so could lead to termination of the grant.

Name (Please print): Signed: Date:

Principal Investigator

I confirm that I have read the Terms and Conditions as published by Muscular Dystrophy UK and agree to abide by them. I understand that the terms and conditions may change throughout the duration of the grant and I would be required to sign my agreement to the new Terms and Conditions. Failure to do so could lead to termination of the grant.

Name (Please print): Signed: Date:

Administrative Authority for example Finance Officer, Bursar, Registrar

The Institution accepts the Terms and Condition as published by Muscular Dystrophy UK and agrees to abide by them. The Institution understands that the terms and conditions may change throughout the duration of the grant and the Institution would be required to sign

agreement to the new Terms and Conditions. Failure to do so could lead to termination of the grant.

Name (Please print): Signed: Date:

Position with the Institution: