

Muscular Dystrophy UK

Lay Research Panel: Terms of Reference

1. Status

- a. The Lay Research Panel is a standing sub-committee of the Board of Trustees of Muscular Dystrophy UK.
- b. The Lay Research Panel is the strategic body responsible for advising on activities relating to basic and medical research from a lay perspective.
- c. These Terms of Reference are subject to review by the Board of Trustees from time to time and subject to amendment as necessary.

2. Purpose of the Panel

- a. The purpose of the panel is to involve people with lived experience of muscle wasting conditions, i.e., individuals and family members, of those living with a neuromuscular condition, to participate in the selection of the best research options to develop treatments and cures for these conditions.
- b. The Muscular Dystrophy UK Lay Research Panel will review, discuss and score Muscular Dystrophy UK plain English research applications and provide feedback to facilitate discussions of the Medical Research Committee (MRC).

3. Main Responsibilities

- a. Make recommendations to the MRC, from perspective of people with lived experience of neuromuscular conditions, on all areas relating to medical research in order to achieve MDUK's strategic objectives and in line with its purpose and values.
- b. Represent the views of people affected directly or indirectly by a neuromuscular conditions when setting the priorities for funding research.

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- c. Assist the Muscular Dystrophy UK Research Team in determining the best ways to communicate research to a lay audience.
- d. Assist in other activities relating to medical research that require a representation of the voice of people with lived experience.
- e. To act as a research ambassador for Muscular Dystrophy UK, where appropriate.
- f. To exercise such other powers and duties as may be delegated to the Panel by the Board of Trustees from time to time.

4. Membership

- a. The Panel consists of the Chair, the Vice Chair and up to thirteen other members. The Muscular Dystrophy UK Director of Research & Innovation, the MDUK Research Team and a relevant volunteer scientist may be in attendance in an advisory capacity.
- b. There will be no more than three medical professionals who do not have a personal/family connection to the conditions as members.
- c. If a prospective Panel member is a member of the medical profession as well as having a personal/family connection to the conditions, the Chair must decide whether having a further medical professional on the Panel might tip the balance away from a truly lay perspective.
- d. Individuals with a strategic role e.g. as a Trustee in another organisation that is also a significant funder of research, might have a conflict of interest and might not be eligible to join the Panel.
- e. Each new member will receive a welcome pack and an induction.
- f. Members may be interested individuals or persons representing a specific support group. If a member representing a support group leaves the Panel, the Chair is not obliged to appoint a new member from within the same support group.

5. Term

- a. Individual or family members are appointed, in consultation with the Director of Research & Innovation, for a probationary year during which time the member will have

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voting rights. Members will review their probationary year with the Director of Research & Innovation and subject to agreement from both parties, the probationary year will be followed by a three-year term. This is renewable once for a further period of up to three years.

- b. The Chair and Vice Chair will be existing members of the Panel and the time he/she has served as Vice Chair/Chair will not count towards the period of serving on the Panel should they wish to return to the Panel following their tenure as Vice Chair/Chair.
- c. The Vice Chair will automatically be appointed Chair, on the retirement of the Chair. They will be appointed to the role of Chair for a two-year term.
 - i. Nominations for Vice Chair can be made by members of the Panel, who can nominate themselves or another Panel member for the role. Nominations should be sent to the Senior Grants Manager or Research Officer. Those who have been nominated by someone other than themselves will be consulted before their name is put forward as a potential candidate at the meeting. Nominations will be discussed at the Autumn Lay Research Panel meeting.
- d. New Vice Chairs will be appointed for a two-year term, from the nominations and majority vote of the members at the meeting.
- e. Any member may retire from membership at any time by informing the Chair or Director of Research & Innovation.
- f. Members (including the Chair and Vice Chair) may not be reappointed onto this Panel until at least three years has lapsed from the end of their previous term of membership.

6. Meetings

- a. The Panel will meet at least once per year.
- b. The quorum will be six members and one advisory members.
- c. The Panel may invite observers or advisors to their meetings as they see fit but they will not have the right to vote.
- d. The Chair and Vice Chair of the Board of Trustees may attend meetings at any time but do not have the right to vote.

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- e. The Chief Executive, Director of Research & Innovation and other staff as required shall be in attendance but do not have the right to vote.
- f. Each member is expected to fairly review and score applications for research into all types of neuromuscular disease. Each member has one vote.
- g. Any member or advisory member who has any connection or conflict of interest on any application may not participate in the discussion of this item and should refer to the Muscular Dystrophy UK Conflicts of Interest Policy for Members of the MRC and Lay Research Panel.
- h. As a volunteer only necessary and incurred expenditure to attend the meetings will be reimbursed.
- i. The Chair and Vice Chair will participate in the MRC meeting to discuss and review the research applications submitting the Lay Research Panel's views and score on each research application. If the science in respect of any application is different from the views of the Lay Research Panel then the Chair and/or Vice-Chair may exceptionally adjust their individual scores up or down by 1 point. Both the Chair and Vice Chair have a vote on the MRC and can vote independently of one another.

7. Sub-committees

- a. Members of the Lay research Panel will be asked to sit on sub-committees of the MRC that have delegated authority to make recommendations to the Board of Trustees. Each sub-committee being on an ad hoc basis or re-formed annually.
- b. If a sub-committee is constituted to make a funding recommendation to the Board, to be quorate, it must consist of a minimum of six voting members and should ideally include equal numbers of members from the Medical Research Committee and the Lay Research Panel.

7. Confidentiality

- a. All papers or electronic documents sent or seen by group members will be treated confidentially and either shredded or destroyed after the meeting. The documents will only be discussed within Lay Research Panel and MRC meetings and not with anybody else.

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8. Member Attributes

- a. An understanding of Muscular Dystrophy UK's overarching strategy 'and its research strategy.
- b. The ability to look beyond their own interests when setting the priorities for research funding.

9. Governance

- a. The Panel is governed by its duty and responsibility to Muscular Dystrophy UK Trustees to assist in selecting the best applications for research.
- b. The Panel or any of its individual or family members has no authority in their own right to contract or review funded projects.
- c. The governance of the Panel is set by the Memorandum and Articles of Association of the Muscular Dystrophy Group of Great Britain and Northern Ireland (known as Muscular Dystrophy UK) and the policies and procedures thereof.
- d. All interpretations of this document are by reference to the appropriate policy and procedure of Muscular Dystrophy UK.

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