

MDUK Lay Research Panel role description

We understand that a diagnosis of muscular dystrophy changes everything. Every day Muscular Dystrophy UK is urgently searching for treatments and cures to improve lives today and transform those for future generations.

What is the Lay Research Panel?

The purpose of the Lay Research Panel is to involve individuals and family members, of those affected by, or interested in, neuromuscular disorders (also known as muscle-wasting conditions), to participate in the selection of the best research options to develop treatments and cures for these conditions. This helps us to deliver research that will have an impact on patients' lives.

How you will make a difference

Members of our Lay Research Panel (LRP) represent the views of people affected directly or indirectly by a muscle-wasting condition when setting the priorities for funding our research.

MDUK funds research into muscle-wasting conditions. We believe that non-scientists can make a valuable contribution to the assessment of research applications and so we ask researchers to provide us with a plain English version of their application. As a member of the Lay Research Panel you will make contributions to the evaluation of these applications and will help us to make decisions about whose research to fund. As someone with experience of a muscle-wasting condition, either through your own experience or through personal or professional connections, you will understand what is valued by the community of people with muscle-wasting conditions and will apply those insights to the assessment of research applications.

Role title: Lay Research Panel member.

Location: Attends meetings at our London-based office or virtually through Teams or Zoom. Please note that we only accept applications from people resident in the UK.

Department: Research.

Frequency:

- The Lay Research Panel meets once a year to assess research applications. This is a half- to one-day commitment or sometimes two half days a year. Panel members will be expected to read and review several applications ahead of this meeting.
- Typically, the Lay Panel meets at one other time of year for a couple of hours to discuss grants that have been funded and areas of strategic importance to MDUK.

Minimum period: 1 year probation, followed by 3 years.

Maximum period: 7 years. If Lay Panel members volunteer for a position as Chair or Vice-Chair their tenure does not count towards the 7-year total.

Summary of role

What you'll get out of the role:

- The opportunity to input into decisions about the funding of research and to ensure that the views of those directly affected by muscle-wasting conditions are heard.
- The chance to learn more about research into muscle-wasting conditions.
- Meet new people and develop teamwork and communication skills.

What you'll be doing:

- Representing the views of people affected directly or indirectly by a muscle-wasting condition when setting the priorities for funding research.
- Reading and assessing the plain language applications prepared by researchers. There is no special training required for this, although we often ask people with associations to a particular condition to assess applications with which they might feel a connection.
- Attending meetings of the Lay Research Panel and discussing your views and those of others about the research applications. You will be asked to read some applications in a little more depth and to present those applications to your colleagues on the Lay Panel.
- Contributing towards a score and a recommendation about funding of applications. This will influence the final recommendations made by our scientific committee (the Medical Research Committee).
- Assisting the MDUK Research Team in determining the best ways to communicate research to a lay audience from time to time.

What you'll bring:

- Members of our Lay Research Panel do not necessarily have a background in science or research but bring their lived experience to their work with MDUK.
- You will bring an interest in the science of muscle-wasting conditions and an enthusiasm for reading about new scientific and medical advances in the treatment of muscle-wasting conditions.

Commitment to volunteers

What we expect from you:

- Enthusiasm and commitment to supporting the work of MDUK.
- To maintain and uphold the reputation and good name of the charity.
- To respect the confidential nature of the applications that you will review. We will ask you to sign a confidentiality agreement.
- To listen to, and work co-operatively with, paid members of staff and other volunteers – treating all with courtesy and respect.

- To take reasonable care of your own health and safety and that of others.
- To support the charity's equal opportunities and diversity policy – helping to promote this to all our supporters.
- To provide us with feedback on how we can improve your volunteering experience with the charity.
- To inform us if your commitment to us, for any reason, can no longer continue.

What you can expect from us:

- We will share the *Volunteers' Handbook* with you.
- Regular email updates on the charity's work.
- Contact with other volunteers working with MDUK.
- Your main contact will work with you to provide any support and training you need to fulfil your role.
- You can claim back pre-agreed reasonable expenses.
- Insurance cover, while volunteering, under MDUK's public liability insurance.
- Your personal data will always be held securely in accordance with GDPR and our Privacy Policy which can be found on our website.
- A formal, written procedure for resolving difficulties; if you have a complaint it will be dealt with promptly and fairly.

Other

GDPR training:	Provided
Confidentiality agreement:	Required
Conflict of interest declaration:	Required
Travel:	Required (from your home to the London office to attend a meeting, alternatively, you will be able to join virtually via Teams or Zoom)
Access to internet:	Required – Needs own equipment

Application process

- The application deadline is Thursday 27 October 2022
- Shortlisting will take place in mid-late November
- Interviews will be in late November-early December. Interviews will be held via Teams/Zoom. The panel will consist of existing members of the Lay Research Panel and members of the Muscular Dystrophy UK Research Team
- You will be notified of the outcome of your application by mid-December