

Muscular Dystrophy UK

Fighting muscle-wasting conditions



Stronger Together

Our equality, diversity and inclusion strategy



Our community makes us stronger.

We'll rally our community of 110,000 people with over 60 different muscle-wasting conditions, so we can all get the healthcare, support and treatments we need to feel stronger, mentally and physically.

Access to care and treatments for muscle-wasting conditions should be equitable for all, and no one should be disadvantaged or discriminated against when it comes to getting the right support.

We know there is still plenty of work to be done to make this possible. We're determined to do what we can to make sure everyone in the muscle-wasting community can get the support they need. And that everyone feels represented and included, every step of the way.

This is our first strategy setting out our goals for improving equality, diversity and inclusion (EDI) at Muscular Dystrophy UK (MDUK).

In this strategy, we've set out some high-level guiding principles, which will underpin all the work we undertake. We'll be regularly monitoring our progress against these principles.

As this is our first EDI strategy, we have begun by focusing on our organisation, our staff, and supporters. As we make progress, we will update and extend these goals.

“I want to make the space my son will be entering for his additional needs a more diverse one”

Tiffany Hesson, Volunteer EDI Ambassador, Muscular Dystrophy UK

Tiffany’s son Roman (pictured) was born with LMNA-related congenital muscular dystrophy. She has been working with MDUK to raise awareness of the need for diverse, inclusive and equitable representation for families like hers affected by muscle-wasting conditions.

In 2021, she met with former Secretary of State for Health and Social Care Sajid Javid to share her perspective as a parent of a child with a rare disease from an ethnic background. She has also attended events for the charity, including BGC Partners' annual Charity Day.



What do we mean by equality, diversity and inclusion?

Equality

A society or workplace free from discrimination, where everyone has the same opportunities and is treated with dignity and respect. Together with our community we're continuously striving to ensure that everyone affected by a muscle-wasting condition is treated equally and given the support they need.

Equity

Knowing that not everyone starts in the same place and that everyone's needs are different. Treating people as individuals and giving them what they need and levelling the playing field is how we achieve equality.

Diversity

Understanding and embracing the full breadth of differences between people, both in society and the workplace. We believe that everyone should be respected and celebrated for who they are. By bringing together our different experiences, skills and ideas, we can achieve incredible things for the muscle-wasting community.

Inclusion

Actively creating an environment and culture in which everyone is comfortable, valued and respected. At MDUK we're striving to build a society free of barriers for people affected by muscle-wasting conditions, where everyone feels like they belong.

Catherine Woodhead, our CEO, has signed a Statement of Intent with leaders from Muscular Dystrophy Australia, Muscular Dystrophy Canada, and Muscular Dystrophy Foundation of South Africa.

The collaboration came after Catherine recognised the need to work more actively on Equality, Diversity and Inclusion within the neuromuscular community on an international scale.

She reached out to each charity's leadership team and invited them to collaborate on the joint Statement of Intent.

Together, the four charities have agreed they will:

- sign up to the shared EDI international vision, commitment, and ambition
- share policies, insights, training and data on how to break down barriers in society and improve workplaces
- create an EDI strategy appropriate to our charity and community needs

We know that we are stronger together and we'll aim to create sustainable change by learning from each other.

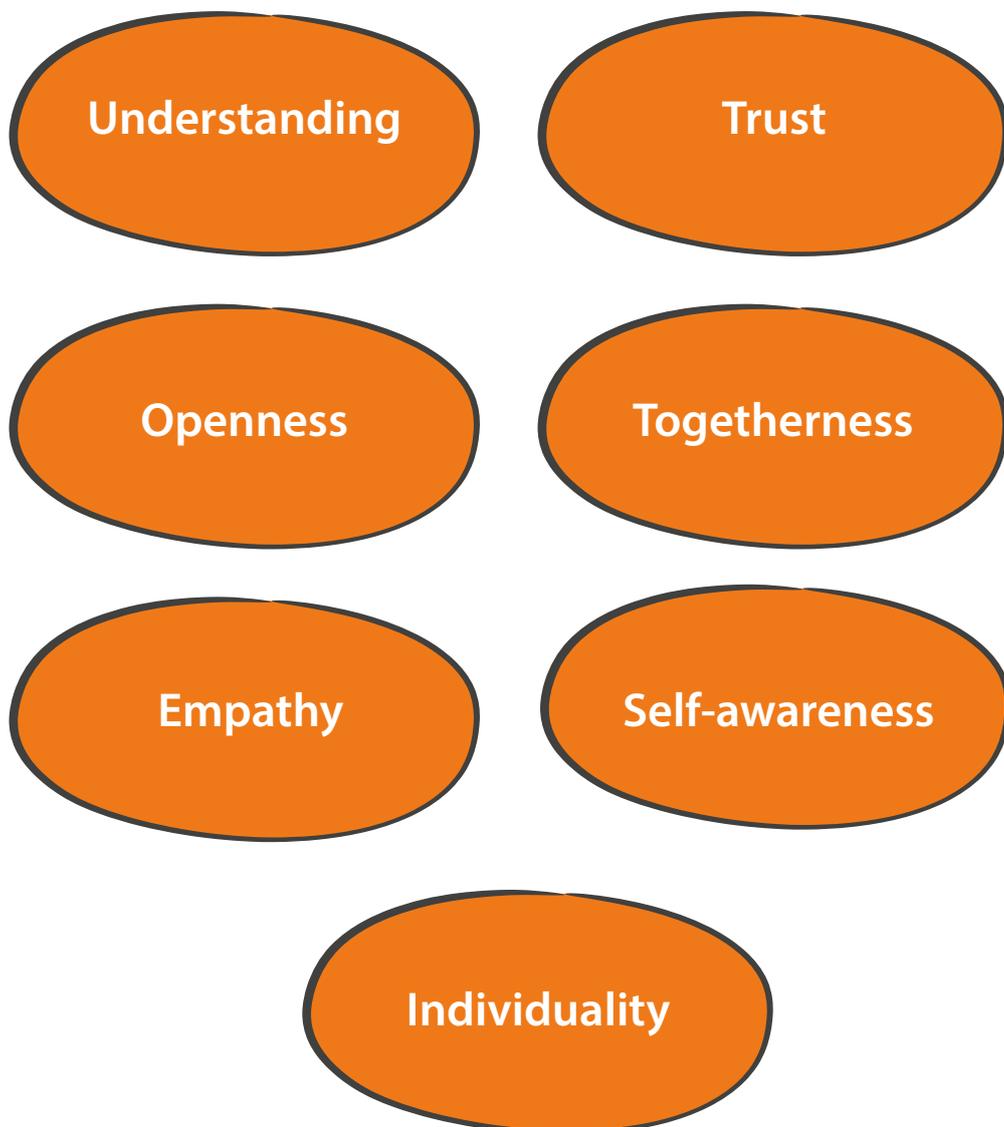
We hope that more muscle-wasting charities across the world will join us in our pledge and sign up to these EDI principles to help support all people living with muscle-wasting conditions.

A spokesperson on behalf of the four charities said:

"We are delighted to have signed a joint Statement of Intent to collaborate on Equality, Diversity and Inclusion that will help break down societal barriers for people living with muscle-wasting conditions. By working together, we are committed to creating an international EDI strategy that recognises our vision, commitment and ambition to actively tackle all forms of racism, discrimination and harassment. We will hold each other accountable and will do all we can to create a more inclusive and accessible society and workplace for those in our community."

Our values

This strategy is based on a set of core values, which have been created collaboratively with MDUK staff. These values sit alongside our existing organisational values, and we will judge ourselves and our progress against them.



How we will hold ourselves accountable

As an organisation

We will develop and use an audit tool to continuously monitor the outcomes of our commitments and ensure we are making progress. Our senior leadership team and trustees will also embed EDI as an integral part the charity's mission.

Through our staff

We will establish EDI champions within each team to ensure their team is actively promoting equality, diversity and inclusion, and has an action plan to help meet our organisational commitments. We will also have regular surveys to give staff members to feedback on our progress.

Through our community

We will continue to listen to people from different backgrounds who are living with a muscle-wasting condition, to make sure we continue to be accessible, inclusive, and responsive to their needs. We also encourage anyone to who has any questions about this strategy or our progress to contact EDI@muscular dystrophyuk.org

The journey so far

1. Recruited EDI Ambassadors
2. Started a charity EDI working group
3. Held workshops and team meetings with external speakers
4. Created our first EDI strategy
5. Put in social hours for menopause, cancer, living with muscular dystrophy and other matters that our team faces
6. Created designated EDI champions for each team

Our guiding principles

Our strategy is split into five guiding principles. These principles will help us achieve our vision of an equitable, inclusive and diverse organisation where our employees and our community feel that they belong, and everyone's voice is heard.

1. Culture

Ensuring our employees embody the values of our organisation, are culturally competent and welcoming to people of all backgrounds.

2. Training

Providing regular training so that all staff have a shared understanding of equality, diversity, and inclusion.

3. Recruitment

Maximising opportunities to attract, develop and retain diverse representation across all job levels within the charity.

4. Accessibility

Identifying and removing barriers that may prevent people who could benefit from our support from accessing it.

5. Identity

Ensuring that MDUK's brand and support services are representative, inclusive, and reflective of a diverse UK population.

1. Culture

Ensuring our employees embody the values of our organisation, are culturally competent and welcoming to people of all backgrounds.

- We will maintain a culture that is reflective of our core EDI values and is respectful of diversity.
- We will encourage staff to challenge norms and play an active role in creating a more inclusive culture at MDUK.
- We will seek employee feedback on changes that will impact their job responsibilities and work environment, through departmental meetings, surveys, wellness action plans and one-to-ones with managers to encourage inclusivity and openness. This will strengthen our commitment to an inclusive workforce.
- We will provide sufficient staffing, increasing transparency, and maintaining relevant and timely objectives (annual reviews).
- We will seek to ensure clear, transparent, and documented decision-making across the organisation, clearly communicated to staff and other stakeholders.
- We will improve the ongoing mental health wellbeing support available for employees and seek to remove the stigma through open conversations and regular activities.
- We will monitor and protect the set of values and related behaviours. Our MDUK champions will ensure that each team within the charity is upholding these values and will report any concerns from staff.

2. Training

Providing regular training so that all staff have a shared understanding of equality, diversity, and inclusion.

- We will provide mandatory EDI training for all staff at regular intervals to promote ongoing learning.
- We will review our EDI training for staff regularly to ensure that it is up-to-date and relevant.
- We will regularly share resources and information related to equality, diversity, and inclusion, to promote continued discussion and help deepen understanding of these issues among staff.
- We will ensure that all training is engaging, accessible and reflective of individual staff requirements. Including providing both online and face-to-face EDI training opportunities.
- We will offer bespoke learning and development opportunities for staff as required.

3. Recruitment

Maximising opportunities to attract, develop and retain diverse representation across all job levels within the charity.

- We will audit our recruitment processes on an ongoing basis to reduce the potential for bias and unintended barriers.
- We will implement our EDI values in every stage of our recruitment and strive to reach a diverse audience through recruitment advertising and campaigns.
- We will continue to run the Moving Up internship scheme for young disabled people, to provide professional development and nurture talent.
- We will measure and monitor our recruitment metrics and trends and strive to become more representative as an organisation of the communities and people that we support.
- We will offer hybrid (home and office) and remote working if the role permits to encourage applicants from outside London.

4. Accessibility

Identifying and removing barriers that may prevent people who could benefit from our support from accessing it.

- We will ensure that all our charity events and our office are fully accessible.
- We will create accessibility guidelines for our communications materials and website and strive to improve the accessibility of all our communications.
- We will undertake a review of the languages into which we should prioritise translating our information resources and content.
- We will identify communities we're not reaching with our Muscle Groups (support groups) and seek to remove any barriers preventing people from accessing this support.
- We will continue regional Muscle Groups across the UK so people can attend face-to-face as well as online.
- We will identify and overcome barriers so that everyone can access the care and support they need as part of our community outreach project.
- We will share the resources we have, for example including the Changing Places toilet map on our website.

5. Identity

Ensuring that MDUK's brand and support services are representative, inclusive, and reflective of a diverse UK population.

- We will improve diversity across our brand and communications – proactively sourcing stories, photography, and content, with the ambition to be fully representative of our community.
- We will produce inclusive language guidelines for the organisation and ensure staff understand and use inclusive language in any communications.
- We will prioritise promoting services which are available nationally (including our helpline and advocacy service), and review how we can improve our regional support offering.
- We will continue to monitor who is accessing our services and supporting the charity, and undertake regular digital and face-to-face feedback, to ensure we are reaching the whole muscle-wasting community.
- We will continue to work with our volunteer Content Advisory Group to ensure our external materials and messaging are representative, accessible and engaging.
- We will continue to work with our Lay Research Panel and Medical Research Committee to ensure that our investment into research for treatments and cures is as diverse as possible without compromising the quality of the science.

A message from our EDI working group

We have come together to create this EDI strategy to ensure we continue to be an inclusive organisation continually led by our values and vision.

Our group held discussions with staff across the charity to develop each of our five principles. Making sure that everyone had a voice and an opportunity to shape the strategy.

Now that the strategy is complete, our group members have become EDI champions for the organisation. Each department has at least one EDI champion who can represent the views and thoughts of their colleagues and feed back any concerns to the group.

Behind this strategy, each department will also have an EDI action plan to meet these goals. We will audit our progress against them every 12 months, share any successes and investigate any roadblocks and issues that have prevented us moving forward.

If you have any feedback on this strategy or want to know more about our progress against these goals, you can email our group directly at EDI@musculardystrophyuk.org



www.musculardystrophyuk.org

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