

Muscular Dystrophy UK

Community survey findings

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Overview

We're the leading UK charity for more than 110,000 people living with one of over 60 muscle wasting and weakening conditions. At the end of 2023 we wanted to build a better understanding of the current priorities of people living with a muscle wasting and weakening condition to inform our work. This report describes the results of a survey of nearly 700 people who shared their experiences, raised issues, and made their voice heard. We're grateful to everyone who took part. These survey findings have helped identify the areas where change is most needed and will help direct our work and our calls to action to others.

The survey results have subsequently been validated against our previous work, our available helpline data, and through sense checking conversations with members of the community.

Read our full briefing or use the contents index on the next page to locate specific areas, such as our key findings.

Method

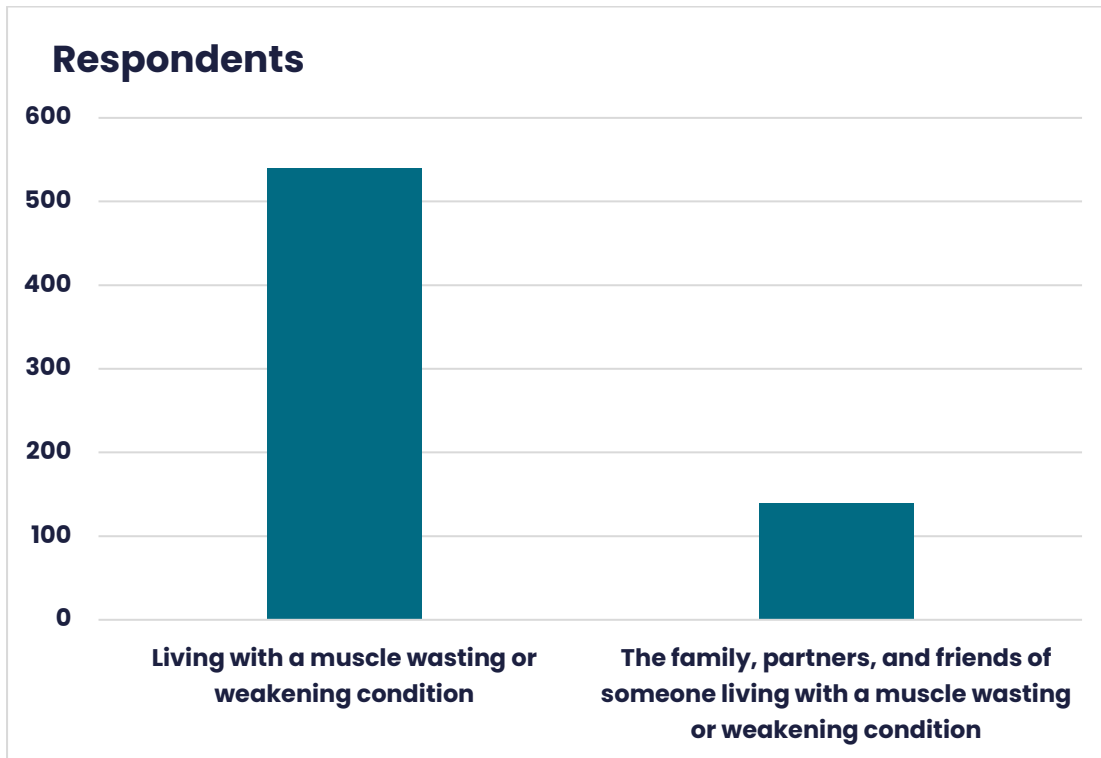
The findings in this report are based on the responses of 679 people across two online surveys - one for people living with a muscle wasting and weakening condition and one for people supporting a person living with a condition. We conducted this survey between 21 November and 21 December 2023 through an online survey promoted via social media and in emails to our supporters.

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Survey demographics

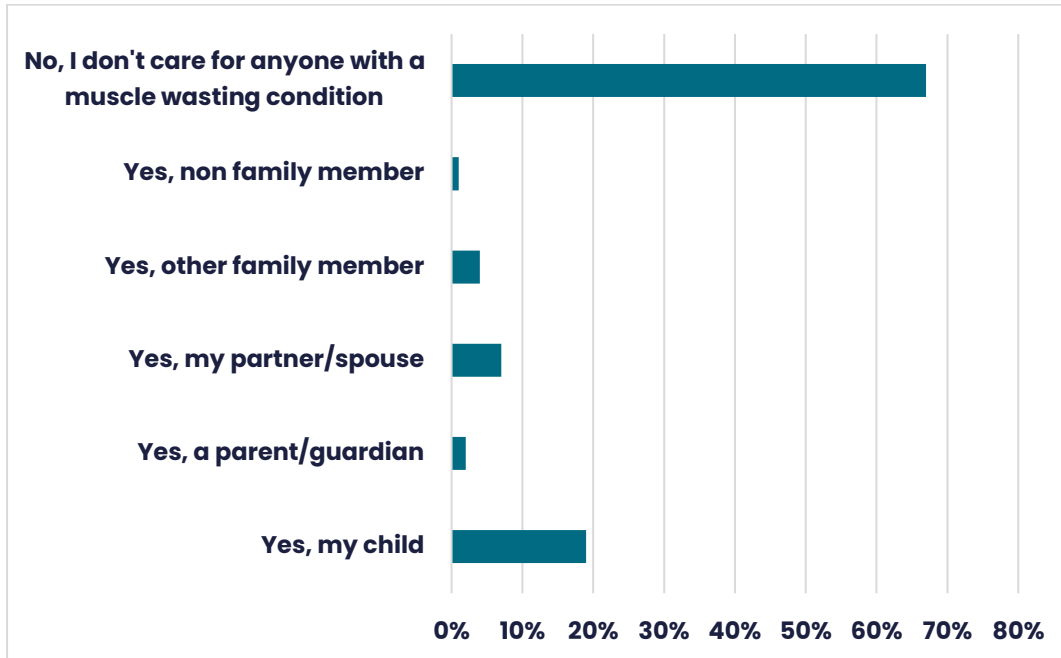
We carried out two surveys, one for those living with a muscle wasting and weakening condition and one for the family, partners and friends of people living with a muscle wasting and weakening condition. The data from both surveys has been amalgamated in this report for presentation purposes.



- A total of 679 people responded across the two surveys.
- 80% of responses were from those living with a condition, and 20% were from family, partners, and friends.

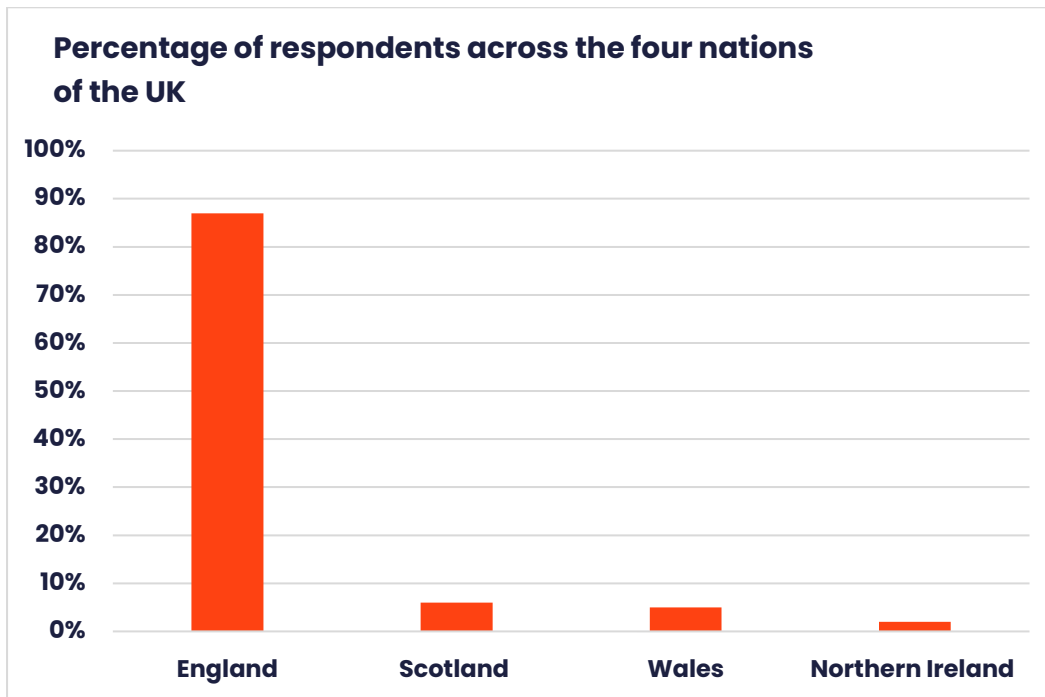
Breakdown of respondents

Q. Do you care for someone with a muscle wasting condition?



- **In total, 33% of respondents had some caring responsibilities. This includes those living with a muscle wasting and weakening condition.**
- **If they had a caring role, respondents were mainly caring for their own child.**

Distribution of respondents across UK four nations



Distribution of respondents across the UK four nations contrasted to the total percentage population across the UK

	England	Scotland	Wales	Northern Ireland
Percentage of respondents across the UK four nations	87%	6%	5%	2%
Percentage of population across the UK four nations	84%	8%	5%	3%

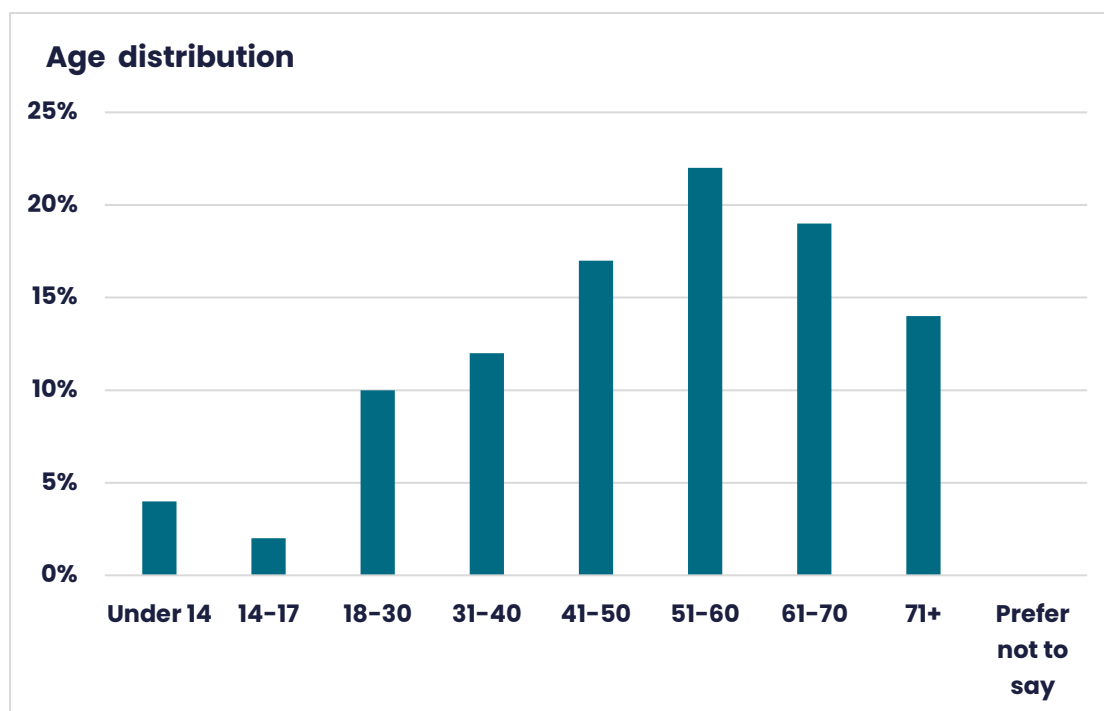
While England is slightly overrepresented in our survey, and work is needed to ensure we continue to represent the views of the muscle wasting and weakening community from across the UK, we were not disproportionately unbalanced when contrasted to the UK population as a whole – see above. This data, therefore, reliably represents the views of the community from across the UK.

Condition awareness

- Over 95% of respondents knew their specific condition.
- A diverse range of conditions were represented in the survey.

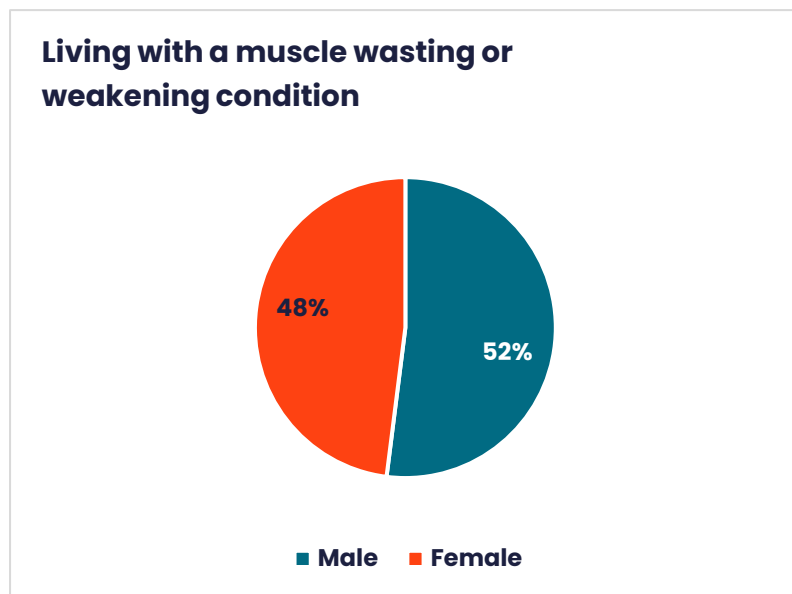
Becker Muscular Dystrophy TYPE 1A Beckers 2a Congenital
 FacioScapuloHumeral muscular dystrophy FSH Muscular Dystrophy
 Myotonic dystrophy DM1 LGMD IBM Marie tooth disease
 Limb Girdle Muscular Myofibrillar myopathy type
 dystrophy type Muscular Dystrophy OPMD
 Myotonic Dystrophy Type MG
 Myotonic Dystrophy Becker FSHD
 Myotonic FSH FSHMD MD Central Core Disease CMT
 Duchenne Muscular Dystrophy Inclusion Body Myositis disease
 girdle muscular dystrophy FSHD1 SMA type 2i myopathy
 SMA4 Charcot Marie tooth Inclusion body Limb girdle
 Bethlem Myopathy

Age distribution

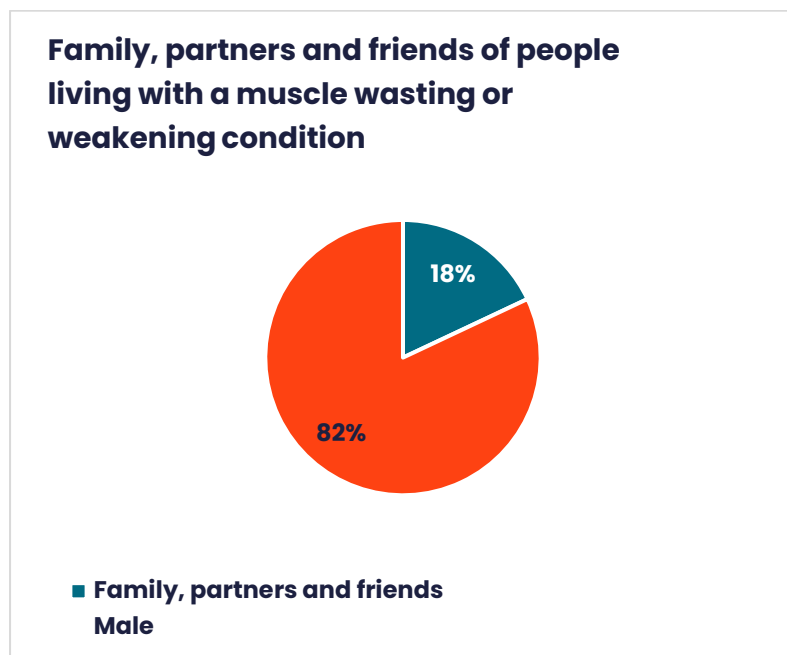


- Over 50% of respondents were over 50, in contrast to 38% of the UK population.
- Only 15% of respondents were under 30, in contrast to 33% of the UK population.

Male/female respondent breakdown

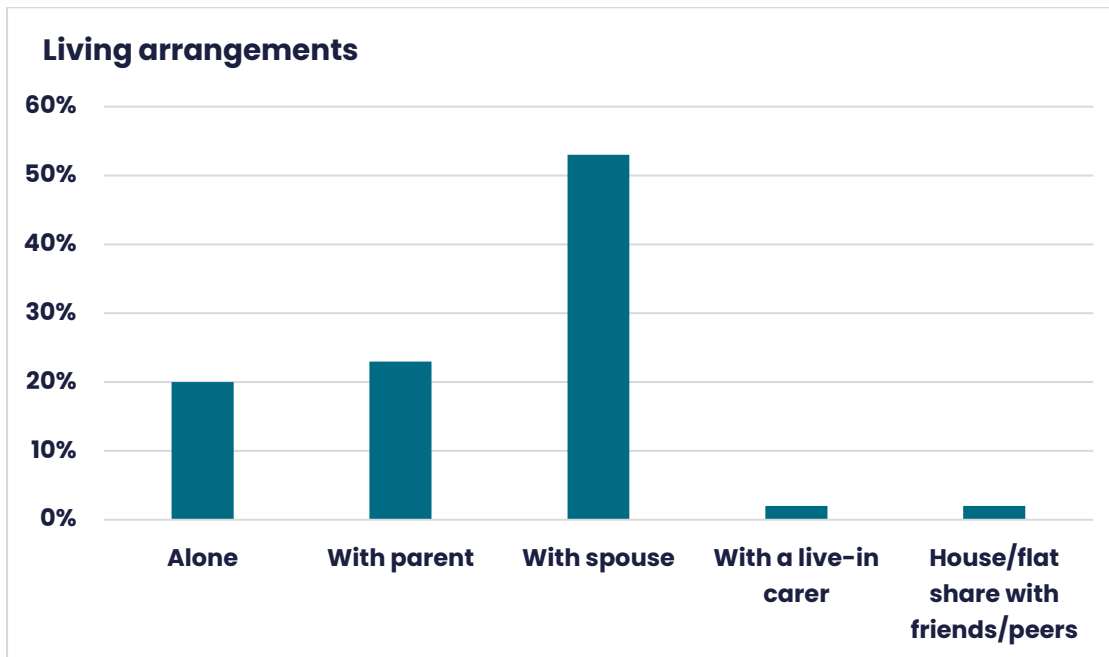


We attained close to male/female parity in terms of responses overall.



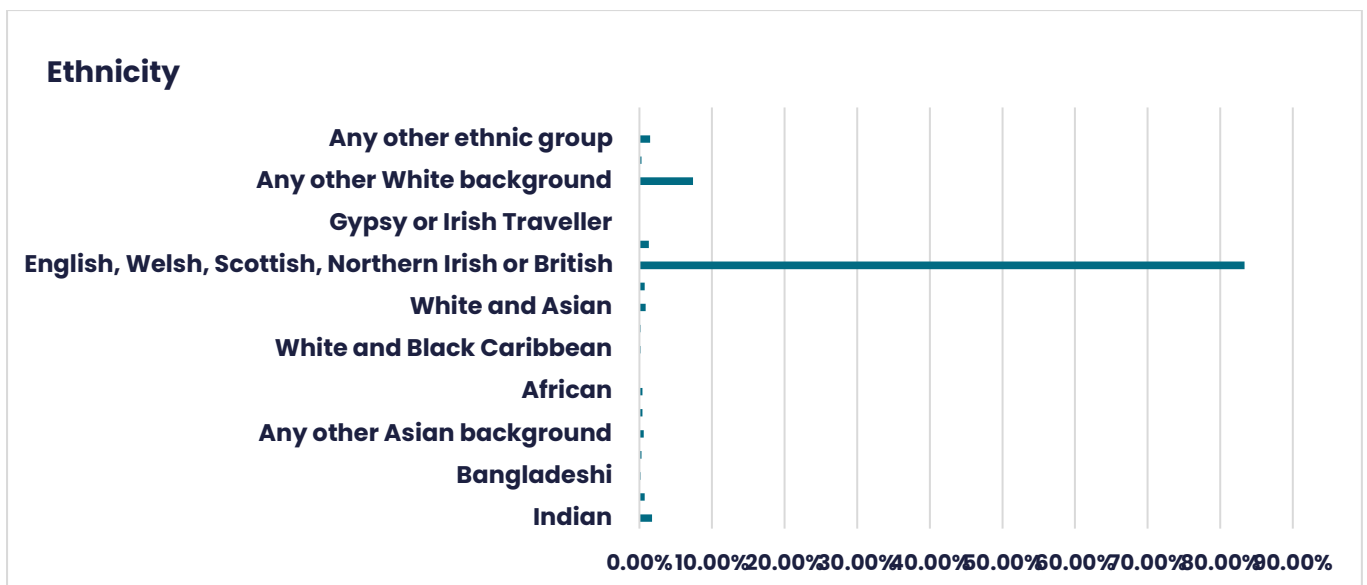
However, 82% of the family, partners, and friends (carers) respondents were female. This is not unique to the muscle wasting and weakening community and is reflective of the broader field of carers.

Living arrangements



- While the majority of respondents live with family (parents 23% or spouse 53%), 20%, one in five, live alone.

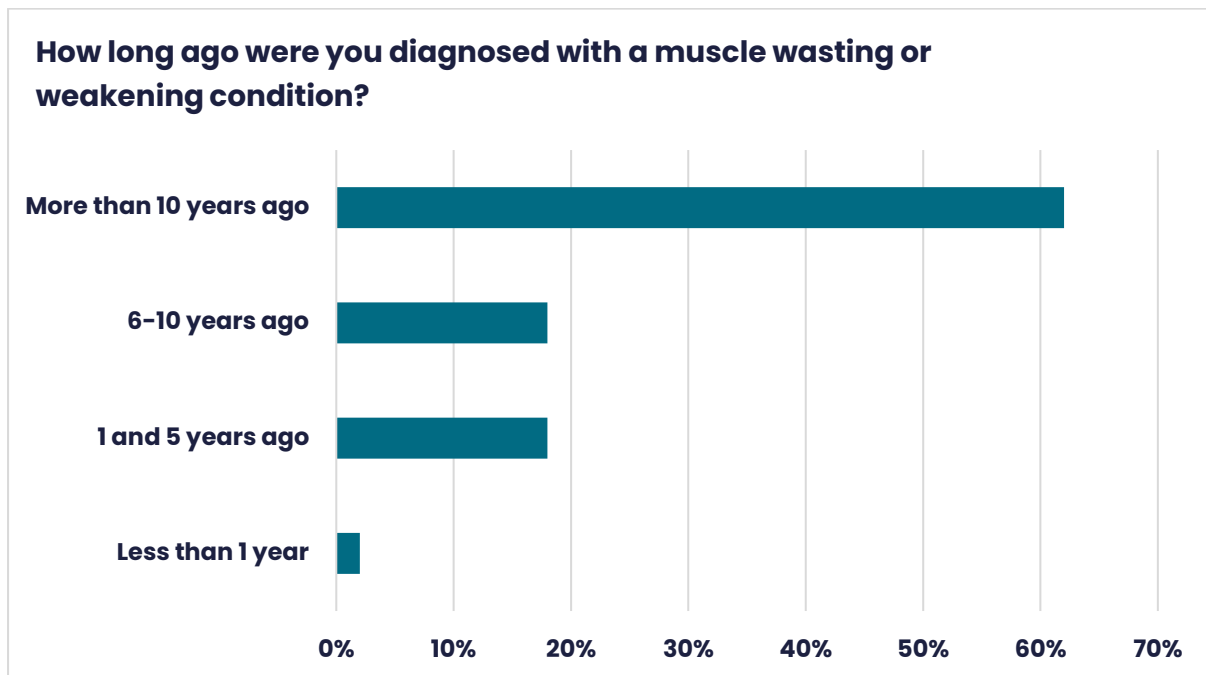
Ethnicity



- 91% of respondents were white, in contrast to 87% in the UK population (82% in England and Wales).

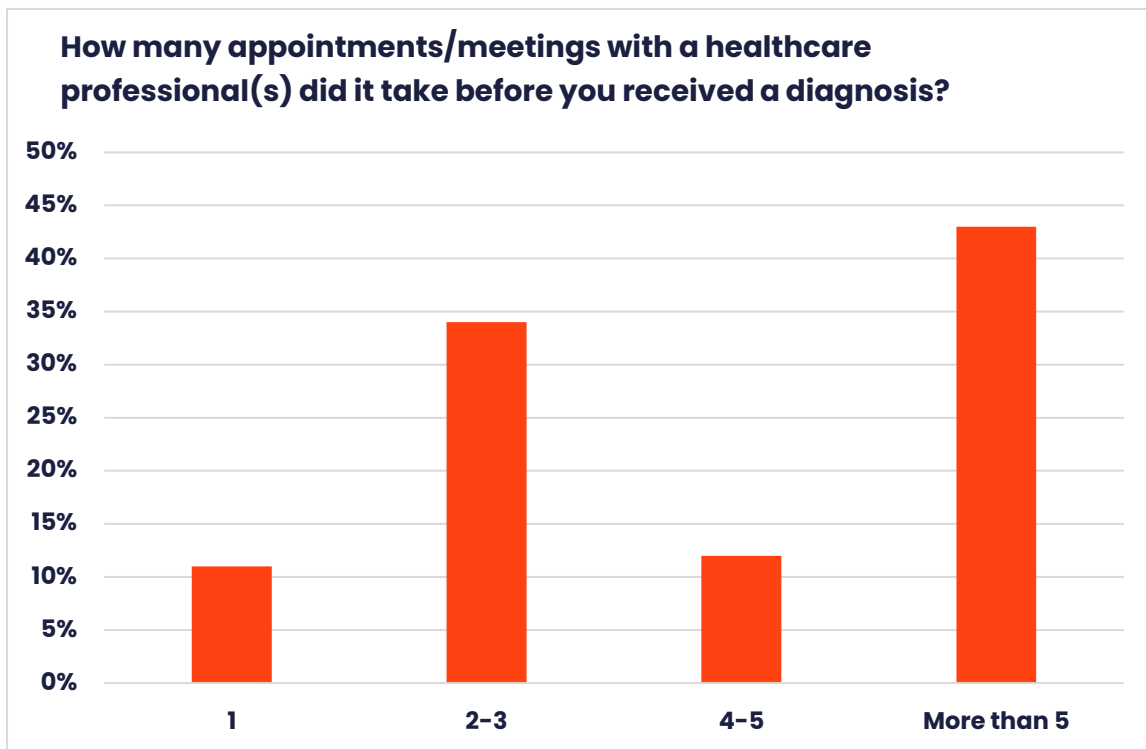
Diagnosis

Timing



- **Over 60% of respondents were diagnosed more than 10 years ago.**
- **Only 2% of respondents were diagnosed within the last year.**

Number of healthcare appointments prior to a diagnosis

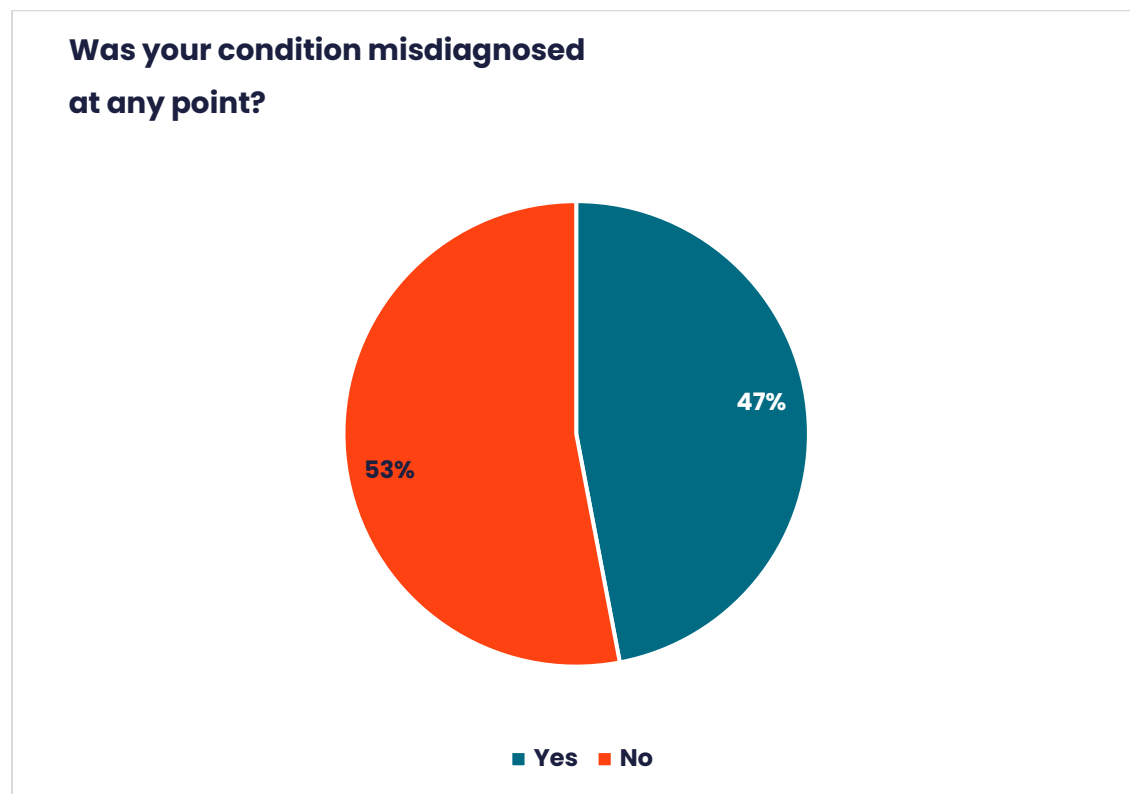


- It took four or more meetings with healthcare professionals for the majority (55%) of respondents to get a diagnosis.
- For 11% of respondents, it took only a single meeting, which is likely explained by a family condition history, for example people told us:

“Niece born with condition. Whole family went for tests.”

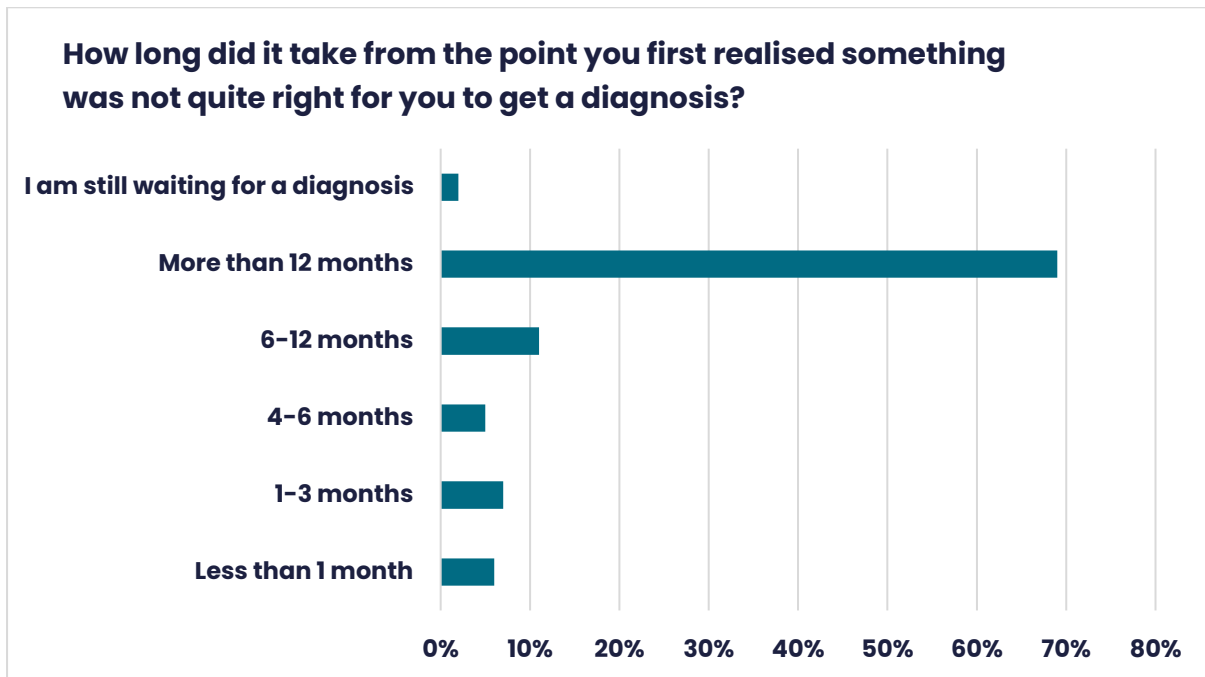
“Older sibling already diagnosed so they knew what to look for in me.”

Misdiagnosis



- **Just under half of all respondents (47%) were misdiagnosed at some point.**

Length of time before diagnosis



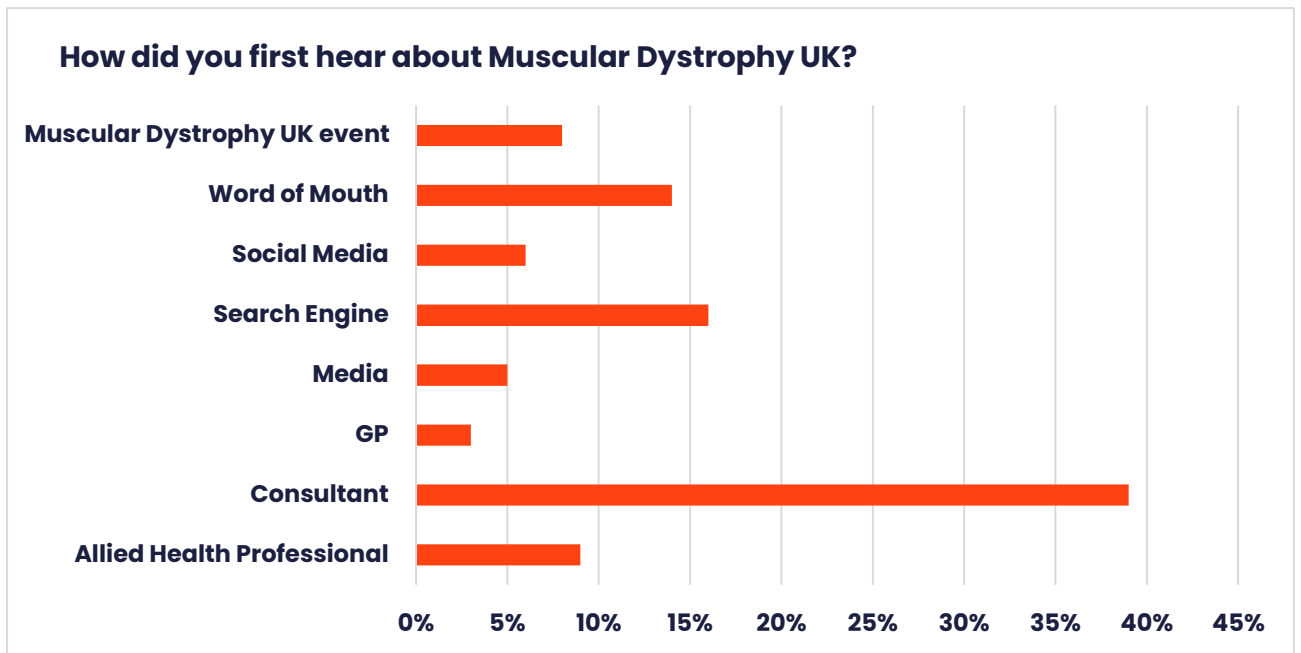
- A significant majority of respondents, 69%, waited more than a year to receive a diagnosis.

“I was 14 when I knew something was wrong. At age 35 I was diagnosed. I was told I was lying and making things up.”

“I had to wait about 10 years for a definitive DNA diagnosis.”

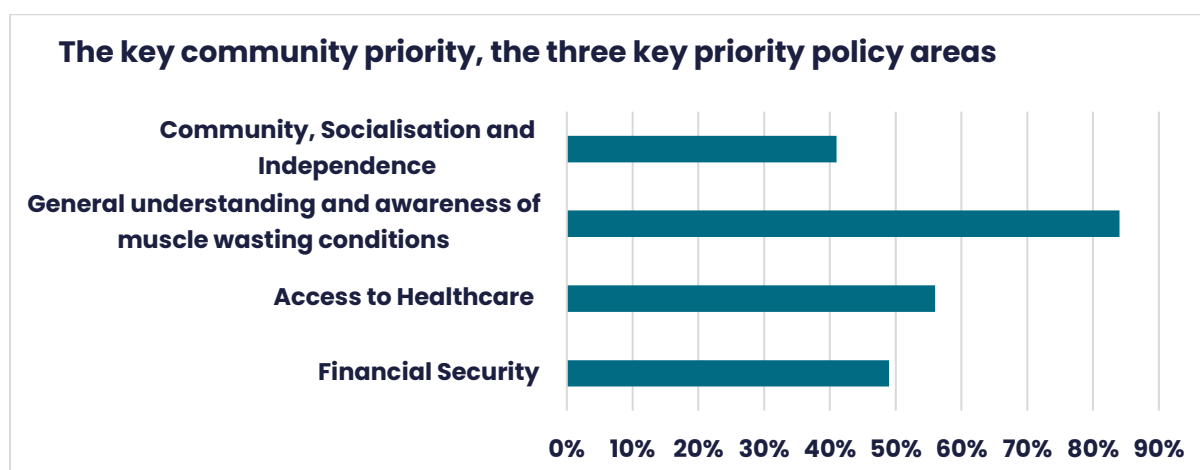
“My first reported symptoms to my GP I was aged 35, then onwards from that, on a regular basis until eventual diagnosis at 65. No one thought to look for FSHD even though my sister has it and I disclosed this in my medical history.”

Contact with Muscular Dystrophy UK



- **Over half of respondents, 51%, first heard of the charity through consultants, AHPs and GPs.**

Key findings



We asked a number of questions, often overlapping, to identify our community's key policy priorities. From directly asking which policy areas respondents would want to see more campaigning work in, and where they would most like to see us working to drive change for the better, to open text questions on the most significant challenges people face.

The results collected were unambiguous. The key community priority was to raise awareness among non-neuromuscular specialised healthcare professionals. This came out throughout the survey questions.

The three key policy priority areas identified were:

- Access to healthcare (physical and mental)
- Financial security
- Community, socialisation, and independence.

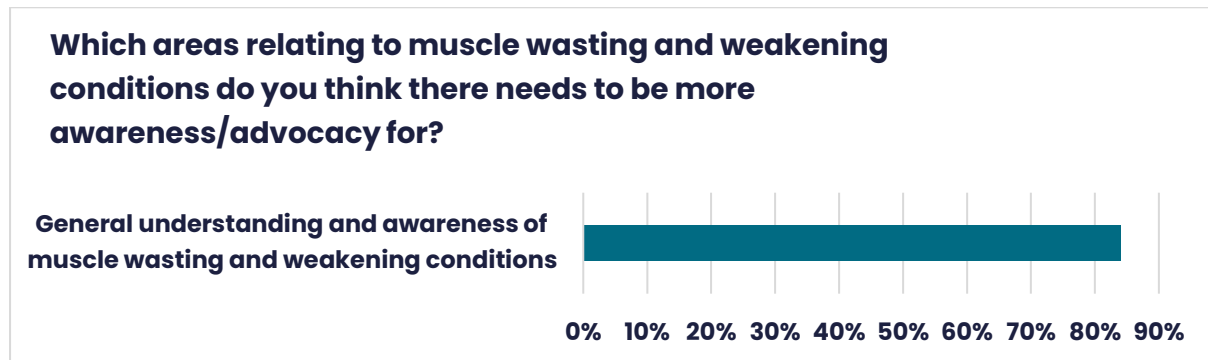
Community insights into barriers and challenges

We also identified community insights into barriers and challenges. There were:

- Issues around mobility
- Fatigue
- The risks of falls
- A desire to see a cure.

While the graphics used above come directly and verbatim from specific questions, the priorities identified were embedded throughout the questions and responses, and the graphic above is an amalgamation.

Key community priority - awareness



- **84% of respondents identified increasing the understanding and awareness of muscle wasting and weakening conditions as a key priority. At 84% this was the clear key priority. The graphic above shows the next three priorities: at 56% access to healthcare, 49% financial security, 41% community, socialisation, and independence.**

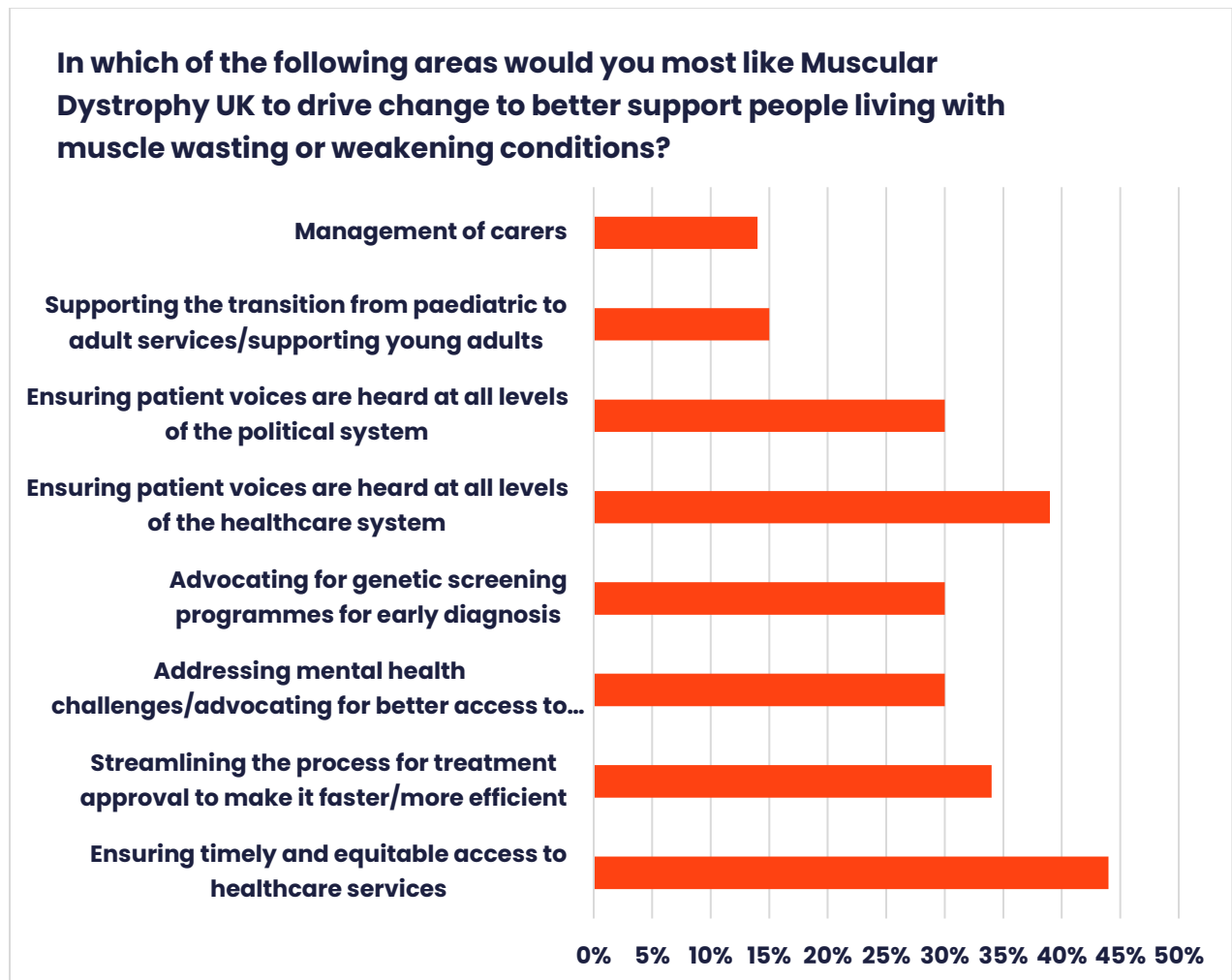
The quotes below illustrate why access to healthcare is the key priority for the community, as identified by the survey.

“Educate GPs, so they are more aware and have a better understanding of these conditions.”

“Better general awareness, specifically within health care. In the 30 + years I've lived with MD, the biggest problems have been finding professionals who understand the complexities of MD's.”

“(We need a) Guide on how to receive any help at all from GPs & Dr's surgeries. As mine are horrendous.”

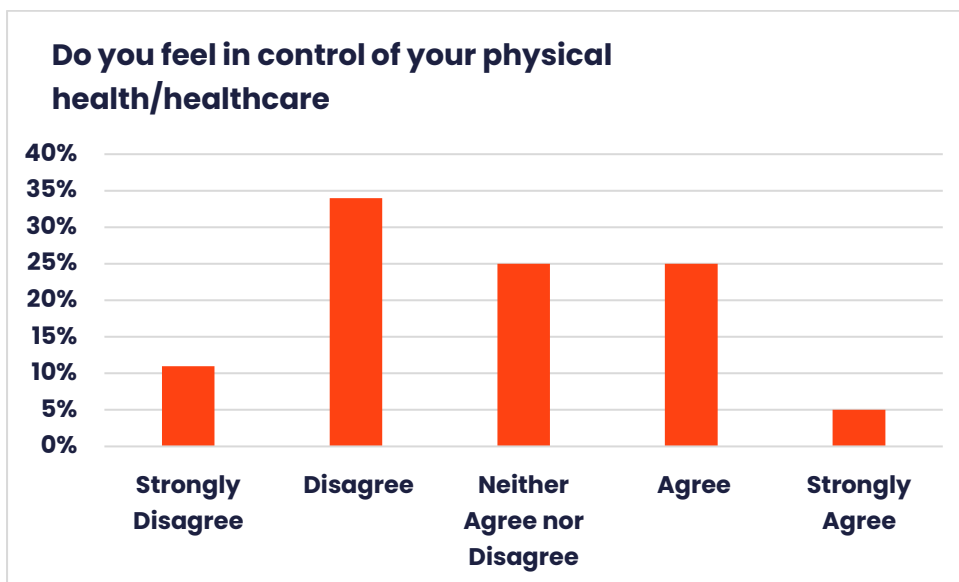
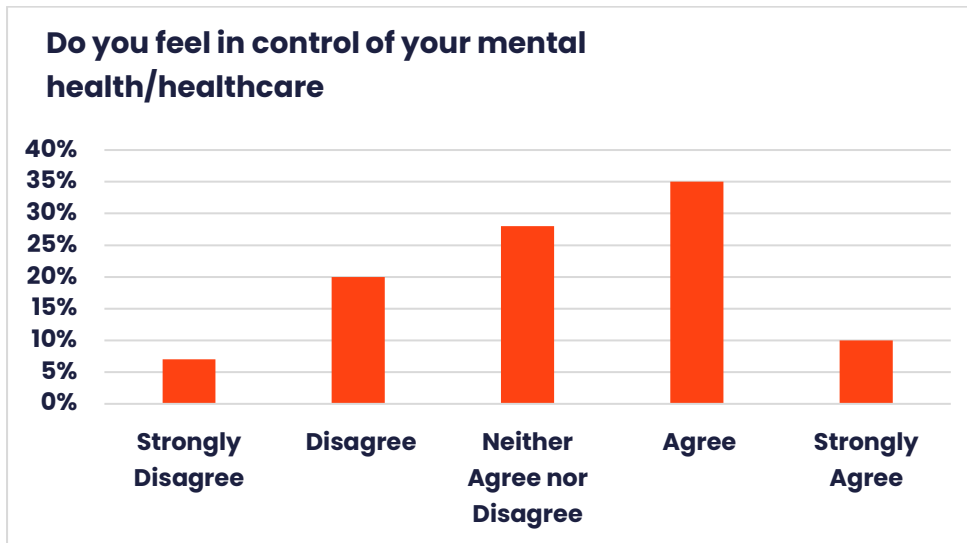
Key community priority - access to healthcare



- **56% of respondents identified access to healthcare as a key policy priority.**
- **In a more granular sense, this policy area primarily covers timely and equitable access to healthcare, both mental and physical, ensuring the community voice is heard at all levels of the health system and streamlining the process for treatment approval to make it faster/more efficient.**

Key community priority – access to healthcare

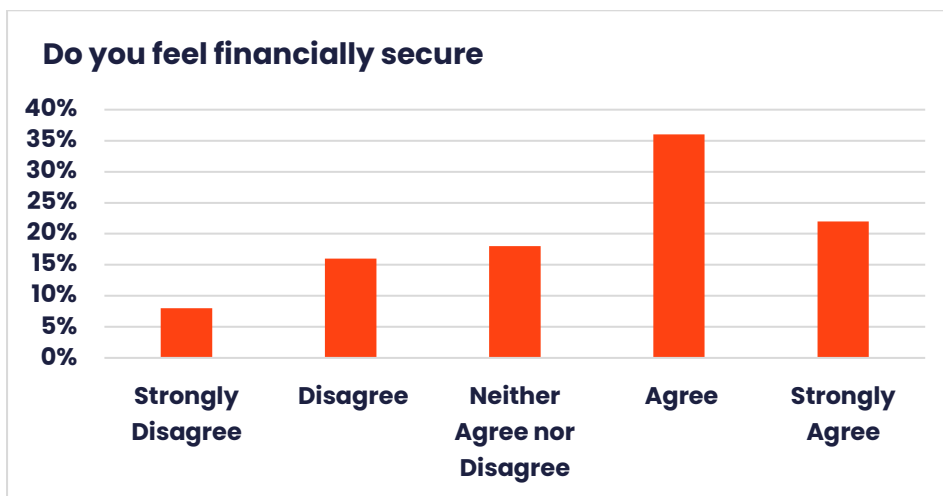
'Feeling' in control of mental health/healthcare



To further illustrate the above, 27% of respondents disagreed or strongly disagreed that they felt in control of their mental health/healthcare, while 45% of respondents disagreed or strongly disagreed they were in control of their physical health/healthcare.

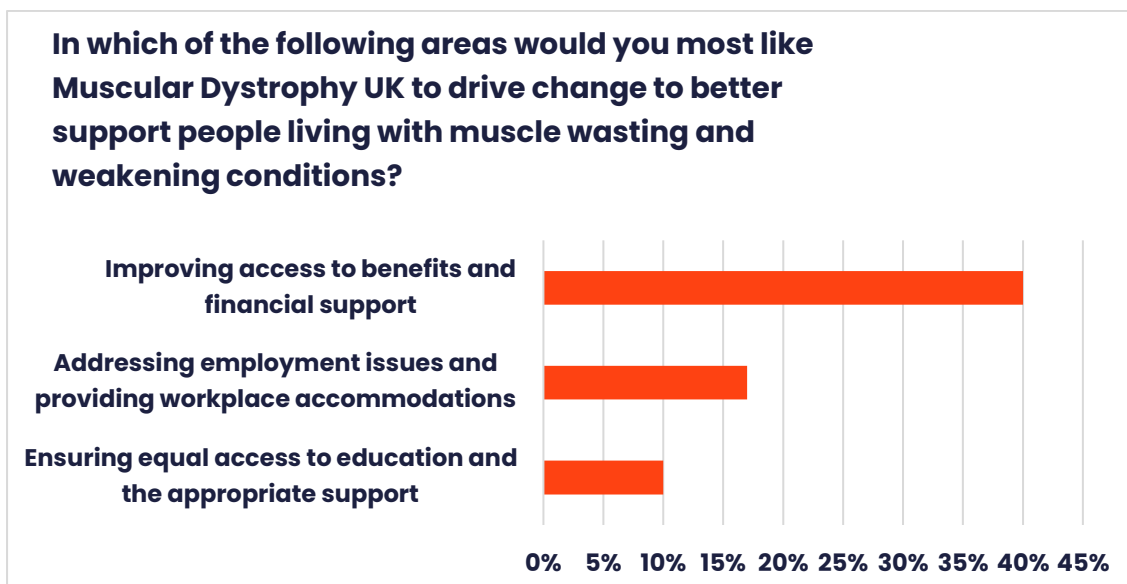
“I want to feel in control of my condition and not feel like it controls me.”

Community priorities – financial security



- 49% of respondents identified financial security as a key policy priority issue for the community.
- 24% of respondents disagreed or strongly disagreed they felt financially secure, in contrast to 58% of respondents who either agreed or strongly agreed that they felt financially secure.

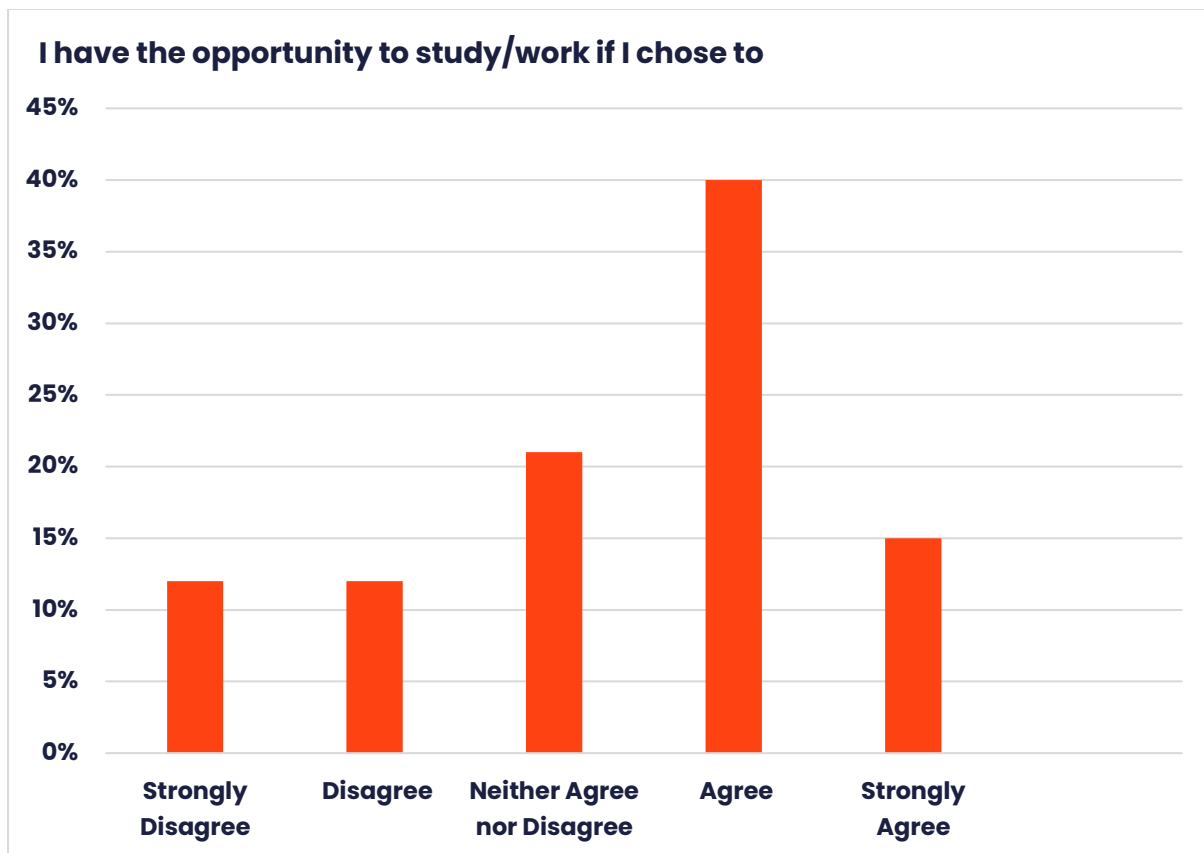
Finance prioritised



In a more granular policy sense, financial security falls into access to benefits and financial support, employment, and educational access.

Community priorities – financial security

Access to study/work



- 24% of respondents disagreed or strongly disagree they had the opportunity to study/work if they chose to, in contrast to 55% that agreed or strongly agreed they could.

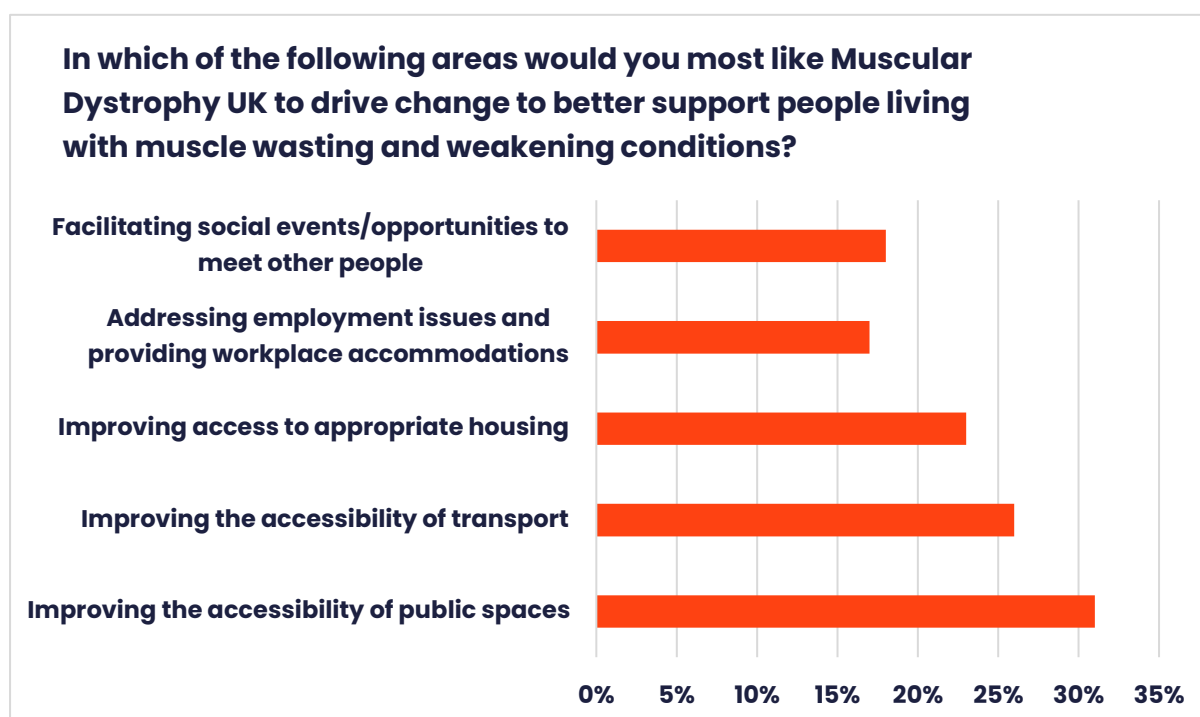
The below quotes begin to illustrate the nuance of this statistic.

“A major challenge, is the time off work to attend all the appointments.”

“I can’t work more than part time due to my MD and I’m struggling greatly for money to support me and my son.”

“Trying to continue with work with limited support from employer despite promises to the contrary.”

Community priorities – community, socialisation, and independence



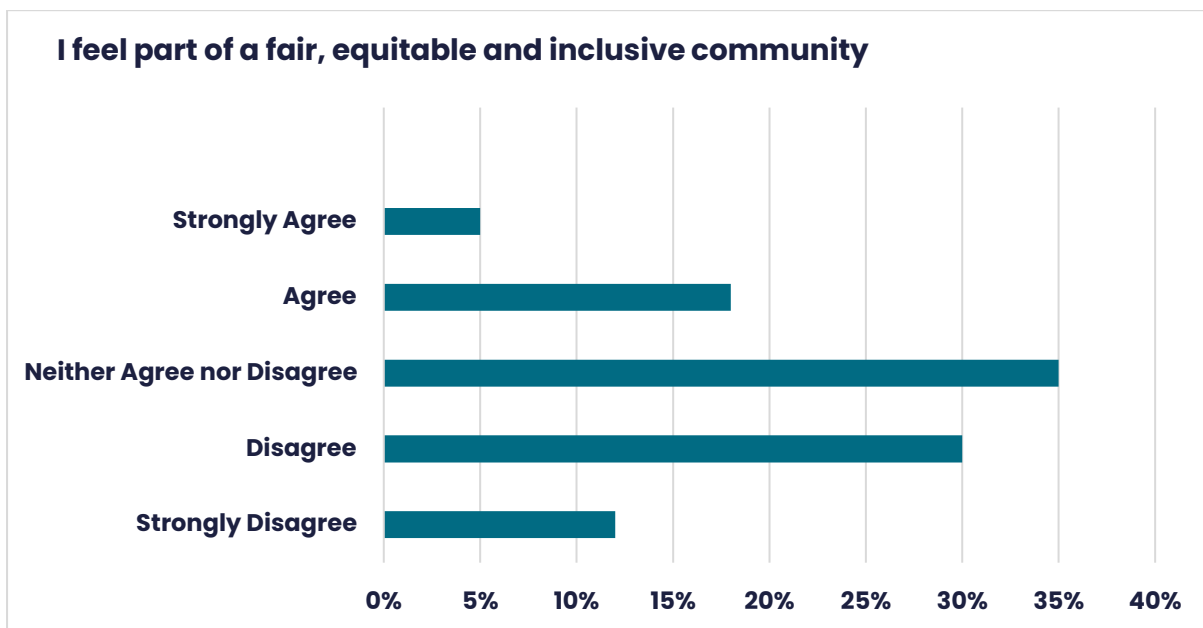
- 41% of respondents identified community, socialisation, and independence as a key priority area.
- In practice, in policy terms, this translates to being able to socialise on a regular basis, having the opportunity to form relationships, feeling part of a community, the opportunity for leisure activities, mobility (covered in the subsequent section), accessibility, transport (not covered here, as it requires additional research) and safe and accessible accommodation (not covered here, as it requires additional research).

Respondents often linked issues here, back to financial security.

“We can't get a ramp on our house due to fear of landlord asking us to leave.”

“We need a bungalow, and we can't afford one.”

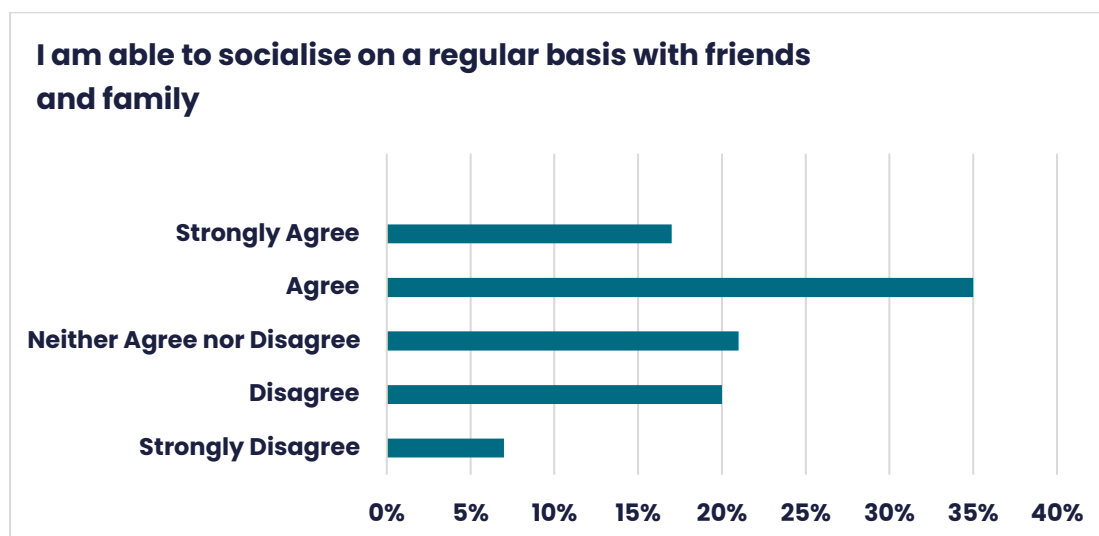
Community priorities – community, socialisation, and independence



- **42% of respondents disagreed or strongly disagreed that they felt part of a fair, equitable and inclusive community. in contrast to only 23% that agreed or strongly agreed they did feel part of a fair, equitable and inclusive community.**

“(We need) more targeted support for young people.”

Socialising

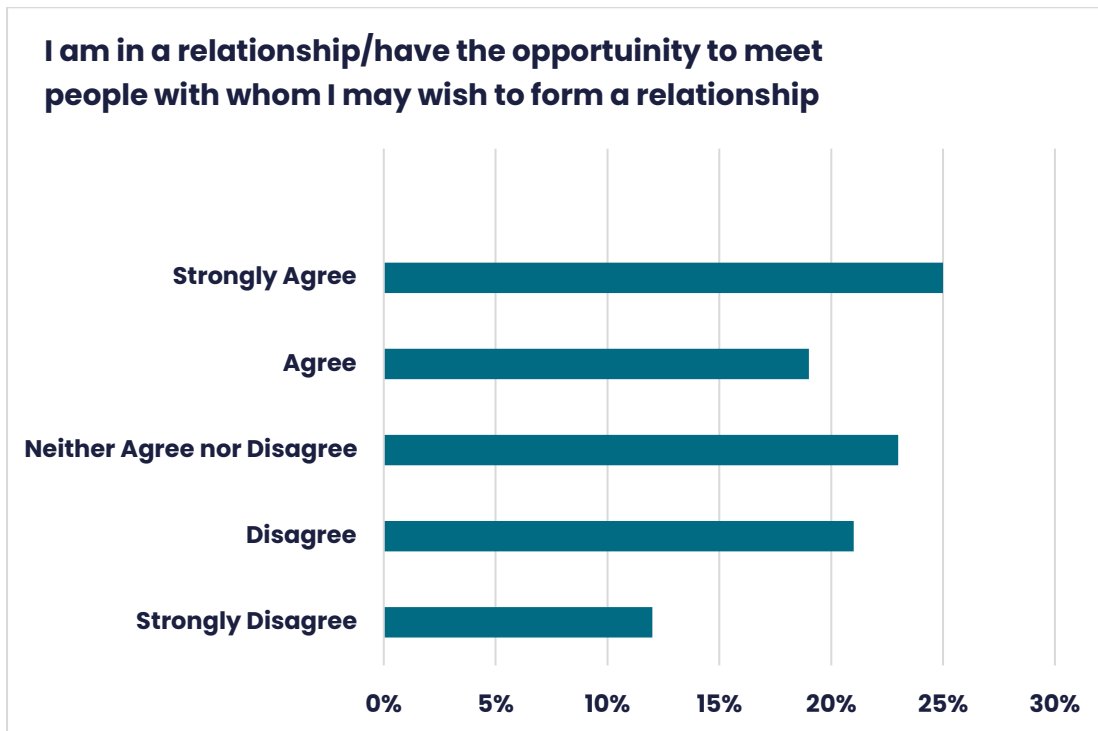


- While 52% of respondents agreed or strongly agreed they were able to socialise on a regular basis with friends and family, 27% disagreed or strongly disagreed that they were able to socialise on a regular basis with friends and family.

“I find it hard to go out with friends now. Most people don't understand, or they complain about their minor issues like comparing my being in constant pain to a cold or headache.”

“I feel a nuisance to friends as I can't walk much and very slowly.”

Relationships

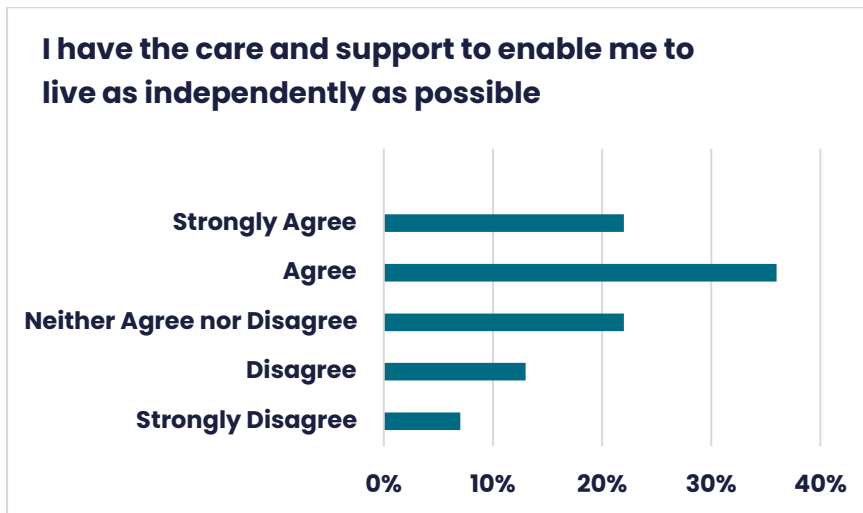


- **44% of respondents agreed or strongly agreed they were either in or had the opportunity to meet people with whom they may wish to form relationships, whereas 33% disagreed or strongly disagreed that they were either in or had the opportunity to meet people with whom they may wish to form relationships.**

“(Biggest concern is) loneliness of never being able to have a romantic relationship.”

“Socialising – physical condition gives issues like anxiety and makes it even harder to fully participate in the community as a young person. It can be easier to not take part, which is bad.”

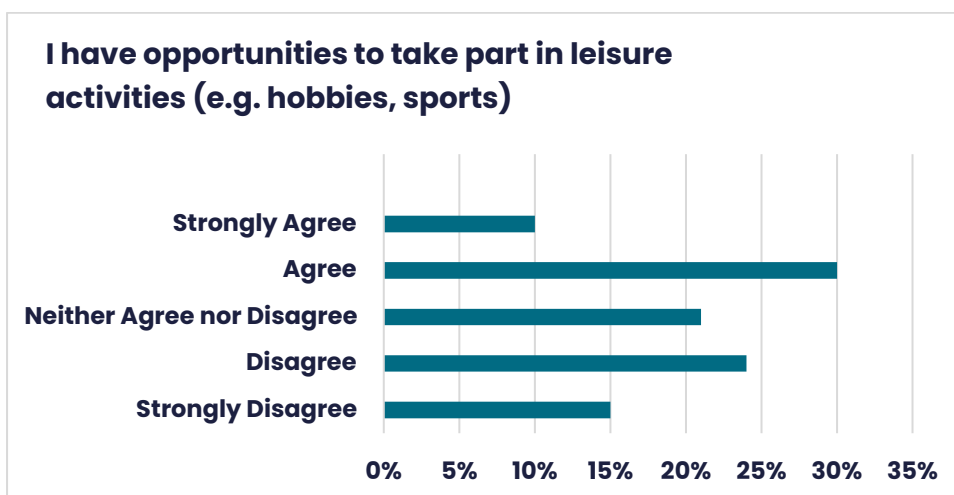
Living independently



- **58% of respondents agreed or strongly agreed they had the care and support to enable them to live as independently as possible, whereas 20% of respondents disagreed or strongly disagreed that they had the care and support to enable them to live as independently as possible.**

“(Regarding carers) I feel that I have been abandoned to my fate, and there is so much wrong that I hardly know where to begin.”

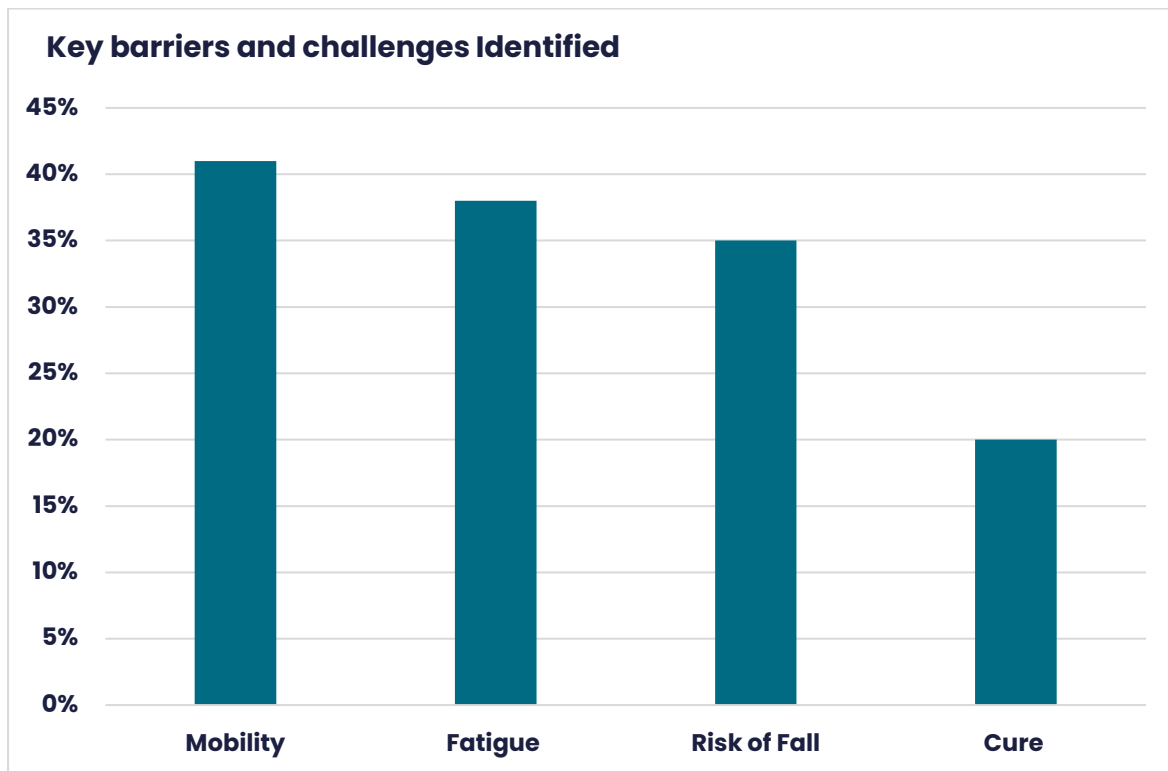
Opportunities to take part in leisure activities



- **40% of respondents agreed or strongly agreed that they had the opportunities to take part in leisure activities, whereas 39% of respondents**

disagreed or strongly disagreed they had the opportunities to take part in leisure activities.

Community insight – overview of barriers and challenges identified



This section – community insights – summarises the key barriers and challenges identified throughout this survey (outside of the community priorities already discussed), which were so prevalent they merited separate discussion.

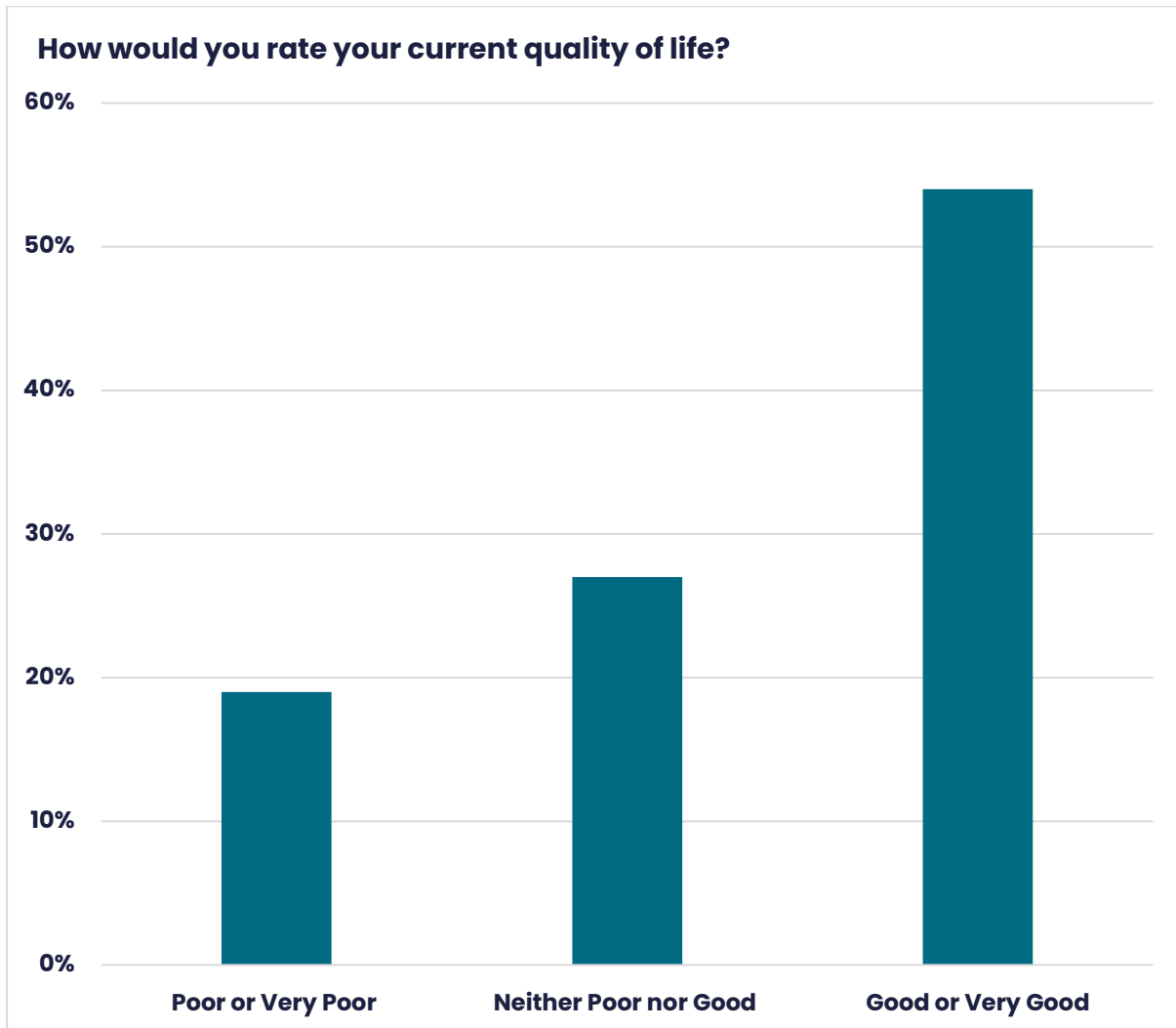
Mobility, fatigue, the risks of falls, and the desire to see work on cures, came out of questions entirely unprompted. As you can see from the graphic above, substantial numbers of respondents chose to write on these issues, demonstrating their importance and impact as barriers and challenges for our community, which we will also be working to mitigate and address.

“Endeavour to speed up the processes of finding cures for all muscle wasting conditions.”

“I have been waiting 10 months for a wheelchair assessment because mine is no longer fit for purpose. After my

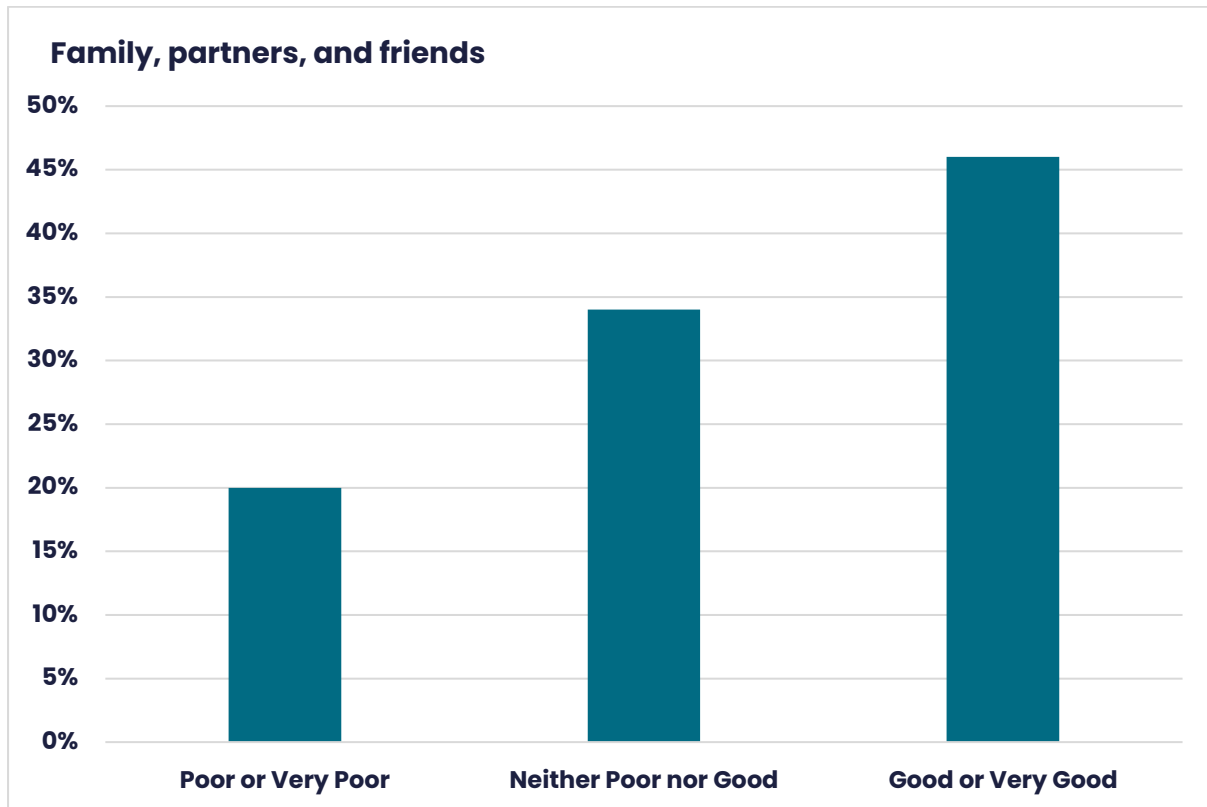
assessment I will undoubtedly have another long wait for a new chair which I will be expected to part fund myself.”

Overall quality of life rating



- Overall, for those living with a condition, 19%, almost one in five, of respondents stated that they had a poor or very poor quality of life.
- However, more than half, 54%, of respondents stated that they had a good or very good quality of life.

Quality of life: family, partners, and friends



- **The experience of families, partners, and friends, very closely mirrors that of those with the condition.**
- **Overall, 20%, one in five, of respondents stated that they had a poor or very poor quality of life.**
- **However, more than half, 46%, of respondents stated they had a good or very good quality of life.**