



SHINING A LIGHT

The impact of COVID-19 and the future of care for people with a muscle-wasting condition

www.musculardystrophyuk.org

Registered Charity No. 205395 and Registered Scottish Charity No. SC039445

**Muscular
Dystrophy UK**
Fighting muscle-wasting conditions



Table of contents

Introduction	3
Executive summary	5
Priorities and recommendations at a glance	5
Methodology	7
Key findings	8
Analysis	10
Priorities and recommendations	13
Mapping our priorities	20
Conclusion	25
About Muscular Dystrophy UK and muscle-wasting conditions	27
Get involved	27

Introduction

In March 2020, the United Kingdom entered a new world of lockdowns and social distancing because of the COVID-19 pandemic.

In the early stages of the pandemic, emails and calls to the MDUK helpline rose by 35 per cent¹ and, for the rest of 2020 and into 2021, 13 per cent of all requests we received for support related to COVID-19. Most related to two fundamental areas of concern. The pandemic had curtailed access to support from a multi-disciplinary team (MDT) of health and care specialists, and to the support networks, including family and friends, that people with muscle-wasting conditions need to deal with the huge impact of living with a condition. There was also widespread concern about the level of risk that COVID-19 represented for people living with muscle-wasting conditions – anyone with a muscle-wasting condition became classed as ‘clinically vulnerable’ or ‘clinically extremely vulnerable’.

Throughout the pandemic, we have worked closely with a wide range of health professionals, volunteers, charities, and individuals to help provide accurate information and advice to support our community. We also began building a picture of the impact that COVID-19 was having on the people we support and the services they rely upon. In early 2021, we decided to solidify this picture by surveying both neuromuscular services and people living with muscle-wasting conditions, as well as holding discussions at our regional

Muscle Group meetings, Regional Neuromuscular Networks and through our Muscles Matter 2021 virtual seminar series. We discovered that COVID-19 not only presented new challenges to people living with muscle-wasting conditions and the services they rely on, but it also exacerbated existing ones.

We are now seeing for the first time expensive, transformative medicines and treatments coming on to the market², national and international standards of care for people with a muscle-wasting condition³, the emergence of organised but unfunded national and regional neuromuscular clinical networks⁴, and a significant increase in the number of people living well into adulthood and requiring support from a multi-disciplinary neuromuscular service⁵. All of these huge developments continue to take place in the treatment and care of people living with muscle-wasting conditions, improving quality of life and in many cases extending lives. But yet it is often still difficult to get access to these services and support.

The good news is that the UK Government and the NHS have expressed a desire to learn from the pandemic to improve overall healthcare provision^{6,7}. With NHS reforms⁸ underway to integrate healthcare and work ongoing to build action plans for the delivery of the UK Rare Diseases Framework⁹, there is an opportunity to address some of these longstanding challenges, while also navigating the immediate needs of people living with muscle-wasting conditions that COVID-19 has created.

¹ 451 phone calls and emails received in February and March and April 2020 vs. 333 received in January and February.

² Muscular Dystrophy UK, Fast track – fast access to specialist treatments: <https://www.muscular dystrophyuk.org/campaign-for-independent-living/fast-track/>

³ Birnkrant et al, Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management, *The Lancet*, 2018: [https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422\(18\)30024-3/references](https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(18)30024-3/references)

⁴ Muscular Dystrophy UK, Regional neuromuscular forums and clinical networks: <https://www.muscular dystrophyuk.org/campaign-for-independent-living/health-care-campaigns/personal-support/regional-neuromuscular-forums/>

⁵ Muscular Dystrophy UK, Improving standards of care and facilitating clinical trials for spinal muscular atrophy: <https://www.muscular dystrophyuk.org/grants/improving-standards-of-care-and-facilitating-clinical-trials-for-spinal-muscular-atrophy/>

⁶ UK Government, COVID-19 mental health and wellbeing recovery action plan, April 2021: <https://www.gov.uk/government/publications/covid-19-mental-health-and-wellbeing-recovery-action-plan/covid-19-mental-health-and-wellbeing-recovery-action-plan>

⁷ NHS England, NHS sets out COVID-19 recovery plan for patient care and staff wellbeing, March 2021: <https://www.england.nhs.uk/2021/03/nhs-sets-out-covid-19-recovery-plan-for-patient-care-and-staff-wellbeing/>

⁸ Department of Health and Social Care, Working together to improve health and social care for all: <https://www.gov.uk/government/publications/working-together-to-improve-health-and-social-care-for-all>

⁹ Department of Health and Social Care, UK Rare Disease Framework, January 2021: <https://www.gov.uk/government/publications/uk-rare-diseases-framework/the-uk-rare-diseases-framework>

This report sets out what we found. It highlights key recovery priorities in the wake of the COVID-19 pandemic and the pressures on services; outlines key priorities to improve long-term outcomes for people with muscle-wasting conditions; and makes recommendations and outlines actions needed within five years to improve outcomes for people living with muscle-wasting conditions.

Muscular Dystrophy UK is hugely grateful to the hundreds of people living with muscle-wasting conditions and to the neuromuscular health professionals who have contributed to this report via surveys and discussions. We've made recommendations for a wide range of stakeholders, and we urge you to work with Muscular Dystrophy UK to understand more about the role you can play in making our recommendations become reality – and how we stand ready to work in partnership with you to make that happen.

People with muscle-wasting conditions told us:

'Due to lack of exercise my leg muscles are not as good. I am pushing my wheelchair 2 to 3 miles a day when the weather is suitable but this does not help my lower body. I worry about the damage done and about interrupted access to swimming pools in the future.'

[On impact of shielding](#)

'I'm unable to swim and therefore more unstable on my legs and falling more often. The government advises to go out for a daily walk. Sadly, I'm not able to do that.'

[On impact of shielding](#)

'The pandemic has highlighted the fact that I get very little support from my GP or the health service and any assistance regarding my condition. I have to find and finance privately.'

[On experience of pandemic](#)

'I just feel so alone, and I am living in fear. Wish I was able bodied and could rely on myself.'

[On experience of pandemic](#)

'The outside world is out of reach and personal confidence and independence have diminished.'

[On experience of pandemic](#)

'I am not going to the office every day, travelling on the bus, opening doors, lifting and carrying items, transferring to the toilet at work. I cannot go swimming or have physio or massage. Instead at home what I do is more limited and I have noticed in particular that my arm strength has deteriorated. I can no longer raise my arms to stir while cooking, for instance, or turn and flush the toilet. I have to ask for help with drinking, in more situations. I am experiencing increasing pain and sometimes have to go lie down in the afternoon because of this.'

[On experience of pandemic](#)

Health professionals told us:

'My first priority is staffing - we are seriously undermanned in our neuromuscular service – and my second priority is making psychology/ neuropsychology services accessible to neuromuscular patients. My third priority would be physio accessibility.'

[On future of neuromuscular services post-COVID-19](#)

'We need to prioritise offering a high standard of care, whether appointments are conducted face to face, via video or telephone with input from the MDT. We also need to ensure that disease modifying treatments are restarted smoothly and without delay.'

[On future of neuromuscular services post-COVID-19](#)

Executive summary

“We’ve lost nearly all of our regular hospital input and accessing appointments. We haven’t been able to physically attend appointments and normally we’d have regular cardiology and respiratory appointments, but these were all put on hold. We’re still chasing results from appointments that took place more than six months ago. I feel scared that it feels like nobody’s really monitoring what’s going on with us. There are massive inequalities to accessing healthcare when you have a disability and COVID-19 has shone a magnifying lens on this.

“Even before the pandemic we had a sense that provision was shrinking dramatically in terms of a specialist and co-ordinated approach to our care. The pandemic has massively exacerbated and accelerated this originally-existing problem, especially in relation to occupational therapy and accessing equipment.

“We’re not at the end-of-life stage and still have plenty of living to do but we’re also not fixable either. There urgently needs to be a more holistic approach to services that span both health and social care.”

Charlotte and Tom Hardwick from the East Midlands, who both live with a muscle-wasting condition

Priorities and recommendations at a glance

Key recovery priorities in the wake of the COVID-19 pandemic and pressures on hospitals

1. Ensure faster access to diagnostics and investigations.

2. Reduce waiting lists, address the growing backlog of new and follow-up appointments.
3. Open face-to-face appointments to people for whose wellbeing it is essential and retain effective digital technology for virtual appointments for clinicians and patients who agree to this approach.
4. Secure the confidence of people living with a muscle-wasting condition and make sure they know that if they are called into a face-to-face appointment, that it will be a safe space.
5. Improve staff support to ensure retention, provide upskilling, and avoid burnout.

Key priorities to improve the long-term outcomes for people with a muscle-wasting condition

1. Equitable access to a specialist neuromuscular MDTs (a core team of specialist consultants, physiotherapists, mental health professionals, neuromuscular care advisors) across the UK.
2. The establishment of NHS-managed neuromuscular clinical networks across the UK, to help raise standards and benchmark services, as well as improve links with and the education of health professionals working in the community.
3. The provision of neuromuscular outreach clinics and improved connection with community services.
4. Equitable access to a psychologist or mental health specialist with expertise in working with people with a muscle-wasting condition.
5. Faster access to new treatments and therapies, from NICE assessment to patient roll-out.
6. Strengthened administrative support for data collection and improved clinic co-ordination.

Recommendations and next steps to be completed within five years to improve outcomes for people living with a muscle-wasting condition

1. A banded national payment system to be established that reflects the cost of specialist MDT care for people living with a muscle-wasting condition.
2. The implementation of a clear commissioning pathway to all recognised NHS England and devolved nation neuromuscular specialist services.
3. The development of and implementation of NHS England national neuromuscular service specifications for specialist care of children and adults.
4. National Institute for Health and Clinical Excellence (NICE) and the Government to fast-track the roll-out of the Innovative Medicines Fund so that no person waits longer than necessary to access new treatments.
5. The establishment of NHS-managed regional neuromuscular clinical networks across the UK.
6. Review already existing NHS databases of people living with a muscle-wasting condition to ensure they are fit for purpose and are administered well.

'Patients with neuromuscular diseases (NMDs) require long-term multi-disciplinary care. In England, this care should be co-ordinated by specialist neuromuscular services that are commissioned at a specialised or highly specialised level. These centres provide diagnostic investigations, symptom management, treatment (when available) and multi-disciplinary care. Such centres also play an important role in the development of translational research. As a result, people with NMDs may experience an improvement in quality of life, prolonged life expectancy and receive advice on adaptations to help them carry out everyday tasks made harder by physical limitations.'

[Clinician from a leading national neuromuscular service](#)

Methodology

We have based this report on the results of two national surveys we conducted in the first half of 2021. The first survey looked at the impact of COVID-19 and shielding for people living with a muscle-wasting condition, as well as their families, between March 2020 and February 2021. Over 400 people responded, providing insight into the impact of shielding and disruption to vital clinical appointments. We also heard of concerns arising because of the pandemic, such as receiving physical and mental wellbeing support.

The second survey looked at the impact of delivering specialist neuromuscular care during lockdown and through the pandemic from a clinical perspective, between March 2020 and February 2021. We received responses from 32 neuromuscular clinical teams (over 50 percent of neuromuscular services in the UK), providing insight into staff redeployment and service gaps, impact on clinics, appointments and treatments, and the use of virtual consultations for people with muscle-wasting conditions.

Muscular Dystrophy UK co-ordinates and partakes in nine regional and national neuromuscular clinical networks across the UK, which aim to improve neuromuscular care and services standards across regions, by bringing together specialist clinicians, people living with a muscle-wasting condition and NHS decision-makers. We discussed the survey findings and the issues uncovered within these networks, as well as at both All Party Parliamentary Group and Cross-Party Group meetings in all four UK parliaments and assemblies. We also discussed this work at our 2021 virtual national conference for neuromuscular care advisors and specialist nurses.

At the heart of this report are the voices of people living with a muscle-wasting condition and the specialist health professionals charged with co-ordinating their multi-disciplinary care. The report

presents a strong and clear narrative of what people have lived through and, indeed, what needs to happen in the future.

'I feel very fearful that if I get ill, I can't go to hospital as people don't understand I need to take regular carers/husband with me. It is still not clear they would let anyone in with me. Also concerned my cardiac care has been absent and respiratory care. If I cannot travel to these far away hospitals, I need some kind of replacement. I still feel travel is not safe into London. My specialist dental care in London was stopped and I was removed as a patient due to COVID. I have no routine dental care now which I badly need as the local hospital is struggling to provide it for practical access/ expertise reasons. I feel I've lost all medical care basically.'

[Feedback from a person living with a muscle-wasting condition on concerns for the future.](#)

'The impact of COVID on our service has been devastating. Our in-patient ward respiratory and cardiac consultants, physios and nurses were redeployed during the first wave. Our team have returned, and we are now housed on a temporary ward. We have been undertaking remote appointments (telephone and video) and we have a huge backlog of patients to see, but patients are still reluctant to come to hospital because they are fearful of catching COVID, despite vaccination. Many are asking to have their antibody levels checked.'

'Remote and video consultations are OK in the short term, but not in the long term and we are at a point in time now where we are starting to see people face to face in clinic. One difficulty, however, is that fewer people can come to outpatients or the ward on any particular day, to maintain social distancing.'

[Clinician feedback on post-pandemic concerns.](#)

Key findings

Impact of shielding

Of people with muscle-wasting conditions who responded:

- 86 percent shielded during the pandemic, regardless of whether they received a letter instructing them to do so or not.
- 68 percent said that lockdown and shielding had a negative impact on their physical health.
- 62 percent said that lockdown and shielding had a negative impact on their mental health.
- 45 percent experienced reduced access to family carers or care workers because of lockdown or shielding.

Disruption to accessing healthcare services because of the COVID-19 pandemic

Of people with muscle-wasting conditions who responded:

- 75 percent experienced disruption or delays to accessing specialist muscle clinical appointments.
- 40 percent said their access to specialist respiratory care had been affected, disrupted, or delayed.
- 54 percent said that access to specialist neuromuscular physiotherapy had been affected, delayed, or disrupted.

Impact on staffing at neuromuscular centres:

- 64% of neuromuscular specialist teams have had members of their MDT redeployed since the start of the COVID-19 pandemic.

Cancellation of specialist and diagnostic appointments

Between March 2020 and February 2021, our findings showed the impact of the COVID-19 pandemic on neuromuscular centres:

- 97 percent had to cancel routine face-to-face neuromuscular clinics.
- 38 percent had to cancel new face-to-face diagnosis appointments.
- 64 percent had to cancel appointments for diagnostic investigations such as muscle biopsy, MRI, EMG.
- 48 percent saw a reduction in the number of new referrals in comparison to a more normal year.
- 63 percent saw an increase in waiting times for face-to-face neuromuscular MDT appointments.
- 72 percent experienced delays in DNA analysis required for diagnosis.
- 63 percent experienced delays in getting cardiac scans (ECHOs).
- 63 percent had to pause clinical trials or other research studies.

Virtual consultations

- 94 percent of respondents said that, overall, holding telephone and video consultations during the COVID-19 pandemic had been successful
- 60 percent of respondents had concerns about the vaccine programme, particularly around vaccine safety for people with a muscle-wasting condition, and prioritisation for them, their carers, care workers and personal assistants.

Our findings indicate that people living with muscle-wasting conditions have struggled to access critical services such as specialist muscle clinical appointments, specialist respiratory care and specialist neuromuscular physiotherapy because of the pandemic and shielding. This lack of provision has had a negative impact on their overall physical and mental wellbeing. As a result,

an ever-increasing backlog of patients is waiting for appointments. Considering the pandemic is still ongoing, these findings offer only a glimpse of these experiences, and the issues will worsen until properly addressed.

In many cases, the delay in access to specialist services may result in a more acute progression of a person's condition. This could lead to the need for additional treatments and longer stays in hospital, in turn putting even more pressure on an already strained service. This is evident as our surveys indicated a significant number of cancelled diagnostic appointments, a reduction in specialist clinic referrals, and increased waiting times for face-to-face appointments. It's clear there needs to be a combination of virtual and face-to-face appointments, depending on individual patient need and preference. There needs to be sufficient numbers of neuromuscular staff to address these problems; those who were not seconded during the pandemic would have been stretched even further to deliver appropriate services, and the many who were seconded are already at risk of burning out.

These findings reflect a worsening situation for people living with muscle-wasting conditions. Most respondents emphasised that delayed access to muscle clinics, physiotherapy and hydrotherapy would result in irreversible muscle weakness and muscle loss. We believe that all people living with muscle-wasting conditions should be able to access MDTs, diagnostics, and clinical services when they need them, no matter where they live in the UK.

Analysis

Muscle-wasting conditions are rare and complex multi-system disorders that cause a wide variety of symptoms. Some of these conditions are life-limiting. As such, people with muscle-wasting conditions require consistent medical/health monitoring, fast access to treatments and access to a MDT. Even before the COVID-19 pandemic, access to these fundamental services was unequal across the country, resulting in a postcode lottery of services. The pandemic has only further exacerbated these barriers to care.

With the focus shifting to recovery of NHS services, now is a critical and opportune time to examine the current state of neuromuscular services and identify the barriers to neuromuscular care affected by the impact of COVID-19. This will secure a clearer footing to implement ways to overcome them to ensure a more resilient and adaptive neuromuscular service in the future.

Impact of the COVID-19 pandemic on neuromuscular services

When the pandemic first broke out, neuromuscular services were provided with the means to offer virtual consultations. Clinician feedback has shown that this was successful in the short term so they could monitor their patients remotely. But this will not be an effective long-term tool as many diagnostic appointments, some assessments, and treatments can only be done in person. Clinical feedback highlighted that it was impossible to gather vital information, such as ambulatory function and muscle strength deterioration, through a screen. Clinicians reiterated that a combination approach might be appropriate in certain circumstances for some patients, but those in more advanced stages of their condition would need face-to-face appointments.

Even when physical appointments have been possible, many people have been unable to attend

because they've been shielding, and so have missed specialist diagnostic tests and treatments. Waiting lists have been growing since March 2020 and there is now a significant backlog. Many of these patients may require more complex care in the future, which, as well as having a significant impact on their wellbeing will be more costly for the NHS and require additional hospital and staff resources. This is not including those still waiting for an initial referral to specialist muscle services.

In order to provide high-quality care in the future, it's vital to prioritise reducing waiting times, implementing effective digital technology, and enabling access to full specialist MDTs and novel treatment. It is only then that neuromuscular services will be able to provide integrated care to support both the physical and mental wellbeing of people living with a muscle-wasting condition.

The introduction of Integrated Care Systems (ICs) may go some way to providing more joined-up neuromuscular care. The principle behind ICs, in theory, should erode the barriers preventing collaboration between crucial services, such as specialised, community and social care services, that play a vital role in neuromuscular care provision.

Best practice and commissioning of neuromuscular services across the UK

Neuromuscular services across the UK have for years experienced variability across paediatric, transition and adult clinical pathways. Such variability has arisen because there is neither a clear NHS service specification for neuromuscular conditions nor a clear commissioning route for neuromuscular services.

NHS service specifications are important to define standards of care expected from organisations providing specialised care. People living with muscle-wasting conditions require access to a range of different services and departments. As such, they have some reference in other

service specifications; but there is no joined-up consensus to outline best care practice. Having a dedicated NHS England national neuromuscular service specification and care pathway will help address the postcode lottery of neuromuscular services across the country by making clear the key core standards that all services should be able to demonstrate, and which services people with muscle-wasting conditions need to be able access. It will also help support specialist centres with requests for additional resources they need to reach these core standards.

However, a service specification for neuromuscular services alone will not be enough to ensure people with muscle-wasting conditions can access all required service. Neuromuscular services across the UK also do not follow the same funding pathways. In England, some neuromuscular services are commissioned through NHS England and delivered through NHS England neuroscience centres, whereas others are currently commissioned through Clinical Commissioning Groups (CCGs). This does not reflect the quality of care provided, with many good practice examples available for both routes. However, it can result in a wide variation in funding received by neuromuscular services, as services across the country will be processed under different sections of the NHS tariff set-up.

Similarly, in the devolved nations, neuromuscular services are inconsistently funded, under-developed to different degrees, sometimes with disjointed multi-disciplinary care. In Wales, some neuromuscular specialists do not have access to a full neuromuscular MDT. The Welsh Health Specialised Services Committee (WHSSC) is responsible for the planning of secondary and tertiary services across all seven Health Boards in Wales. The two neuromuscular centres in Wales: one in Cardiff and one in Swansea, are funded in different ways.

In Northern Ireland, commissioning decisions are made by the Health and Social Care Board (HSCB). However, with fewer than two million people in

Northern Ireland, the HSCB is unable to support highly specialist elements of care for rare diseases locally, instead relying heavily on links with tertiary and quaternary centres across the UK. As a result, neuromuscular services in Northern Ireland have sometimes had inconsistent standards of care from diagnosis onwards. There is also a significant reduction in services when transitioning from paediatric to adult services.

In Scotland, specialised services are commissioned through the NHS Scotland National Planning Board. The Board commissions the Scottish Muscle Network, which is a nationally-managed clinical network for children and adults living with muscle-wasting conditions. The Network is responsible for reviewing neuromuscular services and it has put forward best practice guidelines and disease-specific service specifications. Services for those with muscle-wasting conditions are delivered across Scotland through a collaborative, networked approach. Care is delivered as locally as possible, but people still need to travel to access diagnostics, specialist expertise or specialist facilities.

The upcoming NHS reform in England is an opportunity to establish a single commissioning pathway for neuromuscular services for all types of muscle-wasting conditions, as well as a specific neuromuscular service specification. This will make it easier to implement service provision changes and provide better support to people living with muscle-wasting conditions. We urge the NHS and ICS leads to work together with Muscular Dystrophy UK and neuromuscular specialists. Together, we want to establish a clear, linear commissioning pathway that considers a calculated cost of delivering neuromuscular services through a payment mechanism that ensures centres are reimbursed fairly for care provided.

Implementing a service specification and clear commissioning route has benefited other rare disease areas such as cystic fibrosis (CF). The NHS has published both adult and paediatric

services specifications for CF care, based on recommendations of the Cystic Fibrosis Trust's Standards of Care. Commissioning of CF services is also calculated through a tariff reimbursement scheme, based on UK CF Registry data. These two areas have transformed the way CF services are run, to ensure fair access to care, accurate reimbursement to all specialist centres and clear monitoring in developments of care needs.

Future plans

If adopted, our recommendations in the next section of this report will help overcome barriers to accessing specialist care that existed before, but which have been exacerbated by, the COVID-19 pandemic. These recommendations will ensure all neuromuscular services have the necessary staffing and resources to provide high-quality care across the UK.

Priorities and recommendations

'Building on lessons learnt to develop a wider portfolio of services and using digital platforms to support multi-professional care – i.e., a virtual meeting with hospital/local therapist and neuromuscular team and orthopaedics should improve perioperative management in those referred for possible surgery. By using a combination of face to face and video may allow community therapists to 'attend' a hospital appointment facilitating more 'joined up care and learning'

[Clinical feedback on resuming services post-pandemic](#)

Our survey revealed a set of priorities for both people with a muscle-wasting condition and specialist neuromuscular healthcare providers; in the short term to recover from the COVID-19 pandemic and in the long-term to improve outcomes for people with a muscle wasting condition. We outline these below with a set of recommendations that we believe will help achieve these priorities.

Key recovery priorities in the wake of the COVID-19 pandemic and pressures on hospitals

1. Ensure faster access to diagnostics and investigations

'Our face-to-face appointments are back – but we need to get our biopsy service (with surgeons) back on track and we were developing detailed neuromuscular therapy assessment clinics (mainly for Duchenne muscular dystrophy) which I would be keen to progress with.'

[Feedback from a clinician on the impact of COVID-19 on neuromuscular services](#)

The COVID-19 pandemic has exacerbated delays in accessing diagnostic and other investigations. Our survey showed that 72 percent of neuromuscular centres that took part in our survey experienced delays in DNA analysis required for diagnosis, 63 percent experienced delays in getting cardiac scans (ECHOs) and 64 percent had to cancel appointments for diagnostic investigation such as muscle biopsy, MRI, EMG. These tests are essential for a conclusive diagnosis. Delays mean people with muscle-wasting conditions have been waiting even longer, with the uncertainty of their diagnosis. This was further exacerbated, as 38 percent also had to cancel new face-to-face diagnosis appointments because of the COVID-19 pandemic, at some point between March 2020 and February 2021.

A 2017 Muscular Dystrophy UK report on Unplanned Hospital Admissions in Patients with Neuromuscular Diseases showed that preventable admissions for a person with a neuromuscular condition amounted to 1,164 bed days . These numbers could have been reduced by early referral to a specialist (neurology or neuromuscular) and by preventing delays in diagnosis, as half of these patients had not received a previous diagnosis. The patients that received a new diagnosis at discharge said how important it was to get an early referral to a neurology specialist and/or neuromuscular specialised service for diagnostic investigations to improve symptom management, quality of life, reduction in emergency admissions and fewer delays to discharges.

It's critical to resume face-to-face appointments as soon as possible to avoid delays in giving people a diagnosis, and to be able to fast-track access to a treatment plan and any emotional and welfare support they may need. This aligns with one of the four main priorities outlined in the Rare Disease Framework, to help patients receive a final diagnosis faster and reduce the "diagnostic odyssey" faced by so many¹⁰. We urge the NHS to re-establish these services as soon as possible

by both extending clinic opening times and speaking with clinicians to identify opportunities for increasing capacity.

2. Reduce waiting lists and address the growing backlog of new and follow-up appointments.

'We mostly wish to recover the lost time, prioritise patients based on needs (that might have changed during lockdown), so this is very time-consuming. We would like to capitalise on the home assessment monitoring, but there is no immediate source of funding for expanding in this area.'

[Clinical feedback on resuming services post-pandemic](#)

Neuromuscular services have had to incorporate new ways of attending to patients during the pandemic, with the use of virtual tools. However, this resulted in the cancellation of many critical appointments, with 75 percent of people with a muscle-wasting condition we surveyed having experienced disruption to specialist muscle clinical appointments, 40 percent having experienced disruption to specialist respiratory care appointments and 54 percent having experienced disruption to specialist neuromuscular physiotherapy appointments. As a result, waiting lists have been growing and 63 percent of the neuromuscular centres we surveyed have seen an increase in waiting times for face-to-face neuromuscular MDT appointments, between March 2020 and February 2021.

Services are still taking place virtually, meaning this backlog is only increasing, and it will be difficult to catch up. The King's Fund analysis of current general waiting times concludes that 'the impact of COVID-19 on waiting times for NHS patients will be felt for years to come'. Tackling waiting times cannot wait, particularly as the list does not consider those who are still waiting for an initial referral to a specialist centre. Our survey found 48 percent of neuromuscular centres have seen a reduction in the

number of new referrals in comparison with a more normal year. This suggests that either patients are not seeing their GPs for the early signs of a muscle-wasting condition or GPs are hesitant to refer them.

Extending clinic opening times will enable neuromuscular centres to offer more appointments and ensure those waiting can be seen more quickly. It was reassuring to find, through our survey, that although specialist neuromuscular staff were redeployed across the NHS as part of the response to the COVID-19 pandemic, most have now returned to their normal service. So it may be possible to extend clinical hours in the short term to address the backlog.

3. Open face-to-face appointments to people for whose wellbeing it is essential and retain effective digital technology for virtual appointments for clinicians and patients who agree to this approach.

'We need to return to appropriate face-to-face clinics led by the most appropriate member of the MDT. We also need to find a way to integrate NorthStar/REACH data collection (a registry of people with muscle-wasting conditions) into our adult services.'

[Clinical feedback on resuming services post-pandemic](#)

When the pandemic first began, 97 percent of the neuromuscular centres we surveyed had to cancel routine face-to-face neuromuscular clinics. Even though 94 percent overall found holding telephone and video consultations during the COVID-19 pandemic successful, our findings have shown an urgency to resume critical clinical appointments. It's also clear that virtual consultations are only appropriate in line with the overall wellbeing of the patient. For example, patients with more severe disease progression need to be assessed physically to provide appropriate treatment.

Clinical feedback highlighted that it was

impossible to gather vital information, such as ambulatory function and muscle strength deterioration, through a screen. It was particularly reiterated that a combination approach may be appropriate in certain circumstances for patients who are most well, however those in more advanced stages of their condition need face-to-face appointments.

We have also shown in the previous priorities that without face-to-face appointments there have been delays in diagnosis and a growing waiting list for those waiting for specialist neuromuscular appointments. Anecdotal feedback has shown that some face-to-face appointments are now being offered but that numbers are still limited owing to social distancing measures. However, these patients cannot continue to wait for crucial neuromuscular services. As such, it is imperative to widen the offering of face-to-face appointments and make sure healthcare practitioners have the right tools to review with their patients their need and preference for face-to-face appointments.

4. Secure the confidence of people living with a muscle-wasting condition and make sure they know that if they are called into a face-to-face appointment, that it will be a safe space.

Most specialist appointments for people with muscle-wasting conditions were cancelled to minimise the risk, as they were deemed 'clinically extremely vulnerable' to COVID-19. As a result, many people with a muscle-wasting condition did not feel comfortable leaving their house even to attend their clinical appointments, out of fear of 'catching COVID-19'. With restrictions scheduled to ease fully from 19 July 2021, healthcare providers need to help people living with a muscle-wasting condition feel confident that it is safe to come in for their healthcare appointments. This will require reassurance on infection prevention measures in place when attending their clinics, and an open dialogue between healthcare practitioners and their patients on whether they need a face-to-face

appointment (such as diagnostic testing) rather than a virtual one. People with muscle-wasting conditions may also feel more reassured if a carer or family member can accompany them when attending appointments. Administrative staff also need the tools to address any concerns patients may have about attending appointments and ways to make the patient feel more comfortable about attending them.

5. Improve staff support to ensure retention, provide upskilling, and avoid burnout.

It won't be possible to accomplish any of the above priorities without sufficient numbers of specialist staffing. Even though most staff members who were redeployed amid the pandemic have now returned to their normal work areas, there are rising cases of staff burnout and PTSD within the NHS. For example, NHS providers have previously said the pandemic has put 'sustained physical, psychological and emotional pressure on health staff which is threatening to push them beyond their limits'.

We are concerned that the additional pressure of the pandemic will affect specialist neuromuscular staff and they may not feel able to take on this additional workload. There are also shortages in the number of specialist neuromuscular consultants for children and adults, as well as junior doctors with an interest in neuromuscular conditions in the medical training system. There needs to be safe staffing to ensure the effective functioning of all NHS services but, for rare disease areas, there is already a shortage of specialist clinicians. We are therefore asking the Government and NHS to support staff retention and upskilling to maintain safe staffing levels at neuromuscular centres.

Key priorities to improve the long-term outcomes for people with a muscle-wasting condition

1. Equitable access to a specialist MDT (a core team of specialist consultants,

physiotherapists, mental health professionals, neuromuscular care advisors) across the UK.

'We need to continue to develop and see investment in our service. We are keen to develop more outreach clinics with our regional colleagues and adult services and transition remains an area that needs a lot of development.'

[Clinical feedback on resuming services post-pandemic](#)

Muscle-wasting conditions are rare and complex multi-system disorders that result in a wide variety of symptoms; some conditions result in mild symptoms and slow deterioration, while others are life-limiting. Consequently, effective management of these conditions requires specialist multi-disciplinary care delivered by a team of trained and experienced neuromuscular health professionals, with staffing levels appropriate to the size of the patient population. This team should include at a minimum:

- specialist neuromuscular consultants to monitor deterioration and provide appropriate treatments
- a neuromuscular physiotherapist to help strengthen muscles and promote mobility
- a specialist psychologist who understands the mental health impact of living with a muscle-wasting condition
- access to care advisor support to help assist with welfare and support specific to each patient group.

Given that the management of such conditions involves a great number and range of professionals, a multi-disciplinary approach is the only way to support these patients fully. A 2017 Muscular Dystrophy UK report on *Unplanned Hospital Admissions in Patients with Neuromuscular Diseases* showed that 'unplanned hospital admissions are more likely to happen if care is poorly co-ordinated and not proactive'. The report found that the duration of hospital stay was shorter for admissions

related to patients who had previously been seen at a specialised service (median = eight days) than for patients who were not known to a neuromuscular service (median = 15 days).

Alongside the development of specialist care for children and young people, the development and use of the latest treatments and improved standards of care in recent years has led to a growing population of adults. This older population will now require continuing, high-quality anticipatory care and support to ensure they enjoy the best possible quality of life. With this change in demographics and the revolution in care and treatment for some conditions, we are calling for the development of service specifications in paediatric and adult services, as well as in the transition phase between the two to provide best-practice guidance to neuromuscular services. This would ensure that each service has the tools to establish a managed clinical pathway that incorporates both multi-disciplinary working and access to effective and efficient treatment.

Access to an MDT will also reduce the number of preventable admissions. On average, adults with muscle-wasting conditions have a median stay of 12 days, ranging from 0-231 days¹⁹. This is slightly less for children, who have a median stay of eight days, ranging from 0-114 days. Given the changing demographic, it is important to understand their changing needs so that these numbers of days do not increase even further. The way to do this is through access to an MDT that is equipped to handle their complex care.

With the implementation of ICSs – which will include a move to improved integrated care and a shift in commissioning for some rare diseases – now is the time to invest in securing such MDTs across the country. Not only will this improve care provision, but increased investment into the MDT will also help healthcare professionals tackle more efficiently the backlog of patients waiting for referral, diagnosis, and treatments, by tailoring treatment plans to the individual patient.

2. The establishment of NHS-managed neuromuscular clinical networks across the UK, to help raise standards and benchmark services, as well as improve links with and the education of health professionals working in the community.

‘Organised, effective and compassionate leadership – moving away from medically-led teams. Developmental opportunities for neuromuscular team members to develop into more advanced roles/ banding.’

[Clinical feedback on resuming services post-pandemic](#)

Managed Clinical Neuromuscular Networks usually comprise neuromuscular consultants, specialist physiotherapists, care advisors, cardiac and respiratory specialists, NHS commissioners, and patient representatives. The current funded networks have led to improved services while facilitating relationships between stakeholders across the patient pathway. There are three funded neuromuscular networks across the UK, which focus on identifying both regional best practice and ways to fill gaps in neuromuscular care. The networks ensure that patients have access to a full specialist MDT, offer upskilling events to raise greater awareness of muscle-wasting conditions for healthcare professionals, and develop resources for patients, including condition-specific information and support groups.

Such networks have been essential in improving neuromuscular care across the UK, but they require consistent funding to ensure each is equipped with the appropriate clinical representatives and resources. We are asking the NHS to invest further in Managed Clinical Neuromuscular Networks to address this inconsistency and ensure they each have sufficient provision. For example, only the Southwest, Northwest and Scotland networks receive NHS funding, but even then, they are funded in different ways. This investment will help promote integrated working, ensure patients have access to properly-resourced healthcare and

address unwarranted variation in neuromuscular services across the UK – areas that the NHS reform and Rare Disease Framework have set out to address.

3. The provision of neuromuscular outreach clinics and improved connection with community services.

Many areas across the country do not have easy access to neuromuscular services, resulting in people travelling long distances for their specialist clinics. To address this, some neuromuscular centres provide outreach clinics in areas where patients are not receiving adequate specialist care. Outreach clinics have shown to be successful in addressing the postcode lottery of neuromuscular care and tackling health inequalities within these regions. With the means to provide virtual consultations, there may be scope to offer a combination of face-to-face appointments through outreach clinics for diagnostics and treatment, while offering virtual appointments to support more consistent monitoring.

With the upcoming NHS reform, there is an opportunity to improve joined-up care of neuromuscular services across secondary, tertiary and community services. This will enable smoother transition for patients between services, for example from specialist physiotherapists to community physiotherapists where appropriate.

We are therefore asking for support within outreach clinics and community services not only to improve neuromuscular healthcare provision across the UK, but also to provide staff with additional tools to start tackling the backlog of patients waiting for specialist treatment. This will mean reaching more patients, creating capacity in specialist neuromuscular centres based on need, and improving integrated care across multiple healthcare providers.

4. Equitable access to a psychologist or mental health specialist with expertise in working with people with a muscle-wasting condition.

'If anything has been highlighted by this pandemic, it's the inadequacy of mental health provision.'

[Clinical feedback on resuming services post-pandemic](#)

The mental health of people living with muscle-wasting conditions, many of which are life-limiting and life-shortening, has been overlooked for decades. It's exceptionally difficult being diagnosed with a muscle-wasting condition and adjusting to a new lifestyle, and many people in this situation can feel isolated, anxious, or depressed. This is further exacerbated, as people with muscle-wasting conditions do not have access to specialist psychologists who understand their complex conditions. The NHS Long-Term Plan outlined the Government's commitments to prioritising mental health, particularly for young people. The UK Rare Disease Framework reiterated the Government's ambition 'to ensure that the needs of rare disease patients are appropriately reflected across wider government policy, including mental health and social care.'

The impact of the pandemic and shielding has further exacerbated poor mental health for people living with muscle-wasting conditions, particularly those who have been unable to work from home, those who live alone or who have been isolated from their loved ones. From our survey, 86 percent of people living with a muscle-wasting condition were shielding, with 62 percent of them saying that lockdown and shielding has had a negative impact on their mental health. People with muscle-wasting conditions cannot wait any longer to access specialist psychological services and we urge the Government to consider how access can be fast-tracked in this area.

5. Faster access to new treatments and therapies, from NICE assessment to patient roll-out.

'We need to ensure we catch up on recognising those children who might be eligible for SMA [spinal muscular atrophy] gene therapy, so they don't miss the window for access to new treatments.'

[Clinical feedback on resuming services post-pandemic](#)

'Ensuring catch-up on those who might be eligible for SMA Gene Therapy as some may have missed the EAMS window for Risdiplam.'

[Clinical feedback on impact of the pandemic](#)

Several treatments for muscle-wasting conditions are currently in development, are undergoing market authorisation or have recently been made available on the NHS. Avoidable delays in accessing these treatments are common, causing many people's muscle-wasting conditions to deteriorate further and possibly render them ineligible for these treatments. There have also been further delays to the development of new treatments this year, with 63 percent of the neuromuscular centres we surveyed reporting that they paused clinical trials or other research studies during the pandemic. This reinforced the need for NICE and the Scottish Medicines Consortium to approve new treatments quickly as these treatments are more effective when started as early as possible.

Some treatments are far more effective when given before symptoms even appear. This intensifies pressure on the diagnostic process, as patients are usually diagnosed months after the first symptoms appear. For some conditions, new-born screening offers a way to mitigate this by making it possible to diagnose patients at birth. In the long term, this will minimise lengthy hospital stays, limit the additional treatments and care needed throughout their lives, and reduce NHS resources including staffing and cost.

A prime example is newborn screening for spinal muscular atrophy (SMA), which is available in 16 countries, but not in the UK. Data has shown that treating SMA pre- and post-symptomatically can have as significant an impact as the difference between a patient spending their life in a wheelchair or being fully ambulatory. We therefore urge the Government to implement newborn screening where possible for muscle-wasting conditions, such as for SMA, to help fast-track access to treatments.

We also urge the Government and key decision-makers to consider ways of ensuring that upcoming initiatives (such as the NICE methods review and the Innovative Medicines Fund) result in faster access to new treatments. This will require support throughout the drug authorisation process, from the moment treatments are submitted for licensing until national roll-out to patients.

6. Strengthened administrative support for data collection and improved clinic co-ordination.

It is imperative to continue capturing high-quality data and inputting it into UK national neuromuscular databases to capture the impact of the pandemic and the changing care needs for people with muscle-wasting conditions. This natural history data will help to document the impact of potential treatments and care throughout a person's lifespan and observe changes to this ageing patient demographic to support them better.

Multi-disciplinary working and improved data collection require strengthened administrative support to equip staff to undertake this additional work. We urge the Government to ensure staff have access to any training, technology, or other support they need as the long-term benefits to patients and neuromuscular centres cannot be overlooked. We appreciate this requires further investment and time, but the additional support

provided to other disease areas, such as Cystic Fibrosis (CF), has shown how beneficial this can be in the long term. The UK CF Registry has a 99 percent completion rate to showcase the change in demographics, impact of treatment, observations to changes in care (such as rise in comorbidities as a result of an ageing population). This could not be achieved without the work of the administrative staff who input this data. There is a risk to this first wave of treatments for people with muscle-wasting conditions not being recorded accurately enough to benefit the community they have been developed for.

Recommendations and next steps to be completed within five years to improve outcomes for people living with a muscle-wasting condition

1. A banded national payment system to be established that reflects the cost of specialist MDT care for people living with a muscle-wasting condition.
2. The implementation of a clear commissioning pathway to all recognised NHS England and devolved nation neuromuscular specialist services.
3. The development of and implementation of NHS England national neuromuscular service specifications for specialist care of children and adults.
4. NICE and the Government to fast-track the roll-out of the Innovative Medicines Fund so that no person waits longer than necessary to access new treatments.
5. The establishment of NHS-managed regional neuromuscular clinical networks across the UK.
6. Review already existing NHS databases of people living with a muscle-wasting condition to ensure they are fit for purpose and are administered well.

Mapping our priorities

Many of the priorities we have identified in this report align with the upcoming NHS reform to support NHS organisations in collaborating to improve care and manage resources; and with plans laid out in the Rare Disease Framework to improve the diagnosis, treatment, and access to care for people with a rare condition.

Key recovery priorities in the wake of the COVID-19 pandemic and pressures on hospitals

Priority	Impact on people living with a muscle-wasting condition	NHS reform	Rare Disease Framework
Faster access to diagnostics and investigations.	Our findings have shown that many diagnostics and other investigations were either delayed or cancelled during the pandemic. This delay causes a chain reaction, where people living with muscle-wasting conditions do not receive the right treatment and care, which results in poorer outcomes and faster deterioration in some people's conditions, even missing the opportunity for access to a treatment.	A key objective from the upcoming NHS reform is to ensure that patients benefit from research and innovation that provides earlier diagnosis, more effective treatments, better outcomes, and faster recovery. To achieve this, people living with muscle-wasting conditions will require faster access to relevant tests.	The first priority in the Rare Disease Framework is to help patients get a final diagnosis faster. This will enable them to: manage their condition appropriately; facilitate greater treatment choice and decision-making; link individuals to vital support through patient organisations.
Reduce waiting lists and address the growing backlog of new and follow-up appointments.	During the pandemic, many services were either disrupted or cancelled. As a result, an increasing number of patients are now waiting to access specialist appointments while their condition deteriorates. This is having a profound impact on their physical and mental health, as well as quality of life. They are now also more likely to require more complex care. It is therefore essential patients are seen as soon as possible.	The upcoming NHS reform is focused on building a stronger and more supportive healthcare system for the future. However, care cannot be improved until the NHS has fully recovered from the impact of the pandemic. It is therefore critical to start by addressing the backlog of patients waiting to access crucial services by extending clinic opening times in the short term. This will allow staff to see more patients.	As with the NHS reform, the first step of the Rare Disease Framework will be to address the complications that have arisen for those who have been required to shield and who have not been able to receive sufficient care and treatment during the pandemic, such as people living with a muscle-wasting condition.

Priority	Impact on people living with a muscle-wasting condition	NHS reform	Rare Disease Framework
<p>Open face-to-face appointments to people for whose wellbeing it is essential and retain effective digital technology for virtual appointments where clinicians and patients agree that this is appropriate.</p>	<p>Clinical feedback highlighted that it's impossible to gather vital information, such as ambulatory function and muscle strength deterioration, through a screen. It was reiterated that a combination approach may be appropriate in certain circumstances for patients who are well, however those in more advanced stages of their condition may need face-to-face appointments.</p>	<p>The NHS White Paper has identified that the pandemic enabled new ways to deliver care, using innovative and creative solutions using digital and data, where appropriate. However, there are certain times this will not always be appropriate, and it is therefore essential to resume face-to-face appointments where necessary.</p>	<p>The Rare Disease Framework acknowledges the benefits of virtual tools to support better care co-ordination. However, there are times when a face-to-face appointment is more appropriate or preferred by the patient. Clinicians need to be able to offer either option depending on the type of appointment.</p>
<p>Secure the confidence of people living with a muscle-wasting condition and make sure that if they are called into a face-to-face appointment, they know that it will be a safe space.</p>	<p>Many people with a muscle-wasting condition, (who have been classed as clinically extremely vulnerable and vulnerable) do not feel confident attending their clinical appointments out of fear of 'catching COVID-19'. With restrictions easing, healthcare providers need to reassure patients that infection prevention measures are in place when attending their clinics and have an open dialogue between healthcare practitioners and their patients on whether they need a face-to-face appointment rather than a virtual one.</p>	<p>The NHS White Paper puts patient choice front and centre of the upcoming reform. It is imperative that patients are aware of their appointment choices but that they are also comfortable accessing healthcare when they need to.</p>	

Priority	Impact on people living with a muscle-wasting condition	NHS reform	Rare Disease Framework
Improve staff support to ensure retention, provide upskilling, and avoid burnout.	High numbers of NHS staff were redeployed to support hospitals with COVID-19 patients. Even though most staff have now returned to their normal work areas, there are rising cases of staff burnout and PTSD within the NHS. We are concerned that the additional pressure of the pandemic may affect specialist neuromuscular staff and make them feel unable to take on this additional workload. Safe staffing is crucial to ensuring the effective function of all NHS services but, for rare disease areas, there are already relatively low numbers of specialist clinicians.	The performance of any healthcare system ultimately depends on its people. In many parts of the UK, the NHS has struggled with a high number of unfilled vacancies across many roles.	The Rare Disease Framework acknowledges that caring for rare conditions requires increased awareness of these conditions and providing staff with the education and resources required.

Key priorities to improve the long-term outcomes for people with a muscle-wasting condition

Equitable access to a specialist neuromuscular MDT (a core team of specialist consultants, physiotherapists, mental health professionals, neuromuscular care advisors) across the UK.	People with muscle-wasting conditions require a variety of care, which includes access to neuromuscular clinicians, specialist nurses, physiotherapists, psychologists, and care support workers. This provision of care is currently disjointed across neuromuscular services, resulting in a postcode lottery of access across the UK.	The NHS White Paper acknowledges that the wider determinants of health are best solved when the NHS and local authorities work together to support an individual's physical, mental, social, and economic needs. Investing in the MDT for neuromuscular services will ensure access to the right care as and when needed. Care will also be provided holistically and adapted to individual need, which has been shown to improve outcomes.	The wide variety of needs for rare conditions was also acknowledged in the Rare Disease Framework, which states that: 'Due to the nature of their condition, many rare disease patients require housing adjustments, social care, financial aid, mental health support and special educational needs support. Caring for rare conditions also requires specially trained staff, including nurses, care-workers and consultants.'
--	--	---	--

Priority	Impact on people living with a muscle-wasting condition	NHS reform	Rare Disease Framework
<p>The establishment of NHS-managed neuromuscular clinical networks across the UK, to help raise standards and benchmark services as well as improve links with and the education of health professionals working in the community.</p>	<p>Managed Clinical Neuromuscular Networks are regional bodies, which recommend and ensure the highest quality clinical and non-clinical support is available for individuals living with a muscle-wasting condition. They do this by bringing together the various specialist health professionals involved in the regional care of people living with muscle-wasting conditions to work collectively between different hospitals and community services to drive forward improvements.</p>	<p>The benefit of such networks cannot be overlooked but they require consistent funding across the regions to ensure each network is equipped with the right clinical representatives and resources to fulfil their purpose. We are asking the NHS to invest in Managed Clinical Neuromuscular Networks to address this inconsistency and ensure they each have sufficient provision. This investment will promote integrated working, ensure patients can access properly resourced healthcare, and address unwarranted variation in neuromuscular services across the UK.</p>	<p>Investment in these networks will help patients access testing and care more quickly to ensure faster diagnosis, address gaps in service provision, and ensure people living with a muscle-wasting condition receive the appropriate healthcare when needed.</p>
<p>The provision of neuromuscular outreach clinics and improved connection with community services.</p>	<p>Many areas across the country do not have easy access to neuromuscular services, resulting in people having to travel long distances for their specialist clinics. Some neuromuscular centres therefore provide outreach clinics in areas where patients are not receiving adequate specialist care. Outreach clinics have shown to be successful in addressing the postcode lottery of neuromuscular care and tackling health inequalities within these regions.</p>	<p>Integrating care enables staff to work outside of organisational silos, delivering more user-centred and personalised approaches to care. It also provides an opportunity to tackle health inequalities and the wider determinants of health. Outreach clinics and connections with community services are crucial for extending the reach of neuromuscular care.</p>	<p>The Rare Disease Framework also references health inequalities, with a particular focus on ensuring steps are taken to ‘meet the needs of people with disabilities where these are different from the needs of other people.’</p>

Priority	Impact on people living with a muscle-wasting condition	NHS reform	Rare Disease Framework
<p>Equitable access to a psychologist or mental health specialist with expertise in working with people with a muscle-wasting condition.</p>	<p>People living with a rare condition tend to have poorer mental health. Shielding has further exacerbated this, and many people with muscle-wasting conditions do not have sufficient access to specialist psychologists who understand the particularities of living with a chronic, degenerative condition, or of parents and young children living with these conditions.</p>	<p>The NHS White Paper references mental health in several instances and acknowledges that poor mental health is on the rise. Each ICS will be required to implement integral services that prevent avoidable hospitalisation and tackle the wider determinants of both mental and physical ill-health.</p>	<p>Many people with rare conditions require wider support, such as mental health support. The Rare Disease Framework sets out objectives to implement this support in wider policy development. This needs to include a recognition that improved mental health support is necessary and that all patients have access to appropriate mental health provision.</p>
<p>Faster access to new treatments and therapies, from NICE assessment to patient roll-out.</p>	<p>Avoidable delays in accessing new treatments are common, causing many people’s muscle-wasting conditions to deteriorate and possibly render them ineligible to receive new treatments before they are approved.</p> <p>Some treatments are far more effective when given before symptoms even appear. This intensifies the need for faster diagnosis as patients are currently waiting months after the first symptoms appear. For some conditions, new-born screening offers a way to mitigate this by diagnosing patients at birth.</p>	<p>Prevention is at the heart of the NHS reform to ensure people live longer and fuller lives. While muscle-wasting conditions themselves cannot be prevented, their impact can be lessened. Securing faster access to treatments is a critical part of achieving this. It will ensure patients stay well for longer, which will consequently minimise lengthy hospital stays, reduce additional treatments and care needed later in life, and reduce longer-term use of NHS resources such as staffing and cost.</p>	<p>The Rare Disease Framework explicitly states that the upcoming action plan will support the development of new affordable treatments and improve the pathway to reaching patients. In 2014, important strides were made with the launch of the Early Access to Medicines Scheme (EAMS). This gives people across the UK early access to new medicines that do not yet have a marketing authorisation when there is a clear unmet clinical need. It is important that such flexibilities are incorporated further to widen access.</p>
<p>Strengthened administrative support for data collection and improved clinic co-ordination.</p>	<p>To capture the full impact of the pandemic and the changing care needs for people with muscle-wasting conditions, it is imperative to continue capturing high-quality data and input it into NorthStar (the UK national neuromuscular database). This will ensure patients receive the right care, capture the impact of treatments throughout their lifespan and observe changes to this ageing patient demographic to support them better.</p>	<p>A particular focus for the upcoming reform is the use of data and technology to improve the effectiveness of services. However, extending clinic time and improving data collection requires additional resourcing and incentives to neuromuscular clinics, particularly administrative staff, to equip them with the tools to undertake this additional work.</p>	<p>The Rare Disease Framework also emphasises that effective data sharing and the ability to share and access patient data and registries easily, will be important for supporting MDTs discussing patient care and researchers who are developing new treatments.</p>

Conclusion

It will be life-changing for a person living with a muscle-wasting condition, for the recommendations and priorities outlined in this report to be implemented. The COVID-19 pandemic has had a detrimental impact on all aspects of their lives. With COVID-19 restrictions easing, it is now time to address the short-term implications while considering the long-term priorities. It is only then that every person living with a muscle-wasting condition will have access to appropriate, high-quality care. With a changing demographic and the upcoming NHS reform, it is important to consider the future of neuromuscular services post-pandemic so that services are more resilient and adaptive to a growing patient population.

In the short term, critical specialist face-to-face appointments need to re-start so that a person with a muscle-wasting condition has faster access to diagnostics and investigations. Receiving an earlier diagnosis will allow people to receive treatment and support more quickly. This is essential as treatments are usually more effective the sooner they are administered, but this also means people with muscle-wasting conditions will feel well and able to do their daily activities for longer. This also reduces the burden of care on the NHS in the long term by reducing preventable admissions, reduces co-morbidities, which require more care, and reduces the burden on an already-stretched system. However, to start tackling this backlog on the waiting list and having patients access services again, people living with muscle-wasting conditions need to feel confident to come into the clinic. As such, clear, reassuring communication is vital to decrease anxiety as restrictions are lifted.

In the long term, people with muscle-wasting conditions are living longer as a result of new treatments and therapies and greater awareness of their complex care needs. To ensure this trajectory continues, it is vital they have access

to new treatments and equal access to a full MDT to provide holistic care. To tackle the variation in neuromuscular services, it's imperative to establish NHS-managed neuromuscular clinical networks across the UK and widen the provision of neuromuscular outreach clinics and improved connection with community services, so that no-one is limited by their condition.

These outlined changes will not only ensure neuromuscular services are better placed to be more adaptive and resilient in the future but, as we have highlighted in this report, will help establish more joined-up care, address the diagnostic process, and implement effective digital tools as outlined in the UK Rare Disease Framework and the upcoming NHS reform. Muscular Dystrophy UK is committed to working with the UK Government, NHS decision-makers and clinical stakeholders to support the implementation of these priorities and, where appropriate, to provide patient insight.

'Ensuring that we have a face-to-face review with those people who have been 'left behind' during lockdown.'

[Clinical feedback on resuming services post-pandemic](#)

'We need a good IT infrastructure and a more robust appointment system as well as investment in our MDT.'

[Clinical feedback on resuming services post-pandemic](#)

'We want to be able to offer face-to-face appointments again and get our patient groups back into the community and active again.'

[Clinical feedback on resuming services post-pandemic](#)

'We need to reopen research and catch up on diagnostic investigations.'

[Clinical feedback on resuming services post-pandemic](#)

'We need access to an orthotics service.'

Clinical feedback on resuming services post-pandemic

'We would like to offer the choice between face-to-face and virtual clinics and provide more online resources for patients.'

Clinical feedback on resuming services post-pandemic

'We need to ensure staff do not burn out and try to make sure the waiting list improves.'

Clinical feedback on resuming services post-pandemic

'We need more consultants and an SMA pathway.'

Clinical feedback on resuming services post-pandemic

'We need to regain patient trust/access to our service.'

Clinical feedback on resuming services post-pandemic

'We need to return to face-to-face appointments and employ and retain a Paediatric Neurologist for the MDT.'

Clinical feedback on resuming services post-pandemic

About Muscular Dystrophy UK and muscle-wasting conditions

Muscular Dystrophy UK is the charity bringing individuals, families, and professionals together to fight muscle-wasting conditions.

Founded in 1959, we have been leading the fight against muscle-wasting conditions since then.

- We bring together more than 60 rare and very rare progressive muscle-weakening and wasting conditions, affecting around 70,000 children and adults in the UK.
- We support high quality research to find effective treatments and cures and will not stop until we have found them for all muscle-wasting conditions.
- We are leading the drive to get faster access to emerging treatment for families in the UK.
- We ensure everyone has the specialist NHS care and support they need – the right help at the right time, wherever they live.
- We provide a range of services and resources to help people live as independently as possible.

Muscle-wasting conditions can cause muscle weakness or wasting. They are multi-system disorders that require complex long-term care. There are currently no known cures and few treatments.

People will require vital multi-disciplinary care from specialist neuromuscular consultants, physiotherapists, nurses, care advisors, psychologists, and other therapists and – where necessary – support from specialist respiratory and cardiac consultants. Without this level of care, people experience a reduction in quality of life and in some cases, shortened life-expectancy.

Get involved

If you or your care has been affected by the COVID-19 pandemic and you would like to share your story with us, then please get in touch with Bobby Ancil on b.ancil@muscular dystrophyuk.org. If you are struggling to access the support you need, our advocacy team is here to help. Please get in touch with them at info@muscular dystrophyuk.org or call **0800 652 6352**.