

Centre of Excellence audit report 2023/4



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Foreword

We're delighted to present the findings of our 2023 neuromuscular Centre of Excellence audit. The fourth audit we've conducted since 2012, it continues to be a cornerstone of our work, underpinning our commitment to recognising and promoting excellent neuromuscular care across the UK as well as identifying and helping to address the challenges services face.

The rich data from the audit allows a unique insight into the current state of neuromuscular services. Insights that help to inform our priorities and strategic direction and enable us to support improvements to healthcare services for our community of over 110,000 people living with a neuromuscular condition.

The Centre of Excellence audit, and associated awards, celebrate NHS neuromuscular centres that excel at providing outstanding care, promoting best practice both locally and nationally, and at demonstrating an unwavering commitment to improving health and care for people living with neuromuscular conditions. This year's audit allowed us to identify lots of examples of excellence, such as the introduction of muscle cafés at centres across the country to support patients, and the publication of important research projects to improve quality of service.

However, while there is much to celebrate, the audit findings also show the challenges facing neuromuscular services, such as inequities in accessing neuromuscular centres and key services in different areas of the UK, and the pressures on access to support provided by community services, such as wheelchair provision. While many of the challenges facing neuromuscular services are seen throughout other NHS services, these remain a concern for our community as we continue to hear from people living with neuromuscular conditions about the difficulties they're facing.

We'd like to thank everyone who contributed to our 2023 audit. Your continued support helps us in working towards better health and social care for our community of people living with a neuromuscular condition and their families.



Wojtek Trzcinski
Interim Chief Executive Officer
Muscular Dystrophy UK



Professor Deirdre Kelly CBE
MDUK Trustee and Chair of Services
Development Committee

About Muscular Dystrophy UK

We connect a community of more than 110,000 people living with one of over 60 neuromuscular conditions, and all the people around them. So everyone can get the healthcare, support and treatments needed to feel good, mentally and physically.

- We share expert advice and support people to live well now.
- We fund groundbreaking research to understand the different conditions better and lead us to new treatments.
- We work with the NHS towards universal access to specialist healthcare.
- Together, we campaign for people's rights, better understanding, accessibility, and access to treatments.



1 in 600 people in the UK live with a muscle wasting condition. We're here for everyone, from the point of diagnosis to living the best life possible."

Executive Summary

We have been undertaking regular clinical audits of the specialist care, neuromuscular clinical trials and research being delivered across the UK for more than a decade. The first nationwide clinical audit was undertaken in 2012, followed by audits in 2015, 2018, and in 2023, after a delay caused by the COVID-19 pandemic.

Since it began, the Centre of Excellence audit has aimed to improve care and support for people living with neuromuscular conditions. Our 2023 audit assessed NHS neuromuscular centres across the UK against 23 evidence-based criterion. The audit was undertaken to

promote best practice locally and nationally, and to acknowledge centres who provide outstanding levels of specialist neuromuscular services. The data gathered is critical to improving quality and outcomes for people living with neuromuscular conditions, providing national benchmarking and giving people living with conditions, and the wider community, the opportunity to provide feedback about services to help bring about positive change.

For the participating centres, two categories of award were available – Centre of Excellence and Centre Pursuing Excellence.

Award	Award criteria
Centre of Excellence status	<p>Awarded to centres that could demonstrate, with evidence, how they fully met most of the audit criteria, including:</p> <ul style="list-style-type: none">• Aspects of clinical practice• Clinical management• Organisational management• Engagement with service users• Engagement with other health services and professional networks
Centre Pursuing Excellence	<p>Awarded to centres that couldn't fully meet all the criteria but could demonstrate a high level of clinical achievement and ongoing commitment to developing their centre.</p>

Some centres qualified to have the addition of 'with research' to their award, when in addition to all aspects of service delivery they could also demonstrate conducting high-quality clinical research, including the running of clinical trials. Centres awarded 'research' status were required to contribute to clinical research into neuromuscular conditions above and beyond the submission of routine data to clinical networks and registries, and were required to take part in competitive research grants and research projects.

In January 2024, 16 NHS neuromuscular centres were awarded a Centre of Excellence with Research status, and a further two NHS neuromuscular centres were awarded a Centre of Excellence status. Three NHS neuromuscular centres were also awarded a Centre Pursuing Excellence with Research status, and another three NHS neuromuscular centres were awarded a Centre Pursuing Excellence status. All were recognised for providing outstanding care, promoting best practice locally and nationally and demonstrating their commitment to improving health and care for people living with neuromuscular conditions.

All NHS neuromuscular centres in the UK were invited to take part and the 2023 audit saw the highest level of participation to date, with 27 centres engaging in the process. This report only comments on the findings of those centres audited.

The clinical audit informed a further understanding of what currently works well amongst NHS neuromuscular services, and areas that require further improvement.

In terms of good practice, the following criteria received the highest percentage of centres fully meeting the criterion:

- **Active contributions to clinical networks provide the opportunity for NHS neuromuscular centres to engage with others, sharing best practice, challenges, and the opportunity for NHS staff to stay up to date with the latest information around neuromuscular care.**

A majority, 89%, of participating centres fully met this criterion, demonstrating their active participation in regional neuromuscular networks, their contribution to the NorthStar networks or SMA Reach UK, as well as professional groups.

- **It is important for NHS neuromuscular centres to ensure patients are supported to access the mobility and assistive technology equipment they need to live as independently as possible.**

A majority, 89%, of centres were able to fully meet this criterion, having provided a narrative and evidence of referral pathways that allow their patients to receive such equipment, but also how they work with charitable organisations to help fund equipment and how they work with other services to provide advice and support to ensure suitable equipment is provided.

- **The accessibility of centres is a highly important aspect of neuromuscular services; people with neuromuscular conditions require facilities that are fully accessible, well maintained, and complete with clinical equipment that can support patient care.**

A big majority, 96%, of participating centres fully met this accessibility criterion.

- **Partnering with Muscular Dystrophy UK.**

This was one of the highest scoring aspects of the audit, with 89% of the participating centres fully meeting this criterion. A commitment to partnering with Muscular Dystrophy UK (and other patient organisations) demonstrates the participating centres' commitment to working with patient organisations to improve neuromuscular care – for instance through involvement in patient information events, professional upskilling events, and fundraising activities. We are committed to working with participating centres that have not yet fully met this criterion.

Some key areas of improvement; these final three criterion received the lowest percentages of centres fully meeting the criteria:

- **People living with neuromuscular conditions receive their care from a range of health care professionals, including allied health professionals.**

While a majority of participating centres, more than 80%, have access to a multidisciplinary neuromuscular team, they also often need to rely on part-time provision or referral through staff outside the core team. Active referral pathways enable patients to access some treatments through local and community services if there is not capacity within the specialist team. However, community-based services are likely to have a lower level of

understanding of rare neuromuscular conditions. As a result, patients can end up waiting longer for less optimal treatment. It's important such variations in care should be addressed promptly, in a properly funded manner.

- **Respite care provision remains a scarcity, despite it being critical to improving quality of life for people with neuromuscular conditions, their carers and families.**

Although 67% of participating centres fully met this criterion through active referrals of patients to respite care, the findings of the audit showed a geographic variation in provision and the barriers faced due to age limits and increasingly strict criteria. The findings also showed limited adult respite care provision.

- **NHS neuromuscular centres do not work in isolation in providing neuromuscular care, they work collaboratively with other organisations within the local health care system.**

It's important they regularly seek feedback from the services they partner with to identify what works well in their communication and collaborative approaches in providing services. Only a minority, 15%, of participating centres fully met this criterion as NHS centres don't always gather formal feedback from local services. We recommend all centres ensure issues are formally identified, and that actions are taken as a response.

- **Another key aspect of improvement is how NHS neuromuscular centres can improve patient experience through the availability and frequency of routine feedback from their patients, their families and carers.**

Just over half, 52%, of participating centres fully met this criterion. Routine feedback is important as it provides patients, their families and carers, with the opportunity to say how centres could improve their service. Less than half, 41%, of participating centres also didn't fully meet the criterion on improving patient experience through running a service user forum, whether in-person or virtually, despite them providing an opportunity for patients, their families and carers, to share their experience and provide peer support. We recommend that all centres ensure they consider running better formal feedback gathering processes, as well as forums,

to improve the overall experience of patients and to ensure their concerns are heard.

- **People living with neuromuscular conditions may require rehabilitation management, including neurorehabilitation, to maintain or enhance their function and mobility. While centres may not provide these onsite, they need to make sure effective referral pathways are in place to ensure patients are seen at suitable facilities.**

The audit found that less than two thirds, 59%, of participating centres fully met this criterion, which made it one of the three criteria with the lowest percentage of scores. Muscular Dystrophy UK recommends that all NHS neuromuscular centres put in place efficient and equitable referral processes, and work with local rehabilitative therapy providers to provide interventions that are timely and well-coordinated, meeting patient needs effectively.

16 NHS neuromuscular centres awarded a Centre of Excellence with Research status

2 NHS neuromuscular centres awarded a Centre of Excellence status

3 NHS neuromuscular centres awarded a Centre Pursuing Excellence with Research status

3 NHS neuromuscular centres awarded a Centre Pursuing Excellence status

Methodology

The design of the Centre of Excellence audit has evolved at each iteration over the past decade, but its overall aim has remained the same – to drive improvement in quality and outcomes in neuromuscular care, and to ensure a more equitable neuromuscular service provision across the country.

The 2023 audit was divided into two processes which ran alongside one another:

- A clinical audit based on submissions from participating NHS neuromuscular centres.
- A survey completed by people living with neuromuscular conditions, their families and carers. Participants were required to select the centres they were providing feedback about, which included centres not participating in the clinical audit. The findings from this survey will be published as a separate report.

The clinical audit assessment

The clinical audit assessed participating centres against four sections, subdivided into 23 criterion. Submissions were assessed by specialist neuromuscular health care professionals who volunteered to support the audit. The submission process ran between February to July 2023, and the audit took place from July to October 2023. The process was overseen by Muscular Dystrophy UK’s Services Development Committee, chaired by Professor Deirdre Kelly CBE, and an independent sub-committee, chaired by retired consultant paediatrician Dr Helen Roper.

The criteria were developed in consultation with senior healthcare professionals in neuromuscular services, service users, their families and carers. They relate to clinical practice, taking into account the evidence and guidance, clinical management, organisational management, engagement with service users, engagement with other health services and professional networks, and support for clinical research. The criteria were selected to ensure every aspect of neuromuscular services is thoroughly audited, ensuring high standards of care are being implemented.

List of criteria

Section 1: Overview of service	<ol style="list-style-type: none">1. Consultant physicians2. Multi-professional Care3. Medical specialists4. Multi-professional team meetings5. Centre facilities6. Continuing professional development7. Patient experience
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List of criteria continued

Section 2: Managing the patient journey	8. Referral process 9. Assessment of neonates 10. Diagnosis 11. Treatment provided 12. Inpatient care facilities 13. Rehabilitation services 14. Provision of mobility and assistive technology equipment 15. Transition from children's and young people's services to adult services 16. Access to respite care 17. Access to palliative care
Section 3: Working with external organisations	18. Supporting local services 19. Feedback from the local health system 20. Partnering with Muscular Dystrophy UK 21. Contribution to clinical networks
Section 4: Research	22. Clinical trials 23. Contribution to clinical research

Audit participants

All NHS neuromuscular centres in the UK were invited to take part in the audit. Not all centres chose to, with some citing a lack of capacity to complete the submission process.

27 centres participated in the clinical audit and were required to submit documentary evidence alongside audit statements on how they met the criteria.

Following the audit, 16 neuromuscular centres were awarded a Centre of Excellence with Research status, and a further two neuromuscular centres were awarded a Centre of Excellence status. Three neuromuscular centres were also awarded a Centre Pursuing Excellence with Research status, and a further three were awarded a Centre Pursuing Excellence status. An appeal stage was built into the process, but this was not used by any of the participating centres.



Audit findings

This summary report outlines the key findings of the 2023 Centre of Excellence audit.

Overview of service

This section of the audit submission provided the auditors with an overview of how the participating NHS neuromuscular centres are providing services, especially in the main areas of specialist workforce provision with specialist expertise in neuromuscular conditions; accessibility of centres; feedback given by patients about the services they receive; and whether patients are able to access peer support forums and groups.

Consultant physicians

This criterion measured the availability and accessibility of consultant physicians for neuromuscular patients. Participating centres needed to demonstrate they provide access to care from consultant physicians with a specialist interest in neuromuscular conditions, with access to consultation being widely available. As part of the evidence requirements, participating centres needed to also provide information on cover arrangements during absences and show that cover is available for more acute problems.

While 22 participating centres received a full score for the availability and accessibility of their consultant physicians, it's concerning that five participating centres didn't have enough staff when considering patient numbers and staff absences. This affects not only existing patients, but also patients in primary care waiting to access specialist assessments. It's important such variations in care are addressed promptly, in a properly funded manner.

Table 1:
Consultant physicians

81%	of participating centres fully met this criterion.
15%	of participating centres partially met this criterion.
4%	of participating centres did not meet this criterion.

Multi-professional care

This criterion established and set out the availability and accessibility of clinicians from various disciplines and backgrounds for neuromuscular patients. Participating centres needed to demonstrate two key aspects:

1. They provide care from a range of health care professionals, with a core team including a specialist neuromuscular physiotherapist, neuromuscular care advisor or clinical nurse specialist, and access to an occupational therapist specialising in neuromuscular conditions.
2. Evidence a referral pathway is in place to access professionals, including clinical psychologists, dieticians, speech and language therapists and orthotists, where they are not part of the centre's multi-professional team.

While 23 participating centres reported access to an on-site multidisciplinary neuromuscular team, it's concerning that at four smaller centres patients in need of routine appointments for care and management may have to wait longer as they require referral to external services, including community services. Due to the progressive nature of neuromuscular conditions a longer wait for treatment can potentially lead to conditions becoming more complex. It's important such variations in care should be addressed promptly, in a properly funded manner.

Although most of the participating centres have access to an on-site core multidisciplinary neuromuscular team, it's concerning that in 41% of the participating centres patients may not be able to access a range of important professionals such as specialist neuromuscular speech and language therapists or specialist neuromuscular occupational therapists. There are also centres who still don't have access to specialist neuromuscular mental health professionals within their multidisciplinary teams.

Only 52% of participating centres were identified as having specialist mental health professionals in their team. Six of these centres, 22%, also only have access to part-time roles (0.2-0.6 WTE), which limits the time neuromuscular patients can access psychological support. And while these centres actively provide a referral pathway for patients to receive such treatment through local and community services, demand on community teams who are likely to have a lower level of understanding of rare neuromuscular conditions can lead to longer patient treatment waiting times. It's important that such variations in care should be addressed promptly, in a properly funded manner.

Medical specialists

Care of people living with neuromuscular conditions can often be complex, requiring different aspects of medical specialties including respiratory medicine and cardiology. This criterion was set so that auditors could assess the type of services provided by participating centres, with the expectation that a Centre of Excellence provides dedicated clinics in respiratory medicine and cardiology, as well as demonstrating a clear pathway and coordination with other specialist input, and is able to detail how this managed and monitored.

Many of the participating centres are able to run dedicated clinics in respiratory medicine and cardiology, and in some larger centres are able to run clinics with other medical specialists. Due to its importance, the availability of joint clinics should continue to be properly funded.

Table 2a:
Core Allied Health Professionals

85%	of participating centres fully met this criterion.
15%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

Table 2b:
Other multi-professional care

81%	of participating centres fully met this criterion.
19%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

Table 3:
Medical specialists

85%	of participating centres fully met this criterion.
11%	of participating centres partially met this criterion.
4%	of participating centres did not meet this criterion.

Multi-professional team meetings

This criterion was set so that auditors could assess the holistic approach taken by centres in discussing patients and in making shared clinical decisions. Participating centres needed to demonstrate they hold regular multi-professional team meetings that facilitate a holistic view in responding to patient needs, attended by relevant team members. This is particularly important due to the complex and multi-system nature of neuromuscular conditions. The auditors reviewed how often meetings are held to ensure they are held regularly; how often the team reviews their patients; as well as how these meetings play a role in enabling a well-coordinated, holistic approach to care.

Centre facilities

This criterion documented the accessibility of participating centres, including how fully accessible a centre's facilities are for disabled people, from the accessibility of clinic rooms, availability of disabled parking spaces, Changing Places toilets, and more.

A vast majority of the participating centres received a full score for ensuring their facilities are fully accessible, with some centres offering an onsite accessible gym, a swimming pool, and in some paediatric centres an accessible play garden.

As part of this criterion, the auditors also investigated the digital infrastructure and information pathways of these neuromuscular centres to demonstrate how they could support referrals and care management, including when care is being given in a different part of the hospital, such as an unplanned admission at an A&E department – it's important for neuromuscular centres to have a good digital infrastructure that can support patient care.

As an example of best practice, one centre who received a full score on this criterion was able to demonstrate their record in advanced IT systems, with an up-to-date electronic patient record that can show a thorough clear history and timeline of events which flags all patients with a neuromuscular condition with a specific code. The centre had also developed a suite of neuromuscular-specific forms to flag gaps in patient care and alert the team when a patient with a neuromuscular condition is admitted to the hospital.

**Table 4:
Multi-professional team meetings**

81%	of participating centres fully met this criterion.
19%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

**Table 5a:
Accessibility**

96%	of participating centres fully met this criterion.
4%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

**Table 5b:
Digital infrastructure**

78%	of participating centres fully met this criterion.
22%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

Continuing professional development

This criterion was set so that auditors could assess whether neuromuscular centres are staffed by clinical teams with specialist expertise in neuromuscular conditions, who regularly receive training to understand the most up to date practice.

Staff at many of the participating centres have been able to access regular training to ensure they can provide good care for neuromuscular patients, through classes, conferences, upskilling training events, and others.

Patient experience

Participating centres were required to provide a narrative and evidence on the routine feedback they request from patients, their families and carers, and how they respond to any issues raised.

Various case studies submitted by centres who regularly gather feedback highlighted the importance of such processes. Where, patients, their families and carers, help to identify areas for improvement such as the introduction of a patient newsletter, issues around disabled car parking, communication between different services, including acute hospital settings. Only half of the centres audited were identified as fully meeting this criteria. All participating centres were informed through their audit decision letter that this is an area of importance that requires a centre's action in running more regular routine feedback.

Centres were also asked to provide evidence that they facilitate a forum for patients, their families and carers, to share their experience and provide peer support, with the expectation that staff members are involved so they can take forward actions from these meetings.

Table 6: Continuing Professional Development

85%	of participating centres fully met this criterion.
15%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

Table 7a: Routine feedback

52%	of participating centres fully met this criterion.
41%	of participating centres partially met this criterion.
7%	of participating centres did not meet this criterion.

Table 7b: Service Users Forum

41%	of participating centres fully met this criterion.
33%	of participating centres partially met this criterion.
26%	of participating centres did not meet this criterion.



Participating centres were required to provide a narrative and evidence on the routine feedback they request from patients, their families and carers, and how they respond to any issues raised.”

Managing the patient journey

This section of the audit assessed key pathways and services that shape the patient journey. This included referral and assessment, support available around diagnosis, and several key services provided at/or referred to by neuromuscular centres.

Referral process

Waiting times can often become a crucial issue within the busy pressured clinical setting of the NHS. This criterion was set so that auditors could investigate if participating centres have an efficient and timely referral process and mechanisms in place to protect against lost referrals, and how waiting lists are monitored and reviewed.

The findings of the audit showed some variations to approximate waiting times for referrals, including urgent, new, and follow-up. For routine referrals, this varies from 6 to 18 weeks wait times on average, depending on the region, with new referrals assessed by consultants and triaged on clinical needs. How these referrals are collated also varies between centres – at some smaller centres they're collated as part of the wider neurology service and not separated out, and for some larger neuromuscular centres they're able to set their own referral pathway – including through hiring a service manager or clinics administrator whose job involves management of referrals and preventing any lost referrals.

Assessment of neonates

This criterion was set so that auditors could investigate whether and how participating paediatric centres provide timely assessment for neonates when a neuromuscular condition is suspected – submitting evidence of an effective referral and diagnostic pathway and the involvement of staff in producing a baseline assessment.

Only centres applying for a Paediatric Centre of Excellence were required to submit evidence for this criterion. 93% of participating centres fully met the criterion, with the remaining partially meeting the criterion.

Getting medical diagnosis in a timely manner is one of the most crucial aspects during this age period. It will deliver the best outcomes from available treatment and reduce future healthcare costs. Centres who fully met the criterion demonstrated their ability to provide timely assessment pathways.

**Table 8:
Referral process**

74%	of participating centres fully met this criterion.
26%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

**Table 9:
Assessment of neonates**

93%	of participating centres fully met this criterion.
7%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

Examples of good practice are one participating centre's multidisciplinary team benefit from a full-time consultant neonatal neurologist who works together with all neuromuscular consultants. At another, the neuromuscular clinical nurse specialists and care advisors are regularly involved in providing direct advice to the neonatal units around neuromuscular care and positioning, with the specialist physiotherapist able to provide direct advice and be regularly involved in discussion meetings. Another centre can allow their paediatric physiotherapists to perform baseline assessments in the acute and multi-site settings with a range of assessments taking place to optimise timely assessment of neonatal referrals and reduce unnecessary transfers. When a patient is born at a local district general hospital, the clinical teams at one centre had also been able to provide outreach clinics to DGHs in their region for an inpatient review.

Diagnosis

This criterion was set so that auditors could assess if participating centres could demonstrate if they're able to provide information and support to patients during diagnosis, as well as after. This includes looking at evidence of how patients are signposted to available internal and external resources such as Muscular Dystrophy UK's advocacy services.

Many participating centres were able to provide a good level of help and support for patients after diagnosis, with centres who have received funded investment in care advisor roles being able to coordinate services and signpost patients to charities and other support. Examples of best practice included allied health professionals attending a post-diagnosis appointment to help set and monitor the functioning baseline of patients.

Treatment provided

Participating centres were required to submit a list of the conditions they cover and the treatments they provide, along with the pathway to accessing treatment elsewhere if it's not provided by the centre. This criterion was set so that the auditors could measure treatments provided by centres and the reasons for gaps, if there are any.

Inpatient care facilities

This criterion relates to both planned and unplanned admission, for instance in assessing respiratory status. A centre of excellence is also expected to have prepared emergency care plans that include team details and can be used during acute presentations and admissions. The audit also investigated the suitability of inpatient facilities, either onsite or offsite.

Not all centres are able to provide neuromuscular inpatient beds. In these circumstances, those receiving a full score on this criterion were able to demonstrate they provide links with their acute medicine services, with the consultant providing outreach to the acute wards on a regular basis to ensure inpatient neuromuscular patients are seen and monitored by specialist teams. Also, that inpatient neuromuscular patients are regularly discussed in the multi-disciplinary team meetings.

**Table 10a:
Support during diagnosis**

77%	of participating centres fully met this criterion.
23%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

**Table 10b:
Support after diagnosis**

74%	of participating centres fully met this criterion.
26%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

**Table 11:
Treatment provided**

81%	of participating centres fully met this criterion.
15%	of participating centres partially met this criterion.
4%	of participating centres did not meet this criterion.

Some good examples provided by a centre of excellence is they have been able to provide neuromuscular inpatient beds for patients with complex neuromuscular conditions when they have difficulty attending multiple hospital appointments due to their condition. The centre is able to provide elective multidisciplinary assessment with various medical specialists as well as allied health professionals, depending on the patient's needs.

Rehabilitation services

People with neuromuscular conditions may require rehabilitation management to prolong or enhance their independent mobility and to slow down any contractures. This criterion was set so that auditors could investigate how participating centres provide access to rehabilitation services, including the referral pathway when rehabilitation is provided through community teams. And, to also assess whether arrangements are clear and in place for support if centres cannot provide rehabilitation support. This includes events such as post-spinal surgery or knee, ankle, and foot orthosis (KAFO) rehabilitation, following loss of ambulation in patients who require spinal corrections or have weaknesses in their proximal and distal muscle groups, to improve function and stability.

Provision of mobility and assistive technology equipment

Participating centres were asked for information and evidence as to how they ensure patients are supported to live as independently as possible through access to mobility equipment and assistive technology. Including how the centres work with community teams and charitable organisations with such provision, as well as evidence of an effective pathway in assessing environmental controls.

Many of the participating centres demonstrated their ongoing commitment to help patients with their mobility needs and assistive technology equipment. In centres with funded care advisor and clinical nurse specialist roles, as well as funded neuromuscular occupational therapist roles, these posts play an important role in improving the referral pathway by liaising with community services as well as Muscular Dystrophy UK and other charitable organisations to help fund certain equipment.

**Table 12:
Inpatient care facilities**

81%	of participating centres fully met this criterion.
19%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

**Table 13:
Rehabilitation services**

59%	of participating centres fully met this criterion.
41%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

Table 14: Provision of mobility and assistive technology equipment

89%	of participating centres fully met this criterion.
7%	of participating centres partially met this criterion.
4%	of participating centres did not meet this criterion.

Transition from children's and young people's services to adult services

Transition is a crucial period for a young patient. This criterion was set so that auditors could review how the participating centres provide access to a joint neuromuscular clinic attended by both adult and paediatric multi-professional teams, seeing how transition processes and decisions are taken and arranged.

As best practice, neuromuscular centres need to conduct transition clinics regularly, as transition is one of the most crucial points as a patient. Most participating centres were able to offer these, with just one centre only able to provide a yearly transition clinic, which the auditors deemed insufficient.

Access to respite care

Centres were asked to provide evidence of referral pathways for patients to access respite care, recognising that these services are geographically patchy. This criterion was set so that auditors could investigate the availability of these services across the UK, and how patients and their families can access such services.

The audit findings were that there is a lack of access to respite care for many neuromuscular patients, with many centres reporting very limited respite care provision available in their region.

Access to palliative care

For patients requiring palliative and end-of-life care, participating centres were asked to set out the referral and access routes within the hospital or to an external hospice service or community health services. Again, recognising these can be geographically patchy. This criterion was set so that auditors could measure whether patients in the region could access a good palliative service should they need to.

Participating centres work closely with a number of service providers and charitable organisations in their region, although some noted that access to palliative care can be limited with referral criteria becoming stricter. In one centre the age criteria have been reduced from 25 to 18 years old for a young person.

As examples of good practice, members of the neuromuscular team at some centres provided evidence that they regularly meet with hospice staff and are actively involved in support groups

Table 15: Transition from children's and young people's services

85%	of participating centres fully met this criterion.
11%	of participating centres partially met this criterion.
4%	of participating centres did not meet this criterion.

Table 16: Access to respite cares

67%	of participating centres fully met this criterion.
22%	of participating centres partially met this criterion.
11%	of participating centres did not meet this criterion.

Table 17: Access to palliative care

78%	of participating centres fully met this criterion.
19%	of participating centres partially met this criterion.
4%	of participating centres did not meet this criterion.

provided by the hospice. At another centre, the clinical lead and care advisors had been actively involved through their role as members of the hospice's research committee. At some centres, a hospice's palliative care specialist was also involved in providing joint neuromuscular clinics for young people with Duchenne muscular dystrophy. At another centre with access to neuropsychologists, coffee morning support groups were also held at their regional hospice.

Working with external organisations

Working with external organisations is vital within the neuromuscular field to share expertise, develop services and contribute to clinical databases. This section of the audit assessed how centres interact with local services and their involvement with Muscular Dystrophy UK and regional or national networks.

Supporting local services

NHS neuromuscular centres are regularly required to refer patients to services provided by the local health care system, such as local occupational therapy services and community wheelchair services. As part of the audit, centres were asked to provide information on how they support local services in providing high-quality care to their patients through shared care arrangements and good working relationships. Also, whether specialist centres are involved in providing training events for staff working at local services.

For centres who received a full score, some of the best practice shown includes their commitment to supporting their local services through regular training to staff at local and community services and ensuring a clear communication pathway so that local services can easily contact neuromuscular centres. One centre who regularly undertakes outreach neuromuscular clinics at various sites has also been able to provide educational sessions for local staff on topics including gene therapy, case presentations, and condition-specific learnings. Some other centres have provided regular one-to-one training sessions for community therapists in respiratory management.

Feedback from the local health system

This criterion was set so that auditors could measure whether participating centres receive useful and robust feedback from local health services. As specialist centres work in partnership with local services, centres were asked to provide evidence that they proactively seek feedback on their service provision and how they collaborate with local services. Whether this is through questionnaires or circulated information asking for feedback, and how these are monitored and issues responded to.

This criterion had the lowest percentage of participating centres fully meeting it – while centres do recognise the potential benefits of seeking formal feedback around various aspects of their services, many do not have a formal process or system in place. It's mostly

**Table 18:
Supporting local services**

78%	of participating centres fully met this criterion.
22%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

**Table 19: Feedback from
the local health system**

15%	of participating centres fully met this criterion.
56%	of participating centres partially met this criterion.
30%	of participating centres did not meet this criterion.

taken on an individual basis or through general correspondence. A good example from a centre meeting the criteria was the process they took to audit GP correspondence letters to ensure clarity of specialist clinic letters, with an introduction of a specific GP action section in their letters. Another centre was previously able to set a formal questionnaire for community teams to gauge the level of support currently provided and to see how centres can improve service in the future, triggering some positive changes in partnering with local services.

It was noted in the audit decision letters to all participating centres that this is an important area that requires action to start running a more systematic and regular process to gain feedback from the local health system.

Partnering with Muscular Dystrophy UK

Muscular Dystrophy UK works in partnership with centres across the UK as part of its mission to improve access to the provision of care. As part of the audit, centres were asked to demonstrate their commitment to partnering with the charity, through things like assisting with upskilling events, contributing to regional neuromuscular networks, but also in partnering with other relevant, condition-specific charities.

Muscular Dystrophy UK is delighted to have strong engagement and partnerships with neuromuscular centres across the UK. This audit has allowed a further understanding of centres yet to have this strong partnership, and Muscular Dystrophy UK is committed to improving engagement with staff at these centres.

Contribution to clinical networks

Clinical networks are important in allowing centres to work together. This criterion was set so auditors could assess the level of contribution neuromuscular centres make to the clinical networks they are a part of. Muscular Dystrophy UK is Secretariat to five regional neuromuscular clinical networks – centres outside of these regions may be part of NHS-run regional clinical networks. Participating centres were asked to demonstrate how they contribute to clinical networks, whether this is through regional neuromuscular networks, regional AHP networks, and professional groups. It was expected that centres have active involvement in the NorthStar Network and those with patients with SMA are actively involved in SMA REACH.

Muscular Dystrophy UK is Secretariat to five regional neuromuscular clinical networks.

Table 20: Partnering with MDUK

89%	of participating centres fully met this criterion.
11%	of participating centres partially met this criterion.
0%	of participating centres did not meet this criterion.

Table 21: Contribution to clinical networks

89%	of participating centres fully met this criterion.
7%	of participating centres partially met this criterion.
4%	of participating centres did not meet this criterion.



Research

This section gave auditors an overview of research contributions and clinical trial capacity across the participating centres.

Clinical Trials

This criterion was set to allow auditors to measure the current availability and accessibility of clinical trials for neuromuscular patients in the UK. Centres were asked to demonstrate their support for patients to join clinical trials, whether onsite or signposted elsewhere, and in patients being provided with information on hubs and registries.

Many centres are actively providing clinical trials or are involved in signposting patients to clinical trials elsewhere, and are referring patients to registries on diagnosis. An example of good practice is that some centres actively try to ensure fairer and more equitable access to clinical trials to develop a central recruitment database nationally coordinated. However, barriers to clinical trials infrastructure still exist. Following the COVID-19 pandemic, several centres have been unable to resume their ability and capacity to carry out onsite clinical trials.

Contribution to clinical research

This criterion was set so auditors could measure the contribution provided by the neuromuscular centres to active clinical research in the neuromuscular field. Centres were asked to demonstrate their ongoing contribution to clinical research, beyond submitting routine data to clinical networks and registries. This may include information on research grants received in the recent years, as well as publications of research papers by staff members. Please note that not all centres were applying for a research excellence. In total, five participating centres were not assessed for this criterion.

Many of the centres receiving a full score were able to expand their research portfolio on receiving funding for a neuromuscular research fellow – such funding has also been received by centres from various charitable organisations and pharmaceutical companies. For larger centres where neuromuscular studies have brought in a large income for the research facility in the region, the income has been positively used to create more substantive posts.

Table 22: Clinical trials	
74%	of participating centres fully met this criterion.
19%	of participating centres partially met this criterion.
7%	of participating centres did not meet this criterion.

Table 23: Contribution to clinical research	
86%	of participating centres fully met this criterion.
9%	of participating centres partially met this criterion.
5%	of participating centres did not meet this criterion.



Centres were asked to demonstrate their support for patients to join clinical trials, whether onsite or signposted elsewhere.

Next steps

The findings of our 2023 Centre of Excellence audit have provided an unparalleled insight into the state of neuromuscular services for participating centres, enabling us to support improvements in healthcare services for our community of over 110,000 people living with a neuromuscular condition.

We remain committed to working with all centres across the UK to drive forward further positive change, including those unable to participate in the clinical audit through a formal process. As part of our commitment to ensure everyone can get the healthcare, support and treatments needed to feel good, mentally and physically, going forward the findings from the clinical audit will be supplemented by additional data collection, and the publication of the summary of the patient experience survey that ran concurrently to the clinical audit. This will culminate in the publication of a supplementary report setting out the current state and future of neuromuscular services with examples of best practice and key challenges to overcome in coming years. These findings will also be presented through a national symposium.

Since the audit findings were announced, representatives from our charity have carried out formal engagement visits to meet with the participating centre clinical teams and NHS Trusts regarding their work and the challenges they face. Along with clinical members from centres unable to participate, through a number of different ways such as regular regional neuromuscular network meetings. Plans are also in place to start regular meetings among neuromuscular care advisors and business managers at various centres.

We will also be working towards another clinical audit in future years, in the hope that more centres, especially those who have yet to participate in the audit, including centres across the devolved nations, will be able to participate.



List of award recipients

Centre of Excellence with Research

- Academic Neuromuscular Disorders Unit, Royal Hallamshire Hospital, Sheffield Teaching Hospitals NHS Foundation Trust
- Atkinson Morley Neuromuscular Centre, St George's University Hospitals NHS Foundation Trust, London
- Birmingham Heartlands Hospital, University Hospitals Birmingham NHS Foundation Trust
- Bristol Royal Hospital for Children, University Hospitals Bristol and Weston NHS Foundation Trust
- Evelina London Children's Hospital, Guy's and St Thomas' NHS Foundation Trust, London
- Greater Manchester Muscle Disease Unit, Northern Care Alliance NHS Foundation Trust, Salford
- Neuromuscular at Oswestry (NEMO), The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust, Oswestry
- Neuromuscular Team, Alder Hey Children's NHS Foundation Trust, Liverpool
- Neuromuscular Team, Sheffield Children's NHS Foundation Trust, Sheffield
- North Bristol NHS Trust, Bristol
- Oxford Muscle Service, Oxford University Hospitals NHS Foundation Trust
- Royal Manchester Children's Hospital, Manchester University Hospitals NHS Foundation Trust
- The Dubowitz Neuromuscular Centre, UCL Great Ormond Street Institute of Child Health, Great Ormond Street Hospital for Children NHS Foundation Trust, London
- The John Walton Muscular Dystrophy Research Centre, The Newcastle upon Tyne Hospitals NHS Foundation Trust
- The Neuromuscular Service at Leeds Children's Hospital, The Leeds Teaching Hospital NHS Trust
- The Queen Square Centre for Neuromuscular Diseases, the National Hospital for Neurology and Neurosurgery, University College London Hospitals NHS Foundation Trust, London

Centre of Excellence

- The Wessex Neurological Centre, University Hospital Southampton NHS Foundation Trust
- Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust

Centre Pursuing Excellence with Research

- Regional Neuromuscular Service – Northern Ireland, Belfast Health and Social Care Trust, Belfast
- Royal Preston Paediatric Neuromuscular Service, Lancashire Teaching Hospitals NHS Foundation Trust, Preston
- The Neuromuscular Team, The Walton Centre NHS Foundation Trust, Liverpool

Centre Pursuing Excellence

- Nottingham Adult Neuromuscular Team, Nottingham University Hospitals NHS Trust
- Addenbrooke's Paediatric Neuromuscular Service, Cambridge University Hospitals NHS Foundation Trust
- University Hospitals Plymouth NHS Trust, Plymouth

List of audit contributors

The successful running of the 2023 Centre of Excellence Awards were the results of the contribution from the following individuals and organisations:

Muscular Dystrophy UK's 2023 Sub-Committee on the Centre of Excellence Awards

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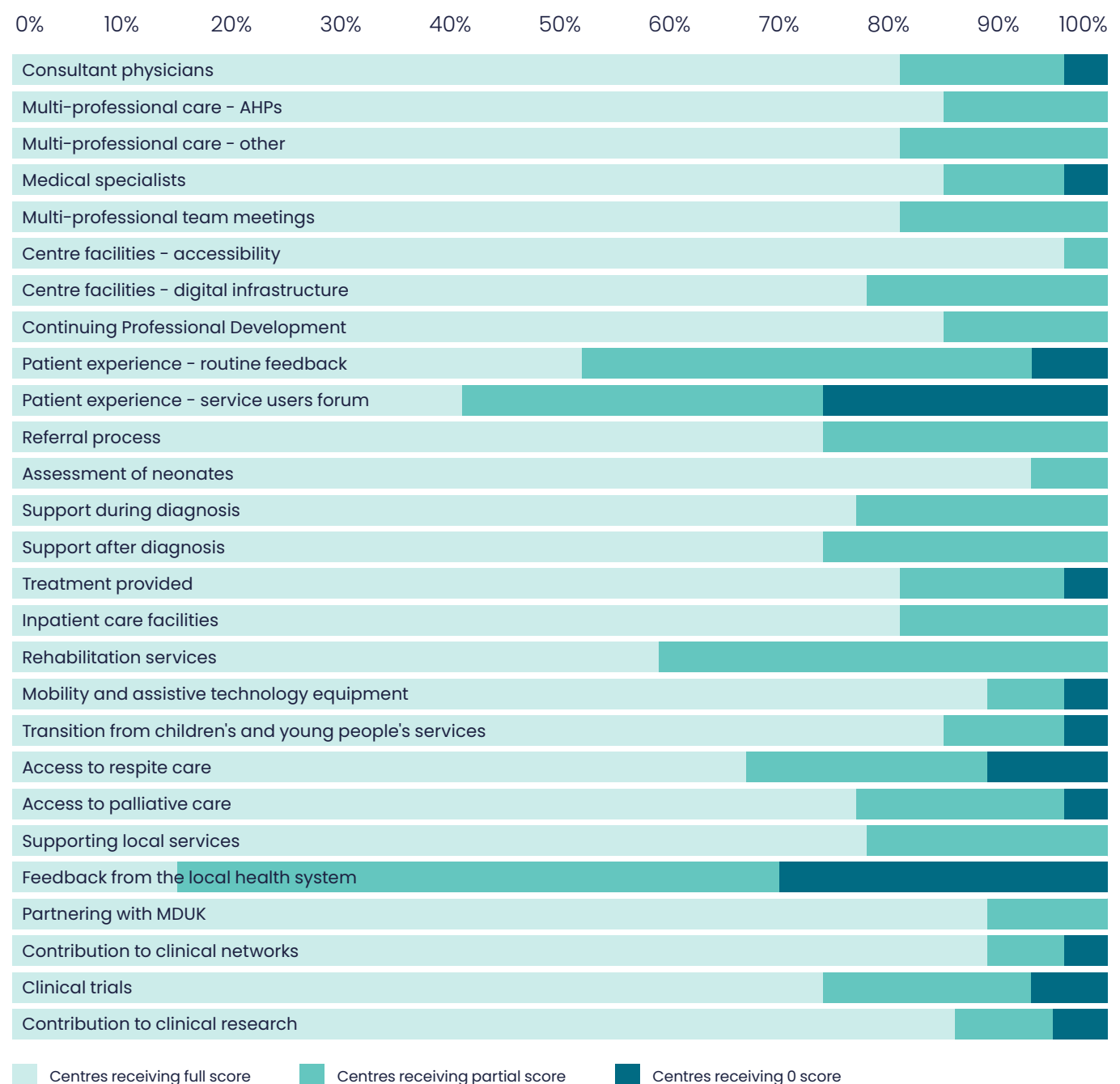
Crisp Quality Improvement Consultancy Ltd

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Appendix: Overview of criteria met

2023 Audit Results Overview



Please note that some criteria may not apply to all of the participating centres. Criterion 9 on neonates only applied to 15 paediatric centres, and five participating centres were not assessed for Criterion 23 on research.