



# The role of the multi-disciplinary team in improving access to high-quality care and clinical research

## Introduction

In 2015, Muscular Dystrophy UK undertook two separate audits on the clinical trial capacity and specialist care delivered in the UK.

We conducted an audit on clinical trials capacity in response to alarming reports from neuromuscular centres that they were being forced to turn down new trials owing to a lack of capacity. We carried out a second audit to assess – and recognise – specialist centres that provide outstanding clinical care for people with muscle-wasting conditions.

The two audits have enabled us to develop a comprehensive overview and national picture of clinical care provision and research capacity at centres UK-wide. In addition, and perhaps more importantly, these audits have helped us identify the key challenges centres are facing in being able to provide the best possible service, at both a clinical and research level.

## The 28 neuromuscular centres who took part in the audit identified these key issues and gaps in the delivery of specialist care:

- ▶ over half urgently need specialist neuromuscular roles to meet current demand
- ▶ access to specialist psychology provision is a major concern for one in four
- ▶ increased or improved neuromuscular physiotherapy provision is a priority for over 40 percent
- ▶ with a 12 percent increase in the number of new referrals to the neuromuscular centres between 2012 and 2015, the number of health professionals supporting these patients has not increased at a similar rate
- ▶ one in three is concerned about the long-term funding of clinical roles
- ▶ a continued increase in the number of patients attending muscle centres is becoming a significant challenge to almost one in three
- ▶ the need for increased care advisor support is an issue for one third
- ▶ twenty percent say they have issues with adequate service administration owing to a lack of personnel capacity and the need for improved IT digital infrastructure, which affects the quality of the databases, problems with the booking of appointments, and follow-up of patients.

## **On the delivery of neuromuscular clinical trials, the audits found the key issues and barriers to be:**

- ▶ a lack of resources and capacity, rather than bad science, means 75 percent of muscle centres are turning down clinical trials
- ▶ significant uncertainty on long-term funding for key roles relevant to clinical care and research, including specialist nurses and physiotherapists
- ▶ work on clinical trials is not counting towards specialist training at 70 percent of centres
- ▶ there is almost no funded time for the key roles (physiotherapists and specialist nurses) needed to support clinical trial participation
- ▶ some centres are at risk of not being able to participate fully in key clinical trials for Duchenne muscular dystrophy owing to a lack of access to biopsies.

The audit findings combined point to the central role played by a comprehensive multi-disciplinary team, in both promoting excellent standards of care and providing some of the staffing capacity and expertise to take part in and conduct research.

Clinical care and research should not be seen as mutually exclusive. Instead, excellent clinical care – with a fully-staffed multi-disciplinary team at the centre – has wide reaching benefits, keeping patients in the best possible health. This, in turn, increases the likelihood of their meeting clinical trial entry criteria. And a multi-disciplinary team capable of recruiting and monitoring patients on trials, in turn, contributes to a centre's ability to attract studies for the benefit of their patients.

It is therefore essential for the National Institute for Health Research, NHS commissioning bodies, neuromuscular centres and patient organisations such as Muscular Dystrophy UK, to work collectively to ensure everyone with a muscle-wasting condition has access to a full multi-disciplinary team. The importance of the role of this team also needs to be formally recognised and protected.

Unfortunately, our audits also found that many leading regional centres struggled to secure or maintain a full and effective multi-disciplinary team. This means that many centres do not have the capacity to take part in clinical trials for muscle-wasting conditions.

## Key findings and challenges facing neuromuscular services in the delivery of specialist care and clinical trials

- a) **Gaps in multi-disciplinary teams – the need for new roles within the multi-disciplinary team was highlighted as a priority by more than half of the services we audited**

*“Although our staffing levels may look impressive, the actual number of NHS-funded staff in our service is rather limited. Additional admin, physiotherapy support and doctors in training rotating in our service would help in improving our service.”* Clinician from a Specialist Neuromuscular Centre.

The strength behind a multi-disciplinary team is that all of the relevant people involved in the treatment of someone with a muscle-wasting condition are able to work collectively. The NHS England adult neurology service specification, which is the standard contract for neurosciences and specialised neurology, states that, “specialised neuromuscular services will be provided to neuromuscular disorders patients of all ages and via a managed clinical pathway that supports multi-disciplinary and cross organisational working”.

The service specification also clearly states that:

*“proactive care management can make a real difference to patients...and can produce better health outcomes, slow disease progression, reduce disability, ensure better management of sudden deteriorations...and result in improved quality of life”.*

Muscular Dystrophy UK is therefore concerned to see that many neuromuscular centres are being undermined by difficulties to provide multi-disciplinary, cross organisational and proactive care management.

Many muscle centres are struggling to fill every role within a neuromuscular multi-disciplinary team. In addition, many centres with fully-staffed multi-disciplinary teams, including some centres of excellence, have found their current team stretched to beyond capacity. This means patients have to endure long waiting times before getting the required treatment.

The need for new roles to support patients with muscle-wasting conditions was the biggest issue in both the 2012 and 2015 audits. Of the 16 centres who answered this question in 2012, 44 percent mentioned the need for more staff including consultants, physiotherapists, care advisors and occupational therapists. In 2015, this need was mentioned by more than half of the centres, who also highlighted the need for clinical nurse specialists and research fellows.

### Clinical trials

As well as not being able to deliver a full package of specialist care for people with muscle-wasting conditions, the clinical trials audit confirmed that many neuromuscular centres were turning down clinical trials owing to a lack of resources. Indeed, between three leading muscle centres, a total of 14 clinical trials had been turned down in the past five years owing to pressures on the capacity of the clinical team.

Perhaps the most frustrating trend in our findings was the number of teams at centres that had clinical trial facilities but could not use them to their full potential, if at all. This is because of pressures on neuromuscular staff and a lack of dedicated roles – such as clinical trial co-ordinators or research fellows.

A number of centres participating in clinical trials reported staff had to do associated work in their own time, owing to a lack of acknowledgement of research activity in job roles. Three major centres reported a lack of clinical staff time and the need to work out of hours, which placed additional strain on already overstretched teams. This also hampered the centres' ability to recruit more patients or to participate in more trials.

Finally, it is clear that trying to secure new roles is a time-consuming process. While the healthcare professionals involved spend time making the necessary submissions for these roles, patients are left with not only less time with the people providing their care, but they also have to wait for that new role to be agreed. Muscular Dystrophy UK was disappointed to see that a handful of centres were reporting in both audits the same need for new roles. They also reported having spent many years arguing their cases with the relevant commissioners.

In light of this, Muscular Dystrophy UK calls on regional NHS bodies and neuromuscular centres to work with us to set national benchmarking guidelines for all professionals within a multi-disciplinary team. There need to be recommendations made on the maximum number of patients a neuromuscular healthcare professional should be expected to see, with support given to teams clearly in need of additional roles.

**b) Physiotherapy – the need for increased or improved neuromuscular physiotherapy provision was highlighted as a priority by 43 percent of neuromuscular services. It is a major barrier to involvement in clinical trials**

**“We really need the services of a peripatetic neuromuscular specialist physiotherapist to visit patients at home, and also a respiratory specialist physiotherapist to visit our patients who need respiratory support.” Clinician from a Specialist Neuromuscular Centre.**

The provision of neuromuscular physiotherapy for people with muscle-wasting conditions varies significantly between adults and paediatric services. Both our 2012 and 2015 audits showed that specialist neuromuscular physio support was more likely to be available to children than adults. In general, physiotherapy for children is provided on the basis that it is needed to support them in their growth. Adult physiotherapy, on the other hand, is focused on securing specific results or outcomes. The provision of physio for maintenance purposes, or to keep an individual ambulant and out of a wheelchair for as long as possible, is not routinely provided or commissioned.

Neuromuscular physiotherapists, for both adults and children, play an important role not only in the management of their patients' condition, but also in the process of commissioning wheelchairs, the provision of cough assist machines and submission to national research databases such as NorthStar.

While NHS England's neurology service specification indicates that a neuromuscular physiotherapist is a required part of a multi-disciplinary team, it does not state the type of physiotherapy which a patient can expect. It also does not state the importance of physiotherapy in the maintenance of robust and comprehensive patient data on neuromuscular conditions.

We know that the provision of neuromuscular physiotherapy, even within a multi-disciplinary team, is often only for very short periods of time or as part of regular check-ups. In addition, when the importance of specialist physiotherapy is not formally recognised, it means that commissioning this service is particularly difficult. This is despite the benefits being known both to patients and to those within a multi-disciplinary team.

Six neuromuscular centres also highlighted the need to recruit an additional physiotherapist, given that many clinical trials relied on physiotherapy input. For some of the major national centres, where a number of clinical trials were already being conducted, this was seen as crucial to maintaining or increasing capacity.

For some of the services where clinical trial participation was more limited, a physiotherapist would help develop the centres' capacity for studies requiring extensive physiotherapy input.

Despite this, it is also clear from our audits that the situation is improving. In 2015, there were 60 neuromuscular specialist physios working across the 28 centres that completed the audit. By comparison, only 25 physios were listed in the 2012 audit of 17 centres. In other words, in 2012 there were an average of 1.45 physiotherapists at every centre, and in 2015 there were 2.13 per centre.

Muscular Dystrophy UK is concerned that commissioners and NHS Trusts under-estimate the importance of physiotherapy provision for neuromuscular patients, particularly adults. It is clear that there must be increased investment in these vital roles.

**c) Long-term funding – concerns around the long-term funding of clinical roles was raised as an issue by one third of neuromuscular services**

**“The service is heavily reliant on research fellows, who are short-term funded.”**

**“Recurrent funding is needed for our Care Advisor, from July 2016.”**

**“New neuromuscular physiotherapy post is funded for one year, initially.”  
Clinicians from a Specialist Neuromuscular Centre.**

Ongoing funding restrictions in the NHS have had a knock-on effect on almost all parts of healthcare provision in the UK. As NHS Trusts and commissioners are encouraged to make as many savings as possible without cutting frontline services, it is understandable that they will be cautious about agreeing to new, long-term investment in new staffing roles.

Unfortunately, despite getting clear cases for the need for these roles, many trusts and commissioners decide to provide funding for a temporary period only. They also require the post-holder, in reporting on their progress, to justify the work they have done in order to continue in post.

In 2012, none of the centres we audited had concerns about a current role which needed its funding secured. In 2015, one third of neuromuscular services had concerns about the continued funding for some posts.

This type of short-term funding makes long-term planning and service development significantly difficult. If short-term posts are terminated, neuromuscular centres find it difficult to apply for funding for other resources, such as equipment, because of the uncertainty about their team and the possibility of other investments becoming unviable.

Muscular Dystrophy UK believes it is unfair to patients who have muscle-wasting conditions to provide a necessarily long-term service for a limited period of time. If these frontline posts are removed without suitable replacements being found, patients relying on these members of staff are at risk of slipping through the gaps in services.

**d) Specialist psychology – improving access to specialist psychology is a major concern for one in four services**

**“At the moment we have no funding for psychology input for these patients, which we have been trying to obtain for the past 10 years.”** Clinician from a Specialist Neuromuscular Centre.

The effect of being diagnosed with a long-term, progressive and degenerative genetic condition is profound. Muscular Dystrophy UK receives hundreds of emails and phone calls every year from individuals and family members struggling to come to terms with a recent diagnosis. In addition, as one's condition progresses, there are certain key, transition stages which can be particularly traumatic and difficult to deal with. For example, moving from children's to adult's services, being required to use a wheelchair for the first time, or beginning to use invasive or obtrusive machines. What is clear is that neuromuscular centres clearly recognise the importance of psychology. Out of the 17 centres who submitted to our 2012 Centres of Excellence audit, only one stated lack of psychological support as one of their main concerns in the development of the service. In 2015, one in every five neuromuscular centres identified expert psychological support as a major gap in their service. Furthermore, more centres in the 2015 audit mentioned plans to have dedicated neuromuscular psychology provision.

In general, our audit showed that the levels of psychological support provided was varied. Many centres said the provision they did have was either stretched or at full capacity. In 2015, nine muscle centres had a neuromuscular psychologist on their staff. This was an increase from 2012 when only three muscle centres had a psychologist as part of their multi-disciplinary team.

**e) Care advisors – the need for increased care advisor support was an issue for one third of neuromuscular services**

**“Our care advisor support is inadequate, with a single practitioner in this area, who has recently gone part-time. So we now have a part-time care advisor being left to deal with all requests and causing delays in the service provided.”** Clinician from a Specialist Neuromuscular Centre.

Neuromuscular conditions are rare and complex conditions, which require specialist support from a range of clinical teams for effective care management. There will often be a need, therefore, for significant support for patients from other departments such as respiratory and cardiology. Identifying the correct care pathway and signposting patients and their families to that pathway is a unique challenge, which specialist neuromuscular care advisors play a vital role in overcoming.

The support of neuromuscular care advisors also has a major impact on the health and wellbeing of people with muscle-wasting conditions, as well as their families. Care advisors provide the vital support, help and advice that patients need to stay as healthy as possible. Indeed, NHS England's neurology service specification identifies access to

the support of a neuromuscular care advisor as being an essential part of the services to be provided by the multi-disciplinary team.

Our 2012 audit showed that the participating centres had 16 care advisors and 10 specialist nurses/clinical nurse specialists in post. In 2015, the audit showed that the participating centres now have 30 care advisors, and 14 specialist nurses/clinical nurse specialists in post.

While it is encouraging to see more care advisors and neuromuscular specialist nurses supporting people living with muscle-wasting conditions, one in three neuromuscular centres identified the need for either new or increased care advisor support, or long-term funding for these vital roles.

Muscular Dystrophy UK believes the role of a care advisor is important. It is worrying to hear from some centres that their care advisors are so over-stretched, they end up taking time off work owing to stress. This is unacceptable. To this end, Muscular Dystrophy UK is calling for care advisors to be given the necessary support and recognition needed. We are calling for the posts of care advisor and clinical nurse specialist, who provide similar holistic support, to be seen as essential parts of a multi-disciplinary team in all formalised guidance.

**e) Administrative issues – difficulties with administrative matters, including a lack of staff capacity and the need for improved digital infrastructure, are faced by almost 20 percent of neuromuscular services**

**“We have little administrative support so have not been able to develop some of the infrastructure, website, up-to-date databases, etc, that we would like to support our service.” Clinician from a Specialist Neuromuscular Centre.**

A worrying trend from our service provision audits is a lack of administrative support in neuromuscular centres. Muscular Dystrophy UK recognises that in the current economic climate, administrative support might be the first cuts made to overall budgets. However, our audits have shown that this short-sighted approach to cost-savings can cost more in the long run. Higher paid clinicians and other allied health professionals are spending their time doing this work instead; taking their time away from patients.

A lack of appropriate administrative support can lead to problems such as:

- ▶ problems with booking regular appointments, which means clinicians may be less likely to spot degeneration in patients' conditions quickly
- ▶ not being able to follow up with more vulnerable patients who have missed appointments
- ▶ not being able to share patient data with other members of a multi-disciplinary team, which means patients may have to repeat themselves or try to remember what other clinicians have told them
- ▶ unnecessary duplication of assessments or work, which wastes time for the clinician/healthcare professionals.

In 2012, only one service listed administrative support as an issue. By 2015, this was mentioned by five centres as a significant challenge to their service.



Muscular Dystrophy UK proposes that when any administrative role is removed, a full impact analysis be conducted, with all tasks specifically re-assigned to a new member of staff.

Muscular Dystrophy UK also proposes that trusts and commissioners recognise the importance of investing in future-proof data infrastructure. The nature of neuromuscular conditions, and the way which the NHS proposes centres should be managing long-term conditions, mean that the sharing of patient data among different teams is important. Not only does data need to be shared within teams at one centre (in particular cardiology and respiratory), but also among external NHS Trust and centres working as part of networks and community outreach, as well as for the benefit of research applications and submissions. Patient data must be kept safe, secure and, when necessary, sharable.

## Clinical trials

A number of neuromuscular centres identified lack of administrative and database support as a key barrier to expanding capacity. One centre mentioned that the breadth of clinical trials supported meant administrative load was very high, but there was no specific funding for this. Other centres highlighted the impact inadequate database and administrative support had on levels of recruitment for some trials. Although both the consultant and physiotherapist were working in their own time, recruitment for the clinical trials couldn't expand without data input capacity.

With more trials coming through for muscle-wasting conditions, there is likely to be an increased competition for patients. Unless centres are supported to enrol their patients on to trials, there is a risk that recruitment potential in some parts of the country will remain untapped.

This is also a lost opportunity for patients and their families. Many see clinical trial participation as a route to accessing a potential effective therapy at an earlier stage of the process.

### **f) Outpatient capacity – a continued increase in the demand and the number of patients is resulting in issues with general outpatient capacity at almost a third of neuromuscular services**

**“The service is heavily reliant on research fellows who are short-term funded. There is also a shortage of space and time to conduct physiotherapy assessments in outpatients. The explosion of experimental therapies is placing an unprecedented pressure on the service.”** Clinician from a Specialist Neuromuscular Centre.

A significant concern for many neuromuscular services has been a general increase in the number of outpatients they care for. This is not surprising, as the population of the UK increases, and as advances in treatments, research and access to therapies means that those with muscle-wasting conditions now have longer life-expectancies than ever before.

Between 2012 and 2015, there was an increase of 12 percent in the number of new referrals into neuromuscular services. This, along with the increasing life-expectancy of people with muscle-wasting conditions, will continue to put pressure on the capacity of neuromuscular services.

## Waiting times

Waiting times for consultations for urgent new cases across the centres in both 2012 and 2015 were found, on average, to be between one and two weeks. However, waiting times for urgent existing cases in 2012 was around two weeks. This improved in 2015 to less than a week, or 'as soon as possible'.

While this slight improvement in the urgent waiting times is to be welcomed, it would appear this has come at the cost of the more routine cases. In 2012, routine new cases were generally seen between four and eight weeks, with this margin decreasing in 2015 when patients are seen, on average, between six and eight weeks.

In general, routine follow-ups had a significantly longer waiting time than new cases, although exact times were often not disclosed by the centres. As general outpatient capacity increases, we are concerned that these waiting times may be affected. Seeing patients quickly, especially when the case is urgent and when those in other departments are unlikely to be able to help sufficiently, is an essential part of a quality service.

Muscular Dystrophy UK proposes that, in order to improve access to general outpatient capacity, NHS England should provide formal guidelines on both the ideal and the maximum number of patients each member of a multi-disciplinary team should be responsible for. These figures are essential evidence for centres across the country to can apply for further support if or when their patient population grows. Patients are given permission to choose which hospital they receive their treatment at, and as such, centres should be able to request additional support if their outpatient capacity changes.

### **g) Patient recruitment for clinical trials**

The key concerns and envisaged difficulties on patient recruitment for clinical trials focused on:

- ▶ an increased number of studies often competing for the same patient population
- ▶ a lack of time and administrative support to recruit patients, even at those centres with a number of patients actively being followed up
- ▶ A concern that trials were concentrated in too few locations, and families were not prepared or able to travel regularly from further afield.

A number of centres highlighted the often onerous demands that intensive Phase 1 clinical trials placed on participants, and their families. Some clinicians questioned whether those involved in the design of trials had sufficient clinical experience. There were concerns that it could be difficult for children to comply with the samples required in early phase trials. Those designing trials should consider the impact this could have on a centre's ability to deliver results and on the pharmaceutical company's evidence base. When participants have significant learning and/or behavioural difficulties, this is even more difficult.

# Recommendations

## Muscular Dystrophy UK calls on:

- ▶ regional NHS bodies and neuromuscular centres to work together with Muscular Dystrophy UK to set national benchmarking guidelines for specialist consultants, physiotherapists, care advisors and other allied health professionals that make up a multi-disciplinary team
- ▶ NHS commissioners and Trusts to avoid funding short-term posts, which create a lack of security for both the post-holder and the people living with long-term conditions
- ▶ neuromuscular care advisors and clinical nurse specialists to be recognised as essential roles within a multi-disciplinary team, with all services and patients having access to these vital posts
- ▶ neuromuscular teams to have access to first-rate administrative support, which ensures patients care is well co-ordinated
- ▶ NHS commissioners and Trusts to recognise that expert and dedicated clinical psychology is a highly valued part of the holistic care required by people with muscle-wasting conditions, and all centres should have access to this support
- ▶ the NIHR, muscle centres and patient groups to work together to ensure sustainable funding for key roles to support clinical trials infrastructure
- ▶ senior trainee clinicians involved in clinical trials to see this activity count towards their clinical training, which would remove the current disincentive
- ▶ Trusts to acknowledge research time in job planning for clinical staff
- ▶ NHS commissioners and Trusts to recognise the value of investing in specialist neuromuscular services to help reduce unplanned emergency admissions, and save the NHS money
- ▶ pharmaceutical firms to consider clinical trial design in relation to the limited extent to which young children, often with learning difficulties, can be expected to comply with at times onerous and intensive requirements, especially during an intensive Phase 1 trial.

**The following neuromuscular services took part in the 2012 and 2015 audits of Centres of Excellence:**

Alder Hey Children's Hospital NHS Foundation Trust  
Barts Neuromuscular Centre Royal London Hospital  
Belfast City Hospital  
Cambridge University Hospitals NHS Foundation Trust  
Dubowitz Neuromuscular Centre, UCL Institute of Child Health/Great Ormond Street Hospital for Children NHS Trust, London  
Evelina Children's Hospital, Guy's and St Thomas NHS Foundation Trust  
Heart of England NHS Foundation Trust  
John Walton Muscular Dystrophy Research Centre  
King's College Hospital NHS Foundation Trust, London  
Lancashire Teaching Hospitals NHS Foundation Trust  
Leeds Teaching Hospitals NHS Trust  
Morrison Hospital, Swansea  
National Hospital for Neurology and Neurosurgery, London  
Nottingham University NHS Trust  
Oxford University Hospitals NHS Foundation Trust  
Plymouth Hospitals NHS Trust  
Robert Jones and Agnes Hunt Orthopaedic NHS Trust  
Royal Manchester Children's Hospital NHS Foundation Trust  
Ryegate Centre, Sheffield Children's NHS Foundation Trust  
Sheffield Teaching Hospitals NHS Foundation Trust  
South West Neuromuscular Operational Delivery Network  
Suffolk Community Healthcare  
The Walton Centre NHS Foundation Trust  
University Hospital of Wales  
University Hospital of Wales (paediatrics)  
University of Birmingham NHS Foundation Trust  
University of Nottingham and Derby Hospitals' NHS Foundation Trust  
Wessex Neurological Centre, University of Southampton NHS Foundation Trust