



The new integrated care model and muscle-wasting conditions: How Integrated Care Systems can implement best-practice

September 2022

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Communications on behalf of
Muscular Dystrophy UK



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



Table of contents

Foreword from Baroness Thomas of Winchester	3
Introduction	4
What does this mean for the management of muscle-wasting conditions?	5
How the commissioning of specialised services for muscle-wasting conditions by ICSs can optimise care	7
About Muscular Dystrophy UK and muscle-wasting conditions	11
Appendix – Commissioning of muscle-wasting conditions under ICSs	12
References	14

Foreword from Baroness Thomas of Winchester

There are now around 110,000 people living with some kind of muscle-wasting condition in the UK. They all cause muscle weakness, but the areas affected and the severity of the symptoms varies tremendously depending on the condition. These are multi-system disorders and so those of us living with a muscle-wasting condition require access to a wide range of healthcare services, including specialist tertiary services to see neuromuscular specialists; community services to access physiotherapists, speech and language specialists and GPs; and social services for housing and employment support..

It has often been difficult in the past for people with a muscle-wasting condition to access all of the services they need due to variability across the country. This was partly because some neuromuscular services were commissioned through NHS England and delivered through NHS England neuroscience centres, whereas others were 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, inconsistency in access does mean many patients are left behind.

I am hopeful that with the newly established Integrated Care Systems (ICSs), there is now potential to address these gaps in services with a more place-based focus on commissioning. For people like me living with a muscle-wasting condition, it is essential that ICSs improve access to the services and care that we so desperately need to live as well as possible.

Baroness Thomas of Winchester

Honorary Life President of Muscular Dystrophy UK

Introduction

In July 2022, Integrated Care Systems (ICSs) were formalised as statutory bodies in the health and social care system across England. The potential benefits that greater integration of care will bring to health and social care are significant and reform may bring positive progress in the management of muscle-wasting conditions.

Given the complexity of muscle-wasting conditions, Muscular Dystrophy UK has produced this report to outline what these changes will mean for people with muscle-wasting conditions and to ensure that healthcare professionals and commissioners are supported to provide best-practice care for people living with muscle-wasting conditions.

This report has been produced for ICS commissioners, Integrated Care Board (ICB) members, primary care networks, and NHS England (NHSE) to support them in the restructured NHS. This can be read alongside the following resources aimed at supporting health professionals and commissioners:

- [Our e-learning modulesⁱ](#)
- [Our condition-specific factsheetsⁱⁱ](#)
- [Our condition-specific alert cardsⁱⁱⁱ](#)
- [Our map of NHS specialist services^{iv}](#)

This report was developed following two workshops with seven multi-disciplinary clinicians on what the new integrated care model might mean for muscle-wasting conditions. We are grateful to these clinicians for their time and valuable insights. Also contributing to these insights was a dedicated roundtable discussion session of the All-Party Parliamentary Group (APPG) on Muscular Dystrophy meeting on this topic held in May 2022 and attended by over 36 health professionals and patients.

This report sets out a number of recommendations to ensure that outcomes for people with muscle-wasting conditions are optimised as part of the new reforms. Together, we can ensure progress in condition management and quality of life for people living with muscle-wasting conditions.

What is changing in England and when in the commissioning of services?

The Health and Care Act 2022 was created to facilitate greater integration across the health and social care system, with a focus on population health, prevention, public health and reducing health disparities.^v To support this focus on integrated care, the Act formally established 42 ICSs from 1 July 2022.^{vi, vii}

ICSs are made up of two parts: Integrated Care Boards (ICBs), and Integrated Care Partnerships (ICPs).^{viii}

- [ICBs will have commissioning responsibility for local and some specialist NHS services. They will have their own leadership team, including members from NHS trusts, local authorities, and general practice.^{ix}](#)
- [ICPs are a joint committee of the ICB and the upper tier local authorities and bring together the wider group of organisations involved in an ICS, such as charities.^{ix}](#)

ICBs will now have commissioning responsibility for some specialised services that were previously commissioned by NHSE. Following a review, a large proportion of specialised services were confirmed by NHSE in May 2022 as suitable and ready for greater ICS leadership. As such, from April 2023, ICBs will take on commissioning responsibility, subject to service suitability and readiness as deemed following an assessment. The criteria used to determine service suitability included having co-dependent services, financial risk, number of providers, and patient and clinical benefit.^x The criteria used to determine service readiness included future horizon scanning, suitability of the provider landscape, and adequate supporting commissioning infrastructure.^x NHSE will continue to commission highly specialised services and other services that were deemed unsuitable or not yet ready for greater ICS leadership.^x

Clinical Reference Groups (CRGs) and national programmes of care will continue to provide clinical leadership to support the development of national standards.^x Furthermore, all specialised services will continue to follow national service specifications and evidence-based clinical policies that NHSE will develop, based on the advice of clinical leaders and CRGs.^x However, NHSE will revise their methodology in the development of specifications to give ICBs more freedom and flexibility to determine how services are delivered.^x

What does this mean for the management of muscle-wasting conditions?

Many muscle-wasting conditions currently fall under Adult Neurology Specialised Services and Paediatric Neurology Specialised Services. Both services were confirmed by NHSE as suitable and ready for greater ICS leadership.^x Some muscle-wasting conditions, such as adult McArdle's disease or paediatric Spinal Muscular Atrophy (SMA), fall into the highly specialised services category and will remain commissioned by NHSE. A full breakdown of how each service has been categorised can be [found here](#).^x

These commissioning changes provide an opportunity to elevate the standards of care for people living with muscle-wasting conditions. Some aspects of disease management will need to be carefully considered or have the possibility of being enhanced; we have illustrated two examples of this.

Paediatric Duchenne muscular dystrophy

- **People with complex conditions need to be able to access all of their healthcare professionals in one place. This needs to be in a tertiary centre, where multi-disciplinary healthcare professionals with expertise and understanding of a patient's care plan can work in tandem with a Neuromuscular Consultant and Care Advisor. Access to respiratory and cardiac specialists in a tertiary centre is especially important for the management of Duchenne. We are concerned that the quality of care will be impacted if this integration of services isn't done in cooperation with tertiary services. Muscular Dystrophy UK is strongly of the view that greater collaboration and communication is needed between tertiary centres and primary and community care so that they better understand patient need.**

Adult-onset muscle-wasting conditions

- Many adult-onset muscle-wasting conditions, such as Inclusion Body Myositis and Charcot-Marie-Tooth Disease fall into the broader specialised service 'Neurosciences Specialised Neurology (Adult)'. It is important that in the commissioning changes, focus and particular attention is paid directly to muscle-wasting conditions, rather than just under a more general neurology banner, given their complexity and the specific care needs people with muscle-wasting conditions have. This can be ensured through the expected update to the neurology service specification.

There is a sense that the role of specialist healthcare professionals may not change noticeably because of the commissioning change. However, in cases where it is appropriate for community healthcare professionals to be more involved in the management of muscle-wasting conditions, neuromuscular specific education and training will be vital.

Case study:

My hopes for the new integrated model of care, as a patient with Limb Girdle Muscular Dystrophy (LGMD)

My name is Andrew Robertson and I have lived with LGMD since I was diagnosed at 18. The initial symptoms are very subtle, and I was incredibly lucky to be seen by a paediatrician who had experience with muscular dystrophy during his training and instantly knew where to signpost me. However, I've had to explain to therapists multiple times that I don't have Motor Neurone Disease or Multiple Sclerosis. The lack of understanding of my condition means I have had to speak out to physiotherapists to ensure that I don't damage my muscles with over exercise or in one case receive too vigorous stretching when I needed some level of stiffness in my muscles to aid with my stability (on that occasion after being stretched I got up from the physio bench and promptly collapsed, unable to walk).

Over the years I've experienced disparity of advice between professionals. On one occasion an occupational therapist recommended lots of adaptations and equipment and then a physio waiting for her to leave the room told me not to use the equipment unless I really had to, to keep using the muscles for as long as I can. This can leave you quite confused as a patient as to whose advice to follow.

I know many people with my condition who sadly find that their condition and the impact it has on their daily lives is not understood and so the patient ends up fighting for access to the basic support that they need. I hope with the introduction of ICSs, situations like the above can be avoided through having greater collaboration between the different healthcare professionals I need to see.

How the commissioning of specialised services for muscle-wasting conditions by ICSs can optimise care

ICS commissioners have a responsibility to maintain the quality of care, but also have a key opportunity to enhance it. They should be provided with support from NHSE, ICBs and healthcare professionals with experience in managing muscle-wasting conditions to achieve this. We have found six key areas which we believe ICSs must prioritise to support best-practice care for people living with muscle-wasting conditions.

Education

There is clear variation in understanding of what is changing and of ICS structures amongst clinicians. Whilst in many cases, clinicians' day-to-day experience will not significantly change, it is important they are provided with a strong understanding of their local organisational structure and where commissioning responsibilities sit in order to support them to develop their services in line with new structures. Muscular Dystrophy UK is committed to supporting this education drive and will be developing a report specifically for healthcare professionals later this year.

- ICBs should directly communicate with healthcare professionals in their region on what has changed and how it might impact them and their patients.
- Health Education England (HEE) should share Muscular Dystrophy UK's factsheets and eLearning modules on muscle-wasting conditions to support community healthcare professionals to care for people living with muscle-wasting conditions.

As well as healthcare professionals being provided with a clear understanding of system changes, it is also important that ICS commissioners are aware of the health and care needs of people living with muscle-wasting conditions. This will ensure the correct allocation of resources and set-up of services locally. We hope that this report is the first step in engaging ICS commissioners on muscle-wasting conditions.

- ICS commissioners should participate in opportunities to be upskilled on muscle-wasting conditions, this includes attending local neuromuscular network meetings and one-to-one meetings with specialist clinicians.
- ICS commissioners should access educational materials, including the condition-specific factsheets available on Muscular Dystrophy UK's website.
- NHSE should ensure that appropriate resources are provided to ICS commissioners on disease management, this includes updated service specifications and condition-specific standards of care including those for Spinal Muscular Atrophy^{xi}, paediatric Duchenne muscular dystrophy and adult Duchenne muscular dystrophy.^{xiii}

Funding

Insufficient funding is a major blocker in ensuring people with muscle-wasting conditions receive the care and support they need. Additionally, the bureaucracy around securing additional funding feels at times impenetrable for clinicians.

Funding request routes will change in new ICS structures, presenting a key opportunity to set a baseline level of understanding and share advice on funding requests.

- Each ICS should create a clear and comprehensive document on who leads on commissioning services for people living with muscle-wasting conditions, and how to submit funding requests.
- NHSE and ICSs to communicate with local Trusts on what their funding priorities are locally, and how clinical services can best access any additional funding.
- NHSE should ensure that resources are provided to ICS commissioners on muscle-wasting conditions, to ensure that they have sufficient knowledge to make educated decisions regarding funding requests.

Holistic care in the community

The whole system and joined-up approach that ICSs provide the framework for has the opportunity to improve the holistic care for a patient. This means moving away from a sole focus on medical care to one that includes social care, education and physical activity, all of which takes place in the community. Importantly, there are instances when it would be inappropriate to move medical care for muscle-wasting conditions to the community and we encourage ICS commissioners to gather clinical insights on this for specific neuromuscular conditions.

- ICS commissioners should provide Neuromuscular Care Advisors with the resources and time to provide community support and cross ICS boundaries, given that there will not be a specialist neuroscience centre in every ICS.
- ICSs should approach the management of muscle-wasting conditions completely holistically, with a 'health-in-all-places' approach. For example, consideration should be made of the role of schools or community hubs in improving the quality of life of people with muscle-wasting conditions.
- ICS commissioners should consider this holistic approach when commissioning services.

Workforce

Across the NHS and social care, vacancies are impacting the timely and appropriate care of patients. We are conscious that significant workforce increases may not happen in the short-term, but ICS commissioners can take some steps to uplift what is available to provide suitable care to patients with muscle-wasting conditions and to take advantage of the more integrated care that ICSs will support.

- ICS commissioners should provide more FTE hours to neuromuscular care advisors, who are crucial to integrate and manage the whole pathway, identify patients, and signpost GPs and patients to specialist services.^{xiv}
- ICS commissioners should place a significant weighting on the multi-disciplinary care needed for patients with muscle-wasting conditions, such as occupational therapy and psychological care, in their commissioning decisions.
- ICS commissioners should ensure every neuroscience centre employs a specialist neuromuscular consultant neurologist.

Case study:

My experience navigating a number of ICSs to improve my neuromuscular service offered to patients in South West London & Surrey

Dr Niran Nirmalananthan, Consultant Neuromuscular Neurologist and Co-chair of the South West London & Surrey Neurosciences Network

I have been working within neuromuscular services for many years and appreciate recent NHS reforms can be daunting. However, with the primary focus of ICSs on collaboration at system level, I am excited at the opportunities this has opened up to work across organisational boundaries within our region to provide more holistic and seamless care for our patients.

With most neuromuscular services being delegated to ICSs to commission, there is a real opportunity to bring together historically fragmented commissioning to deliver integrated care for neuromuscular disease. ICSs now manage NHS Trusts, mental health services, community services and primary care together over large population footprints (typically 750,000 to 3 million). As neuromuscular patients have complex diagnostic, treatment and care needs which often require significant input from community services this enables the whole-pathway transformation required to truly benefit patients.

The plan for population health budgets for ICSs also makes it easier to take a population-focused approach to reducing inequalities in access. By working through the South West London ICS & Surrey Heartlands ICS, we have been able to set up several neuro-specific initiatives such as funded neuroscience networks, funded patient engagement groups, and the development and funding of specific system-based neuromuscular roles to meet the needs of the whole population.

Through bringing together primary, community, secondary and tertiary care leaders with an interest in neurological disorders, we have been able to use our collective voice to more strongly advocate for patient needs and gain high level engagement with neuromuscular service needs within the ICS. It can, however, be challenging initially to identify the right people to engage within ICSs, particularly as management structures are still being set up following the recent NHS restructuring. I am confident this will become easier as the new structures bed in over time.

Data

High quality and regularly updated data are vital for oversight of the quality of care, service planning and service improvements. Whilst some good data are collected for muscle-wasting conditions, the shift to integrated care presents an opportunity to establish new datasets as well as maintaining those already in place. Datasets that present an overview of a patient's flow through the patient pathway once commissioning moves to ICSs would be beneficial for an oversight of care.

- NHSE should create a data dashboard, split by ICS, to outline key datasets for muscle-wasting conditions, such as condition prevalence, time and route to diagnosis, mortality, admissions, and treatment. This will allow ICSs to have an overview of care in their area, and what aspects of care or parts of the pathway require attention.
- NHSE, particularly the transformation directorate, should urgently improve digital systems involved in the sharing of data across Trusts and ICSs, and make patient records easy to use.

Prioritisation of muscle-wasting conditions

It is essential that ICS commissioners and other health system stakeholders prioritise care improvements for people living with muscle-wasting conditions in England. It is particularly important that muscle-wasting conditions are not 'lost' in the expected update to service specifications, given that many muscle-wasting conditions fall under the much broader neurology service specification. Muscular Dystrophy UK commits to supporting ICSs to elevate the standards of care for people living with muscle-wasting conditions.

- The Government, NHSE, and ICSs should prioritise care developments in muscle-wasting conditions, considering them as a set of conditions, rather than under a general neurology banner, and take action to drive progress in care and reduce disparities.
- NHSE, in its update to service specifications, should take particular care to ensure that sufficient detail is provided, and resources signposted to muscle-wasting conditions.

About Muscular Dystrophy UK

Muscular Dystrophy UK is the charity for the 110,000 people living with muscle disease in the UK. We bring together people affected by more than 60 rare and very rare progressive muscle-weakening and wasting conditions. We provide vital information, advice, resources, and support for people with these conditions, their families and the professionals who work with them.

We have created condition fact sheets for all the muscle-wasting conditions that we cover.ⁱⁱ We also have a service where you can find your Regional Neuromuscular Forum and Clinical Network.^{xv}

Please get in touch with us at campaigns@muscardystrophyuk.org if you have any comments, questions or require further support on topics relating to this report.

Appendix – Commissioning of muscle-wasting conditions under ICSs^{xvi}

Services suitable and ready for greater ICS leadership

- Neuropsychiatry services (adults and children)
- Highly specialised palliative care service for children and young adults
- Adult specialist neuroscience services
 - Neurology
 - Neurophysiology
 - Neuroradiology
 - Neurosurgery
 - Mechanical Thrombectomy
- Highly specialist metabolic disorder services for adults and children
- Clinical genomic services (adults and children)
 - Pre-Implantation genetic diagnosis and associated in-vitro fertilisation services

Services suitable but not ready for greater ICS leadership

- Adult specialist neurosciences services
 - Neurosurgery – Low Volume Procedures (Regional)
 - Neurosurgery – Low Volume Procedures (Neuroscience Centres)
- Clinical genomic services (adults and children)
 - Genomic laboratory testing services
 - Specialist clinical genomics services
 - Molecular diagnostic service
- Specialist services to support patients with complex physical disabilities (excluding wheelchair services) (adults and children)
 - Specialist augmentative and alternative communication aids
 - Specialist environmental controls
- Adult secure mental health services
- Secure and specialised mental health services (adult) (Medium and low) – including LD / ASD / WEMS / ABI / DEAF
 - Secure and specialised mental health services (adult) Medium Secure Female WEMS
 - Secure and specialised mental health services (adult) (Medium and low) - ABI
 - Secure and specialised mental health services (adult) (Medium and low) - DEAF
- Tier 4 child and adolescent mental health services
 - Tier 4 CAMHS (MSU)
 - Tier 4 CAMHS (children's service)

Services not suitable for more integrated commissioning

- Diagnostic service for rare neuromuscular disorders (adults and children)
- Specialist neuroscience services for children
 - Spinal Muscular Atrophy (SMA)
- McArdle's disease service (adults)
- Rare mitochondrial disorders service (adults and children)
- Adult specialist neurosciences services
 - Neurosurgery – Low Volume Procedures (National)
 - Transcranial magnetic resonance guided focused ultrasound (TcMRgFUS)

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