

**Muscular  
Dystrophy UK**

Fighting muscle-wasting conditions



# Managed Clinical Neuromuscular Networks



# The case for Managed Clinical Neuromuscular Networks

## 1. Executive summary

Muscular Dystrophy UK believes that Managed Clinical Neuromuscular Networks play a key role in ensuring that people living with muscle-wasting conditions receive the best possible support no matter where they live in the UK.

Recent changes within the NHS have led to an increasing emphasis on the importance of networks across a range of different health areas, including cancer and mental health. The success of these networks has demonstrated that working in collaboration can lead to improved services and can open up relationships between stakeholders across the patient pathway.

The NHS has also identified neurological conditions as a health area in which networks could play a key role in improving the quality of life of this patient group. Currently, managed clinical neuromuscular networks exist in some regions of the UK, but large parts of the country are still without a network to help drive forward service improvements in the region.

This document aims to provide information and support to commissioners on the need for such an intervention and how to go about establishing a Managed Clinical Neuromuscular Network in their area.

## 2. Introduction to networks

NHS England has identified the importance of creating and managing networks for the care of people with long-term conditions. The *NHS Five Year Forward View*<sup>1</sup> recommends developing stronger links between specialist hospital healthcare, primary care and community services, through networks led by specialist teams at tertiary centres.

**'Long-term conditions are now a central task of the NHS; caring for these needs requires a partnership with patients over the long term rather than providing single, unconnected 'episodes' of care. As a result there is now quite wide consensus on the direction we will be taking.**

**Services need to be integrated around the patient. For example a patient with cancer needs their mental health and social care coordinated around them. Patients with mental illness need their physical health addressed at the same time.'**<sup>2</sup>

Clinical networks form a vital part of improving care for different patient groups within the NHS. Networks do this by combining the experience of clinicians, the input of patients and the organisational vision of NHS staff; they have supported and improved the way in which care is delivered to patients in distinct areas, delivering true integration across primary, secondary and tertiary care. For example, Cancer Networks have raised standards, supported easier and faster access to services and encouraged the spread of best practice.<sup>3</sup> Stroke Networks have enabled a transformation in the way services are delivered in many parts of the country leading to measurable improvements in both outcomes and experience for patients.

<sup>1</sup> [www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf](http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf)

<sup>2</sup> NHS Five Year Forward View, p. 16

<sup>3</sup> [tvscn.nhs.uk/networks/cancer/](http://tvscn.nhs.uk/networks/cancer/)

## Case study

The South London Cardiovascular and Stroke Network consists of work streams that focus on each area along the patient pathway, from prevention through to rehabilitation.

Dedicated resources in the Network provide expert assistance across the board from service improvements, to collaborative commissioning, to patient and public involvement. For example, in its first year of operation the South London Cardiovascular and Stroke Network saw the following outcomes:<sup>4</sup>

- ▶ all local hospitals setting care plans and referral systems for cardiovascular and stroke patients
- ▶ over 500 health professionals in the region attending cardiovascular and stroke education events
- ▶ lowering the cost of stroke patients on the NHS
- ▶ the development of patient passports outlining individual healthcare needs.



Cancer and Stroke networks are the most advanced of all condition-specific networks. There has also been huge progress in operational delivery networks for other services such as burns care, critical care, neonatal and trauma care. These have brought providers and commissioners together to co-ordinate patient pathways over a wide geographic area to ensure access to specialist resources and expertise.

## Networks within the NHS

### Strategic Clinical Networks

Forming networks is a key part of NHS policy, as outlined in their *The Way Forward: Strategic Clinical Networks*<sup>5</sup> report. The report demonstrates that the NHS is focusing on ensuring formal networks are created and retained to ensure consistently high quality of care for all patients within a specific area and with a specific condition.

To help achieve this, Strategic Clinical Networks (SCN) were created to focus on the main health issues identified by the NHS. The decision to establish SCNs was based on achieving significant and lasting change. Priority health areas that SCNs have been set up for are:

- ▶ cancer
- ▶ cardiovascular disease (incorporating cardiac, stroke, diabetes and renal disease)
- ▶ maternity and children
- ▶ mental health, dementia and neurological conditions.

### Operational Delivery Networks

Operational Delivery Networks (ODN)<sup>6</sup> also form a vital part of improving care. These networks have been established to bring improvements to clinical pathways or areas where many professional groups and organisations are involved in the development and delivery of care. They have typically had formal leadership and governance structures and have operated with a mandate from commissioners and service providers to work on their behalf and ensure that the quality of care for all patients is consistently high. The South West has a provider-led Neuromuscular ODN.

<sup>4</sup> [www.slcsn.nhs.uk/files/newsletters/annual-report/annual-report-2011-12.pdf](http://www.slcsn.nhs.uk/files/newsletters/annual-report/annual-report-2011-12.pdf)

<sup>5</sup> NHS Commissioning Board (2012) *The Way Forward: Strategic Clinical Networks*. Available at: [www.england.nhs.uk/wp-content/uploads/2012/07/way-forward-scn.pdf](http://www.england.nhs.uk/wp-content/uploads/2012/07/way-forward-scn.pdf)

<sup>6</sup> [tvscn.nhs.uk/networks/cancer/](http://tvscn.nhs.uk/networks/cancer/)

## Clinical Reference Groups

The direct specialised commissioning function of NHS England is supported by Clinical Reference Groups (CRGs)<sup>7</sup>, covering all prescribed specialised services.

CRGs bring together clinicians, commissioners, and public health experts with the patients and carers who use the relevant services. Members are volunteers who have a particular interest, knowledge or experience of a specific area of specialised healthcare and wish to contribute to its development.



CRGs are the primary source of clinical advice on the development and assurance of specialised services contract products (such as specifications and commissioning policies). The CRGs are the leaders in developing the products required for the effective commissioning of specialised services. CRGs publish service specifications that outline what needs to be in place within a specialised service to provide high-quality healthcare. It has been said that clinical networks can play a major role in operationalising and delivering these service specifications.

## 3. Managed Clinical Neuromuscular networks

Managed Clinical Neuromuscular Networks are regional bodies, which are in place to recommend and ensure that the highest quality clinical and non-clinical support is available to individuals in that region with a neuromuscular condition. Managed Clinical Neuromuscular Networks do this by bringing together the various specialist health professionals involved in the care of people in the region with neuromuscular conditions to work collectively, between different hospitals and community services, to drive forward improvements.

The benefits of formal Managed Clinical Neuromuscular Networks are clearly documented in the neuromuscular annex of the neurosciences specification<sup>8</sup> which outlines:

**'A Clinical Network, in place to support multidisciplinary and cross organisational working, providing effective and efficient treatment, care and support to patients and their families is vital to support specialist care for patients with muscle-wasting conditions.'**

Managed Clinical Neuromuscular Networks often have a structure led by a steering group, which includes:

- ▶ a network chair
- ▶ consultant neurologists
- ▶ physiotherapists
- ▶ care advisors
- ▶ cardiac and respiratory specialists
- ▶ NHS England or commissioner representation
- ▶ patient representation.

<sup>7</sup> [www.england.nhs.uk/commissioning/spec-services/npc-crg/](http://www.england.nhs.uk/commissioning/spec-services/npc-crg/)

<sup>8</sup> [www.england.nhs.uk/wp-content/uploads/2013/06/d04-neurosci-spec-neuro.pdf](http://www.england.nhs.uk/wp-content/uploads/2013/06/d04-neurosci-spec-neuro.pdf)<sup>9</sup> [tvscn.nhs.uk/networks/cancer/](http://tvscn.nhs.uk/networks/cancer/)

This group influences the aims and priorities of the Network to improve neuromuscular services and support for people across the region with muscle-wasting conditions and can bring about significant service improvements. Therefore, ensuring that every area in the UK is covered by a Managed Clinical Neuromuscular Network is essential to eradicate any gaps in neuromuscular services.

As of the summer of 2015, there are six Managed Clinical Neuromuscular Networks – either in place or emerging – across the UK:

- ▶ South West Neuromuscular Operational Delivery Network
- ▶ Scottish Muscle Network
- ▶ Welsh Neuromuscular Network
- ▶ North West Neuromuscular Clinical Network
- ▶ London and the South East Coast Neuromuscular Clinical Network
- ▶ North East Neuromuscular Interest Group.

These networks are all funded and managed differently, with support coming from NHS England, hospital trusts, NHS Scotland, Public Health Wales and/or Muscular Dystrophy UK.

#### **4. Evidence on why it matters to bring health professionals, patients and NHS commissioners together as part of a Managed Clinical Neuromuscular Network**

Hospital admissions for patients with neuromuscular conditions are often extremely costly and avoidable. For example, the 2011 Muscular Dystrophy UK report *Invest to Save* found admission to a specialist ward could cost the NHS up to £1,925 per day<sup>9</sup>. Investment in preventative services across the whole of the UK could therefore result in savings of an estimated £31m.

An audit led by Professor Mike Hanna, Consultant Neurologist and Director of the National Hospital for Neurology and Neurosurgery, Queen Square, of unplanned emergency admissions of people with muscle-wasting conditions, in London and the South East, found that over a third of admissions were preventable, and a further five percent were 'possibly' preventable. The subsequent report<sup>10</sup> recommended the consideration of Managed Clinical Neuromuscular Networks as a method to provide improved care.

Both the *Invest to Save* report, and Professor Hanna's audit of unplanned emergency admissions of people with muscle-wasting conditions identified the need for a clear approach on bringing together health professionals and commissioners in Managed Clinical Neuromuscular Networks. These would ensure the effective running of services both to improve the care that patients receive and save the NHS money.

This approach of integrated care, moving away from the fragmentation of health services that many patients experience, has been advocated by the Kings Fund<sup>11</sup> who outline that co-ordinated care is essential to help people live healthy, fulfilling and independent lives. This means providing integrated care, with health and social care professionals working together to ensure care is co-ordinated around the patient.

<sup>9</sup> [www.muscular-dystrophy.org/assets/0002/4945/Muscular\\_Dystrophy\\_Campaign\\_Invest\\_to\\_Save\\_Report.pdf](http://www.muscular-dystrophy.org/assets/0002/4945/Muscular_Dystrophy_Campaign_Invest_to_Save_Report.pdf)

<sup>10</sup> [www.cnmd.ac.uk/documents/AIAU\\_NMD\\_Emg\\_Ad\\_Audit\\_2012.pdf](http://www.cnmd.ac.uk/documents/AIAU_NMD_Emg_Ad_Audit_2012.pdf)

<sup>11</sup> [www.kingsfund.org.uk/leadership/leading-integrated-care](http://www.kingsfund.org.uk/leadership/leading-integrated-care)

## 5. How to set up a Managed Clinical Neuromuscular Network

Once it is agreed that a network will be formed, a common approach can be taken to begin building its infrastructure and mould its priorities, to begin to make an impact. All of these steps can be supported by Muscular Dystrophy UK who provide administrative support and sit on the steering groups of all existing neuromuscular networks.



While networks are all different, a governance structure to create a network could include the following steps:

1. deciding upon a network chair who will lead the network. This can be done in conjunction with an SCN or NHS commissioner and interviews can be held.
2. developing a steering group of around 20 members. The network chair and others would establish who should feature on this group, but it should include members from a range of backgrounds: patients, commissioners, consultant neurologists, physiotherapist, care advisors and cardiac and respiratory specialists.
3. recruiting from a wider pool of stakeholders in the region who can be involved in shaping the priorities of the network, professional development events and much more of the network's work to improve services in the region.
4. creating terms of reference and aims and priorities of the network. These documents can be created by combining common goals for providing high-quality care to patients with muscle-wasting conditions, as well as regional priorities that differ across the country. Examples of some of the priorities that other networks have identified are featured later in this document.

## 6. Aims of Managed Clinical Neuromuscular Networks

Each neuromuscular network will set its own management/organisational structure as well as regional aims and objectives. Although aims and objectives will differ from one region to another, all Managed Clinical Neuromuscular Networks will share a common goal of improving the care of people with muscle-wasting conditions as well as the support for specialist and community professionals.

### Common themes include:

- ▶ mapping service provision and patient population in the region to establish strengths and gaps in care
- ▶ developing the knowledge of professionals on muscle-wasting conditions
- ▶ improving resources for patients
- ▶ ensuring gaps in services are filled.

### Common work that is undertaken to address these themes include:

- ▶ holding community upskilling events for health professionals
- ▶ improving the provision of outreach clinics to areas that patients are not receiving adequate care
- ▶ auditing services against the neuromuscular services specification
- ▶ ensuring patients have alert cards and care plans to reduce unplanned emergency admissions

- ▶ organising patient information days on important topics, for example transition
- ▶ developing strong working relationships with Clinical Commissioning Groups (CCGs) and GPs to ensure that community services are being kept up-to-date with the needs of patients with muscle-wasting conditions, and that CCGs are aware of the services they are responsible for in the Neuromuscular Annex to the Neurosciences Service Specification<sup>12</sup>
- ▶ developing and finalising a patient pathway for children and adults with muscle-wasting conditions
- ▶ creating a one-stop regional contact number/details so patients and community health professionals can always have access to expert regional advice on muscle-wasting conditions
- ▶ Holding regional neuromuscular information roadshow events at district general hospitals three times a year
- ▶ identifying local health professionals who see people with muscle-wasting conditions and creating community champions who can lead on improving local healthcare, creating profession-specific groups such as speech and language therapists and physiotherapist groups
- ▶ updating all stakeholders via a quarterly e-newsletter
- ▶ creating a website, as well as social media accounts, as a resource for patients, health professionals and commissioners.

## 7. How existing Managed Clinical Networks have been created

There are various methods that can be undertaken to create a regional Managed Clinical Neuromuscular Network. These are demonstrated by the work of the four different networks in England as well as the Scottish and Welsh networks.

### The North West Neuromuscular Network

This Network began as an informal, un-funded network of clinicians in the region. It has evolved from Muscular Dystrophy UK's North West Neuromuscular Forum into an NHS-funded Neuromuscular Managed Clinical Network. It brings together health professionals, patient groups such as Muscular Dystrophy UK, with an interest in the care of people with muscle-wasting conditions, and families with an interest or involvement in the care of people with muscle-wasting conditions. The Network has also secured funding for a part-time co-ordinator to drive forward the Network's activities.

### London and the South East Coast Neuromuscular Clinical Network

This new Network has been created through a partnership between Muscular Dystrophy UK and NHS England in both London and the South East Coast regions. It covers two Strategic Clinical Network areas, and will be formally launched in the autumn of 2015 and will link up neuromuscular services across the area and strengthen relationships between the major London neuromuscular tertiary centres and the community services supporting families in the South East Coast living with muscle-wasting conditions.

### South West Neuromuscular Operational Delivery Network

This Network<sup>13</sup> is funded by North Bristol NHS Trust and was formed in 2009. It was created in response to Muscular Dystrophy UK's *Building on the Foundations: The Need for a Specialist Neuromuscular Service across England* report.<sup>14</sup>

<sup>13</sup> [www.nbt.nhs.uk/south-west-neuromuscular-operational-delivery-network](http://www.nbt.nhs.uk/south-west-neuromuscular-operational-delivery-network)

<sup>14</sup> [www.muscular-dystrophy.org/assets/0000/0454/buildingonFoundations.pdf](http://www.muscular-dystrophy.org/assets/0000/0454/buildingonFoundations.pdf)

The South West Neuromuscular Operational Delivery Network (SWNODN) is a clinically-driven network of key stakeholders including doctors, allied health professionals, NHS managers, commissioners, patients, carers and families of patients.

### **Scottish Muscle Network and the Welsh Neuromuscular Network**

Both the Scottish Muscle Network (SMN)<sup>15</sup> and the Welsh Neuromuscular Network (WNMN) are funded by the NHS.



The SMN is a national, managed clinical network originally established in 1998 with charitable funding from Muscular Dystrophy UK. It is now funded by NHS National Services Division (NSD).

The WNMN, established in 2011, is funded by NHS Wales and hosted by Welsh health boards. It has brought together clinical and management colleagues, along with service users, to undertake a review and evaluation of existing services and service access in order to put forward practical recommendations on workforce infrastructure, based on a case for change.

### **North East Neuromuscular Special Interest Group**

This Network is being developed through a partnership between Muscular Dystrophy UK and NHS England's Northern England Strategic Clinical Networks.

## **8. Why Managed Clinical Neuromuscular Networks are important**

“Clinical Networks enable a more co-ordinated approach to service provision, based on agreed service models, standards and known patient pathways. Such Networks usually comprise health professionals from a range of NHS organisations working in a co-ordinated manner across institutional and local boundaries in order to ensure the efficient and equitable provision of high-quality and clinically effective services.

The Welsh Neuromuscular Network (WNMN), established in 2011, has brought together clinical and managerial colleagues, along with service users, to undertake a review and evaluation of existing services and service access in order to put forward practical recommendations on workforce infrastructure, based on a case for change.”

### **Welsh Neuromuscular Network**

“In collaboration with our colleagues, NHS partner organisations, and patients, their carers and their families, the SWNODN recommends and aims to deliver the highest quality clinical and non-clinical support to individuals with a neuromuscular condition. The Network aims to establish centres of excellence across the South West with the guidance of clinical leadership in the field of neuromuscular service provision.”

### **South West ODN**

“A National Managed Clinical Network in Scotland is the ideal way to ensure local professionals are empowered and supported to deliver care locally and are armed with robust care pathways into a specialist unit when this is necessary.”<sup>16</sup>

### **Scottish Muscle Network**

<sup>15</sup> [www.smn.scot.nhs.uk/aboutus.html](http://www.smn.scot.nhs.uk/aboutus.html)

<sup>16</sup> [www.smn.scot.nhs.uk/documents/Annual%20Report%202005%202006.pdf](http://www.smn.scot.nhs.uk/documents/Annual%20Report%202005%202006.pdf)

“I believe that having a new formalised network in the North West is an important step forward which will play a part in driving forward care and support for people with these conditions across the whole region. I hope that we can reach out to more physiotherapists, and other health professionals to ensure they can provide a first-rate service to people with muscle-wasting conditions.”

**Shazad Hussain from Blackburn, who has Becker muscular dystrophy**



“Although the specialist teams in London are among best in the country, there is little understanding of neuromuscular conditions among local health professionals. I hope the new network will help to build up knowledge and services across the South East of England.”

**Justine McAlister from East Grinstead, whose son has Ullrich congenital muscular dystrophy**

## 9. Next steps

This document demonstrates the benefit that Managed Clinical Neuromuscular Networks can have on patient outcomes across the UK, through developing stronger links between the health professionals involved in the care of neuromuscular patients and commissioners.

As previously outlined, networks play a vital role in establishing gaps within neuromuscular services in any region and are an important body in enabling the filling of these, ensuring neuromuscular services continue to improve across the UK.

Muscular Dystrophy UK is available to provide support in the process of setting up a network, as we have done with all of the Managed Clinical Neuromuscular Networks mentioned in this document. If you would like to learn more these Networks and how to set one up in your region, please get in touch with **Bobby Ancil, Neuromuscular Outreach Manager** on **07920 188970** or at **[b.ancil@muscular dystrophyuk.org](mailto:b.ancil@muscular dystrophyuk.org)**.