NHS England

South West Neuromuscular Operational Delivery Network (ODN)

Operational Policy

South West Neuromuscular Operational Delivery Network

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Description	This document outlines a template for Operational Delivery Networks to assist in the development of an Operational Policy to underpin the National Governance Process. Indicative headings are provided with a description of suggested section content.
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Purpose of Operational Policy

This South West Neuromuscular Operational Delivery Network (ODN) Operational Policy provides the framework within which the Network operates as well as describing the procedures within it. The document describes the region geographically and demographically, the composition of the Network and the governance processes. A separate Network Work Plan for 2015-16 shows objectives, actions and who is responsible and identifies the NHS Outcomes Framework Improvement Areas which are interlinked to the Network objectives.

This policy will be reviewed by the Network Executive Board at least every year to accommodate developments within the Network.

Introduction

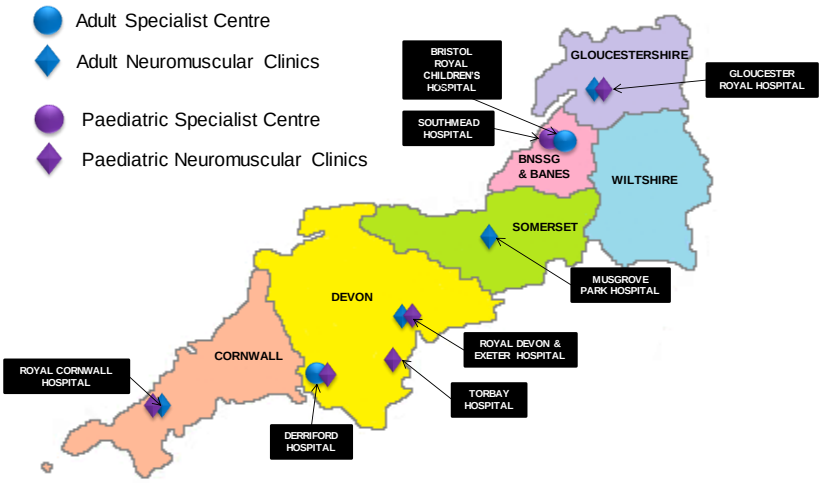
Background

The South West Neuromuscular Network was formed in 2009 in response to a report entitled "*Building on the Foundations: The Need for a Specialist Neuromuscular Service across Englan*d" [1] produced by the Muscular Dystrophy Campaign. The report highlighted inequalities in the services available to people with a neuromuscular condition and prompted an All Party Parliamentary Group for Muscular Dystrophy to investigate this further. This resulted in *"Access to Specialist Neuromuscular Care – The Walton Report"* [2]. The Network was originally hosted by the South West Specialised Commissioning Group, but following the Health and Social Care Act 2012[3] the Network was taken forward as an Operational Delivery Network, governed by NHS England and hosted by North Bristol NHS Trust.

Overview

The South West Neuromuscular ODN is the only Neuromuscular ODN in England. It covers a geographical area of 23,829Km^2 from Cheltenham to Truro, which also makes it one of the largest networks in England. The ODN referral criteria is based on conditions listed within ICD10 (Definition Set 8) *(Appendix 1)* and patients must live within the geographical region as shown in Figure 1.

Figure 1 – SW Neuromuscular ODN Area.



The majority of the region the ODN covers is largely rural with just three major cities; Bristol, Plymouth and Exeter, whose populations are 428,100, 258,000 and 123,400 respectively. The overall population of the region is approximately 5.5million and it is estimated that there are approximately 5000 individuals with a neuromuscular condition within this population.

Therefore, the ODN faces great challenges in delivering its Mission Statement:

"In collaboration with our colleagues, NHS partner organisations, and patients, their carers and their families, the SW Neuromuscular ODN will recommend and 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 and with the approval of the ODN Executive Board and NHS England (South) commissioners"

Network Governance Arrangements

External Governance

As a non-statutory organisation, the South West Neuromuscular ODN has to be hosted by an NHS organisation. North Bristol NHS Trust is the host for the ODN and has a Service Level Agreement with NHS England which sets out the roles and responsibilities of all parties.

From February 2015 a new ODN Oversight Board is being established by NHS England (South). The SW Neuromuscular ODN will report to this Board three times a year as per The Governance Model for Operational Delivery Networks South West Specialised Commissioning (version 1, Sept 2014).

Internal Governance

The Network itself has the following boards/groups:

- **Executive Board**
- **Management Team**
- **Physiotherapy Group**
- **Neuromuscular Advisor Group**
- **Patient and Public Voice (PPV) Group**
- **Working Groups:**
    - **Clinical Pathways/Standards**
        - **Transition sub-group**
    - **Research and Data**
    - **Education and Training** (currently in collaboration with the Muscular Dystrophy Campaign to deliver their "Bridging the Gap" project in the SW).

New Working Groups will be agreed by Executive Board as required to deliver specific projects.

Principal Network Stakeholders

The South West Neuromuscular ODN has many stakeholders:

- Patients, their families and carers
- Health and Social Care professionals delivering care and support for people with a neuromuscular condition in the community, GP practices (600+) and acute trusts (13).
- Clinical Commissioning Groups:

CCG Code	Clinical Commissioning Group
11H	NHS Bristol
11E	NHS Bath & NE Somerset
11M	Gloucestershire
11N	NHS Kernow
99P	NHS North, East & West Devon
11T	NHS North Somerset
11X	NHS Somerset
99Q	NHS South Devon & Torbay
12A	NHS South Gloucestershire
12D	Swindon
99A	NHS Wiltshire

- National Programme of Care and Clinical Reference Groups:
    - Trauma – Group D
        - D01 - Complex disability equipment Clinical Reference Group
        - D04 – Neurosciences Clinical Reference Group
    - Women and Children – Group E
        - E01 – Medical Genetics Clinical Reference Group
        - E09 – Paediatric Neuroscience Clinical Reference Group
        - E13 – Multi-system Disorder Clinical Reference Group

The South West Neuromuscular ODN will also need to forge links as required with:

- South West Clinical Senate
- South West Strategic Clinical Networks
    - Maternity and Children's Network
    - Mental Health, Dementia and Neurological Conditions Network
- West of England Academic Health Science Network
- Health Education South West

Purpose of the Network

The South West Neuromuscular ODN is a clinically driven network of key stakeholders including doctors, allied health professionals, NHS managers, commissioners, patients, carers and relatives of patients. Our aim is to develop and establish world class and equitable care for people of all ages living with rare neuromuscular conditions in the South West of England, and to improve their quality of life and overall experience of NHS services. To achieve this we will work with

health and social care professionals to develop the appropriate services and increase the knowledge and skills required to manage these complex conditions.

The overall aims of the SWNODN, in alignment with the *National Service Specification for Adult Neuroscience*[4] are to:

- Ensure an equitable and accessible service for individuals with a neuromuscular condition, and their families and carers, in the South West;
- Determine a strategic direction for neuromuscular services (including pathways of care) in the South West;
- Plan and develop neuromuscular services, including service configuration, care and treatment pathways (supported by referral policies and procedures) and service specifications (incorporating published Standards of Care and appropriate quality measurements);
- Raise standards of care and support for individuals with a neuromuscular condition, and their families and carers, in the South West;
- Promote the work of the SWNODN and agree a communication strategy with professionals and the public to maximise user involvement;
- Identify and share good practice and common aims across organisations and health communities.

Patient Profile and Philosophy of Care

Based on the fact that the overall population of the region is approximately 5.5 million and our service users are located across a very large and mostly rural geographical region, the South West Neuromuscular ODN has a massive task in delivering an equitable and accessible service to everyone.

The ODN consists of key network specialists based across the region in acute and community trusts (Appendix 2). The ODN agreed in the early stages of its development, and in line with the Neurosciences Service Specification[4], that the best delivery of care is through a multi-disciplinary approach. Therefore, as illustrated in Figure 1, three acute trusts across the region have become specialist centres (North Bristol NHS Trust, Plymouth Hospitals NHS Trust and University Hospitals NHS Foundation) and host the Consultant Neurologists who have a specialist interest in neuromuscular conditions and provide the clinical leadership for the ODN. The Consultant Neurologists are supported by a team of Specialist Neuromuscular Physiotherapists, Clinical Psychologists and Neuromuscular Care Advisors.

Patient Profile

- Paediatric and adults patients
- Living in South West region covered by the Network (Figure 1)
- With a confirmed diagnosis of a neuromuscular condition listed in ICD-10 Definition Set 8 (Appendix 1)

Philosophy of Care

To meet the recommendations made in the Neurosciences Service Specification[4] to provide holistic care to individuals with a neuromuscular condition via a multi-disciplinary team (MDT) approach and to support individuals in self-management of their condition. We will achieve this via:

- MDT paediatric and adult neuromuscular clinics delivered by the ODN team of Consultant Neurologists, Specialist Physiotherapists, Clinical Psychologists and Neuromuscular Care Advisors.
- MDT joint specialty paediatric and adult clinics delivered by ODN team members in conjunction with other specialists (eg, cardiac, respiratory and genetics).
- Clinics delivered across the region to provide more choice and opportunity for patients to be seen closer to where they live.
- Provision of home visits for particularly complex or vulnerable patients/families.
- Training and up-skilling of local acute and community physiotherapists to provide a wider resource for access to high quality therapies.
- Provision of patient workshops to educate and support patients and their families/carers in self-management on the neuromuscular condition.

Network Communication Strategy

A Communication Strategy for the ODN has been developed which needs to fulfil a number of objectives:

- Identify and engage actively with all stakeholders to help us achieve our overall organisational objectives.
- Ensure internal and external audiences are well informed about the current Network activity and its future developments.
- Ensure all clinicians and health and social care professionals are aware of the specialist resource the network can offer in providing education, knowledge and training
- Change practice and attitudes where necessary to ensure positive change.
- Ensure patients are supported in self-management of their condition.
- Demonstrate the success of our work.

Audit and Research

The ODN currently has a basic Microsoft Access database to record patient details. This is in need of development to support an ODN wide audit and research programme. A Research and Data Working Group has been set up to address this issue and identify the needs of the ODN. Unlike other ODNs, the South West Neuromuscular ODN does not have access to a national database.

A programme of audit needs to be agreed and developed and included within contracts with acute trusts providing services for neuromuscular patients.

Education and Training

Patients, Families and Carers

The South West Neuromuscular ODN organises a number of events and courses each year for patients and their families. Our aim is to equip patients and their families with the knowledge and skills to better manage their condition and improve their quality of life.

With this in mind, the Network holds a yearly Neuromuscular Information Day. Three workshops were piloted in Bristol during 2014 and we plan to develop these in Bristol and roll out similar workshops in the South of the region. These consisted of:

- Living Well with a Muscle Disease
- Transitioning from Paediatric to Adult Services
- Information Day for Parents of a child with recently diagnosed Duchenne Muscular Dystrophy

Health and Social Care Professionals

We also run a number of events for professionals. These include the South West Interest in Muscles (SWIM) Conference held twice a year. As well as providing support for local therapy teams via in-house training sessions, or attendance at clinics, we are also working with the Muscular Dystrophy Campaign on their "Bridging the Gap Project" which aims to up-skill staff in working with people with neuromuscular conditions.

Funding

NHS England recognises that there is still a degree of transition required for ODNs to embed fully within provider contracts, until the tariff and reference costs solutions take effect. The transitional funding approach, which utilised 0.1% of CQUIN monies, will continue throughout 2014/15, whilst future funding options are developed for 2015/16.

Partial funding was approved in December 2014 to continue current funding level for 2015/16. Future funding arrangements for the SW Neuromuscular ODN beyond March 2016 are yet to be clarified.

References

1. "Building on the Foundations: The Need for a Specialist Neuromuscular Service across England"
2. "Access to Specialist Neuromuscular Care – The Walton Report"
3. https://www.gov.uk/government/publications/health-and-social-care-act-2012-fact-sheets
4. 2013/14 – NHS Standard Contract for Neurosciences: Specialised Neurology (Adult)

Appendix 1 – ICD-10 Codes Relating to Neuromuscular Conditions.

G12 Spinal muscular atrophy and related syndromes
G12.0 Infantile spinal muscular atrophy, type I [Werdnig-Hoffman]
G12.1 Other inherited spinal muscular atrophy
Progressive bulbar palsy of childhood [Fazio-Londe]
Spinal muscular atrophy:
· adult form
· childhood form, type II
· distal
· juvenile form, type III [Kugelberg-Welander]
· scapuloperoneal form

G12.8 Other spinal muscular atrophies and related syndromes
G12.9 Spinal muscular atrophy, unspecified

G13* Systemic atrophies primarily affecting central nervous system in diseases classified elsewhere
G13.0* Paraneoplastic neuromyopathy and neuropathy
Carcinomatous neuromyopathy (C00-C97+)
Sensorial paraneoplastic neuropathy [Denny Brown] (C00-D48+)

G60 Hereditary and idiopathic neuropathy
G60.0 Hereditary motor and sensory neuropathy
Disease:
· Charcot-Marie-Tooth
· Déjerine-Sottas
Hereditary motor and sensory neuropathy, types I-IV
Hypertrophic neuropathy of infancy
Peroneal muscular atrophy (axonal type) (hypertrophic type)
Roussy-Lévy syndrome
G60.1 Refsum's disease
G60.2 Neuropathy in association with hereditary ataxia
G60.3 Idiopathic progressive neuropathy
Inflammatory polyneuropathy

G61.0 Guillain-Barré syndrome
Acute (post-) infective polyneuritis

G61.1 Serum neuropathy
Use additional external cause code (Chapter XX), if desired, to identify cause.
G61.8 Other inflammatory polyneuropathies
G61.9 Inflammatory polyneuropathy, unspecified

G62 Other polyneuropathies
G62.0 Drug-induced polyneuropathy
Use additional external cause code (Chapter XX), if desired, to identify drug.
G62.1 Alcoholic polyneuropathy
G62.2 Polyneuropathy due to other toxic agents
Use additional external cause code (Chapter XX), if desired, to identify toxic agent.
G62.8 Other specified polyneuropathies
Radiation-induced polyneuropathy
Use additional external cause code (Chapter XX), if desired, to identify cause.
G62.9 Polyneuropathy, unspecified
Neuropathy NOS

G63* Polyneuropathy in diseases classified elsewhere
G63.0* Polyneuropathy in infectious and parasitic diseases classified elsewhere
Polyneuropathy (in):
· diphtheria (A36.8+)
· infectious mononucleosis (B27.-+)
· leprosy (A30.-+)
· Lyme disease (A69.2+)
· mumps (B26.8+)
· postherpetic (B02.2+)
· syphilis, late (A52.1+)
· congenital syphilis, late (A50.4+)
· tuberculous (A17.8+)

G63.1* Polyneuropathy in neoplastic disease (C00-D48+)
G63.2* Diabetic polyneuropathy (E10-E14+ with common fourth character .4)
G63.3* Polyneuropathy in other endocrine and metabolic diseases (E00-E07+ , E15-E16+ , E20-E34+ , E70-E89+)
G63.4* Polyneuropathy in nutritional deficiency (E40-E64+)
G63.5* Polyneuropathy in systemic connective tissue disorders (M30-M35+)
G63.6* Polyneuropathy in other musculoskeletal disorders (M00-M25+, M40-M96+)
G63.8* Polyneuropathy in other diseases classified elsewhere
Uraemic neuropathy (N18.8+)

G70 Myasthenia gravis and other myoneural disorders
Excludes: botulism (A05.1) and transient neonatal myasthenia gravis (P94.0)
G70.0 Myasthenia gravis
Use additional external cause code (Chapter XX), if desired, to identify drug, if drug-induced.
G70.1 Toxic myoneural disorders
Use additional external cause code (Chapter XX), if desired, to identify toxic agent.
G70.2 Congenital and developmental myasthenia
G70.8 Other specified myoneural disorders
G70.9 Myoneural disorder, unspecified

G71 Primary disorders of muscles
Excludes: arthrogryposis multiplex congenita (Q74.3), metabolic disorders (E70-E90), myositis (M60. -)

G71.0 Muscular dystrophy

Muscular dystrophy:
· autosomal recessive, childhood type, resembling Duchenne or Becker
· benign [Becker]
· benign scapuloperoneal with early contractures [Emery-Dreifuss]
· distal
· facioscapulohumeral
· limb-girdle
· ocular
· oculopharyngeal
· scapuloperoneal
· severe [Duchenne]
Excludes: congenital muscular dystrophy:
· NOS (G71.2)
· with specific morphological abnormalities of the muscle fibre (G71.2)

G71.1 Myotonic disorders

Dystrophia myotonica [Steinert]
Myotonia:
· chondrodystrophic
· drug-induced
· symptomatic
Myotonia congenita:
· NOS
· dominant [Thomsen]
· recessive [Becker]
Neuromyotonia [Isaacs]
Paramyotonia congenita
Pseudomyotonia
Use additional external cause code (Chapter XX), if desired, to identify drug, if drug-induced.

G71.2 Congenital myopathies

Congenital muscular dystrophy:
· NOS
· with specific morphological abnormalities of the muscle fibre
Disease:
· central core
· minicore
· multicore
Fibre-type disproportion
Myopathy:
· myotubular (centronuclear)
· nemaline

G71.3 Mitochondrial myopathy, not elsewhere classified

G71.8 Other primary disorders of muscles

G71.9 Primary disorder of muscle, unspecified Hereditary myopathy NOS

G72 Other myopathies

Excludes: arthrogryposis multiplex congenita (Q74.3)
dermatopolymyositis (M33.-)
ischaemic infarction of muscle (M62.2)
myositis (M60.-)
polymyositis (M33.2)

G72.0 Drug-induced myopathy
Use additional external cause code (Chapter XX), if desired, to identify drug.
G72.1 Alcoholic myopathy
G72.2 Myopathy due to other toxic agents
Use additional external cause code (Chapter XX), if desired, to identify toxic agent.
G72.3 Periodic paralysis
Periodic paralysis (familial):
· hyperkalaemic
· hypokalaemic
· myotonic
· normokalaemic
G72.4 Inflammatory myopathy, not elsewhere classified
G72.8 Other specified myopathies
G72.9 Myopathy, unspecified

M33 Dermatopolymyositis
M33.0 Juvenile dermatomyositis
M33.1 Other dermatomyositis
M33.2 Polymyositis
M33.9 Dermatopolymyositis, unspecified

M60 Myositis
M60.0 Infective myositis
Tropical pyomyositis

Use additional code (B95-B97), if desired, to identify infectious agent.
M60.1 Interstitial myositis
M60.2 Foreign body granuloma of soft tissue, not elsewhere classified
Excludes: foreign body granuloma of skin and subcutaneous tissue (L92.3)
M60.8 Other myositis
M60.9 Myositis, unspecified

M61 Calcification and ossification of muscle
M61.0 Myositis ossificans traumatica
M61.1 Myositis ossificans progressiva
Fibrodysplasia ossificans progressiva
M61.2 Paralytic calcification and ossification of muscle
Myositis ossificans associated with quadriplegia or paraplegia
M61.3 Calcification and ossification of muscles associated with burns
Myositis ossificans associated with burns
M61.4 Other calcification of muscle
Excludes: calcific tendinitis (M65.2)
· of shoulder (M75.3)
M61.5 Other ossification of muscle
M61.9 Calcification and ossification of muscle, unspecified

G73* Disorders of myoneural junction and muscle in diseases classified elsewhere
G73.0* Myasthenic syndromes in endocrine diseases
Myasthenic syndromes in:
· diabetic amyotrophy (E10-E14+ with common fourth character .4)
· thyrotoxicosis [hyperthyroidism] (E05.-+)

G73.1* Eaton-Lambert syndrome (C80+)
G73.2* Other myasthenic syndromes in neoplastic disease (C00-D48+)
G73.3* Myasthenic syndromes in other diseases classified elsewhere
G73.4* Myopathy in infectious and parasitic diseases classified elsewhere
G73.5* Myopathy in endocrine diseases
Myopathy in:
· hyperparathyroidism (E21.0-E21.3+)
· hypoparathyroidism (E20.-+)
Thyrotoxic myopathy (E05.-+)

G73.6* Myopathy in metabolic diseases
Myopathy in:
· glycogen storage disease (E74.0+)
· lipid storage disorders (E75.-+)

G73.7* Myopathy in other diseases classified elsewhere
Myopathy in:
· rheumatoid arthritis (M05-M06+)
· scleroderma (M34.8+)
· sicca syndrome [Sjögren] (M35.0+)
· systemic lupus erythematosus (M32.1+)

E74.0 Glycogen storage disease
Cardiac glycogenosis
Disease:
· Andersen
· Cori
· Forbes
· Hers
· McArdle
· Pompe
· Tauri
· von Gierke
Liver phosphorylase deficiency

Appendix 2 – South West Neuromuscular ODN Specialist Team (August 2015)

Host Trust: North Bristol NHS Trust

Name & Post	WTE	AfC Band	Date Recruited	Base
Dr Andria Merrison Consultant Neurologist	1.0	n/a	01/03/2010	Southmead Hospital
Elaine Burrows Neuromuscular Advisor	1.0	6	25/11/2013	Southmead Hospital
Ann Morgan Neuromuscular Advisor	1.0	6	09/12/2013	Southmead Hospital
Nicola Doran Specialist Physiotherapist	1.0	7	07/02/2011	Southmead Hospital
John Ashworth Counselling Psychologist	0.4	8a	20/04/2015	Southmead Hospital
Sharon Standen ODN Coordinator	1.0	6	01/05/2014	Southmead Hospital
Joanne Smart ODN Manager	1.0	7	02/11/2015	Southmead Hospital
Clare Chamberlain Medical Secretary	1.0	4	01/03/2010	Southmead Hospital

Host Trust: University Hospitals Bristol NHS Trust

Name & Post	WTE	AfC Band	Date Recruited	Base
Dr Anirban Majumdar Consultant Paediatric Neurologist	0.7	n/a	09/03/2011	Bristol Royal Hospital for Children
Dr Kayal Vijayakumar Consultant Paediatric Neurologist	0.3	n/a	02/09/2013	Bristol Royal Hospital for Children
Bev Toms Specialist Paediatric Physiotherapist	0.5	7	01/09/2011	Bristol Royal Hospital for Children
Jane Berry Medical Secretary	1.0	4	23/02/2015	Bristol Royal Hospital for Children

Host Trust: Plymouth Hospitals NHS Trust

Name & Post	WTE	AfC Band	Date Recruited	Base
Dr Elizabeth Househam Consultant Neurologist	1.0	n/a	02/05/2011	Derriford Hospital
Clare Stayt Neuromuscular Advisor	1.0	6	05/01/2015	Derriford Hospital
Tamara Eaton Neuromuscular Advisor	1.0	6	02/03/2015	Derriford Hospital
Clare Frimpong-Ansah Specialist Paediatric Physiotherapist	0.2	6	01/01/2011	Plymouth Child Development Centre
Craig Newman Specialist Clinical Psychologist	0.3	8a	07/10/2013	Derriford Hospital
Rhiannon Stephens Medical Secretary	1.0	3	08/09/2014	Derriford Hospital

Host Trust: Northern Devon Healthcare NHS Trust

Name & Post	WTE	AfC Band	Date Recruited	Base
Geraldine Goldsmith (nee Lavallee) Specialist Physiotherapist	0.4	6	01/06/2012	Exeter Community Hospital, Exeter
Louise Tricker (maternity cover for Geri)	0.4	6	18/01/2016	Exeter Community Hospital, Exeter

Host Trust: Peninsula Community Health

Name & Post	WTE	AfC Band	Date Recruited	Base
Janet McCay Specialist Physiotherapist	0.4	6	09/12/2014	Camborne Redruth Community Hospital

Host Trust: Royal Cornwall Hospitals NHS Trust

Name & Post	WTE	AfC Band	Date Recruited	Base
Claire Eddy Specialist Paediatric Physiotherapist	0.2	6	01/06/2011	Royal Cornwall Hospital