SCHEDULE 2 – THE SERVICES

A. Service Specification

Service Specification No.	E09/S/(HSS) tba
Service	Paediatric Onset Multiple Sclerosis
Commissioner Lead	
Provider Lead	
Period	
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

This specification outlines the hub and spoke model of care for a highly specialised national service for children with suspected Paediatric Onset Multiple Sclerosis (POMS) and related conditions.

It is well recognised that early diagnosis of Paediatric Onset Multiple Sclerosis with resulting access to appropriate personalised treatments significantly improves cognitive outcome, lessens motor disability and in the long term reduces healthcare costs.
The service will enable the care of children to be managed in the most appropriate location depending on the severity of their condition.

The POMS service will comprise three Hubs based in the North, Middle and South of England, dependent on pre-existing expertise. Each Hub will have a named Lead Centre which will relate to a network of specialist acute spoke units within a specified geographic area. The service will include multi-disciplinary teams (MDTs) which will be located within each Hub Lead Centre which will use defined disease-specific protocols and pathways in the delivery of the service.

Hub Lead Centres will:

- jointly provide a 'virtual multidisciplinary MDT' demyelination assessment and diagnostic clinic to the clinical teams in spoke units. This will include undertaking a 'case note review' of the assessment undertaken in the spoke unit to include the history, examination and specialist investigations, then offer advice to the spoke units on diagnosis and suggest tailored management plans for each patient, identifying those elements of care that can be delivered locally. For those patients who require further investigation, the virtual MDT will recommend that the patient is referred to the national service. Provide inpatient provision for relapsing patients where this is not available locally.
- individually provide a dedicated (MDT) clinic at each Hub Lead Centre.

There are three categories of care to cater for children with different levels of need:

- Level 1: those patients who meet clinical criteria for relapsing remitting MS, and whose diagnosis and management follows the expected trajectory. These patients will be managed in shared care, with diagnosis and annual review by a Hub Lead Centre, but most care will be delivered by specialists at the spoke unit.

- Level 2: those whose presentation is unusual, whose onset is less than 12 years of age or who have aggressive disease with frequent relapses. These patients will be managed mainly by the Hub Lead Centres, with shared care with local specialists in spoke units as appropriate
- Level 3: those patients whose underlying condition is challenging to diagnose, whose treatment is challenging or who require highly specialist input will be managed by the appropriate Hub Lead Centre but discussed jointly by MDT regularly.

The use in POMS of new, highly efficacious drugs will significantly reduce disease activity and reduce the rate of emergency admissions arising from relapses and secondary complications.

The POMS service will:

- contribute to a marked improvement in the pace and accuracy of diagnosis,
- improve long term outcomes for patients and
- enhance the patient's and their family or carers' experience of the care journey.

Two key deliverables for each Hub Lead Centre will be:

- support and develop expertise in spoke units within their geographic area and,
- via the Hub Lead Centre MDT service, provide leadership for evidence-based best practice in paediatric MS treatment, standardising investigation guidelines and disseminating information to professionals, patients and their families and/or carers.

Given that patients with these conditions frequently have co-morbidities, the provision of holistic care requires the involvement of multiple health professionals both in the community / local hospital services and in the tertiary setting. Currently most centres will have formally established links between the tertiary centre and the regional community/ district general hospital setting which are central to the ability to provide a comprehensive package of care to the children and their families.

National context

Multiple sclerosis (MS) is a condition of the central nervous system (CNS) characterised by chronic brain inflammation and occurs when the coating around nerve fibres (myelin) becomes damaged (known as demyelination). There is no cure for MS so once diagnosed, a patient will have the condition for life, but treatments and specialist help can help to control disease activity, decrease disability from the condition and reduce ongoing symptoms.

MS in those under 18 years of age is called Paediatric Onset MS (POMS). POMS and related disorders are rare, and lack of awareness frequently results in diagnostic delay. There is evidence from both a UK and Canadian study that at least 5% of MS cases appear in childhood, but often go unrecognised. (Banwell et al 2007 Lancet Neurol. 6(10): 887-902); Harding et al. J Neurol Neurosurg Psychiatry. 2013 Feb;84(2):141-7)

As in adults, POMS can be diagnosed when a patient presents with evidence of demyelination in different areas of the brain over time. International consensus criteria have been developed to ensure early diagnosis, but also to highlight mimics and events that are not MS and also not likely to relapse (Krupp et al 2013 Mult Scler. 19(10): 1261-7).

In a recent paediatric surveillance study in the UK, 125 first episodes of such cases of myelin inflammation were identified. Of these, 40 involved inflammation in many regions and are termed acute disseminated encephalomyelitis (ADEM). In 85, specific regions of the brain were selectively involved, including the eyes (optic neuritis; 30 cases), spine (transverse myelitis; 25 cases) and other areas in the brain (30 cases); collectively these are termed clinically isolated syndrome (CIS). Together these 125 give an incidence of 9.83 per million children per year (95%CI 8.18-11.71; Absoud et al 2013 Mult Scler. 19(1): 76-86).

Following a first demyelinating episode, 30% of children go on to have a recurrent demyelinating syndrome (reviewed in Banwell et al 2007 Lancet Neurol 6(10): 887-902).

Prevalence

Each year in UK, there are likely to be 38 new patients who present with recurrent demyelination and another 48 who have a high risk of relapse (56% of CIS as identified in study), giving a total of 86 new patients per year.
A final steady state cohort of 516 patients is expected, of which approximately 200 will be expected to have a diagnosis of MS, given: a mean age presentation of ten years; transition to the adult service beginning at 17; children being with the service for an average of six years before transitioning.

Treatments of these disorders are complex, costly and can have significant side-effects. The service will support evidenced-based practice to meet the need for pharmacological and symptomatic treatment of symptoms. Cognitive difficulties, fatigue, and neuropsychiatric disorders are increasingly recognised as significant co-morbidities in the POMS population (Goretti et al 2012 *Mult Scler.* **18**:329-334) as in the adult population. Cognitive deficits include difficulties with learning, memory, attention and executive functioning. An increasing number of therapies are recognised for these disorders but currently are not readily available for children.

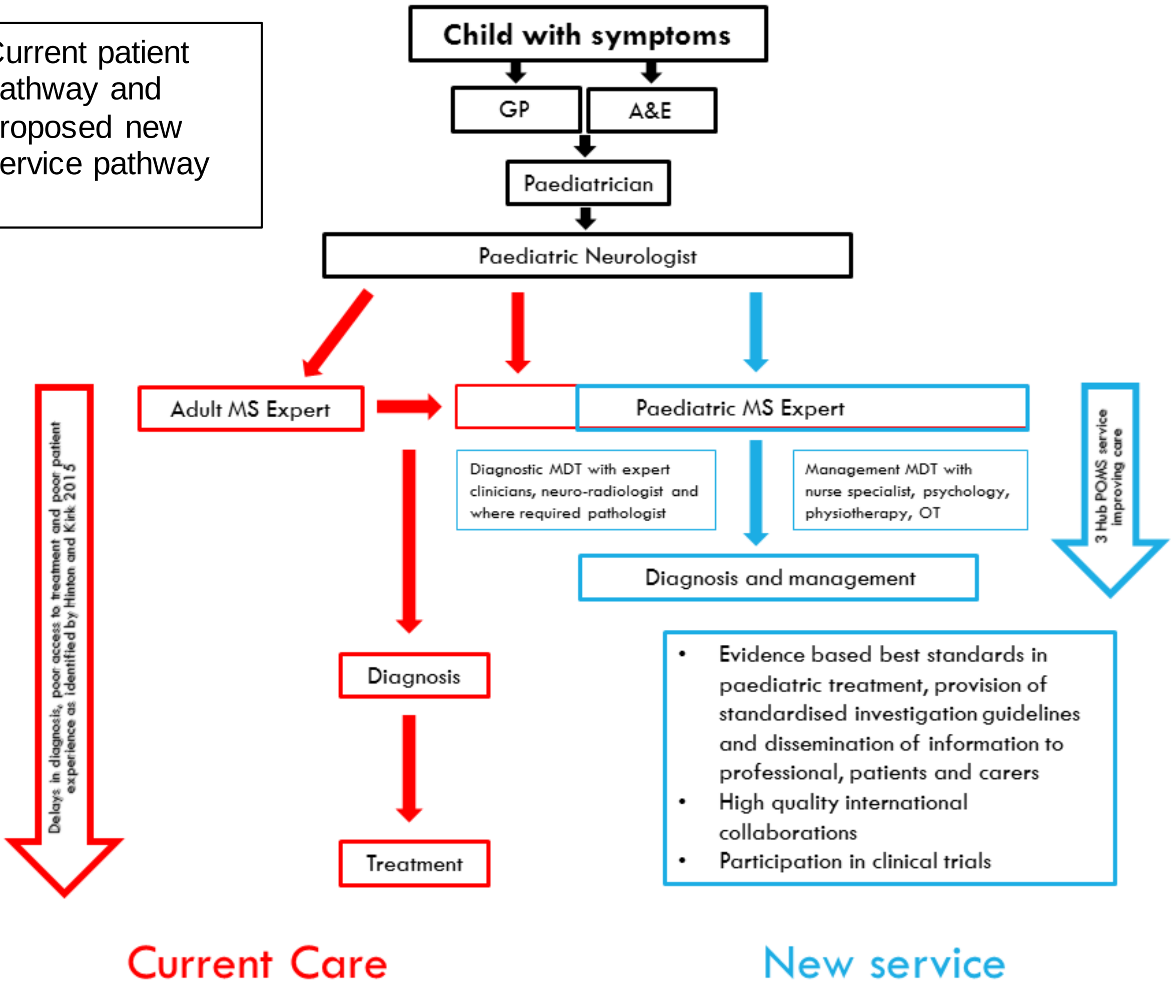
Support and advice for families and carers

The national POMS service will educate and share clinical insight with patients and families/carers to ensure that they are appropriately supported and are provided with appropriate information about the condition, countering previous gaps (National MS Society Meeting, London 2007; Hinton and Kirk 2015 *Arch Dis Child*. **100(7):**623-9).

Current and proposed pathways

The diagram below illustrates the current patient pathway and proposed new service.

Current patient pathway and proposed new service pathway



2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	**Preventing people from dying prematurely**	✓
Domain 2	**Enhancing quality of life for people with long-term conditions**	✓
Domain 3	**Helping people to recover from episodes of ill-health or following injury**	✓
Domain 4	**Ensuring people have a positive experience of care**	✓
Domain 5	**Treating and caring for people in a safe environment and protecting them from avoidable harm**	✓

The service will cover acquired recurrent demyelination of the central nervous system in childhood for the following conditions:

- paediatric Onset Multiple Sclerosis
- first demyelination with high risk of relapse
- recurrent demyelination syndromes presenting with optic neuritis (ON), acute transverse myelitis (ATM), acute disseminated encephalomyelitis (ADEM), aquaporin-4 (AQP4) antibody positive neuromyelitis optica (NMO) and NMO spectrum disorders (NMOSD) (for NMO/SD we will work alongside the existing nationally commissioned NMO service), and other antibody-mediated demyelination.

The service will address gaps in early diagnosis, care provision and treatment availability of POMS and related conditions in England, resulting in major health benefits and will ultimately result in cost savings across primary and secondary care.

The service should rectify differences identified in England across Domains 1 to 5 as follows:

Domain 1: Preventing people from dying prematurely

POMS and its related disorders have effective treatments available that are generally well tolerated by patients. Importantly, such treatments are beginning to show not only the benefits of slowing disability, but also the promise to reverse disability, thus preventing people from dying prematurely. These therapies though can have serious side effects, and need to be used judiciously and monitored appropriately. Failure to do this can have serious consequences. New therapies are constantly being evaluated, approved and introduced for the treatment of adult MS. The European Medical Agency (EMA) now mandates a Paediatric Investigation Plan (PIP) for all such new therapies and there is thus an increasing demand to evaluate these new medications rigorously in the paediatric population. The national programme should co-ordinate clinical trials with the potential to increase life expectancy and quality by reducing disability and suffering.

Domain 2: Enhancing Quality of Life for people with long-term health conditions

Overarching indicators:

- preventing the development of motor and cognitive disability
- high quality assessment of cognitive difficulties and provision of recommendations to educational systems to promote learning in those with disability
- management of fatigue, mood and psychiatric health to ensure full participation
- patient Quality of Life (QL) indicators, which will include access to full time education, hospital admissions, participating in social and extracurricular activities, and transitioning into vocational training and employment

Improvement area:

- the service should provide a patient registry and platform to enable systematic studies to be performed
- consistent neurocognitive and neuropsychiatric assessment and treatment of all patients

Domain 3: Helping people to recover from episodes of ill-health or following injury

Overarching indicators:

- relapse rate reduction towards the ideal of NEDA (no evidence of disease activity)
- where this is not possible-
    - early recovery following relapse (institution of early appropriate therapy)
    - enhanced recovery following relapse (rehabilitation) with early access to local MDT

Improvement area:

- early access to appropriate disease modifying therapy
- early access to MDT assessment following first presentation and at relapse
- access to cognitive, psychiatric and fatigue diagnosis and treatment.

Early diagnosis, care provision and treatment availability across the UK in POMS will reduce the burden of disease on patients and family. A key area identified as a weakness has been the inadequate diagnosis of POMS and its related conditions. Other unnecessary delays in initiating treatment include inherent logistical delays such as consistent supply and delivery of treatment to patient at home. A robust process will be required for patients presenting with the first demyelinating event through to subsequent relapses.

A key role of the service will be to identify the most efficient way to deliver this complex pathway nationally, and set appropriate measures by which the quality of service could be evaluated.

Domain 4: Ensuring that people have a positive experience of care

Overarching indicator:

- patient experience of hospital and out of hospital healthcare

Improvement area:

- patient experience of in-patient and outpatient services

The POMS service will provide outcomes data on:

- the number of people who are referred to specialist care with POMS and related conditions.
- patient experience of outpatient services through a patient questionnaire developed and validated following collation from two childhood studies commissioned by the MS Society (Hinton and Kirk 2015 Arch Dis Child. 100(7):623-9; Carroll and Chalder, Study in Progress),

Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm

Overarching indicator:

- patient safety incidents reported
- safety incidents involving severe harm or death

Improvement area:

- incidence of deviation from treatment monitoring pathways or medication errors resulting in significant harm to patients as defined by the Clinical trials classification of adverse events (CTCAE). Patients with NMO treated with MS treatments have been observed to have severe exacerbation of demyelination.
- robust pathways for ensuring appropriate, local, cost-effective monitoring for potential complications of treatments.

With the use of highly specialised drugs which are required for the management of POMS and related conditions, complex procedural pathways will be required. Hub Lead Centres will deliver these treatments, the majority of which have significant inherent risks and require high levels of expertise to manage. The Hub Lead Centre MDT meeting will evaluate and propose best treatment options for patients based on the best risk/benefit ratio for that individual.

3. Scope

3.1 Aims and objectives of service

Aim

The aim of the service is to provide a highly specialised, multi-centre Hub and Spoke POMS service that will provide consistently high quality healthcare, promote early diagnosis and enable access to therapy for all patients with Paediatric Onset Multiple Sclerosis (POMS) and related disorders. Hubs will be based in the North, Middle and South of England dependent on pre-existing expertise. Hubs will provide multidisciplinary education for local healthcare professionals and collaboration on national and international research to further advances in long term care.

The service will support and work together with local providers and networks, enabling the patients to be managed and treated as close to home as possible.

Objectives

The National POMS service will deliver this aim by:

- providing a Hub and Spoke service that will comprise three Hubs, each with a named Hub Lead Centre which will establish a network with the participating specialist acute spoke units for the management of children with POMS in their geographic area.
- Hub Lead Centres will jointly provide a multicentre assessment that will be undertaken as a virtual clinic; this will offer advice regarding diagnosis (following review of history examination and specialist investigations) and further management. In cases of first line treatment failure, the MDT will suggest escalating treatment in an appropriate manner.
- Hub Lead Centres will provide a multi-disciplinary demyelination clinic where patients will be reviewed and managed jointly in shared care with the referring local hospital team.

Hub Lead Centres will promote education to develop expertise within their Hub area and jointly develop evidence-based best standards in paediatric MS treatment, provision of standardised investigation guidelines and dissemination of information to professionals, patients and carers.

3.2 Service description/care pathway

Service description

Diagnosis and comprehensive management of patients with POMS, rare recurrent demyelination syndromes and first demyelination with high risk of relapse which will be delivered from the Hub Lead Centres, each of which will:

- provide strategic coverage of their identified geography in England
- have a paediatric neurologist with a special interest in MS who sees patients with MS and other complex demyelination and neuroinflammatory disorders
- provide a multi-disciplinary demyelination clinic where patients can be reviewed and treated, given the complexity of selecting the most appropriate agents and course length with the newer treatments available for POMS and its related conditions.

The Hub and Spoke networks will provide: MDT decision-making undertaken by teams experienced in the treatment of POMS; the appropriate initiation of treatment; and continued surveillance of patients. Hub Lead Centres will work with their spoke units to further develop expertise, thereby ensuring better equity of access and improved outcomes for patients.

Hub Lead Centres will jointly provide multicentre assessment that will be undertaken as a virtual clinic, offering advice on diagnosis (following review of history, examination and specialist investigations). Advice will be given to clarify diagnosis and on further management.

Expert-led MDTs in Hub Lead Centres will support the best quality of clinical care and enable clinically appropriate and cost effective prescribing of high cost drug treatments in accordance with NHS England policy/NICE Technology Appraisals as they become available.

In addition, when required, Hub Lead Centres will support tertiary centres by providing a second opinion for patients with severe MS-related disability and complex patients in whom there has been a failure in response to initial treatments to reduce inflammation, (initial treatments are referred to as first line disease modifying treatment (DMT).

Staffing

The multi-professional clinic in each Hub Lead Centre will include the following experts: paediatric neurologist, neuroradiologist, clinical nurse specialist, neuropsychologist, plus other staff members as required (e.g. psychiatry, occupational and physiotherapy).

The Hub and Spoke network model will support:

- a specified network of care for POMS with a named Hub Lead Centre hosting the virtual MDT
- specialised centres with a caseload to develop and maintain expertise in the treatment of the condition
- MDT decision-making by experienced teams on the appropriateness of continued surveillance or initiation of treatment in affected patients and the optimal treatment regimen to use
- oversight of treatments with the potential for serious side effects requiring specialist support and expertise on the range of drug on drug interactions
- access to treatment services locally through partnership and outreach models
- optimal partnership working with local experts to engage hard to reach groups in treatment programmes
- cost-effective use of high cost drug treatments in accordance with national NHS England

policy/ NICE TAs and guidelines
- co-ordination of treatment trials
- development of an adult transition pathway
- development of research to support future commissioning policy
- development of a national database of treatment and outcomes
- education, patient information and professional awareness of POMS and related conditions
- collaboration with adult Multiple Sclerosis specialists to facilitate transition planning.

The service will enable better access to clinical therapeutic trials, contributing to the evidence base for treatment. Commercial trials that provide investigative medicinal product (IMP) will have the added benefit of cost savings to the NHS England drug budget.

Overview of the POMS service

- a network of three geographic Hubs dependent on pre-existing expertise which will provide care for POMS, each with a named Hub Lead Centre hosting the regional MDT and supporting the co-ordination of care at the spoke units in its identified geographic area
- each Hub Lead Centre will have a virtual MDT, with all clinical disciplines represented including at least three paediatric neurologists with an interest in MS, one neurorehabilitation consultant, MS Clinical Nurse Specialists and one neuro-radiologist with experience in the management of recurrent demyelination syndromes. At least once a year, all Hub Lead Centres will join together in a single, virtual MDT meeting
- Hub Lead Centres will provide emergency cover within and across the Hubs as part of a rota to cover both clinical and clinical trial patients
- there will be partnership and outreach models across all units which will ensure the promotion of local access to treatment, the optimisation of partnership working and the use of local expertise in engaging hard to reach groups in treatment programmes
- education about POMS and associated diseases will be delivered in a constructive and sympathetic manner. Educational material will be developed and made available for medical staff, as should suitable age-specific and patient information sheets to patients and their families/carers
- all Hub Lead Centres and spoke units will adhere to clinically and cost effective use of high cost drug treatments in accordance with NHS England policy / NICE TAs
- all Hub Lead Centres and spoke units will contribute to network audit and research to support future commissioning policy
- all Hub Lead Centres and spoke units will contribute to national data collection of treatment and outcomes and support development of a national database
- there will be agreement on the respective providers' roles and the partnership arrangements within the service
- the service will reach agreement on the provision and support of outreach and in-reach within the constraints of the funded service.

Inpatient and outpatient service criteria

Each of the specialist POMS Service Hub Lead Centres will put the following criteria in place, see below for the description of each:

- **appropriate expertise and caseload**
- **dedicated specialist nursing support**
- **access to an MDT for the acute and follow-up evaluation of patients**
- **Appropriate paediatric and relevant clinical support**
- **Appropriate infrastructure**
- **Robust patient support processes**

1) Appropriate expertise and caseload:

- demonstration of a caseload of complex and non-complex patients to develop and maintain expertise in the treatment of POMS and related conditions
- a substantive body of consultant paediatric neurologists to manage acute childhood demyelination and its complications
- access to neuro-imaging and a designated radiologist to discuss and report neuro-imaging

2) Dedicated specialist nursing support:

- allocation of MS Clinical Nurse Specialist time to deal with the number of patients being treated. The nursing resource should take into account the network role, the patient caseload and clinical commitments. A minimum of one dedicated nurse specialists should be designated in each specialist centre plus cross-cover.

3) Access to an MDT for the acute and follow-up evaluation of patients:

- access to psychology (clinical and educational) for assessment, rehabilitation of individual patients and advice for other patients.
- access to physiotherapy and occupational therapy for assessment, rehabilitation of individual patients and advice for fatigue management
- MDT Members who have a designated role but need not work exclusively with the service.

4) Appropriate paediatric and relevant clinical support:

- access to paediatric specialities required to support the management of children with complex and recurrent demyelination
- access to appropriate laboratory support for the diagnosis and management of POMS and related conditions.
- a designated pharmacist(s) (full or part time) to manage pharmaceutical needs of patients including adherence support, medication review, provision of specialist medications and advice about drug interactions
- a dedicated adult neurologist with an expertise in MS who will provide support for transition of care
- links to primary care and community services and secondary care paediatricians.

5) Appropriate infrastructure:

- dedicated ring-fenced clinic facility
- an administrator with appropriate supporting staff to provide administrative support to the network (mandatory for lead centre). This will be an essential element to achieve value-based returns for commissioners and to ensure best equity and access for patients locally
- facilities (including teleconferencing facilities) for multi-disciplinary meetings which are accessible by all out-reach services
- administrative support to ensure accurate recording of information, and timely

communication of decisions to patients and other care providers

6) Robust patient support processes:
- provision of adherence support
- access to welfare advice and support

Hub Lead Centres will adequately provide all components of the service requirement (Criteria 1) to 6)); and work with the spoke units in their hub to establish and develop expertise (Criteria 1)) and provide selective components of specialist nursing (Criteria 2)) and MDT support (Criteria 3)).

All participating centres will be expected to meet criteria 4) to 6).

Shared Care

Shared care will be a key part of the service model, with local specialists providing follow- up as required and links developed with local services.

Education and training

The POMS Hub Lead Centres will undertake a training and education role including:

- training of professionals working within the centre, such as trainee doctors and nursing staff.
- education for professionals within referring units such as meetings, workshops educational material
- education for other agencies such as education, social services

Education about POMS and its consequences is of great importance and will be delivered in a constructive and sympathetic manner. Educational material, both literature and web based will be developed for patients and their families/carers, with age appropriate material where relevant.

Documentation and Information Technology

Following each multidisciplinary clinic, the staff will produce a single clinic letter which will integrate the reports from each clinician. This will be sent out to the patient and their family or carer; the patient's GP/and/or specialist.

POMS clinic notes and correspondence be will be stored at each centre (computerised) and included in the hospital-wide computerised patient records of the patient. The provider local administrator will have responsibility for ensuring safe storage and adherence to the Data Protection Act (1998) for computerised data. Offsite backup storage will also be arranged.

Facilities

Each centre will have designated conference room facilities with electronic image viewing facilities (PACs and IEP) and video-conferencing facilities to enable diagnostic MDTs.

Paediatric Outpatient facilities will include facilities for height, weight, consultation and discussion, image viewing, blood taking, urine measurement and blood pressure (BP) measurement.

Equity of access to services

Service access is paramount to success. As outlined above, it is not expected that all patients will need to travel to specialised centres.

Therefore, the service will be tiered so that as much of the specialist care as possible will be delivered by local specialist clinicians, with the patient only travelling to the highly specialised national centres when there is need for additional review or input.

Risk Management

Services delivered by POMS service providers must be of a nature and quality to meet the standards, specification and agreement for the service. It is the provider Trust's responsibility to notify the commissioner on an exceptional basis should there be any breaches of the standards. Where there are breaches any consequences will be deemed as being the Trust's responsibility.

3.3 Population covered

Children under the age of 18 with a demyelination syndrome as set out in Section 3.4 - Patient referral.

The service outlined is for patients ordinarily resident in England*; or otherwise the commissioning responsibility of the NHS in England (as defined in Who Pays?: Establishing the responsible commissioner and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127393).
*Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP Practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP Practice in England.

3.4 Any acceptance and exclusion criteria and thresholds

Acceptance criteria

The service will accept referrals of patients with a demyelination syndrome where any of the listed conditions are established or being considered:-

- paediatric Onset Multiple Sclerosis
- recurrent demyelination syndromes presenting with optic neuritis (ON), acute transverse myelitis (ATM), acute disseminated encephalomyelitis (ADEM), aquaporin-4 (AQP4) antibody positive neuromyelitis optica (NMO) and NMO spectrum disorders where the service will work alongside the existing nationally commissioned NMO service; and other antibody mediated demyelination.

- first demyelination with high risk of relapse

All eligible patients will have access to care and treatment services irrespective of their sexual orientation, gender, race, disability, psycho-social circumstances or geographical location. An important feature of all services is that appropriate pathways are developed for socially disadvantaged patients who are often difficult to engage.

Exclusion Criteria

Patients managed in the Highly Specialised Service for neuromyelitis optica will continue to be managed in that service.

Transition

The careful management of children from the children's POMS service through to adult services will prevent children from feeling vulnerable and anxious. The service will manage transition by setting out clear communications and processes, and establishing links with regional adult services.

A careful transition plan for the patient will begin at 12 years of age, with identification of the respective adult service, and then tailored depending on the specific problems identified for the child until transfer at 17 years and 11 months.

Transition will be co-managed and co-ordinated between the paediatric and adult services, with respective services providing specific input.

3.5 Interdependencies with other services/providers

Within each Hub Lead Centre, the service will demonstrate that it has well-established links to:-

- neurorehabilitation services ranging from specialist spinal units to neurocognitive services
- formal links to other specialist centres to facilitate transfer of care as required
- formal pathways to support transition of paediatric patients to adult services as required
- formal pathways to transition paediatric MS patients on trials to adult research facilities
- child and adolescent mental health services for patients with significant mental health needs – ranging from third sector support services to clinical psychology, liaison psychiatry and liaison with community mental health services in patients' place of residence.
- third sector services to support adherence, peer support and self-management programmes

The POMS service will also ensure that it describes the links and interfaces of its services and care with other relevant pathways and organisations (e.g. Local Authorities) as required.

4. Applicable Service Standards

4.1 Applicable national standards e.g. NICE

None currently but will be adapted from the adult NICE guidance.

4.2 Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)

To follow

4.3 Applicable local standards

The providers of the service must ensure they are fully integrated into their Trust's corporate and clinical governance arrangements and must comply fully with clinical negligence scheme for trusts (CNST) and Care Quality Commission (CQC) requirements in terms of quality and governance.

5. Applicable quality requirements and CQUIN goals

5.1 Applicable quality requirements (See Schedule 4 Parts A-D)

- patients receiving disease modifying therapy will have a named care provider
- patients initiating therapy must have been discussed at a POMS MDT meeting with documentation of the recommendations provided to the patient, general practitioner and local paediatric services.
- delay in treatment initiation should be discussed if this exceeds four weeks from network target
- networks must develop a plan to improve partnership working
- a minimum defined standardised data set should be agreed and collected on all patients throughout their treatment course

There is a requirement to hold national audit meetings involving all designated centres on an annual basis.

Each Hub Lead Centre must assure that:-

- all practitioners participate in continuous professional development and networking
- patient outcome data is recorded and audited across the service
- all spoke units must participate in the national audit commissioned by NHS England.

Audit meetings should address:

- clinical performance and outcomes
- process-related indicators, such as efficiency of the assessment process, prescribing policy, bed provision and occupancy, outpatient follow-up.
- stakeholder satisfaction, including feedback

5.2 Applicable CQUIN goals (See Schedule 4 Part E)

To be agreed with the commissioner.

6. Location of Provider Premises

The Provider’s Premises are located at:

The POMS service will comprise three Hubs, each with a Hub Lead Centre networking with a number of identified specialist acute spoke units across a defined geographic area – these will be defined through the compliance process.

7. Individual Service User Placement

Not Applicable

Glossary of Terms		
	Autoimmune	An **autoimmune** disorder occurs when the body's immune system attacks and destroys healthy body tissue by mistake.
CNS	Central Nervous System	The nervous system is made up of two main components: the central nervous system (CNS) and the peripheral nervous system (PNS): The CNS consists of the brain and the spinal cord, and contains billions of specialised cells known as neurons. Neurons have specialised projections called dendrites and axons that contribute to their unique function of transmitting signals throughout the body. Dendrites carry electrical signals to the neuron, while axons carry them away from the neuron. The PNS consists of the nerves and nerve cells that are outside the brain and spinal cord.
CTCAE	Common Terminology Classification of Adverse Events	The NCI Common Terminology Criteria for Adverse Events v3.0 is a descriptive terminology which can be utilised for Adverse Event (AE) reporting. A grading (severity) scale is provided for each AE term http://ctep.cancer.gov/protocolDevelopment/electronic_applications/docs/ctcaev3.pdf
	Demyelination, demyelinating episode	An immune dysregulation (impairment) involving the nervous system in which the myelin sheath of central nervous system neurons is damaged. This damage reduces the conduction of signals in the affected nerves and results in long term scarring.
IMP	Investigative medicinal product	The active treatment that is tested in a clinical trial
MDT	Multi-Disciplinary Team	Team of specialists composed of members from different healthcare professions with specialised skills and expertise. The members collaborate together to make treatment recommendations that facilitate quality patient care.
MS	Multiple Sclerosis	Multiple sclerosis (MS) is a neurological condition which affects around 100,000 people in the UK. Most people are diagnosed between the ages of 20-40, but it can affect younger and older people too
NEDA	No evidence of disease activity	A newly evolving concept of using a wider range of clinical and investigative measures to make sure the condition is dormant whilst on treatment
NICE	National Institute for	https://www.nice.org.uk/about

TA	Health and Care Excellence – Technology Appraisal	The National Institute for Health and Care Excellence (**NICE**) provides national guidance and advice to improve health and social care. Technology appraisals are mandatory recommendations on the use of new and existing medicines and treatments within the NHS. These can include the use of medicines, medical devices, such as hearing aids or inhalers or diagnostic techniques - tests used to identify diseases.
NMO	Neuromyelitis optica	Condition where there in immune mediated inflammation in the spine and eyes

References

(Absoud et al., 2013; Banwell et al., 2007; Goretti et al., 2012; Harding et al., 2013; Hinton and Kirk, 2015; Krupp et al., 2013)

Absoud, M., et al., 2013. Paediatric acquired demyelinating syndromes: incidence, clinical and magnetic resonance imaging features. Mult Scler. 19, 76-86.
Banwell, B., et al., 2007. Multiple sclerosis in children: clinical diagnosis, therapeutic strategies, and future directions. Lancet Neurol. 6, 887-902.
Goretti, B., et al., 2012. Fatigue and its relationships with cognitive functioning and depression in paediatric multiple sclerosis. Mult Scler. 18, 329-34.
Harding, K.E., et al., 2013. Long-term outcome of paediatric-onset multiple sclerosis: a population-based study. J Neurol Neurosurg Psychiatry. 84, 141-7.
Hinton, D., Kirk, S., 2015. Paediatric multiple sclerosis: a qualitative study of families' diagnosis experiences. Arch Dis Child. 100, 623-9.
Krupp, L.B., et al., 2013. International Pediatric Multiple Sclerosis Study Group criteria for pediatric multiple sclerosis and immune-mediated central nervous system demyelinating disorders: revisions to the 2007 definitions. Mult Scler. 19, 1261-7.

Appendix One

PROVISION OF SERVICES TO CHILDREN

Aims and objectives of service

This specification annex applies to all children's services and outlines generic standards and outcomes that would fundamental to all services.

The generic aspects of care:

The Care of Children in Hospital (Health Service Circular 1998/238) requires that:

- Children are admitted to hospital only if the care they require cannot be as well provided at home, in a day clinic or on a day basis in hospital.
- Children requiring admission to hospital are provided with a high standard of medical, nursing and therapeutic care to facilitate speedy recovery and minimize complications and mortality.
- Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities.
- Children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care.
- Good child health care is shared with parents/carers and they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interest of the child. Accommodation is provided for them to remain with their children overnight if they so wish.

Service description/care pathway

All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.

The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease.

Services should therefore be organised and delivered through "integrated pathways of care" (National Service Framework for children, young people and maternity services (Department of Health & Department for Education and Skills, London 2004)

Interdependencies with other services

All services will comply with *Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies* – Department of Health (DH)

Imaging

All services will be supported by a 3 tier imaging network ('Delivering quality imaging services for children' DH 13732 March 2010). Within the network:

- It will be clearly defined which imaging test or interventional procedure can be performed and reported at each site
- Robust procedures will be in place for image transfer for review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements

- Robust arrangements will be in place for patient transfer if more complex imaging or intervention is required
- Common standards, protocols and governance procedures will exist throughout the network.
- All radiologists, and radiographers will have appropriate training, supervision and access to continuing professional development
- All equipment will be optimised for paediatric use and use specific paediatric software.

Specialist Paediatric Anaesthesia

Wherever and whenever children undergo anaesthesia and surgery, their particular needs must be recognised and they should be managed in separate facilities, and looked after by staff with appropriate experience and training.1 All UK anaesthetists undergo training which provides them with the competencies to care for older babies and children with relatively straightforward surgical conditions and without major co-morbidity. However those working in specialist centres must have undergone additional (specialist) training 2 and should maintain the competencies so acquired 3 *. These competencies include the care of very young/premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).

As well as providing essential co-dependent service for surgery specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example MRI scans and percutaneous nephrostomy) and medical interventions (for example joint injection and intrathecal chemotherapy), and for assistance with vascular access in babies and children with complex needs such as intravenous feeding.

Specialist acute pain services for babies and children are organised within existing departments of paediatric anaesthesia and include the provision of agreed (hospital wide) guidance for acute pain, the safe administration of complex analgesia regimes including epidural analgesia, and the daily input of specialist anaesthetists and acute pain nurses with expertise in paediatrics.

*The Safe and Sustainable reviews of paediatric cardiac and neuro- sciences in England have noted the need for additional training and maintenance of competencies by specialist anaesthetists in both fields of practice.

References

1. Guidelines for the Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. RCoA 2010 www.rcoa.ac.uk
2. Certificates of Completion of Training (CCT) in Anaesthesia 2010
3. Continuing Professional Development (CPD) matrix level 3

Specialised Child and Adolescent Mental Health Services (CAMHS)

The age profile of children and young people admitted to specialised CAMHS day/in-patient settings is different to the age profile for paediatric units in that it is predominantly adolescents who are admitted to specialised CAMHS in-patient settings, including over-16s. The average length of stay is longer for admissions to mental health units. Children and young people in specialised CAMHS day/in- patient settings generally participate in a structured programme of education and therapeutic activities during their admission.

Taking account of the differences in patient profiles the principles and standards set out in this specification apply with modifications to the recommendations regarding the following:

- Facilities and environment – essential Quality Network for In-patient CAMHS (QNIC) standards should apply (http://www.rcpsych.ac.uk/quality/quality,accreditationaudit/qnic1.aspx)
- Staffing profiles and training - essential QNIC standards should apply.
- The child/ young person's family are allowed to visit at any time of day taking account of the child / young persons need to participate in therapeutic activities and education as well as any safeguarding concerns.
- Children and young people are offered appropriate education from the point of admission.
- Parents/carers are involved in the child/young person's care except where this is not in the best interests of the child / young person and in the case of young people who have the capacity to make their own decisions is subject to their consent.
- Parents/carers who wish to stay overnight are provided with accessible accommodation unless there are safeguarding concerns or this is not in the best interests of the child/ young person.

Applicable national standards e.g. NICE, Royal College

Children and young people must receive care, treatment and support by staff registered by the Nursing and Midwifery Council on the parts of their register that permit a nurse to work with children (Outcome 14h Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

- There must be at least two Registered Children's Nurses (RCNs) on duty 24 hours a day in all hospital children's departments and wards.

- There must be an Registered Children's Nurse available 24 hours a day to advise on the nursing of children in other departments (this post is included in the staff establishment of 2RCNs in total).

Accommodation, facilities and staffing must be appropriate to the needs of children and separate from those provided for adults. All facilities for children and young people must comply with the Hospital Build Notes HBN 23 Hospital Accommodation for Children and Young People NHS Estates, The Stationary Office 2004.

All staff who work with children and young people must be appropriately trained to provide care, treatment and support for children, including Children's Workforce Development Council Induction standards (Outcome 14b Essential Standards of Quality and Safety, Care Quality Commission, London 2010).

Each hospital who admits inpatients must have appropriate medical cover at all times taking account of guidance from relevant expert or professional bodies (National Minimum Standards for Providers of Independent Healthcare, Department of Health, London 2002)."Facing the Future" Standards, Royal College of Paediatrics and Child Health.

Staff must carry out sufficient levels of activity to maintain their competence in caring for children and young people, including in relation to specific anaesthetic and surgical procedures for children, taking account of guidance from relevant expert or professional bodies (Outcome 14g Essential Standards of Quality and Safety, Care Quality Commission, London 2010).

Providers must have systems in place to gain and review consent from people who use services, and act on them (Outcome 2a Essential Standards of Quality and Safety, Care Quality Commission, London 2010). These must include specific arrangements for seeking valid consent from children while respecting their human rights and confidentiality and ensure that where the person using the service lacks capacity, best interest meetings are held with people who know and understand the person using the service. Staff should be able to show that they know how to take appropriate consent from children, young people and those with learning disabilities (Outcome 2b) (Seeking Consent: working with children Department of Health, London 2001).

Children and young people must only receive a service from a provider who takes steps to prevent abuse and does not tolerate any abusive practice should it occur (Outcome 7 Essential Standards of Quality and Safety, Care Quality Commission,
London 2010 defines the standards and evidence required from providers in this regard). Providers minimise the risk and likelihood of abuse occurring by:

- Ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them
- Ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.
- Ensuring that people who use services are aware of how to raise concerns of abuse.
- Having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern.
- Having effective means of receiving and acting upon feedback from people who use services and any other person.
- Taking action immediately to ensure that any abuse identified is stopped
- and suspected abuse is addressed by:
    - having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
    - separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by removing the opportunity for abuse to occur, where this is within the control of the provider
    - reporting the alleged abuse to the appropriate authority
    - reviewing the person’s plan of care to ensure that they are properly supported following the alleged abuse incident.
- Using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.
- Working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.

- Participates in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- Having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.
- Taking into account relevant guidance set out in the Care Quality Commission's Schedule of Applicable Publications
- Ensuring that those working with children must wait for a full CRB disclosure before starting work.
- Training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010

All children and young people who use services must be:

- Fully informed of their care, treatment and support.
- Able to take part in decision making to the fullest extent that is possible.
- Asked if they agree for their parents or guardians to be involved in decisions they need to make.

(Outcome 4I *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010)

Key Service Outcomes

Evidence is increasing that implementation of the national Quality Criteria for Young People Friendly Services (Department of Health, London 2011) have the potential to greatly improve patient experience, leading to better health outcomes for young people and increasing socially responsible life-long use of the NHS.

Implementation is also expected to contribute to improvements in health inequalities and public health outcomes e.g. reduced teenage pregnancy and STIs, and increased smoking cessation. All providers delivering services to young people should be implementing the good practice guidance which delivers compliance with the quality criteria.

Poorly planned transition from young people's to adult-oriented health services can be associated with increased risk of non-adherence to treatment and loss to follow-up, which can have serious consequences. There are measurable adverse consequences in terms of morbidity and mortality as well as in social and educational outcomes. When children and young people who use paediatric services are moving to access adult services (for example, during transition for those with long term conditions), these should be organised so that:

- All those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services.

The National Minimum Standards for Providers of Independent Healthcare, (Department of Health, London 2002) require the following standards:

- **A16.1** Children are seen in a separate out-patient area, or where the hospital does not have a separate outpatient area for children, they are seen promptly.
- **A16.3** Toys and/or books suitable to the child's age are provided.

- **A16.8** There are segregated areas for the reception of children and adolescents into theatre and for recovery, to screen the children and adolescents from adult patients; the segregated areas contain all necessary equipment for the care of children.
- **A16.9** A parent is to be actively encouraged to stay at all times, with accommodation made available for the adult in the child's room or close by.
- **A16.10** The child's family is allowed to visit him/her at any time of the day, except where safeguarding procedures do not allow this
- **A16.13** When a child is in hospital for more than five days, play is managed and supervised by a qualified Hospital Play Specialist.
- **A16.14** Children are required to receive education when in hospital for more than five days; the Local Education Authority has an obligation to meet this need and are contacted if necessary.
- **A18.10** There are written procedures for the assessment of pain in children and the provision of appropriate control.

All hospital settings should meet the Standards for the Care of Critically Ill Children (Paediatric Intensive Care Society, London 2010).

There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. These require:

- A choice of suitable and nutritious food and hydration, in sufficient quantities to meet service users' needs
- Food and hydration that meet any reasonable requirements arising from a service user's religious or cultural background
- Support, where necessary, for the purposes of enabling service users to eat and drink sufficient amounts for their needs
- For the purposes of this regulation, "food and hydration" includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed
- Providers must have access to facilities for infant feeding, including facilities to support breastfeeding (Outcome 5E, of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards.

All children and young people should have access to a professional who can undertake an assessment using the Common Assessment Framework and access support from social care, housing, education and other agencies as appropriate.

All registered providers must ensure safe use and management of medicines, by means of the making of appropriate arrangements for the obtaining, recording, handling, using, safe keeping, dispensing, safe administration and disposal of medicines (Outcome 9 Essential Standards of Quality and Safety, Care Quality Commission, London 2010). For children, these should include specific arrangements that:

- They are supported to have a health action plan
- Facilities meet the appropriate requirements of the Disability Discrimination Act 1995

They meet the standards set out in Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services. Department of Health, 2006, London.

Appendix Two
Quality standards specific to the service using the following template:

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Domain 1: Preventing people dying prematurely			
Patients initiating therapy should achieve disease remission as currently defined (NEDA)	>50%	Annual - National database	To be addressed in annual service audit meeting
Domain 2: Enhancing the quality of life of people with long-term conditions			
Patients being diagnosed early and have appropriate management should have enhanced QOL	>50%	Annual - Service evaluation and proposed study	To be addressed in annual service audit meeting
Domain 3: Helping people to recover from episodes of ill-health or following injury			
Patients with relapses should be managed promptly in an appropriate acute service with direct liaison with the specialist provider within this service network	>90%	Annual - Service evaluation	To be addressed in annual service audit meeting
Domain 4: Ensuring that people have a positive experience of care			
Patients with a diagnosis of POMS and related condition should have a named care provider within the specialist network	>90%	Annual - Local database	To be addressed in annual service audit meeting

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm			
Patients initiating therapy should have been discussed at a multi-disciplinary meeting with documentation of the recommendations provided to the patient and the general practitioner	> 85% of patients	Annual - Local database	To be addressed in annual service audit meeting