

SCHEDULE 2 – THE SERVICES

A. Service Specifications

| | |
|----------------------------------|---|
| Service Specification No: | 200139S |
| Service | Refractory Epilepsy Specialist Clinical Advisory Service Governing the period 1 st January 2020 – 31 st March 2022, subject to periodic review |
| Commissioner Lead | NHS England, Specialised Services (London Region) |
| Provider Lead | Great Ormond Street Hospital for Children NHS Foundation Trust (<i>Lead TBA</i>) |

1. Scope

1.1 Prescribed Specialised Service

This Service Specification (the 'specification') covers the provision of a specialist Clinical Advisory Service (the 'Advisory Service' or 'Service'), advising and supporting clinicians working with patients to optimise the treatment of refractory epilepsy.

1.2 Description

The Specification establishes a specialist 'clinician to clinician' Clinical Advisory Service covering the geography of the United Kingdom.

The service will host a platform for virtual /digital conferences that will bring together paediatric neurologists with expertise in epilepsy based across the UK in order to provide advice and support in the management of patients. The Service will offer advice and guidance to doctors in tertiary neuroscience centres (including Specialised Paediatric Neuroscience centres). This will include tertiary clinicians able to initiate cannabinoid-based treatments, who may have been approached by other clinicians in their region, supporting children and their families considering new, or changes to, treatment, or supporting ongoing epilepsy treatment under direct or shared care arrangements. This service will be accessed through the regional paediatric neurologists based in tertiary centres/specialist neurosciences centres only (see paragraph 2.2), who in turn manage patients with other clinicians (Paediatricians with interest in epilepsy) jointly in shared care arrangements.

In England, this specification should be read in conjunction with the following published service specifications:

NHS England - Paediatric Neurosciences: Neurology

NHS England - Paediatric Neurosciences: Neurodisability
NHS England - Children's Epilepsy Surgery Service (CESS)

In Wales, this specification should be read in conjunction with the NHS Wales Neurological Conditions Delivery Plan.

1.3 How the Service is Differentiated from Services Falling within the Responsibilities of Other Commissioners

This is a UK wide Service commissioned by NHS England as a specialised service, on behalf of the NHS in England, Northern Ireland, Scotland and Wales. Clinical Commissioning Groups in England do not commission this service.

2. Care Pathway and Clinical Dependencies

2.1 Care Pathway

Children with refractory epilepsy, particularly those with complex co-morbidities, require a sustained and integrated network of care involving a variety of specialist organisations and professionals often over a prolonged period. Services operate within managed networked pathways to provide care that revolves around the individual child's needs.

Consideration should be given to the breadth of available treatments including non-medical treatments (e.g. diet), drug-based therapies and, where appropriate, surgery.

Where it is appropriate to consider a cannabinoid-based product for medicinal use, clinicians must be on the Specialist Register in a relevant sub-speciality and clinicians should prescribe only within the area of expertise associated with the relevant specialist registration. For children with intractable epilepsy, any potential prescription of a cannabinoid derivative should be initiated by a Consultant Paediatric Neurologist from a tertiary neuroscience centre.

The Service will be able to provide advice on good prescribing practice, BPNA guidance, the latest position on licenced indications, NICE guidance and guidelines, NHS England clinical commissioning policies, available clinical trials and other relevant networks (e.g. specialist epilepsy surgery). Advice from an expert panel will also be provided to paediatric neurologists where a patient or family seeks treatment outside of national guidance / guidelines, particularly where there is a concern that doing so might not be in the patient's best interests.

The Service is advisory only and the responsibility for initiating and monitoring treatment remains with patient's paediatric neurologist.

2.2 Access to the Network

Clinicians must initially seek advice from their local tertiary neurosciences centre, in line with existing local, regional or national networked arrangements. The paediatric neurologist will then request, if required, the support of the 'National Advisory Service'.

Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) will act as the point of contact for the national Advisory Service, supporting paediatric neurology consultants who wish to discuss/seek additional advice about identifying and optimising any further treatment options. GOSH will host and facilitate the discussion through a panel of established specialists nationally and internationally.

GOSH, together with the national specialist organisation for Paediatric Neurologists (the BPNA) will have in place guidelines, pathways and protocols with other paediatric neurology tertiary centres to support access to the advisory service. A variety of appropriate portals for referral will be in place, including nhs.net email, and telephone.

GOSH will provide administrative, data and video-conferencing support to the MDT, which will include consultant level paediatric neurology, pharmacy, neuroradiology, neurophysiology and genetics input.

The service will acknowledge all referrals within two working days and, for accepted referrals, confirm the planned national MDT meeting date to referrers within 5 working days. Only in very urgent cases (i.e. patients requiring decisions whilst on intensive care) will interim advice be provided pending formal discussion in the next available MDT meeting. MDT meetings will be held fortnightly.

Written advice will be provided to the referrer within 5 working days of the MDT meeting at which the referral has been discussed.

The BPNA and relevant administrations (e.g. NHS England, NHS Wales etc) will ensure that information about how to access the Service is cascaded to relevant clinicians.

2.3 Access to Trials

It is recognised that more evidence is required to support current and future treatment options. The Service will keep up to date with planned and open trials and support clinicians wishing to identify trials potentially relevant to their patient(s).

2.4 Interdependence with other Services

The Service is consultant led, supported by a pharmacy team specialising in paediatrics.

3. Population Covered and Population Needs

3.1 Population Covered By This Specification

The Service outlined in this Specification is for clinicians responsible for the care of patients of all ages resident in the UK, and falling within the commissioning responsibilities of the NHS in England, Northern Ireland, Scotland and Wales (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).

3.2 Population Needs

Epilepsy is one of the most common serious neurological conditions. It affects around 600,000 people in the UK. This means that almost 1 in 100 people in the UK have epilepsy.

Refractory, or drug resistant, epilepsy occurs in around 25-30% of patients and is where a person has failed to achieve adequate seizure control with adequate trials of two or more anti-epileptic drugs (AEDs), taken individually or in combination.

3.3 Expected Significant Future Demographic Changes

Not applicable.

3.4 Evidence Base

The advice provided by the Service will be based on the available evidence.

4. Outcomes and Applicable Quality Standards

4.1 Quality Statement – Aim of Service

The aim of the Advisory Service is to offer timely and evidence-based specialist advice and guidance from a UK national expert panel to tertiary paediatric neurology consultants, who jointly manage patients with other clinicians in order to support local discussions in relation to the treatment of refractory epilepsy.

The Service will also act as a source of advice to NHS commissioners in England and Wales in responding to individual patient funding requests linked to treatments for refractory epilepsy.

The Service will collect data regarding requests for advice, and the advice given to inform future Service provision.

NHS Outcomes Framework Domains

| | | |
|----------|--|---|
| 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 safe environment and protecting them from avoidable harm | √ |

4.2 Indicators Include:

| Number | Indicator | Data Source | Outcome Framework Domain | CQC Key question |
|--------------------------|--|--------------------|--------------------------|-----------------------|
| Clinical Outcomes | | | | |
| 101 | The proportion of referrals acknowledged two working days of receipt | Provider submitted | 2, 4, 5 | responsive, effective |
| 102 | The proportion of accepted referrals for which a MDT date is confirmed to the referrer within 5 or less working days | Provider submitted | 2,4,5 | responsive, effective |

| | | | | |
|------------------------------|---|--------------------|------------|---------------------------------------|
| 103 | The proportion of accepted referrals for which written advice has been provided within 5 or less working days of the MDT meeting at which the referral has been discussed | Provider submitted | 2,4,5 | responsive, effective |
| 104 | The proportion of accepted referrals for which urgent advice has been provided ahead of formal MDT discussion | Provider submitted | 2,4,5 | responsive, effective |
| 105 | The number of referrals received from the North West region | Provider submitted | 2, 4, 5 | responsive, effective |
| 106 | The number of referrals received from the North East and Yorkshire region | Provider submitted | 2, 4, 5 | responsive, effective |
| 107 | The number of referrals received from the East of England region | Provider submitted | 2, 4, 5 | responsive, effective |
| 108 | The number of referrals received from the Midlands region | Provider submitted | 2, 4, 5 | responsive, effective |
| 109 | The number of referrals received from London region | Provider submitted | 2, 4, 5 | responsive, effective |
| 110 | The number of referrals received from the South East region | Provider submitted | 2, 4, 5 | responsive, effective |
| 111 | The number of referrals received from the South West region | Provider submitted | 2, 4, 5 | responsive, effective |
| 112 | The number of referrals received from Northern Ireland | Provider submitted | 2, 4, 5 | responsive, effective |
| 113 | The number of referrals received from Scotland | Provider submitted | 2, 4, 5 | responsive, effective |
| 114 | The number of referrals received from Wales | Provider submitted | 2, 4, 5 | responsive, effective |
| 115 | The proportion of referrals directed to alternative treatment options excluding clinical trials. | Provider submitted | 2, 4, 5 | responsive, effective |
| 116 | The proportion of patients directed to clinical trials | Provider submitted | 2, 4, 5 | responsive, effective |
| 117 | The number of instances where the service provider has sought advice from other national or international teams | Provider submitted | 2, 4, 5 | responsive, effective |
| Structure and Process | | | | |
| 301 | The Refractory Epilepsy Specialist Clinical Advisory Service is established as detailed in the service specification. | Self declaration | 2, 4, 5 | well led, effective, responsive, safe |
| 302 | The MDT is constituted as per the service specification | Self declaration | 2,4,5 | well led, effective, responsive, safe |
| 303 | The service provider has a process in place to record the advice offered. | Self declaration | 4, 5 | well led, effective, responsive, safe |
| 304 | The service provider has an agreed communication framework. | Self declaration | 4, 5 | well led, responsive |
| 305 | There are agreed access guidelines as per the service specification. | Self declaration | 1, 2, 3, 5 | safe, effective, caring. |
| 306 | The service provider reports to NHS England on a quarterly basis. | Self declaration | 4,5 | safe, effective |

| | | | | |
|---|--|------------------|---------|-----------------|
| 307 | The service provider reviews the advice offered at least annually and liaises with tertiary service providers. | Self declaration | 4, 5 | safe, effective |
| 308 | The provider considers all patients for research, clinical trials and other well designed studies, where available | Self declaration | 2, 4, 5 | safe, effective |
| 4.3 Commissioned providers are required to participate in annual quality assurance and collect and submit data to support the assessment of compliance with the service specification as set out in Schedule 4A-C | | | | |
| 5. Applicable Service Standards | | | | |
| 5.1 Applicable Obligatory National Standards NICE Technology Appraisal (TA614) Cannabidiol with clobazam for treating seizures associated with Dravet syndrome. Published 18 th December 2019. NICE Technology Appraisal (TA615) Cannabidiol with clobazam for treating seizures associated with Lennox–Gastaut syndrome. Published 18 th December 2019. [England only]: Care Quality Commission (CQC) Interim policy position on cannabis-based medicinal products. Published 31 st October 2019. [England only]: NHS England Children’s Epilepsy Surgery Services (CESS) Service Specification. Published January 2018. | | | | |
| 5.2 Other Applicable National Standards NICE Guideline (NG144) Cannabis-based Medicinal Products. Published November 2019 BPNA Guidance on the Use of Cannabis-based Products for Medicinal Use in Children and Young People with Epilepsy October 2018 [Scotland only:] Scottish Intercollegiate Guideline Network (SIGN) guideline 143 - diagnosis and management of epilepsy in adults | | | | |
| 5.3 Other Applicable Local Standards Not applicable. | | | | |
| 6. Designated Provider | | | | |
| Great Ormond Street Hospital for Children NHS Foundation Trust. | | | | |
| 7. Abbreviation and Acronyms Explained | | | | |
| The following abbreviations and acronyms have been used in this document: BPNA - the British Paediatric Neurology Association GOSH - Great Ormond Street Hospital for Children NHS Foundation Trust NHS – the National Health Service NICE – the National Institute for Health and Care Excellence | | | | |

Date published: January 2020
First Planned Service Review: August 2020