

Document Detail		
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Document name	Referral Protocol and Pathway for: <ol style="list-style-type: none"> 1. Tertiary review 2. Children's Epilepsy Surgery Service (CESS) including Vagal Nerve Stimulation (VNS) 3. CESS Referral Proforma For Children and Young People living within South Thames Paediatric Network (South East London, South West London, Kent & Medway, Surrey Heartlands and Sussex ICSs)	
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Relevant external law, regulation, standards	National Bundles of Care for Epilepsy NHS England » National bundle of care for children and young people with epilepsy NICE Overview Epilepsies in children, young people and adults Guidance NICE SETPEG Home South East Thames Paediatric Epilepsy Group (setpeg.net)	
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Date	Change details, since approval	Approved by

Index	
Slide 1	Title page
Slide 2	Index
Slide 3	Referral Protocol and Pathway for Tertiary Review
Slide 4	Routine and Urgent referral details
Slide 5	Protocol and Pathway for Referral to CESS and VNS
Slide 6	Criteria for Referral to CESS Services including VNS
Slide 7	CESS pathway
Slide 8	VNS pathway
Slide 9	CESS Referral Proforma

1. Referral Protocol and Pathway for Tertiary Review

All Children and Young People (CYP) with Epilepsy who meet criteria for Tertiary Neurology referral should have timely access to a review by a tertiary specialist with an expertise in managing complex Epilepsy. **Referrals will be accepted from Secondary or Tertiary care (hospital or community based) only.**

The review may be an initial discussion between the referring team and Tertiary specialist or via a MDT discussion. The review should be within two to four weeks from referral depending on criteria set out in NICE guidelines and outlined below ([NG217, 3.1.3 and 3.1.4](#)). A more urgent referral may be needed in specific situations which would usually be where the child is an inpatient.

Assessment will include consideration of all potential treatment modalities including an evaluation for epilepsy surgery subject to meeting criteria. An initial appointment in Tertiary care may be held at the Tertiary centre or through a locally held Paediatric Epilepsy / Neurology outreach clinic.

Criteria for referral:

1. Where there is diagnostic uncertainty
2. Children under the age of 3 or under the age of 4 years if they have myoclonic seizures.
3. Where there is an accompanying learning and / or behavioural difficulty and particularly where there has been developmental slowing (in learning or language) or plateauing in skills in conjunction with the epilepsy.
4. Where the person has an epilepsy syndrome likely to be drug-resistant* such as Dravet syndrome or an evolving developmental epileptic encephalopathy.
5. Where seizures are drug resistant, or their treatment is associated with intolerable adverse effects.
6. For access to specialist assessment tools including EEG telemetry and to specialist treatments including Ketogenic Diet, Cannabidiol and other restricted medications. Discussions around initiating Sodium Valproate in children will also need a shared discussion with secondary and tertiary care.
7. To access the epilepsy surgery (CESS) pathway – see separate link below. Children referred for consideration of epilepsy surgery should also continue to be seen within their usual complex Epilepsy service while this evaluation is ongoing.
8. CYP is eligible for and wishes to participate in a clinical trial or research study.

Drug resistant epilepsy is defined as:

- (i) Failure of adequate trials of 2 tolerated and appropriately chosen and used anti-seizure medications (whether as monotherapy or in combination) to achieve sustained seizure freedom or
- (ii) Continuing seizures after 2 years regardless of number of medications used.

ROUTINE REFERRAL POINTS OF ACCESS

Please provide a comprehensive clinical history via PDF attachment

Evelina London: gst-tr.ELCHpaedneuroreferrals@nhs.net

King's College Hospital: kch-referrals@nhs.net or by post

St George's Hospital : paedneuoppcc@stgeorges.nhs.uk

(N.B. referrals accepted from linked District Epilepsy Teams at agreed DGHs only)

URGENT REFERRAL POINTS OF ACCESS

Evelina London: Contact the paediatric on call Neurology Registrar via hospital switchboard (020 7188 7188) bleep 1148/1183

King's College Hospital: Contact the Paediatric Neurology Consultant of the week on 07974 632170 Monday- Friday office hours
Out of hours via hospital switchboard (020 3299 9000)

St George's Hospital: DGH Epilepsy Team to contact linked named Paediatric Neurologist or the on-call acute team via hospital switchboard (020 88672 1255)

2. Protocol and Pathway for Referral to CESS and VNS

Service for children and young people aged 0-18 years old (up to 19th Birthday). Adult service also provided at King's College Hospital so care will be transferred if needed.

To ensure the service is run as efficiently as possible and to avoid any delay please follow the process below.

Referrals: ONLY Accepted from Consultant Paediatricians and Consultant Paediatric Neurologists

- Not accepted directly from parents or GPs.
- All referrals must be sent to **Kch-tr.cesskingsreferrals@nhs.net** using the CESS Referral Proforma (see Slide 9)
- **sent with** local EEG and imaging **reports** so the CESS team can arrange access to the imaging data

NOTE: Missing information will result in delay

Next steps:

- All referrals will be reviewed at the CESS Referrals MDT Preliminary Epilepsy Surgery meeting which is attended by Consultant Paediatric Neurologist, Neuroradiologist and Epilepsy surgeon.
- The meeting summary conclusion will be sent
 - to the referrer
 - copied to the family and GP

Please ensure families are aware that if Epilepsy Surgery is not suitable an appointment will not be offered.

References:

- National Bundles of Care for Epilepsy [NHS England » National bundle of care for children and young people with epilepsy](#)
- NICE [Overview | Epilepsies in children, young people and adults | Guidance | NICE](#)
- SETPEG [Home | South East Thames Paediatric Epilepsy Group \(setpeg.net\)](#)

Criteria for Referral to CESS Services including VNS

1. Epilepsy with a focal lesion on imaging e.g. a focal cortical dysplasia, developmental tumour, focal acquired brain injury or hippocampal sclerosis. This may include children who are under follow up in the benign brain tumour service, but where a decision has been made for ongoing review rather than surgery for the lesion itself. (Note does not require drug resistance or a decision at referral about whether eloquent cortex)
2. Children of any age with 'MRI negative' focal epilepsy that have failed treatment with ≥ 2 appropriate anti-seizure medications
3. Epilepsy associated with congenital hemiplegia that have failed treatment with ≥ 2 appropriate anti-seizure medications or sooner if concerns
4. Specific syndromes requiring special consideration including Tuberous Sclerosis, Sturge Weber syndrome, Rasmussen syndrome, hypothalamic hamartomas
5. Children with drug resistant epilepsy who do not otherwise meet the criteria above would also be eligible for discussion of VNS treatment (see pathway below).
6. Children who have 'drop attacks' as part of a more complex epilepsy, with or without structural brain abnormalities, may also be suitable for a corpus callosotomy

Please note: Children under 3 years of age with suspected focal seizure onset with or without identifiable lesion on brain MRI (including those with severe onset epilepsy and developmental regression) *should all be referred to their Tertiary Epilepsy/Neurology service as per the Tertiary pathway. This allows prompt access to a range of Epilepsy services which would include both drug and non-drug treatments such as Ketogenic diet and Epilepsy surgery*

Drug resistant epilepsy is defined as:

1. failure of adequate trials of 2 tolerated and appropriately chosen and used anti-seizure medications (whether as monotherapy or in combination) to achieve sustained seizure freedom.
2. Continuing seizures after 2 years regardless of number of medications used



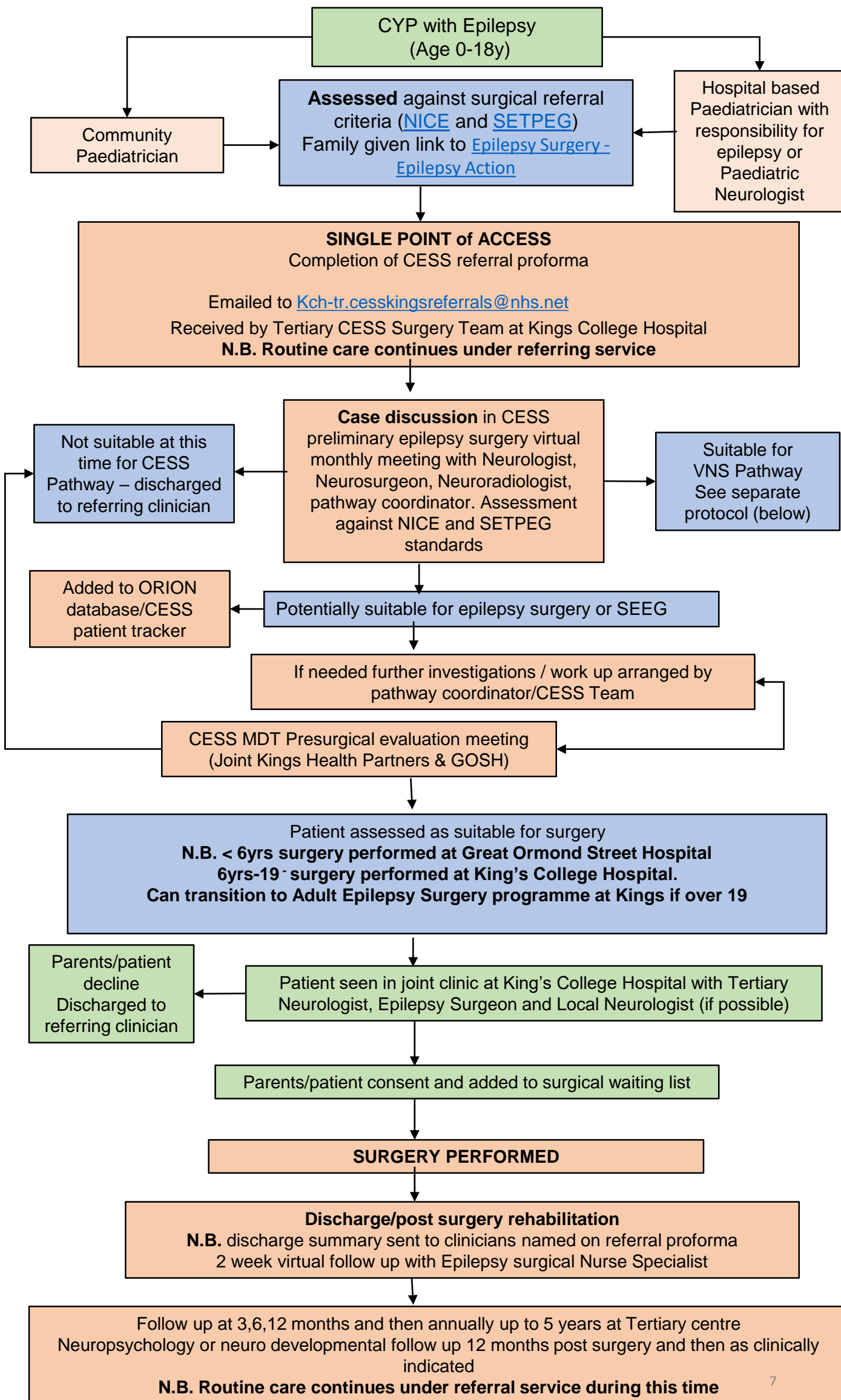
Scan to link to CESS referral proforma

Link:

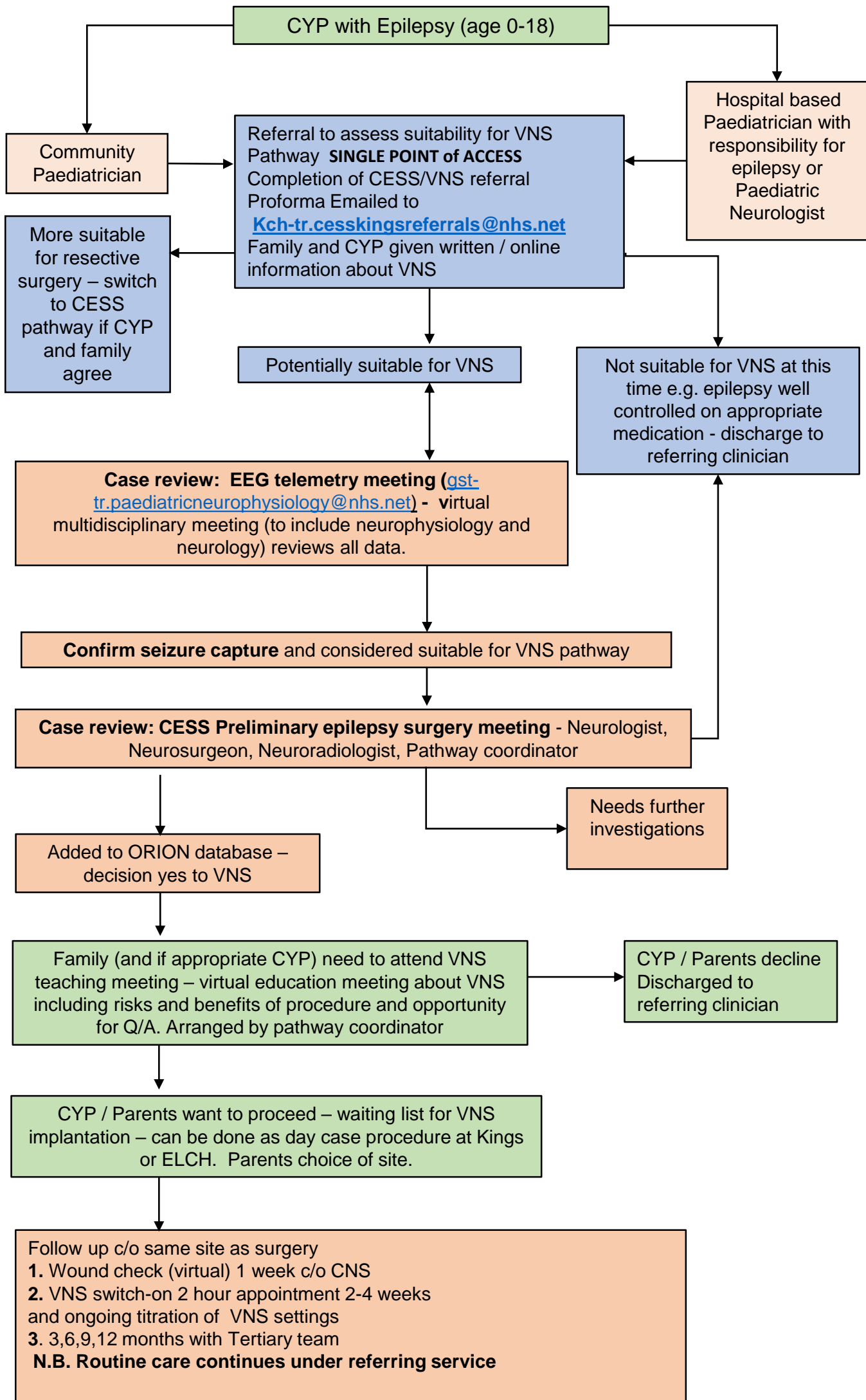
[CESS-Referral-Proforma-template-final-26.2.2024.pdf \(stpn.uk\)](https://www.stpn.uk/CESS-Referral-Proforma-template-final-26.2.2024.pdf)

Also available from STPN.uk Epilepsy Workstream documents section

CESS Pathway



VNS Pathway



Referrals to the Kings Epilepsy Surgery pathway (part of the National CESS programme)

CESS Referral Proforma:

[CESS-Referral-Proforma-template-final-26.2.2024.pdf \(stpn.uk\)](#)

- I would like to refer the patient below for evaluation on the epilepsy surgery pathway including for VNS (referrals accepted from paediatricians and paediatric neurologists). The child and family will be offered an appointment in the epilepsy surgery clinic if accepted onto the pathway.
- I would like to refer the patient below directly for discussion by the CESS MDT at the epilepsy surgery meeting (**please note this option can only be accepted if referral is made by the regional paediatric neurology service**)
- I have discussed this referral with the family so that they are aware that they may be contacted directly by the Kings Epilepsy Surgery team.

Name	
Date of birth	
NHS number	
Address	
GP	
Referring Consultant	
Lead Regional Paediatric Neurologist and regional neurosciences centre (if not referrer)	
Reason for referral (see CESS criteria)	
Any significant perinatal history	<input type="checkbox"/> No <input type="checkbox"/> Yes details:
Genetic diagnosis or chromosomal abnormality?	<input type="checkbox"/> No <input type="checkbox"/> Yes details:
Structural abnormality on MRI	<input type="checkbox"/> No <input type="checkbox"/> Yes details:
Details of seizures	
Age of onset	
Is there a history of spasms?	Yes/No. Details if yes:
Is there a history of febrile seizures?	Yes/No. Details if yes:

Seizure type at onset, and subsequent if different from current		
Current Seizures	Frequency	
Type 1	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly	Description of seizure (please include details of any aura, clinical features observed and triggers)
Type 2	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly	
Type 3	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly	
Is there a history of status epilepticus (please give details)	Yes/No If yes details:	
Have seizures been captured on video EEG telemetry?	<input type="checkbox"/> No <input type="checkbox"/> <i>If Yes, please state clearly where this was performed</i>	
Current medication and dose		
Previous medications		

Neurodevelopment	
<p>Developmental milestones:</p> <p>Motor:</p> <ul style="list-style-type: none"> <input type="checkbox"/> normal <input type="checkbox"/> delayed <input type="checkbox"/> plateauing <input type="checkbox"/> regression, age: <p>Language:</p> <ul style="list-style-type: none"> <input type="checkbox"/> normal <input type="checkbox"/> delayed <input type="checkbox"/> plateauing <input type="checkbox"/> Language regression, age: <input type="checkbox"/> Changes in speech, age: <p>Cognition:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Typical <input type="checkbox"/> Global developmental impairment <input type="checkbox"/> Diagnosis of intellectual disability/ learning difficulties, Severity (if known): 	<p>Current skills:</p> <p>Language :</p> <ul style="list-style-type: none"> <input type="checkbox"/> typical for age <input type="checkbox"/> delayed/impaired <input type="checkbox"/> nonverbal <p><i>Expressive skills:</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> single word <input type="checkbox"/> phrases <input type="checkbox"/> sentences <p><i>Receptive skills:</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> Words <input type="checkbox"/> 1 step instruction <input type="checkbox"/> 2 step + instructions <p>Motor:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Hemiplegia (right/left) <input type="checkbox"/> Bilateral movement disorder (upper limb/lower limb/four limb) <input type="checkbox"/> GMFCS/equivalent:
<p>Schooling:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Preschool <input type="checkbox"/> Mainstream <input type="checkbox"/> Mainstream with EHCP <input type="checkbox"/> Special school <input type="checkbox"/> Other _____ 	<p>Academic progress:</p> <ul style="list-style-type: none"> <input type="checkbox"/> As expected. <input type="checkbox"/> Below level expected <input type="checkbox"/> Plateauing <input type="checkbox"/> Regression, age: <input type="checkbox"/> Specific difficulties <input type="checkbox"/> Not known <p>Comments:</p>
<p>Developmental comorbidities:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Autism <input type="checkbox"/> Attention Deficit (Hyperactivity) Disorder <input type="checkbox"/> Behaviour that challenges <input type="checkbox"/> Mood disorders <input type="checkbox"/> Anxiety <input type="checkbox"/> Other _____ 	<p>If over 6, estimate of overall level of functional skills:</p> <ul style="list-style-type: none"> <input type="checkbox"/> As expected for age <input type="checkbox"/> Needing some more support than expected for age eg prompting <input type="checkbox"/> Skills at a preschool level- eg needing adult help for self-care <input type="checkbox"/> Fully dependent on adults <input type="checkbox"/> Unknown
<p>Has the child previously had a formal neuropsychology or developmental assessment?</p>	<ul style="list-style-type: none"> <input type="checkbox"/> No <input type="checkbox"/> Yes (please send any reports available)
<p>Risk discussions:</p> <p>Safeguarding concerns:</p>	<p>Have you had a conversation with family and young person about risk in relation to epilepsy, including risk of SUDEP?</p> <p>Yes</p> <p>No</p> <p>Yes/No</p> <p>If Yes, details:</p>

EEG	Please confirm <input type="checkbox"/> All relevant EEG reports enclosed (mandatory information - we cannot process referral without this)
MRI Images (other neuroimaging)	Please confirm <input type="checkbox"/> Reports attached (please state Hospital where MRI (s) were performed and date(s))
Genetic investigation performed	<input type="checkbox"/> No <input type="checkbox"/> Yes: all reports attached which tests: <input type="checkbox"/> Results pending: which tests:
Other investigations if undertaken: Please tick as appropriate <input type="checkbox"/> Metabolic <input type="checkbox"/> Autoimmune	Please summarise relevant results:
Any additional relevant information: eg other professionals who should be included in communication	
Email completed form <i>together with</i> local EEG and imaging reports to Kch-tr.cesskingsreferrals@nhs.net	