SETPEG
South East Thames
Paediatric Epilepsy Group

OPEN UK
Organisation of Paediatric Epilepsy Networks in the United Kingdom

# SETPEG SECONDARY EPILEPSY SERVICE OPERATIONAL FRAMEWORK 2025

*Ratified by the OPEN UK working group for adoption as a UK resource on 24TH November 2025*

**Introduction:**

There is an ongoing need to improve the quality of, and reduce the variation in, care for children with epilepsy in the UK in line with the recommendations in NICE clinical guideline CG137 Epilepsies: diagnosis and management.

In a further effort to achieve the above, a dedicated SETPEG working group has summarised and supplemented existing national guidelines offered by NICE, NHS England and the RCPCH Epilepsy12 Audit into this Operational Framework document. The aim of this document is to provide an easy reference framework of standards that need to be achieved, but also to stipulate the *minimum* resources needed in order for a paediatric secondary epilepsy service to be able to achieve those goals.

**Expected standards from a SETPEG Secondary Paediatric Epilepsy Service:**

1. To have a designated Paediatric Epilepsy Lead who is a Consultant Paediatrician with a Specialist interest in Epilepsy[3,5].
2. To employ Paediatric Epilepsy Nurse Specialist(s)[2,3,4].
3. To offer a First Seizure Clinic outpatient review to children presenting with a first unprovoked seizure with a Paediatrician with Epilepsy special interest within 2 weeks of presentation[2].
4. To offer all children with Epilepsy registered to the service a review with an Epilepsy Consultant Specialist and Epilepsy Nurse Specialist at least once per year[2].
5. To be able to provide children and their families with results of EEG, MRI brain and routine blood investigations within 4-8 weeks of the tests being requested[2].
6. To provide children with Epilepsy with an agreed, comprehensive, personalised, written care plan that includes relevant contact details, sources of further information on epilepsy, emergency advice, safety advice and information for schools[2,3].
7. To maintain an up-to-date database of all patients with confirmed or suspected Epilepsy that are under follow up with the service[5].
8. To include Regional Tertiary Epilepsy Clinics with a visiting Paediatric Neurologist[1].
9. To include specific face to face transition clinics for young people with Epilepsy held jointly with the Adult Neurology Service[2,3].
10. To fully participate in the RCPH Epilepsy12 National Audit[3] and to also perform local audits on service performance at least annually.
11. To have agreed referral pathways for children with Epilepsy who also have diagnoses of ASD, ADHD and mental health concerns[3].
12. To aim to develop co-located mental health provision in Epilepsy clinics[3].
13. To have set mechanisms for obtaining patient feedback at least annually[3], future plans for peer review and regional accreditation for secondary Epilepsy services[5].

**Operational requirements of a SETPEG Registered Secondary Paediatric Epilepsy Service to facilitate delivery of above standards:**

**Medical & Nursing Staffing**:

1. To employ one or more Whole Time Equivalent (WTE) Consultant General Paediatricians with a Special Interest in Epilepsy. To qualify for this designation a Consultant Paediatrician must have completed the first three parts of the British Paediatric Neurology Association Paediatric Epilepsy Training, they must be registered members of SETPEG and also include in their job plan at least 1 designated paediatric epilepsy clinic per week (or pro rata if not full time). They must also attend Regional Clinics with tertiary Neurologists regularly[5]. RCPCH Epilepsy SPIN completion is desirable[5]. Such Consultants should also demonstrate ongoing professional development in the field of Paediatric Epilepsy via their annual appraisal process.
2. To employ at least one WTE Consultant Paediatrician with Special Interest in Epilepsy as defined above per 200-250 patients registered with the service.
3. To employ at least one WTE Paediatric Epilepsy Nurse Specialist per 200-250 patients registered with the service.

**Consultant Job Plan Considerations**:

1. To have a Jobplan that allows for every specialist paediatric Consultant 0.5 PAs (2 hours) per clinic of DCC Admin. This equates to 15-17min of admin time per epilepsy outpatient seen, during which time a clinic letter can be composed, relevant investigations can be requested, results can be reviewed and communications between clinic appointments (including via the Epilepsy Nurse Specialist) can be addressed[5].
2. To have a Jobplan that allows for every specialist paediatric Consultant 0.5 PAs (2 hours) per week for Epilepsy12 audit, epilepsy database maintenance, complex patient MDT, whole genome sequencing request form filling and other related activities[5].

**Clinic Frequency and Structure**:

1. To provide at least 55 4-hour epilepsy clinics per 250 registered patients and per 120 new referrals per year[5].
2. To have a set clinic structure per 4-hour Paediatric Epilepsy clinic that includes provision for joint review with a specialist Consultant Paediatrician and a Clinical Nurse Specialist. The clinic should allow a minimum of 40-minute appointments for new patients and 30 minutes for follow up reviews. It should accommodate on average 3 new patients and 4-5 follow up patients or any equivalent combination.

**Access to Investigations**:

1. To have access to a Neurophysiology service that can provide urgent inpatient EEG within 2 working days, urgent outpatient EEG within 2 weeks and routine outpatient EEG within 4-8 weeks[5]. NICE guidelines stipulate that if an EEG is requested after a first seizure, it should be performed as soon as possible (ideally within 72 hours after the seizure). If routine and sleep-deprived EEG results are normal and diagnostic uncertainty persists, ambulatory EEG (for up to 48 hours) should be available[1].
2. To have access to a Neuroradiology service that can provide urgent MRI brain imaging within 1 week, routine awake or sedated MRI brain scan within 4-6 weeks and routine MRI brain scan under general anaesthetic within 3 months[1,5]. There should also be a process for provision of expert Neuroradiology opinion on performed MRI brain scans.

**Access to Specialist Clinics, Specialist Services and Admin Support**:

1. To have access to at least one Regional Tertiary Epilepsy Clinic per 50 registered patients per year, to be run jointly with a Consultant Paediatric Neurologist. This clinic should cater for children with epilepsy where there is diagnostic ambiguity, drug resistance, in need of tertiary specific services (e.g. ketogenic diet, epilepsy surgery) and for children diagnosed with epilepsy aged less than 3 years old (or less than 4 in case of myoclonic seizures)[1].
2. To have a transition set-up that offers 1-2 joint transition clinics per year with Adult Neurology per 250 patients registered with the service, with such clinics replacing one scheduled clinic in the annual job plan[1,3,5].
3. To have access to at least 0.5 WTE of a Paediatric Secretary for provision of administration support per 1 WTE Paediatric Epilepsy Consultant and 1 WTE Paediatric Epilepsy Nurse Specialist[5].
4. To aim to employ one Epilepsy Pathway Co-ordinator per Secondary Epilepsy Service who can maximise utilisation of the service and monitor performance in accordance with national standards[5].
5. To aim to employ a 0.5 WTE of a Child Psychologist per Secondary Epilepsy Service who can be embedded to the service and provide clinics for children with a diagnosis of epilepsy and related mental health issues[3,5].

**Framework approved and supported by**:

1. Dr Dennis Grigoratos, Consultant Paediatrician, Paediatric Epilepsy Lead & SETPEG Chair
   Princess Royal University Hospital, King's College Hospital NHS Foundation Trust
2. Dr Jyothi Khanna, Consultant Paediatrician, Paediatric Epilepsy Lead & SETPEG Secretary
   Darent Valley Hospital, Dartford and Gravesham NHS Trust
3. Dr Kate Irwin, Consultant Paediatrician, Paediatric Epilepsy Lead & SETPEG Audit Lead
   Evelina London Children's Hospital, Guy's & St Thomas' NHS Foundation Trust
4. Dr Mike Wacks, Consultant Paediatrician, Clinical Lead in General Paediatrics & SETPEG Member
   King's College Hospital, King's College Hospital NHS Foundation Trust
5. Dr Rahele Tavanayan. Consultant Paediatrician, Epilepsy Clinical Lead & SETPEG Member
   Queen Elizabeth Woolwich Hospital, Lewisham and Greenwich NHS Trust
6. Dr Kum Gomez, Consultant Paediatrician, Epilepsy Lead & Honorary SETPEG Member
   University Hospital Lewisham, Lewisham & Greenwich NHS Trust
7. Dr Vicky Ho, Consultant Community Paediatrician & SETPEG Member
   University Hospital Lewisham, Lewisham & Greenwich NHS Trust
8. Dr Sharmila Jeyasingh, Consultant Paediatrician, Epilepsy Clinical Lead & SETPEG Member
   Royal Alexandra Children's Hospital, University Hospitals Sussex NHS Foundation Trust
9. Dr Priya Mathad, Consultant Paediatrician, Epilepsy Clinical Lead & SETPEG Member
   Royal Alexandra Children's Hospital, University Hospitals Sussex NHS Foundation Trust
10. Dr Rajesh Gupta, Consultant Paediatrician, Epilepsy Clinical Lead & SETPEG Member
    Maidstone and Tunbridge Wells NHS Trust
11. Dr Ameen Siddiqui, Consultant Paediatrician, Paediatric Epilepsy Lead & SETPEG Member
    William Harvey Hospital, East Kent Hospitals University NHS Foundation Trust
12. Dr Jan Stanek, Consultant Paediatrician, Clinical Site Lead in Child Health & SETPEG Member
    QEQM Hospital Margate, East Kent Hospitals University NHS Foundation Trust
13. Dr Adina Munteanu, Consultant Paediatrician, Paediatric Epilepsy Lead & SETPEG Member
    Medway Maritime Hospital, Medway NHS Foundation Trust
14. Dr Heva Lalani, Consultant Paediatrician, Paediatric Epilepsy Lead & SETPEG Member
    Conquest Hospital & Eastbourne District General Hospital, East Sussex Healthcare NHS Trust

**References:**

1. NICE Guideline
2. NICE Quality Standards
3. Best Practice Tarriff
4. Epilepsy12 Audit
5. SETPEG Working Group Expert opinion