Pre-market Engagement and Specification Development Meeting
National Clinical Audit of Seizures and Epilepsies in Children and Young People

Minutes

Wednesday 29 October 2025, 1:30pm – 4:30pm

Attendees

Pre-market Engagement only

Calvin Down
Head of Audits, RCPCH

Colin Dunkley
Clinical Lead, RCPCH

Alison Fuller
Director for Health Improvement and Influencing, Epilepsy Action

Nicola Greenway
NICE Measurement Lead

Jane Hanna
Director of Policy and Influencing, SUDEP Action

Catherine Hodder
Head of Voice, Policy and Influencing, Young Epilepsy

Angela Mensah
Head of Grants and Partnerships, RCPCH

Brian Moulder
Senior Business Development manager, Newcastle upon Tyne Hospitals NHS Foundation Trust

Lewis Paxton
Analyst, Acute & Ambulance, CQC

Vicky Patel
NQICAN Chair

Suresh Pujar
The Prince of Wales's Chair of childhood epilepsy

Niky Raja
Project Manager, RCPCH

Pre-market Engagement and SDM

Simon Kenny (Chair)
National Clinical Director - Children and Young People, NHS England

Sandra Keogh- Bootland (Part 1 only)
Clinical Audit & Effectiveness Manager, Health & Care Jersey

Heather Payne
Senior Medical Officer, Welsh Government

Sophia Struszczyk
Policy Advisor - Children and Young People, NHS England

HQIP

Tina Strack
Associate Director

Jill Stoddart
Director of Operations

Yvonne Silove
Associate Director

Jonathan Williams
Senior Procurement Manager

Judith Hughes (Part 1 only)
Associate Director of Procurement

Kim Rezel
Head of Patient and Carer Engagement

Rachael Sample
Associate Director

Thomas Salisbury
Clinical Fellow

Grace Cuff
Project Manager

Item

1. Welcome & introductions

SK opened the meeting by welcoming attendees and outlining the purpose: to gather feedback to inform the scope of the next epilepsy audit tender. He emphasized the importance of improving care for children with epilepsy and aligning with NHS England's long-term plan.

2. Objectives of the meeting

TS provided an overview of the meeting purpose.

The Healthcare Quality Improvement Partnership (HQIP) is a non-profit organisation that commissions and manages the National Clinical Audit and Patient Outcomes Programme (NCAPOP) on behalf of the funders. At its simplest NCAPOP is a commissioning mechanism to drive improvement against standards. More than just quality assurance, it is a vital part of quality improvement, and we want to think about how audits and clinical data can support this.

The epilepsy audit is one of about 40 projects that make up the NCAPOP. The contract to deliver the programme is coming to an end in March 2027, so we are preparing to retender. Purpose of this meeting is to gather feedback to shape a requirements specification to take out to tender

HQIP want to ensure that we commission a programme that can add value, which promotes quality improvement and quality assurance functions at local, regional and national. We want to be innovative and forward-thinking in terms of what will make the biggest difference to patients. However, we need to be realistic about what is possible to deliver. An audit programme cannot do everything. We want a focussed audit that is clear on its quality improvement aims.

3. Audit overview

TS provided an overview of the audit's purpose, structure, and current delivery: The audit is a mechanism to drive improvement in care by measuring against standards and assesses service availability. The audit has been organised into cohorts that follow children diagnosed with epilepsy over their first year of care post-diagnosis. There is no age limit other than care must have been provided in a paediatric setting.

The audit scope covers NHS-funded services in England, Wales, and publicly funded services in Jersey. The audit is limited to 10 key metrics to maintain focus. Outputs include a concise annual state of the nation report, monthly updated interactive dashboards and online improvement resources. The audit supports national initiatives like NICE, CQC, NHS RightCare, NHS England National bundle of care and Welsh Government initiatives.

4. Patient and Public Involvement

KR shared the following insights from extensive engagement with young people, families, and charities:

- **First Year of Diagnosis:** This was described as overwhelming with children often experiencing anxiety, sleep issues, and lack of support. Families struggled with medical jargon, medication side effects, and the impact on education. There was emotional toll on siblings and parents, including financial strain.
- **Transition to Adult Care:** The transition from child to adult services was described as abrupt and poorly supported. Young people felt unprepared and often lost access to familiar clinicians.
- **Mental Health:** Children experienced long waits for psychologists and a lack of access to psychiatric support.
- **Peer Support & Education**: Schools often misunderstood epilepsy, restricting the children from certain activities. They noted a need for epilepsy nurses to educate schools.
- **Concerns for teens:** There were concerns for teenagers over driving, sports, contraception, and fertility.

Item

- **Resources:** Young people were unaware of the audit outputs so there is a need for the resources to be accessible, age-appropriate, and widely distributed. Positive feedback was received on the checklists and visual materials.

JH presented on SUDEP (Sudden Unexpected Death in Epilepsy) and emphasised:

- **Lack of Awareness:** SUDEP is under-discussed by clinicians despite its seriousness and families are often unaware of the risk until after a death. Conversations about SUDEP should occur within the first year.
- **Young People's Views:** Children want honest, balanced information and prefer to be informed early to self-advocate.
- **Checklist Tool:** This tool was developed with Young Epilepsy and has proven to increase communication from 20% to 80%.
- **Audit Role:** The audit should signpost clinicians to SUDEP resources to improve awareness and reduce risk. SUDEP should also be included in the metrics or outputs to ensure visibility.

In response to JH's point on SUDEP, NR highlighted that KPI 9b in the epilepsy audit does in fact include SUDEP risk discussions however JH noted that she would prefer to see the measure related to SUDEP risk have greater visibility in the audit.

5. Group discussion

The following themes emerged from the group discussion:

SUDEP

- JH highlighted that there has been four prevention of death reports in last 12 months so clear signposting to existing resources that have been recommended by NHS RightCare and Coroners, such as the children's checklist, is required.
- HP supported the idea of the children's checklist as an important priority.

Transition

- CH noted that transition is a major concern for young people but not currently a metric.
- NG stated that NICE's quality standard highlights transition as a priority and supported its inclusion in the audit.
- CH shared the Young Epilepsy transition research: Transition from paediatric healthcare to adult healthcare for young people with epilepsy in the UK and a video summary: #epilepsyresearch #transitioncare #epilepsyawareness #healthresearch | Young Epilepsy

Measuring Impact

- SK highlighted that the current metrics are process-based but measuring actual impact and understanding is very important.
- YS and HP suggested measuring system accountability and service-level PROMs/PREMs. They also discussed the challenge of measuring what families receive and understand, not just what is provided.
- SS mentioned the upcoming UK epilepsy information standard that could support automated data collection and outcome reporting.

Data Linkage

- SK emphasised the potential of the NHS App and EPRs to reach families and collect real-time data. He also suggested school attendance would provide a more holistic picture of the impact on children. He also noted the importance of primary care data integration.

Item

- SS supported exploring future data integration opportunities.
- KR suggested exploring integration with tools like the ready steady go programme https://www.readysteadygo.net/hello-to-childrens-services.html

Audit Use

- NG noted that NICE uses the epilepsy audit data to assess guideline uptake and identify barriers.
- SK highlighted that the audit data supports NHS England's Core20PLUS5 framework and the epilepsy transformation programme.

6. Summary and next steps

JW explained the aspirational measures of the audit are non-mandatory elements that could be added if funding allows. They will be listed in the specification but not scored. They will be managed via contract modifications.

SK thanked participants for attending and closed the meeting.

Epilepsy audit – Overview

(aka National Clinical Audit of Seizures and Epilepsies in Children and Young People)

Tina Strack

Associate director

Aims and objectives of National Clinical Audit

NCAs stimulate healthcare improvement through the provision of high-quality information

Outcomes are benchmarked against national guidance and standards

Data is most useful locally for healthcare improvement when it is timely, refreshed regularly with appropriate support

Identify variation

Epilepsy audit overview

Inclusion criteria:

- NHS-funded services in England and Wales (and Jersey)
- People having a first paediatric assessment for a paroxysmal (seizure) episode/episodes
- No specified age range, must be within a paediatric service

Exclusion criteria:

- People seen only in adult services, emergency departments or a GP service, who are not then referred

Core components

- Clinical audit
- Organisational audit

Key Performance Indictors (KPIs)

- 1. Paediatrician with expertise in epilepsies
- 2. Access to Epilepsy Specialist Nurse
- 3.a. Tertiary input
- 3.b. Epilepsy Surgery Referral

Evidence of appropriate assessment

- 4. ECG
- 5. MRI within 6 weeks

Mental Health

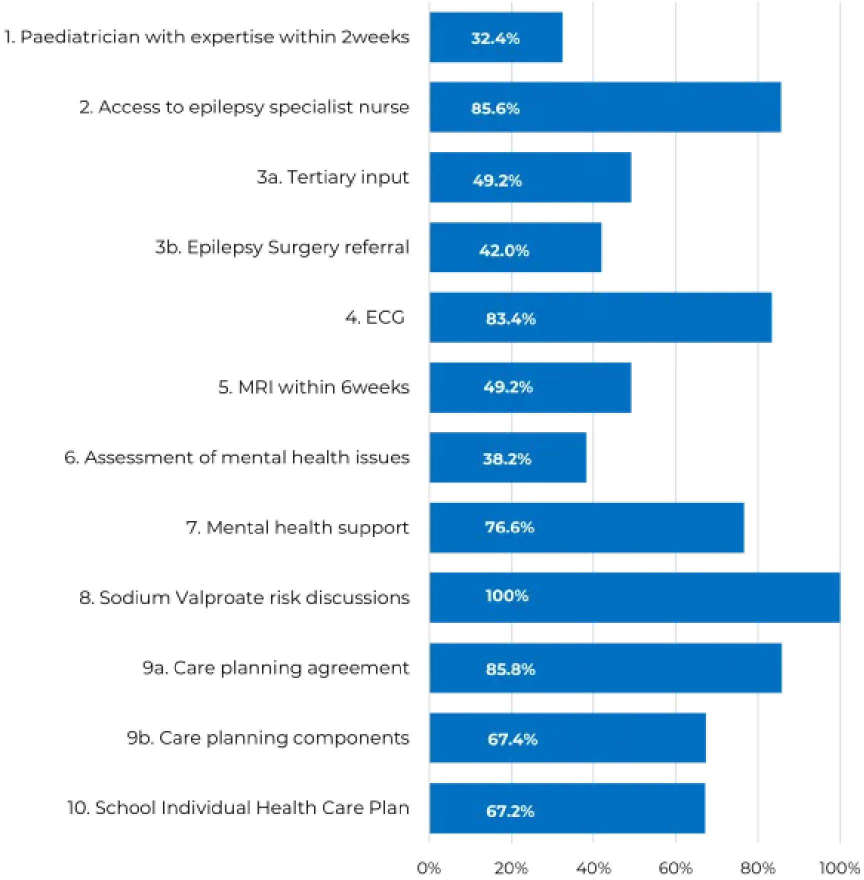
- 6. Assessment of mental health issues
- 7. Mental health support

Care Planning

- 8. Sodium Valproate / Medication and reproduction risk
- 9.a. Care planning agreement
- 9.b. Care planning components
- 10. School Individual Healthcare Plan

Cohort 6 – care delivered between 1/12/23 and 30/11/24

The below chart shows an overview of the 10 KPIs for England and Wales combined in cohort 6.



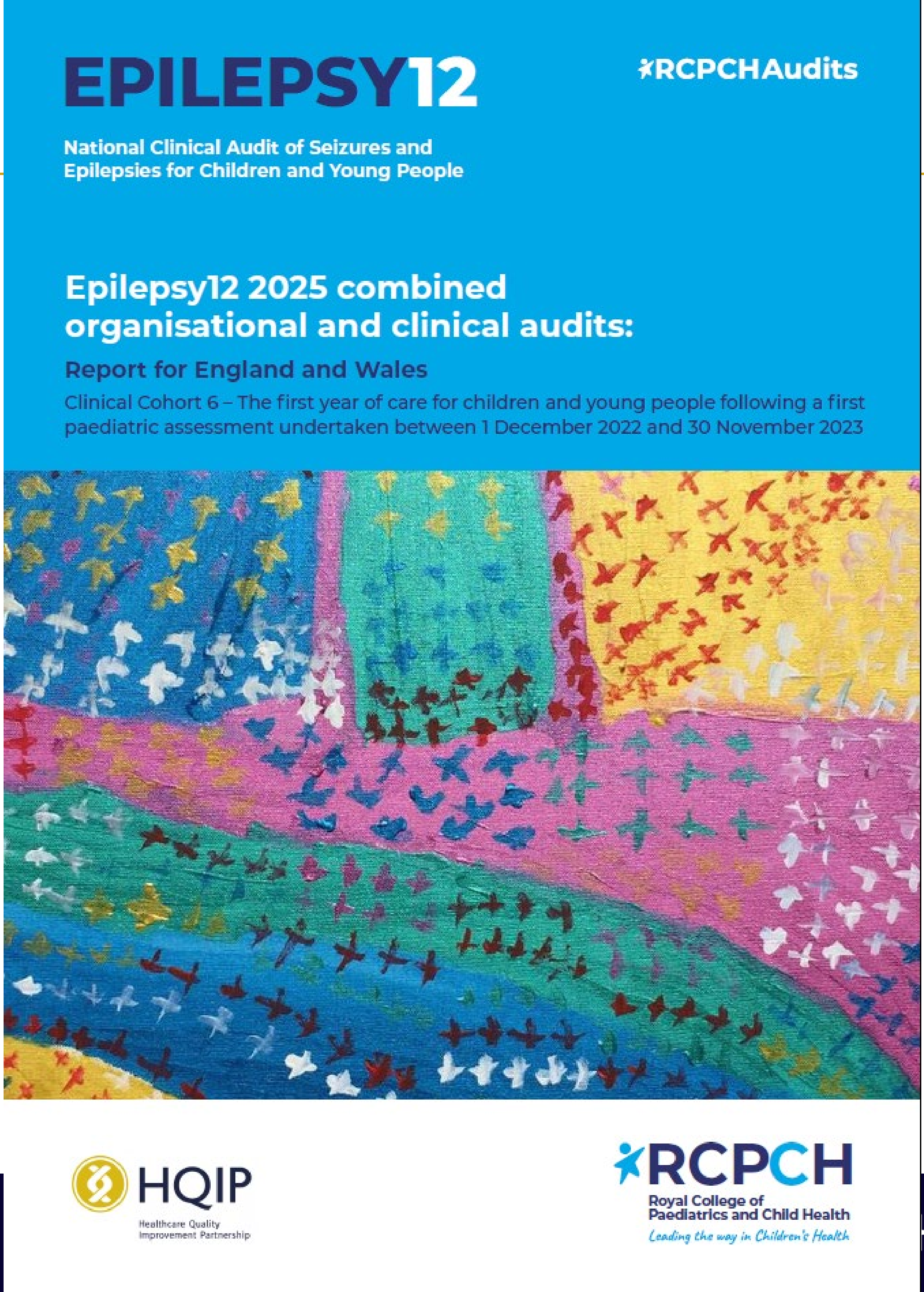
Data

Audit data is used to assess compliance or performance in national initiatives:

- NHS Best Practice Criteria
- CQC positive and negative outlier reporting
- NHS England National bundle of care
- NHS RightCare: Epilepsy Toolkit
- Epilepsy12 aligns with the Welsh Government's quality statement for neurological conditions

Audit outputs

- Replace the annual report with an annual state of the nation summary (maximum of 10 pages and 5 national recommendations)



EPILEPSY12

RCPCHAudits

National Clinical Audit of Seizures and
Epilepsies for Children and Young People

Epilepsy12 2025 combined organisational and clinical audits:

Report for England and Wales

Clinical Cohort 6 – The first year of care for children and young people following a first paediatric assessment undertaken between 1 December 2022 and 30 November 2023

HQIP
Healthcare Quality
Improvement Partnership

RCPCH
Royal College of
Paediatrics and Child Health
Leading the way in Children's Health

Audit outputs

- Replace the annual report with an annual state of the nation summary (maximum of 10 pages and 5 national recommendations)
- Replace local recommendations with online improvement resources

Return back to top

Case studies

Epilepsy12 invited epilepsy services in England and Wales to provide case studies of their quality improvement activities undertaken in the last year to improve the care provided to children and young people with epilepsies.

2024

Reducing wait times at Airedale NHS Foundation Trust +

Improving care planning content at Sherwood Forest Hospitals NHS Foundation Trust +

Introducing mental health screening at South Tyneside and Sunderland NHS Foundation Trust +

Improving SUDEP discussions at South Tyneside and Sunderland NHS Foundation Trust +

Video platform use at South Tyneside and Sunderland NHS Foundation Trust +

2023

Audit outputs

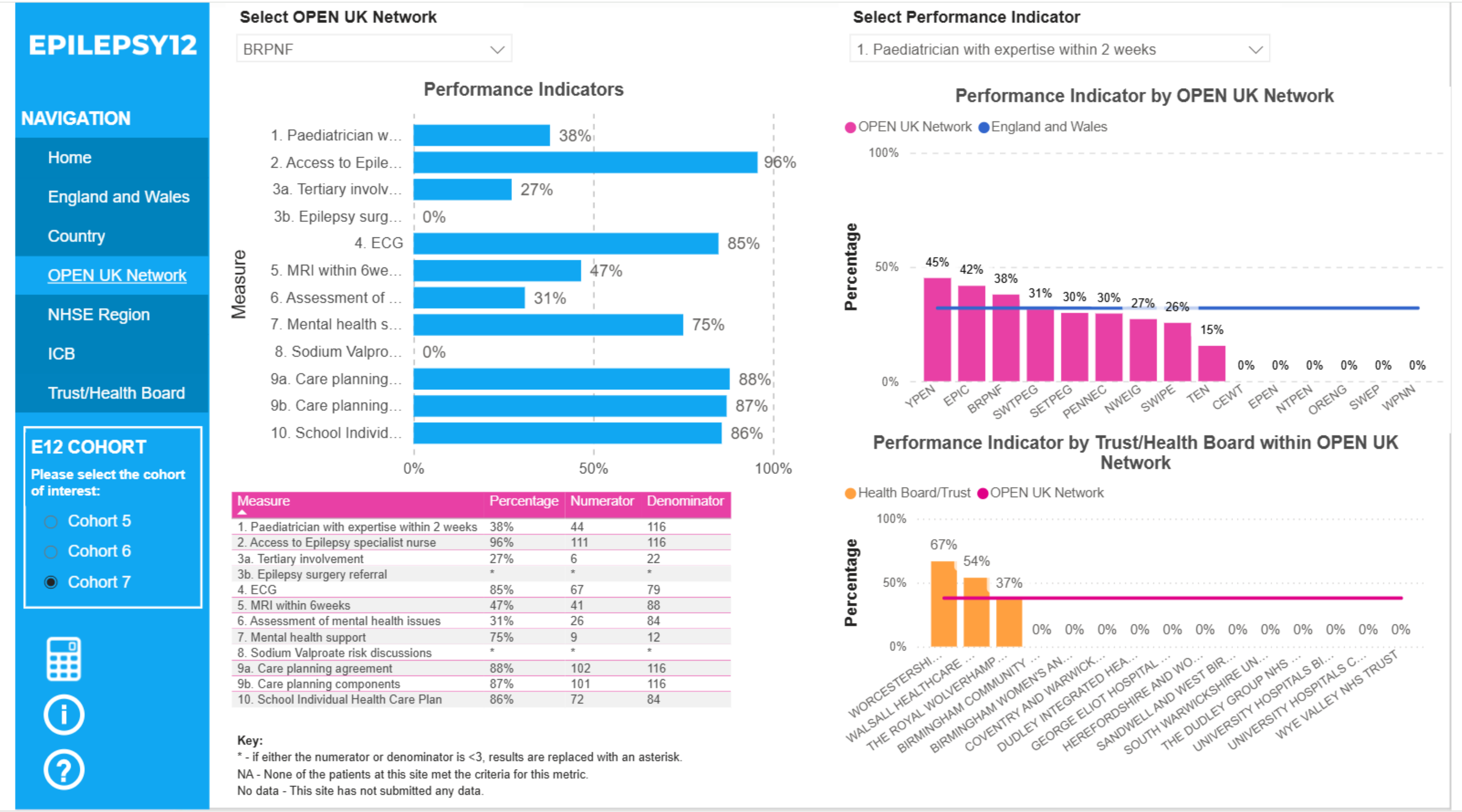
- Replace the annual report with an annual state of the nation summary (maximum of 10 pages and 5 national recommendations)
- Replace local recommendations with online improvement resources

Audit outputs

- Replace the annual report with an annual state of the nation summary (maximum of 10 pages and 5 national recommendations)
- Replace local recommendations with online improvement resources
- Develop a Quality Improvement plan, reviewed annually.

Audit outputs

- Replace the annual report with an annual state of the nation summary (maximum of 10 pages and 5 national recommendations)
- Replace local recommendations with online improvement resources
- Limit the number of performance metrics to 10
- Develop a Quality Improvement plan, reviewed annually.
- Make all audit performance metric results available in an interactive format online to all users



Select OPEN UK Network

BRPNF

Select Performance Indicator

1. Paediatrician with expertise within 2 weeks

Measure	Percentage	Numerator	Denominator
1. Paediatrician with expertise within 2 weeks	38%	44	116
2. Access to Epilepsy specialist nurse	96%	111	116
3a. Tertiary involvement	27%	6	22
3b. Epilepsy surgery referral	*	*	*
4. ECG	85%	67	79
5. MRI within 6weeks	47%	41	88
6. Assessment of mental health issues	31%	26	84
7. Mental health support	75%	9	12
8. Sodium Valproate risk discussions	*	*	*
9a. Care planning agreement	88%	102	116
9b. Care planning components	87%	101	116
10. School Individual Health Care Plan	86%	72	84

Key:
* - if either the numerator or denominator is <3, results are replaced with an asterisk.
NA - None of the patients at this site met the criteria for this metric.
No data - This site has not submitted any data.

HQIP Healthcare Quality Improvement Partnership

Epilepsy Audit – voices of CYP and families

Kim Rezel

Head of patient and carer engagement

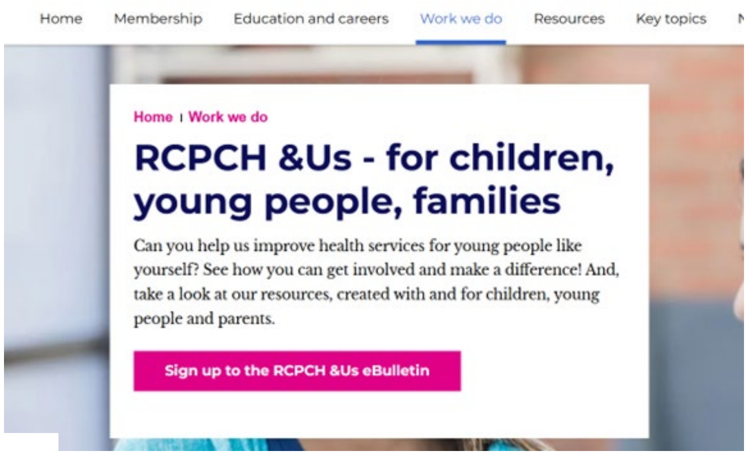
29th October 2025

Engagement for the specification

Young Epilepsy

aypH

EPILEPSY ACTION



Home | Work we do

RCPCH &Us - for children, young people, families

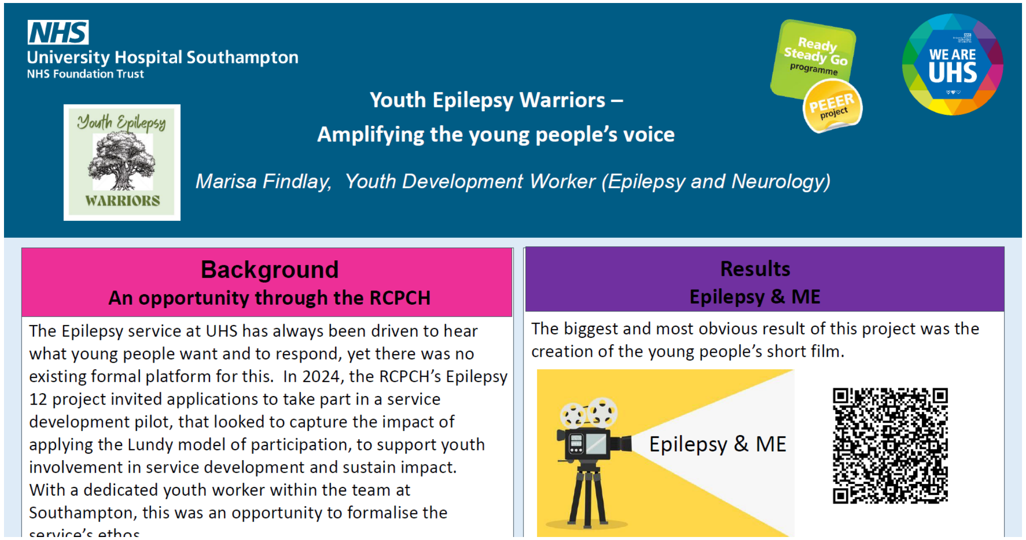
Can you help us improve health services for young people like yourself? See how you can get involved and make a difference! And, take a look at our resources, created with and for children, young people and parents.

SUDEP Action

Making every epilepsy death count

Focused on

- First year of diagnosis
- Priorities for CYP and families
    - SUDEP slides
- Transition to Adult care
- Audit information



University Hospital Southampton
NHS Foundation Trust

Youth Epilepsy Warriors –
Amplifying the young people's voice

Marisa Findlay, Youth Development Worker (Epilepsy and Neurology)

Background
An opportunity through the RCPCH

The Epilepsy service at UHS has always been driven to hear what young people want and to respond, yet there was no existing formal platform for this. In 2024, the RCPCH's Epilepsy 12 project invited applications to take part in a service development pilot, that looked to capture the impact of applying the Lundy model of participation, to support youth involvement in service development and sustain impact. With a dedicated youth worker within the team at Southampton, this was an opportunity to formalise the service's ethos

Results
Epilepsy & ME

The biggest and most obvious result of this project was the creation of the young people's short film.

Concerns in the first year of diagnosis

Being less able to be independent

How do I know if anxiety/low mood is caused by my new epilepsy or a side effect of medication when choosing the medication which is right for me

Worrying for my parents to let me be alone

Not getting enough sleep

How can I keep myself safe during a seizure of if I sense one coming and I'm alone?

The unpredictability of my fits, honestly it's still pretty scary and uncertain. The lack of support medically was really difficult too

i felt like i was the only one

Feeling lonely and not understanding and knowing that others are also feeling the same

Social isolation out of anxiety

i had to go through a number of number of medications

Lack of independence

it made my parents and i difficult to describe the type of seizures I have

My life had changed dramatically and it was hard to admit that

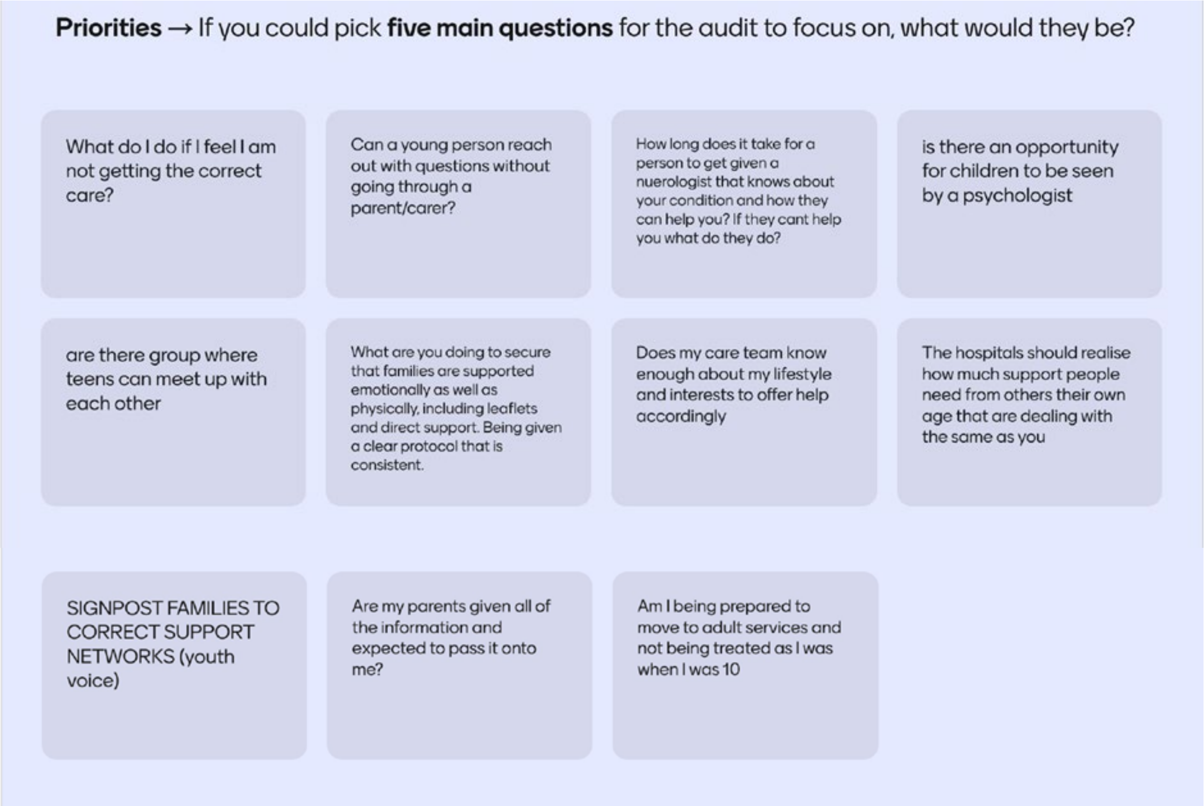
I was too young to remember

What do you do when you lose your physiotherapist and psychological when going into adulthood

Concerns in the first year of diagnosis

- Learning about the condition
- Medication and side effects
- More than seizures
- Impact on behaviour at school
- Well-being – impact on the whole family
- Involvement in own care
- Concerns about the future
- Pinch-points – moving schools, transition to adult care
- Access to surgeries
- SUDEP

Priorities for CYP and families



Priorities → If you could pick **five main questions** for the audit to focus on, what would they be?

What do I do if I feel I am not getting the correct care?

Can a young person reach out with questions without going through a parent/carer?

How long does it take for a person to get given a nuerologist that knows about your condition and how they can help you? If they cant help you what do they do?

is there an opportunity for children to be seen by a psychologist

are there group where teens can meet up with each other

What are you doing to secure that families are supported emotionally as well as physically, including leaflets and direct support. Being given a clear protocol that is consistent.

Does my care team know enough about my lifestyle and interests to offer help accordingly

The hospitals should realise how much support people need from others their own age that are dealing with the same as you

SIGNPOST FAMILIES TO CORRECT SUPPORT NETWORKS (youth voice)

Are my parents given all of the information and expected to pass it onto me?

Am I being prepared to move to adult services and not being treated as I was when I was 10

Priorities for CYP and families

EPILEPSY ACTION

EPILEPSY SAYS STOP. WE SAY GO.

Support for You:

- **Helpline** – phone, webchat or email
- **Talk and Support Groups** – online & in-person
- **Befriending** – online or phone
- **Counselling** – Wales
- **Family support** – NI & Wales
- **Website** – high-quality information about all things epilepsy
- **Epilepsy awareness courses**

epilepsy.org.uk/support

scan for more

0808 800 5050

Roadmap

Overview

Resources for schools/to share with family and friends

Wider support from clinicians

Peer support

Practical questions

MH support

Sexual Health support

Priorities for CYP and families

I think that because its not talked about a lot of people don't think epilepsy is serious....

It's important people know about SUDEP and epilepsy risks so that less children die from it, and they get the right information, rather than potentially exaggerated info from other sources....

It was never talked about for me, so I did my own research to understand.

Which means when you mention it to a health professional, they don't take you seriously....

It is a real risk, and if we can do anything to avoid it then most of us would rather do that, than take the risk.....

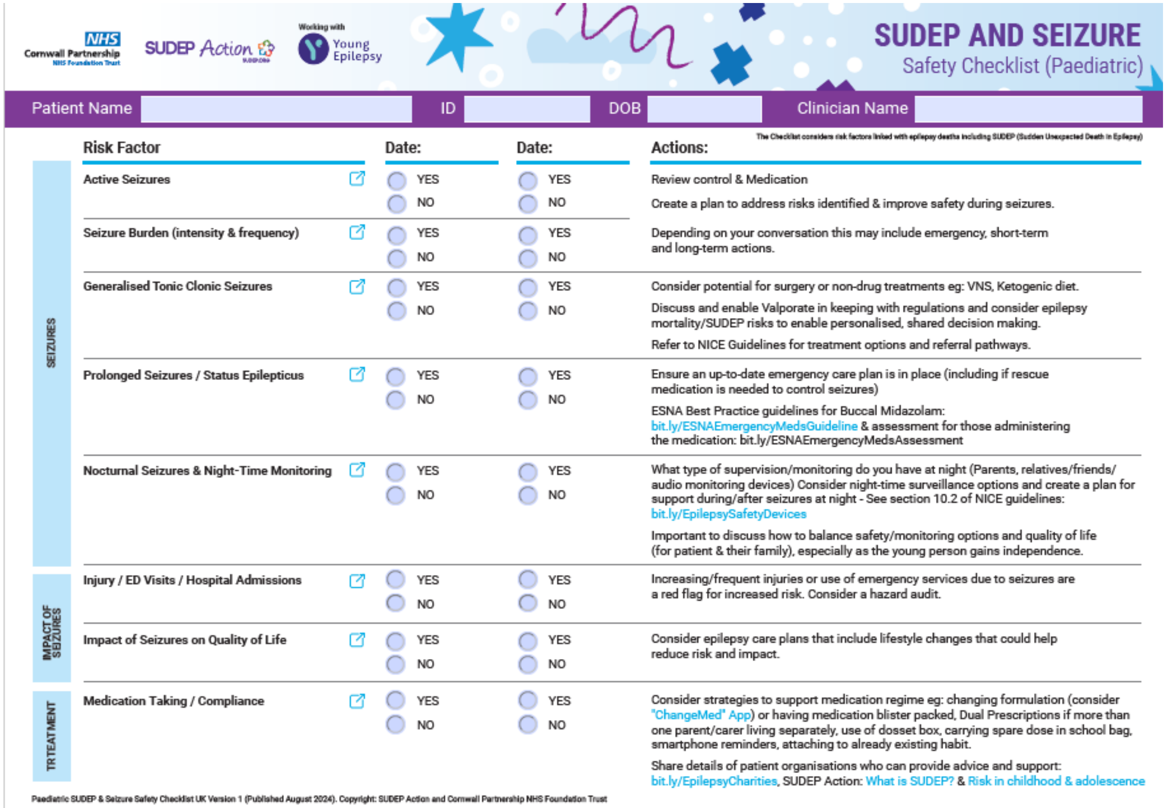
If we are aware of the risks we would know what to pay attention to, and how to keep ourselves safe....

Quotes from young people with epilepsy

SUDEP Action

Making every epilepsy death count

Priorities for CYP and families



Working with

SUDEP AND SEIZURE

Safety Checklist (Paediatric)

Patient Name	ID	DOB	Clinician Name	

The Checklist considers risk factors linked with epilepsy deaths including SUDEP (Sudden Unexpected Death in Epilepsy)

	Risk Factor	Date:	Date:	Actions:
SEIZURES	Active Seizures	○ YES ○ NO	○ YES ○ NO	Review control & Medication Create a plan to address risks identified & improve safety during seizures.
	Seizure Burden (intensity & frequency)	○ YES ○ NO	○ YES ○ NO	Depending on your conversation this may include emergency, short-term and long-term actions.
	Generalised Tonic Clonic Seizures	○ YES ○ NO	○ YES ○ NO	Consider potential for surgery or non-drug treatments eg: VNS, Ketogenic diet. Discuss and enable Valporate in keeping with regulations and consider epilepsy mortality/SUDEP risks to enable personalised, shared decision making. Refer to NICE Guidelines for treatment options and referral pathways.
	Prolonged Seizures / Status Epilepticus	○ YES ○ NO	○ YES ○ NO	Ensure an up-to-date emergency care plan is in place (including if rescue medication is needed to control seizures) ESNA Best Practice guidelines for Buccal Midazolam: bit.ly/ESNAEmergencyMedsGuideline & assessment for those administering the medication: bit.ly/ESNAEmergencyMedsAssessment
	Nocturnal Seizures & Night-Time Monitoring	○ YES ○ NO	○ YES ○ NO	What type of supervision/monitoring do you have at night (Parents, relatives/friends/ audio monitoring devices) Consider night-time surveillance options and create a plan for support during/after seizures at night - See section 10.2 of NICE guidelines: bit.ly/EpilepsySafetyDevices Important to discuss how to balance safety/monitoring options and quality of life (for patient & their family), especially as the young person gains independence.
IMPACT OF SEIZURES	Injury / ED Visits / Hospital Admissions	○ YES ○ NO	○ YES ○ NO	Increasing/frequent injuries or use of emergency services due to seizures are a red flag for increased risk. Consider a hazard audit.
	Impact of Seizures on Quality of Life	○ YES ○ NO	○ YES ○ NO	Consider epilepsy care plans that include lifestyle changes that could help reduce risk and impact.
TRTEATMENT	Medication Taking / Compliance	○ YES ○ NO	○ YES ○ NO	Consider strategies to support medication regime eg: changing formulation (consider "ChangeMed" App) or having medication blister packed, Dual Prescriptions if more than one parent/carer living separately, use of dosset box, carrying spare dose in school bag, smartphone reminders, attaching to already existing habit. Share details of patient organisations who can provide advice and support: bit.ly/EpilepsyCharities, SUDEP Action: What is SUDEP? & Risk in childhood & adolescence

SUDEP Action

Making every epilepsy death count

- SUDEP discussion recommended good practice (NICE) since 2004. Use of SUDEP and Seizure Safety Check tool significantly supports practice raising communication in adults to 80% (from 20%)
- Four Prevention of Death Reports last 12 months, theme epilepsy as cliff edge condition needs to be understood esp for access to medication, treatment and support and for person-centred decisions
- Epilepsy Deaths Register Report 53% did not know epilepsy could kill

Transition

Transition to adult care → What matters most to you when moving from children's to adult services?

Competence

Financial information e.g. medical exemption certificates

It could've been easier if maybe we talked to some people already in adult care so i can ask my question

That my parent stay involved in the whole process because I like my mum around all the time to help me in appointments

Confidence and time to explain and learn how to speak for myself because I haven't done it before

Also if my parents could talk to other parents

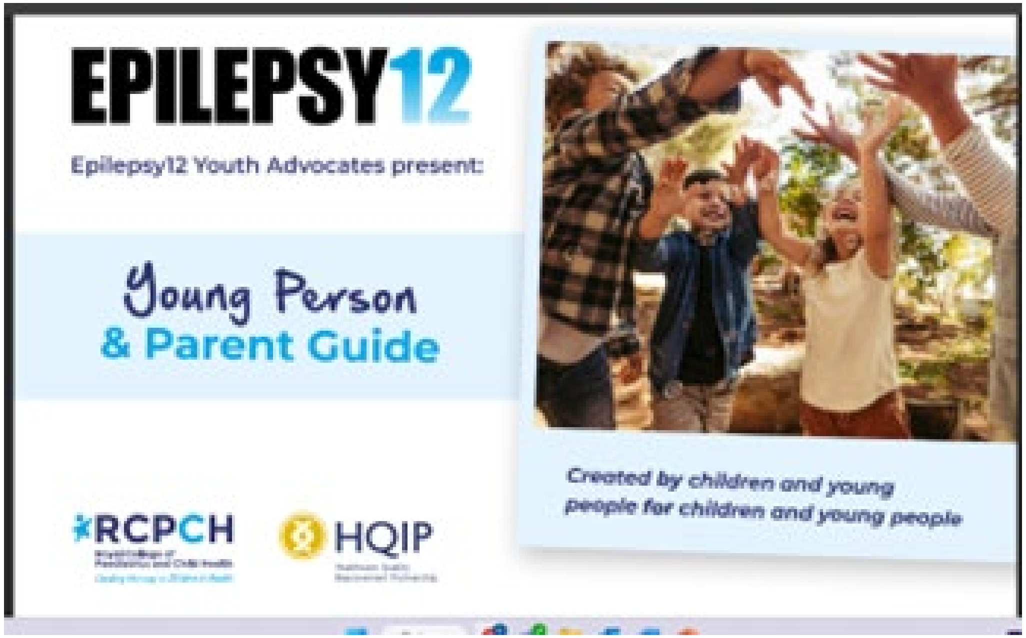
More discussion about uni life

I wanted to know that I was going to lose my physiotherapist and psychologist

I feel like 16 is still too young as an adult

Audit resources

- Good use of colours
- Really helpful checklist
- Diversity in the pictures
- Mix of pictures and words
- Information easy to understand
- A checklist for adult services



EPILEPSY12

Epilepsy12 Youth Advocates present:

Young Person & Parent Guide

Created by children and young people for children and young people

Key points

- Person-centred care
- Staffing/resources
- Signposting
- Understanding inequities accessing care
- MH support
- PPI

Kim.rezel@hqip.org.uk

Aspirational Intent

- The specification is expected to include elements of aspiration which are 'outside scope' at point of award but have the **potential** to be included should the need arise, and funding is available.
- The purpose of aspirational intent is to be clear and transparent with all bidders, on the potential aspirations of the project.
- The specification will detail the aspirational measures that may be included as part of the contract, the funding range and mechanisms for invoking.
- The ability to meet these aspirational measures is **not a scored requirement**, so will have no impact on your bid responses. It will, however, give us visibility on bidder's capability to deliver these measures should the need arise, and funding becomes available.
- Aspirational intent will be managed via contract modifications and mutually agreed between HQIP and the successful provider.
- There is **no guarantee** that HQIP will invoke any aspirational measures throughout the contract lifecycle.

Timelines

- The below are to be taken as **indicative** only, and whilst the authority intends to stick to these milestones, it reserves the right to deviate.

Key Milestone	Start Date	End Date
Premarket Engagement Session	29th October 2025	29th October 2025
Tender Live	8th December 2025	22nd January 2026 – To account for the holiday period.
Deadline for Bidder Clarification Questions	8th December 2025	8th January 2026 – Responses to CQs to be issued to bidders by 15/01/26
Evaluator Clarifications	22nd January 2026	11th February 2026
Deadline for Response to Evaluator Clarifications	22nd January 2026	19th February 2026
Evaluation of Bids	22nd January 2026	26th February 2026
Moderation	March 2026	March 2026
Feedback Letters Issued & Standstill Commences	May 2026	June 2026
Contract Start Date	1st April 2027	-