

EPILEPSY12

Update

Epilepsy12 & OPEN UK Conference
Wednesday 18 September 2024

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A landscape photograph showing a dirt road winding through a field. The road is light brown and leads from the bottom center towards the horizon. The field is green and occupies the middle ground. In the distance, there's a small, dark, rounded object on the horizon line. The sky is blue with white, fluffy clouds. The overall scene is bright and open.

Let's empower people for their life journey...

...not simply navigate our 'patient journey'

@drcolindunkley

Outline

- Intro
- 2024 key England/Wales results
- Emerging landscapes and new connections
- New platform and aspirations
- New longitudinal data
- Dashboard developments
- On the Horizon...

2024

EPILEPSY12

#RCPCHAudits

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

Epilepsy12 2024 combined organisational and clinical audits:

Report for England and Wales

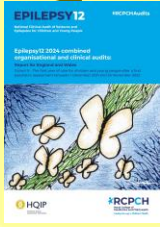
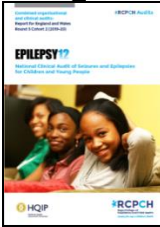
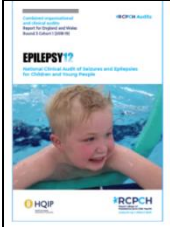
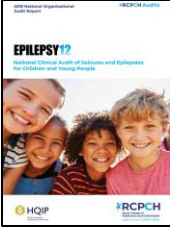
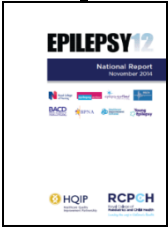
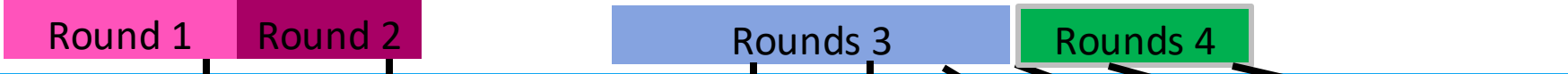
Cohort 5 – The first year of care for children and young people after a first
paediatric assessment between 1 December 2021 and 30 November 2022



‘White Butterflies’
Courtesy Jeremy Ryan
Smith

Neurographic art as
part of art therapy
collection

*"Epilepsy and mental
health go together.
I've been using mixed
media drawings to
process the complex
emotions I've been
dealing with for many
years."*



NHSE data packs:



HBT reports:

Other outputs:



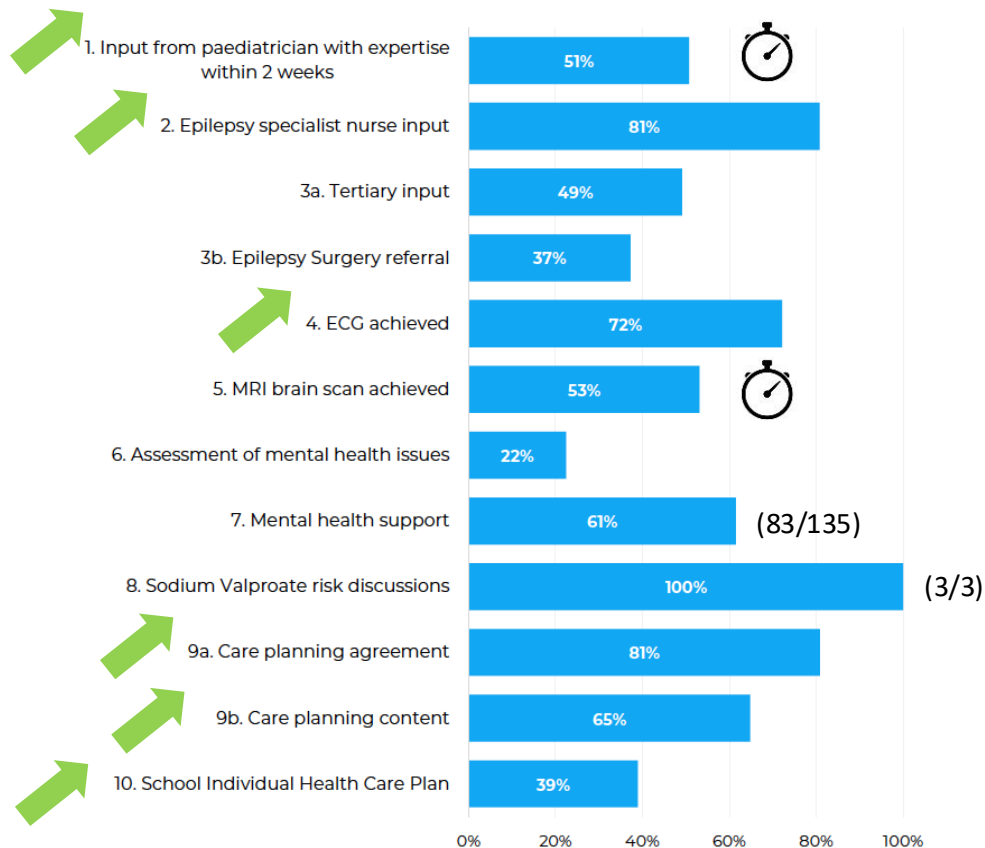
Cohort 5 England/Wales Results, 2024

Organisational data – ‘1 November 2023 Snapshot’

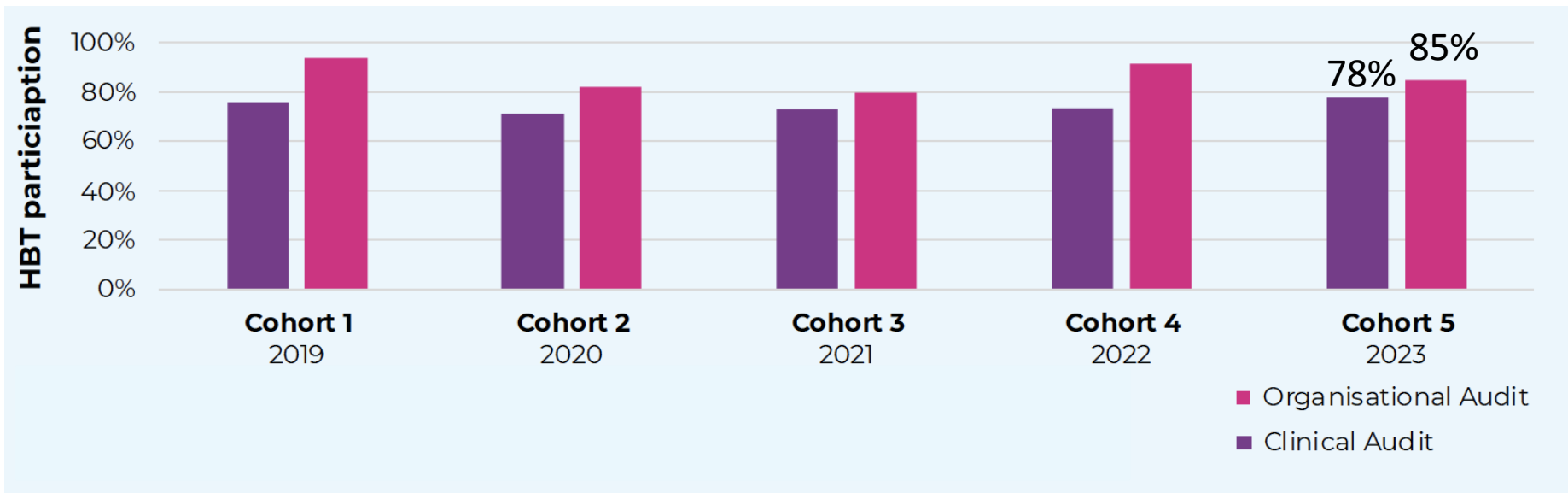
Clinical data:

- Children and young people with new epilepsy diagnosis
- First paediatric assessment between
1 December 2021 - 30 November 2022 (cohort 5)
- All completed a first year of care
- Submitted to Epilepsy12 by January 2024
- **N = 2212**

Our '10' Key Performance Indicators, 2024



Key Findings 1 - Contributing and participating



Regional variation

Organisational audit participation range 67-100%

Clinical audit participation range 56-100%

Recommendation 1 - Contributing and participating

Support Epilepsy teams not yet participating in the audit to value, contribute and improve together through Epilepsy12 participation. This might be through promotion of the audit, training, workforce and team development, job planning or identifying and solving specific local barriers. ICBs should identify supporting routes and engage with quality improvement programmes, such as the Epilepsy Quality Improvement Programme (EQIP), managed by the RCPCH, to assess quality of care and provision within those services not yet participating.

Action by: Integrated Care Boards (ICBs) in England and local Health Boards in Wales, in collaboration with OPEN UK regional networks.

Outlier process - Contributing and participating

examples of 2024 outlier responses...

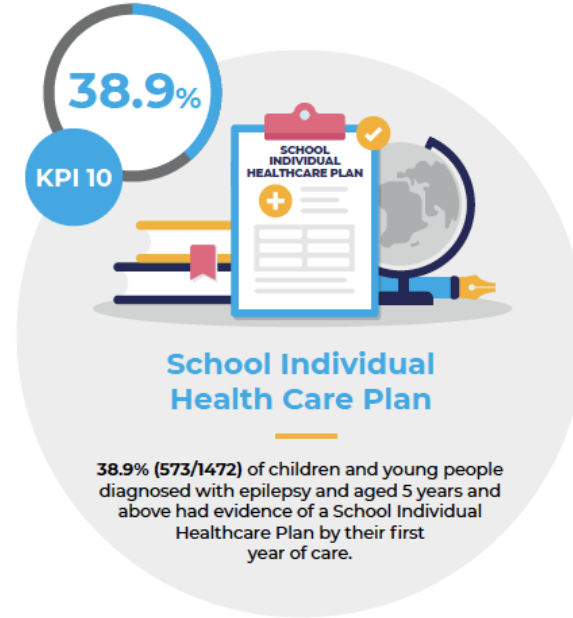
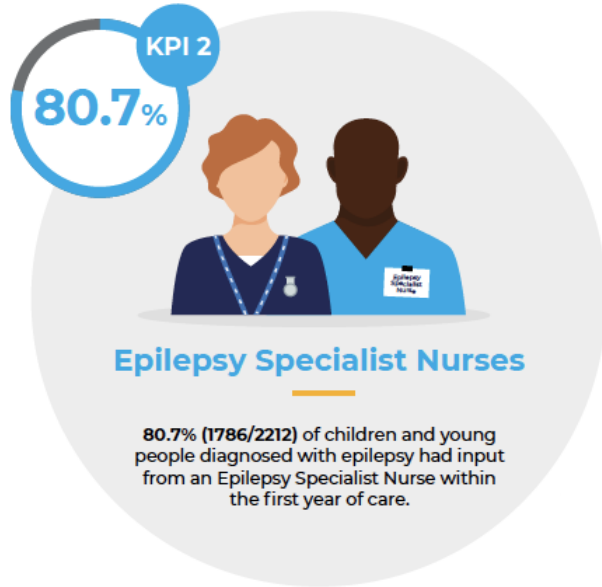
Additional nursing and admin hours have been agreed to support Epilepsy12 participation, recruitment has begun to fill a neurology admin vacancy and audit duties will be incorporated into job plans for the clinical team.

...an administrator is now in post to support future data entry.

The Trust have agreed to participate in Epilepsy12 going forward, risk assess the paediatric epilepsy service as a priority, consider recruiting a paediatric ESN and undertake QI projects relevant to the paediatric epilepsy service and audit.

27 trusts
published as non-
participation
outliers

Key Findings 2 – Widening and strengthening epilepsy team provision



Key Findings 2 – Widening and strengthening epilepsy team provision



Care planning

64.8% (1433/2212) of children and young people with epilepsy had documented evidence of communication regarding core elements of care planning.

SUDEP

Within this indicator, the proportion with evidence of SUDEP discussions was 66.3%, whereas performance was >90% for all other care planning sub-metrics.

Transition

56% (65/117) had outpatient clinics specifically for young people with epilepsy and **68% (80/117)** involved both adult and paediatric professionals in transition services.

‘Contactability’

Typical response time of specialist advice

Same weekday	7.9% (9/114)
Next weekday	47.4% (54/114)
3 – 4 weekdays	36.8% (42/114)
Within the working week	7.9% (9/114)

Key Message 2 – Widening and strengthening epilepsy team provision



Epilepsy Specialist Nurses (ESNs) are essential members of epilepsy teams for children and young people, and have extending key responsibilities including care planning, and within this, discussions around Sudden Unexpected Death in Epilepsy (SUDEP), 'service contactability', planning with schools, transition and mental health support.

Recommendation 2– Widening and strengthening epilepsy team provision

Increase the scope and breadth of the epilepsy team and ensure sufficient provision of Epilepsy Specialist Nurses (ESN) and other professionals to support their population needs. Core and specialised competences required within a team to match population needs might include mental health, transition from paediatric to adult services, learning difficulties, neurodisability, medical complexity, etc.

Action by: Integrated Care Boards (ICBs) in England and local Health Boards in Wales.

Key Message 3 - Ensuring timeliness of input



KPI 1 Paediatrician with expertise in epilepsies

50.8% (1123/2212) of children and young people with epilepsy received input by a 'consultant Paediatrician with expertise in epilepsies' within two weeks of initial referral.

50.8%



92% when
timeliness
removed

KPI 5 MRI

53.1% (385/725) of children and young people with epilepsy and defined indications for an MRI had an MRI brain scan within 6 weeks of request.

53.1%



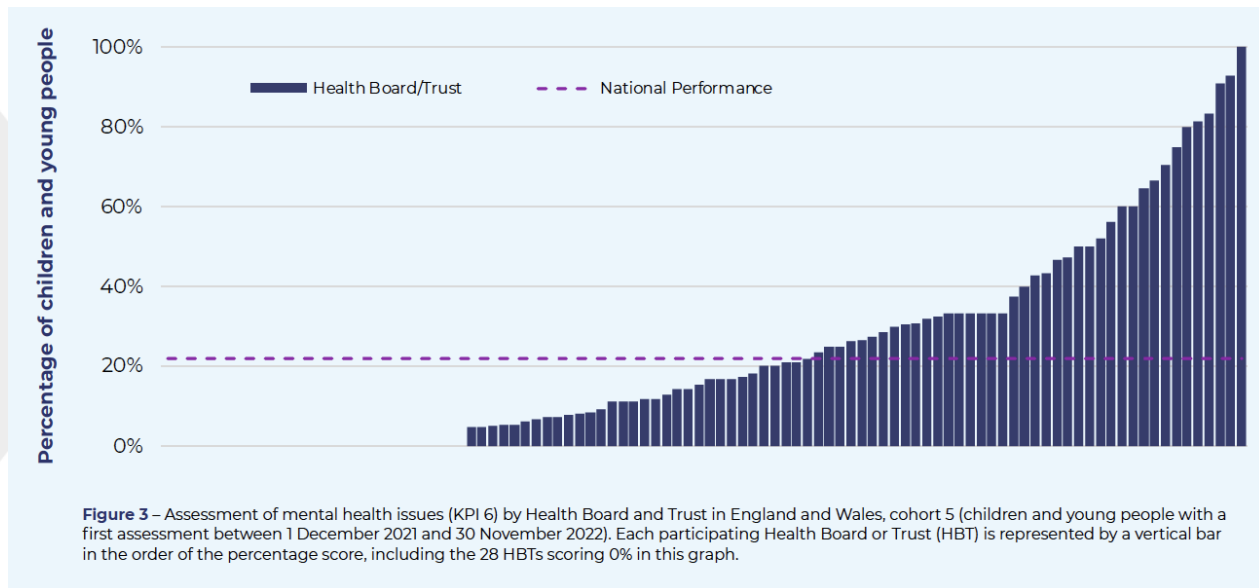
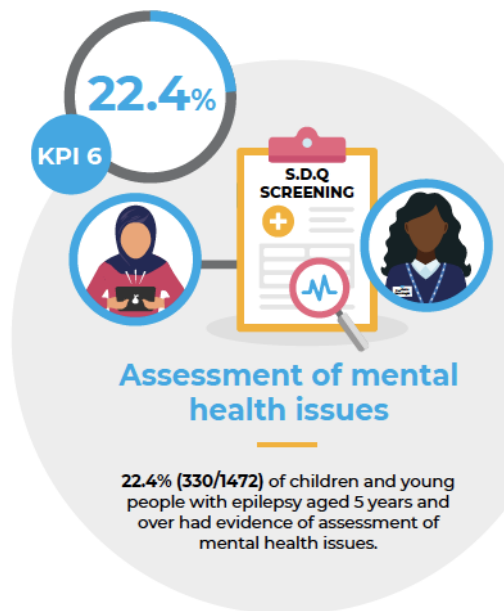
74% when
timeliness
removed

Recommendation 3- Ensuring timeliness of input

Establish or improve the processes and pathways in place to ensure children and young people receive timely access to care. This could include identifying and understanding where the gaps in provision are, or establishing structured referral pathways with designated coordinators.

Action by: Integrated Care Boards (ICBs) in England and local Health Boards in Wales.

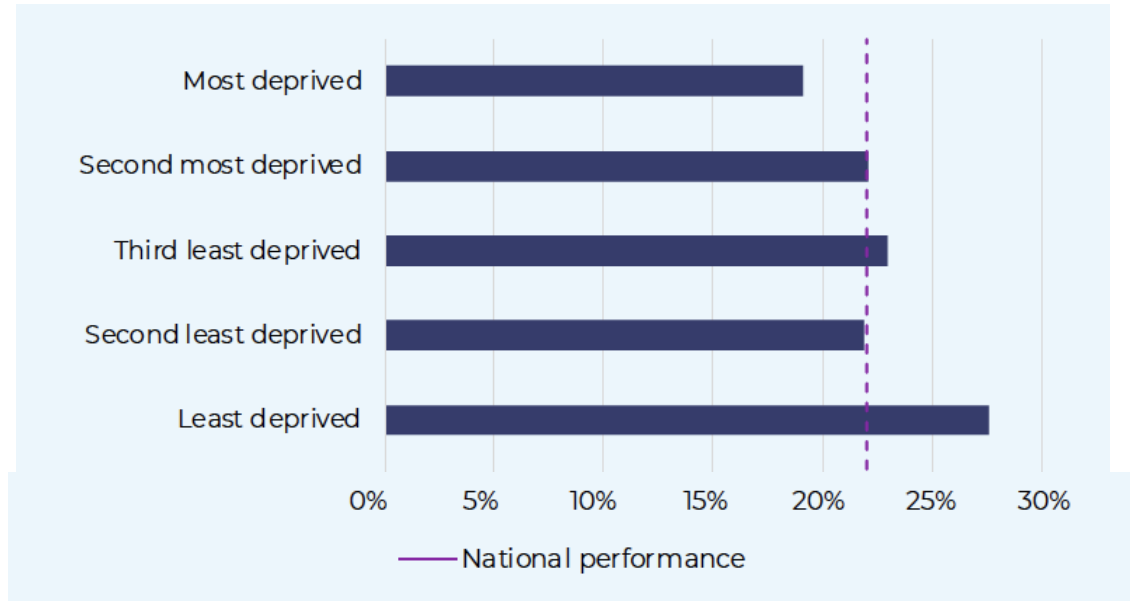
Key Findings 4 – Tackling variations in care



Key Findings 4 – Tackling variations in care



Variation in mental health assessment rates according to deprivation



Recommendation 4 – Tackling variations in care

Integrated Care Boards (ICBs) and local Health Boards should develop models of engagement that enable groups where there may be inequalities, eg. Within the Core20PLUS5 framework, to contribute to service improvement. This can be by identifying challenges and co-creating alternative service models to ensure equitable access and care for epilepsy aligned with work supporting other long-term health conditions.

Action by: Integrated Care Boards (ICBs) in England and local Health Boards in

Recommendation 5

Support participation and benchmarking against relevant ongoing quality improvement projects, in order to promote system-wide shared learning, collaboration and knowledge exchange.

Action by: Integrated Care Boards (ICBs) in England and local Health Boards in Wales

Other results outputs, 2024

- Full organisational & clinical report
- HBT level results – narrative reports soon
- NHSE deliverables outcomes
- Longitudinal report
- Monthly public facing dashboard

New Platform 2024

- Epilepsy only
- 'Quicker & slicker'
- Real-time reporting
- Open-source, clinician built
- Built for direct data exchange with hospital systems and families

EPILEPSY12

The screenshot displays the EPILEPSY12 platform interface. On the left is a sidebar menu with a pink header and a blue footer. The menu items are: 'Verification and registration' (Getting started...), 'First paediatric assessment' (The first visit), 'Epilepsy Context' (Background and risk factors), 'Multiaxial diagnosis' (DESCRIBE definition), 'Milestones' (Important milestones), 'Tests' (EEG, ECG and MRI), 'Treatment and care planning' (Medication, other treatment, teams and care plans), '8 Performance summary' (Key performance indicators), and 'Back to child and young person view'. The main content area has a blue header 'Audit view - Performance summary for Sandy Evelyn'. It is divided into two sections: 'Clinical Team' and 'Investigations'. Each section contains a table with 'Indicator' and 'Performance' columns. In the 'Clinical Team' table, '1. Paediatrician with expertise in epilepsies' has a warning icon, '2. Epilepsy Specialist Nurse' has a checkmark, '3. Tertiary input' has a checkmark, and '3b. Epilepsy surgery referral' has a checkmark. In the 'Investigations' table, '4. ECG' and '5. MRI' both have checkmarks.

Verification and registration
Getting started...

First paediatric assessment
The first visit

Epilepsy Context
Background and risk factors

Multiaxial diagnosis
DESCRIBE definition

Milestones
Important milestones

Tests
EEG, ECG and MRI

Treatment and care planning
Medication, other treatment, teams and care plans

8 Performance summary
Key performance indicators

[Back to child and young person view](#)

Audit view - Performance summary for Sandy Evelyn

Clinical Team

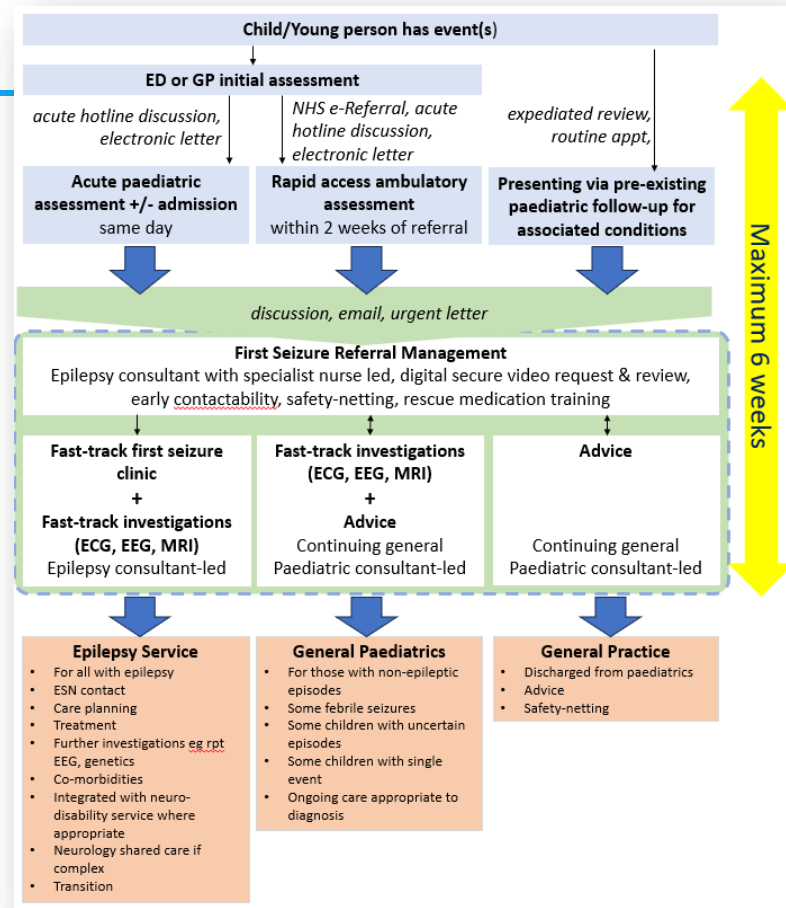
Indicator	Performance
1. Paediatrician with expertise in epilepsies	⚠
2. Epilepsy Specialist Nurse	✓
3. Tertiary input	✓
3b. Epilepsy surgery referral	✓

Investigations

Indicator	Performance
4. ECG	✓
5. MRI	✓

Reorientating...

Rather than a child
on our
'patient journeys'
and 'care pathways'...



Reorientating...

...healthcare to accompany and enable
the child's life journey!



Connecting...

NHS Local
Health Records



RCPCH audit engine

PRSB

EPILEPSY12



EPILEPSY12

 **RCPCH**

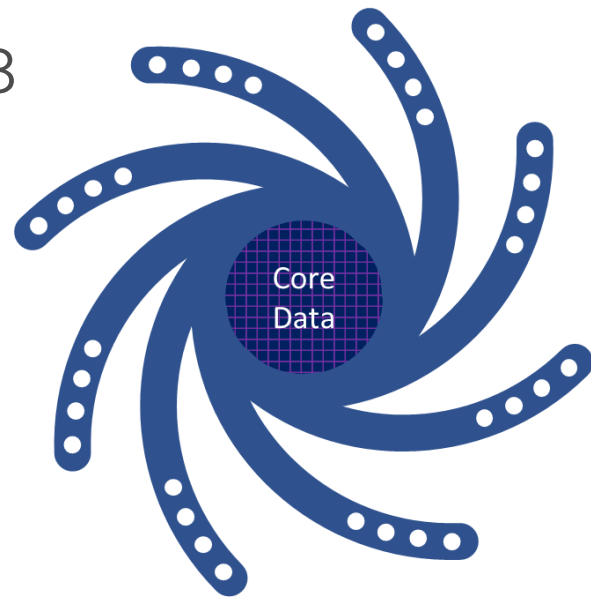


Professional
Record
Standards
Body

UK Epilepsies Data Standard

- Completed initial phases and published draft data model v0.8
- Outcomes and formulation
- Stage 3 commenced, September 2024 towards widening consultation
- Info in, info out!

...Join in?!



EPILEPSY12



THE
NEUROLOGICAL
ALLIANCE



Young
Epilepsy



EPILEPSY RESEARCH
INSTITUTE UK



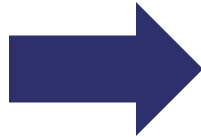
RCPCH

Longitudinal analyses

Epilepsy12 defined 10 new KPI measures for cohort 5.

- 3 measures removed
- 2 new measures around mental health
- 🕒 Timeliness added to 2 measures ; paediatrician with expertise and MRI
- Several criteria updated to align with 2022 NICE guidelines

**Challenges in
comparing
cohorts**



**Opportunity to
explore longitudinal
trends over time**

Longitudinal Trends

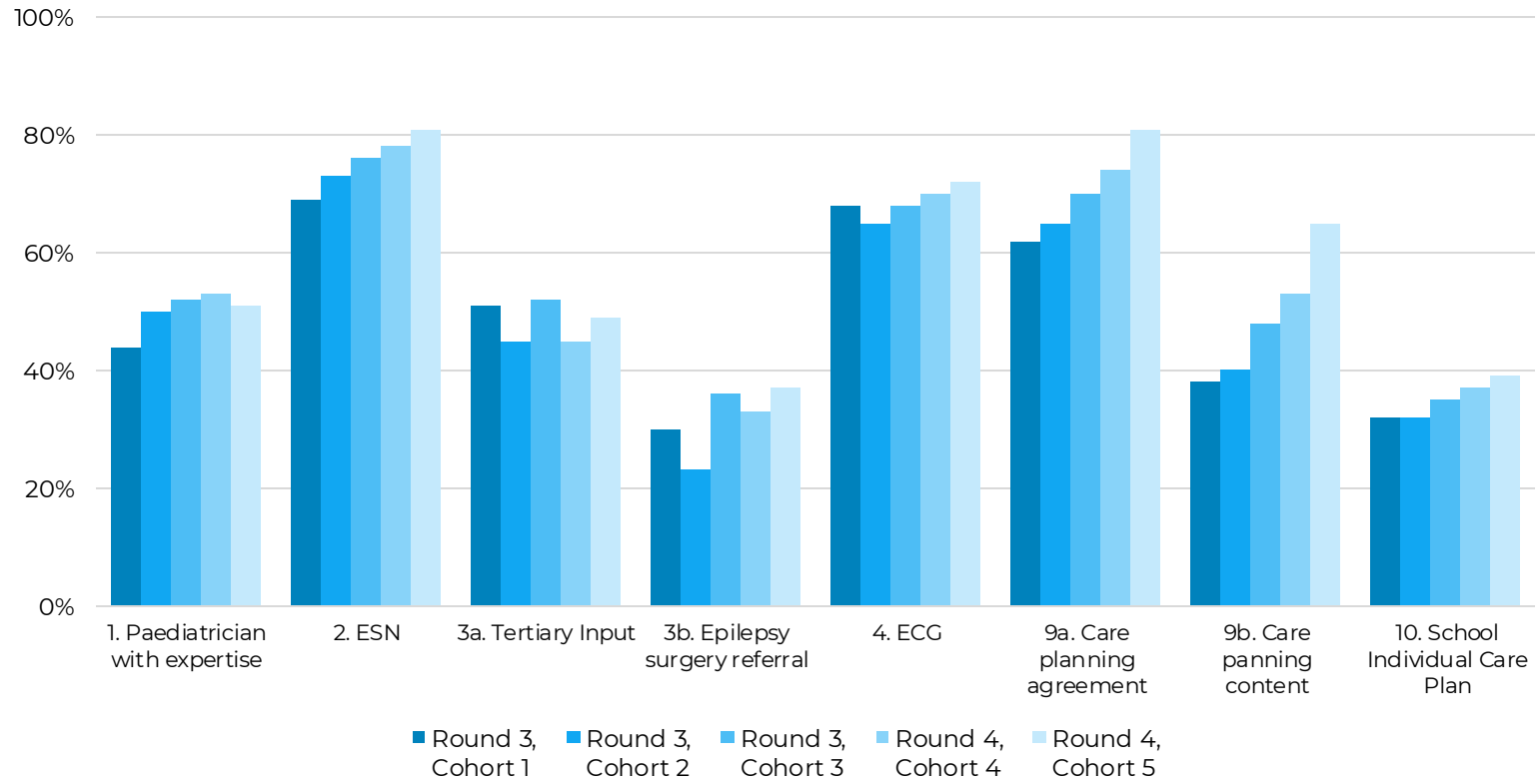


Figure 30: Longitudinal data for KPI measures for England and Wales combined across the 5 cohorts.

Longitudinal Trends - regional

*provisional data

KPI 1. Percentage of children with epilepsy, with input by a 'consultant paediatrician with expertise in epilepsies' within two weeks from first paediatric assessment



Longitudinal Trends - regional

*provisional data

KPI 9b. Percentage of children diagnosed with epilepsy with documented evidence of communication regarding core elements of care planning.



Conclusions



There is opportunity to explore longitudinal trends within Epilepsy12 audit data



National results show improvements in quality of care over time



Performance varies across England and Wales



Longitudinal analyses can be challenging..

Frequent reporting Dashboard



THE E12 TEAM HAVE
CREATED A DASHBOARD

- Display **clinical data** at national, country, regional, ICB and Trust/Health Board level
- Refreshes every **month**
- Be **interactive** and user friendly
- Be available in the **public domain**

Cohort 6 so far



EPILEPSY12

Home

England and Wales

Country

OPEN UK Network

NHSE Region

ICB

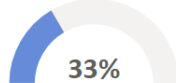
Trust/Health Board

Cohort 5

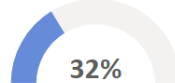


England and Wales Combined - 645 CYP

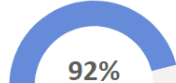
1. Paediatrician with expertise



6. Assessment of mental health issues



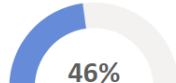
2. Epilepsy specialist nurse



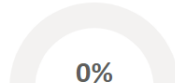
7. Mental health support



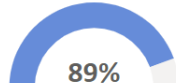
3a. Tertiary involvement



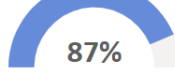
8. Sodium valproate



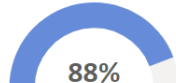
3b. Epilepsy surgery referral



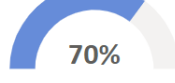
9a. Comprehensive care planning agreement



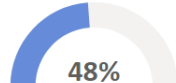
4. ECG



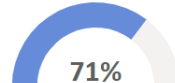
9b. Comprehensive care planning content



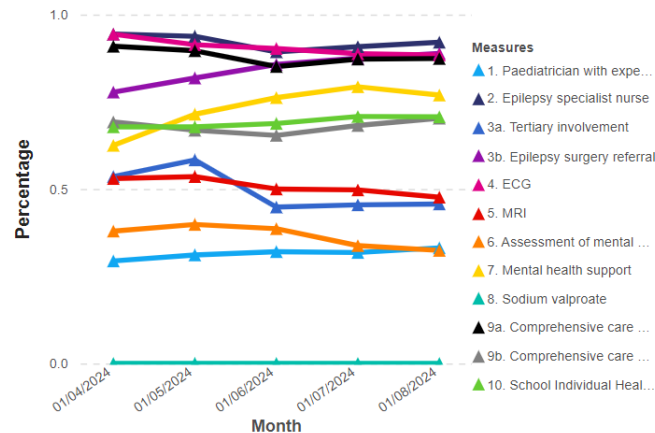
5. MRI



10. School Individual Health Care Plan



Performance Indicators by Quarter



Measure	Percentage	Numerator	Denominator
1. Paediatrician with expertise	33%	213	643
2. Epilepsy specialist nurse	92%	592	643
3a. Tertiary involvement	46%	96	210
3b. Epilepsy surgery referral	89%	24	27
4. ECG	88%	359	406
5. MRI	48%	243	510
6. Assessment of mental health issues	32%	137	423
7. Mental health support	77%	30	39
8. Sodium valproate	NA	0	0
9a. Comprehensive care planning agreement	87%	562	643
9b. Comprehensive care planning content	70%	452	643
10. School Individual Health Care Plan	71%	299	423

Cohort 6 so far



EPILEPSY12

Home

England and Wales

Country

OPEN UK Network

NHSE Region

ICB

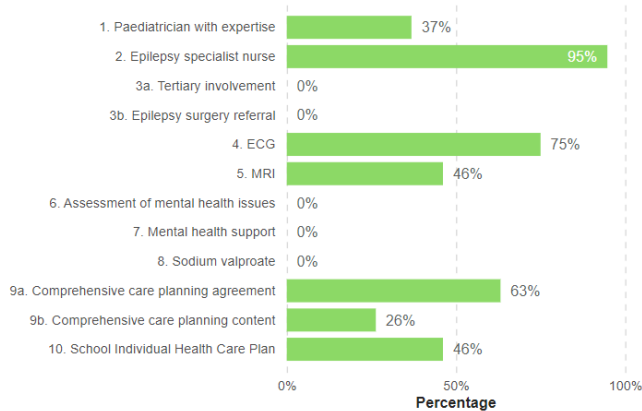
Trust/Health Board

Cohort 5



Select NHSE Region

Performance Indicators



Measure	Percentage	Numerator	Denominator
1. Paediatrician with expertise	37%	7	19
2. Epilepsy specialist nurse	95%	18	19
3a. Tertiary involvement	*	*	*
3b. Epilepsy surgery referral	NA	0	0
4. ECG	75%	6	8
5. MRI	46%	6	13
6. Assessment of mental health issues	*	*	*
7. Mental health support	*	*	*
8. Sodium valproate	NA	0	0
9a. Comprehensive care planning agreement	63%	12	19
9b. Comprehensive care planning content	26%	5	19
10. School Individual Health Care Plan	46%	6	13

Key:

* - if either the numerator or denominator is <3, results are replaced with an asterisk.

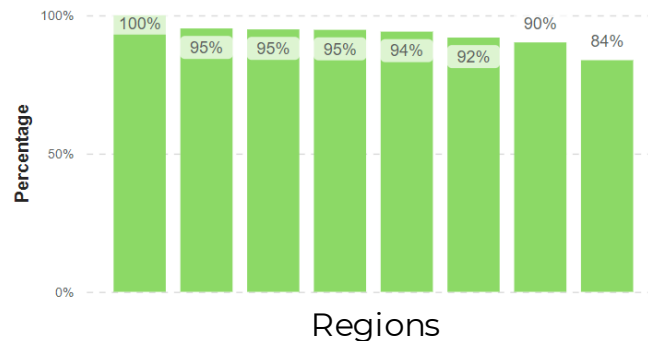
NA - None of the patients at this site met the criteria for this metric.

No data - This site has not submitted any data.

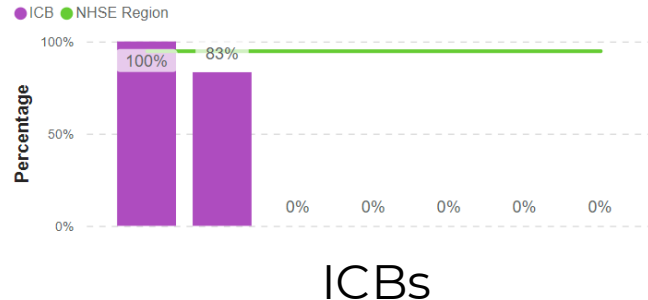
Select Performance Indicator

2. Epilepsy specialist nurse

Performance Indicator by NHSE Region



Performance Indicator by ICBs within NHSE Region



On the horizon...

Data- Access requests; Health Economics, LeDeR and Mental Health projects

New data on autism, global developmental delay/learning disabilities -> Core20plus5

Sodium valproate ARAF

Any Questions?

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[@epilepsy_12](https://twitter.com/epilepsy_12)