EPILEPSY12

Update

EPILEPSY12 and OPEN UK Conference, 2025

Colin Dunkley, Niky Raja

RCPCH

“I’m pickin’ up good ‘connections’…!”

Connect you…

- To improvements and connections in our latest Epilepsy12 results
- To updates in the platform and reporting dashboards
- To a 15 year long view!
- To what’s next and future steps…

Since 2009…

2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025	2026

Round 1

Round 2

Cohort 1-3

Cohort 4-6

Cohort 7-8

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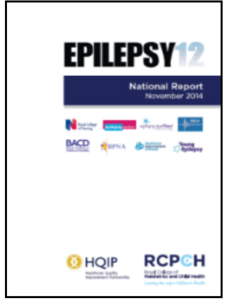
United Kingdom collaborative clinical audit of health care for children and young people with suspected epileptic seizures

National Report
September 2012

RCPCH



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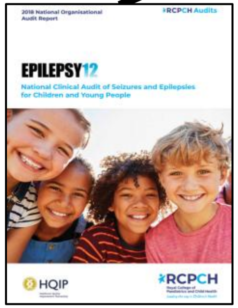
National Report
November 2014

HQIP

RCPCH



2018 National Organisational Audit Report

RCPCH Audits

EPILEPSY12

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

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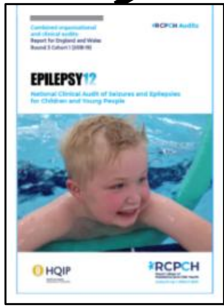

Combined organisational and clinical audits:
Report for England and Wales
Round 3 Cohort 1 (2018-19)

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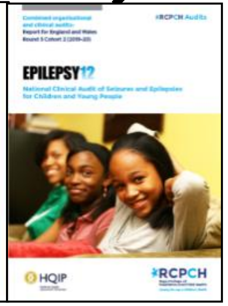

Combined organisational and clinical audits:
Report for England and Wales
Round 3 Cohort 2 (2019-20)

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

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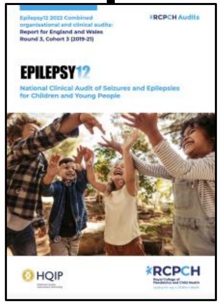

Epilepsy12 2022 Combined organisational and clinical audits:
Report for England and Wales
Round 3, Cohort 3 (2019-21)

RCPCH Audits

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

Epilepsy12 2023 combined organisational and clinical audits:
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Round 4, Cohort 4 (2020-22)

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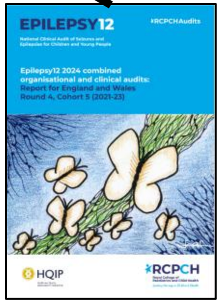

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National Clinical Audit of Seizures and Epilepsies for Children and Young People

Epilepsy12 2024 combined organisational and clinical audits:
Report for England and Wales
Round 4, Cohort 5 (2021-23)

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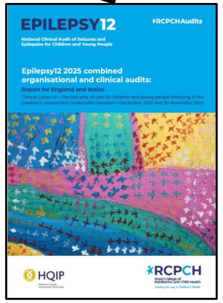

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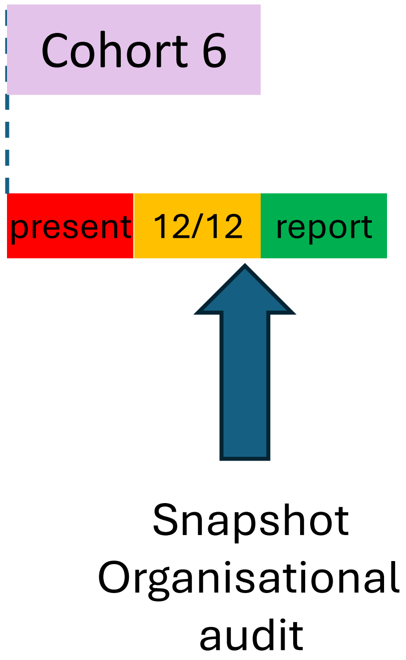
Front Cover – ‘**Live your Dream 1**’ is an artwork created by Janet Lee, an international artist from Malaysia who lived with epilepsy (1989 - 2023). This was created using acrylic paints on a canvas surface, and with the following message: *someone once said, “You’ll never know how far you can fly until you spread your wings. It is another glorious day. Follow your heart and set yourself free.”*

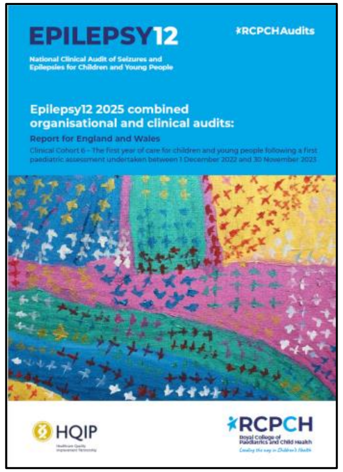
Cohort 6 published, 2025



Snapshot Organisational audit

Inclusion criteria:

- Child or young person with a first diagnosis of an epilepsy
- First paediatric assessment date for first seizure(s) within a defined yearly cohort within England/Wales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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

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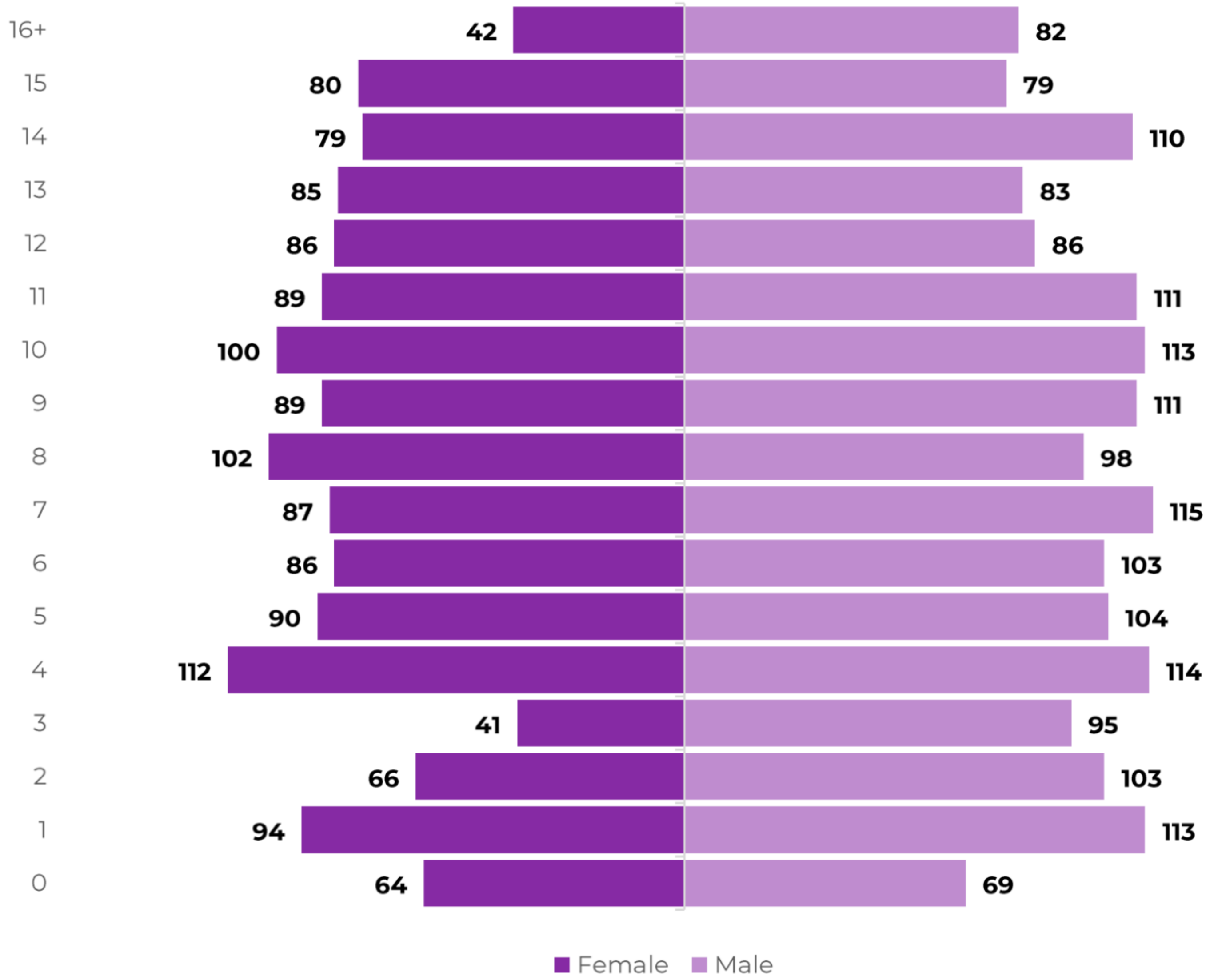
Cohort 6 published, 2025

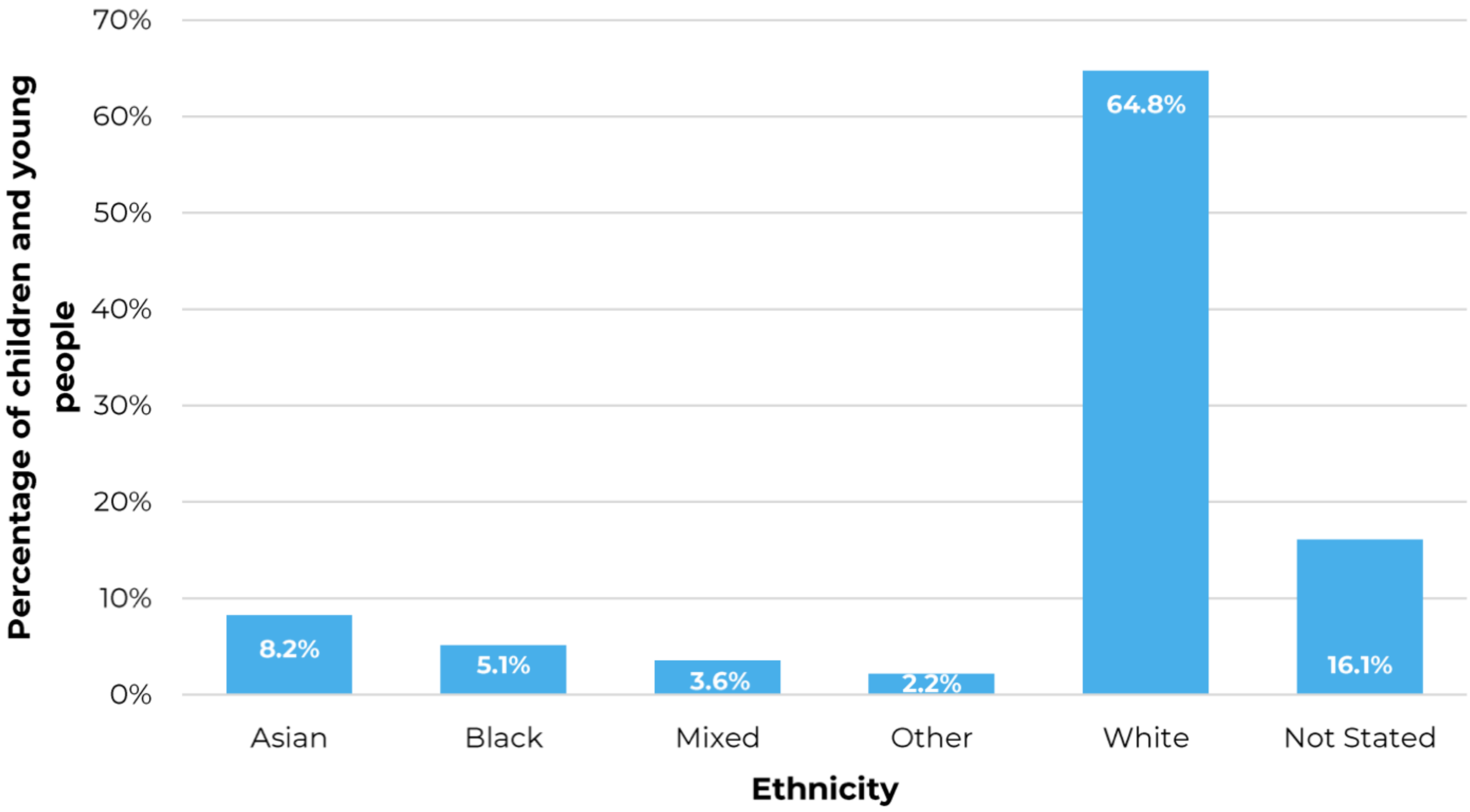
N= 3,105

- 120 hospital and community services
- 54% male, 46% female
- 28% (854/3,105) had a neurodevelopmental condition and/or learning disability

Age at first assessment & sex distribution

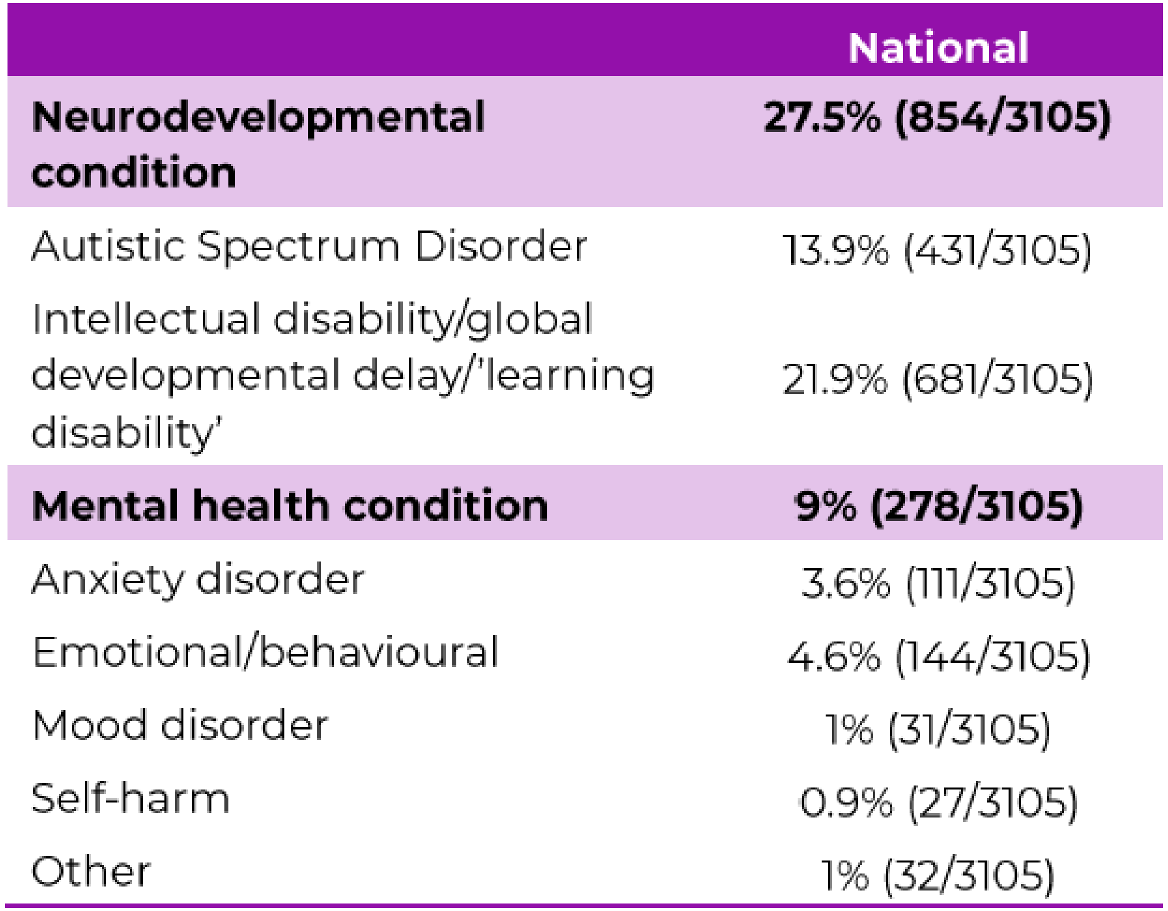


Ethnicity



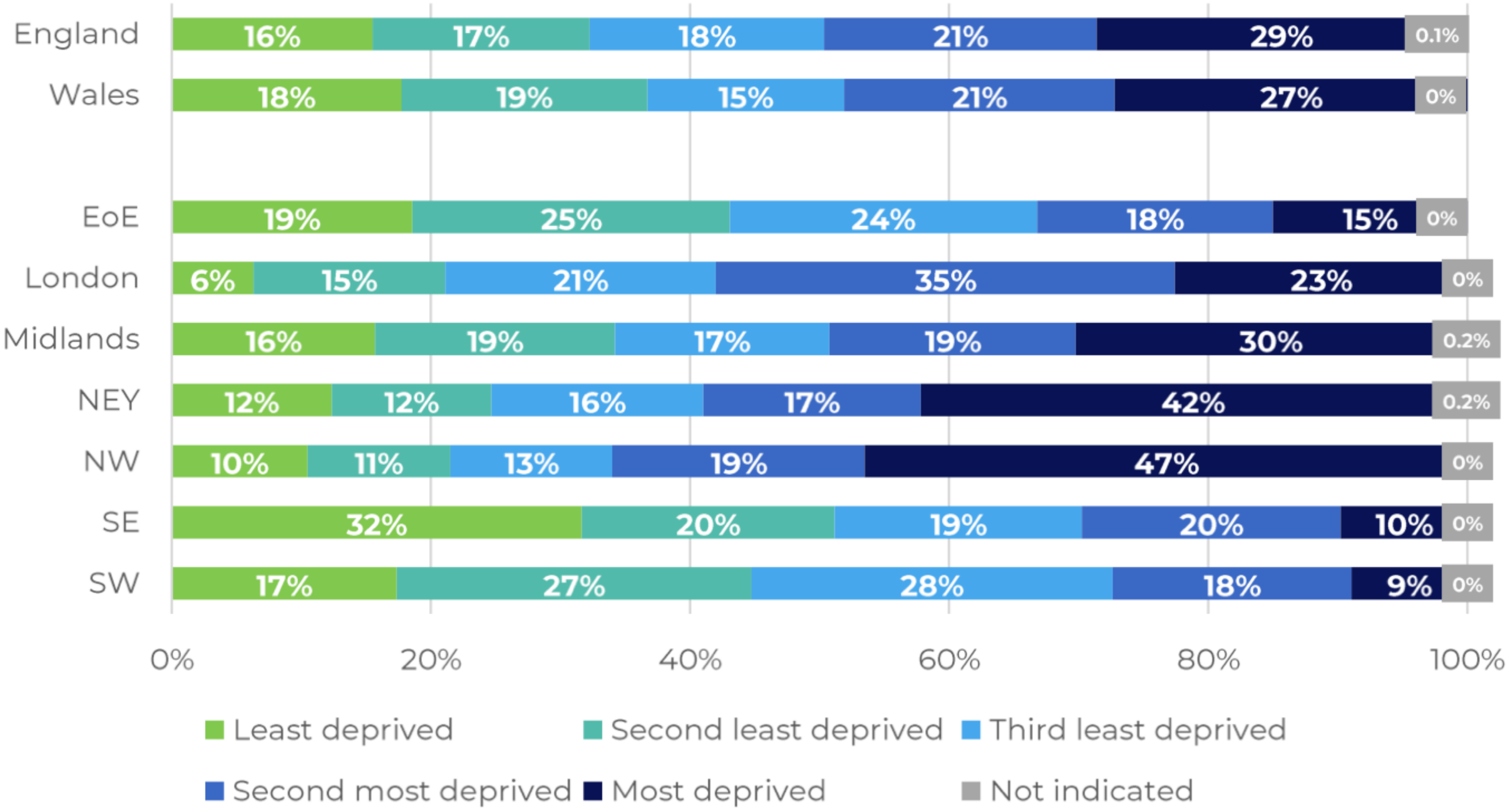
70%
60%
50%
40%
30%
20%
10%
0%
Percentage of children and young people
8.2%
5.1%
3.6%
2.2%
64.8%
16.1%
Asian
Black
Mixed
Other
White
Not Stated
Ethnicity

Neurodevelopment and mental health

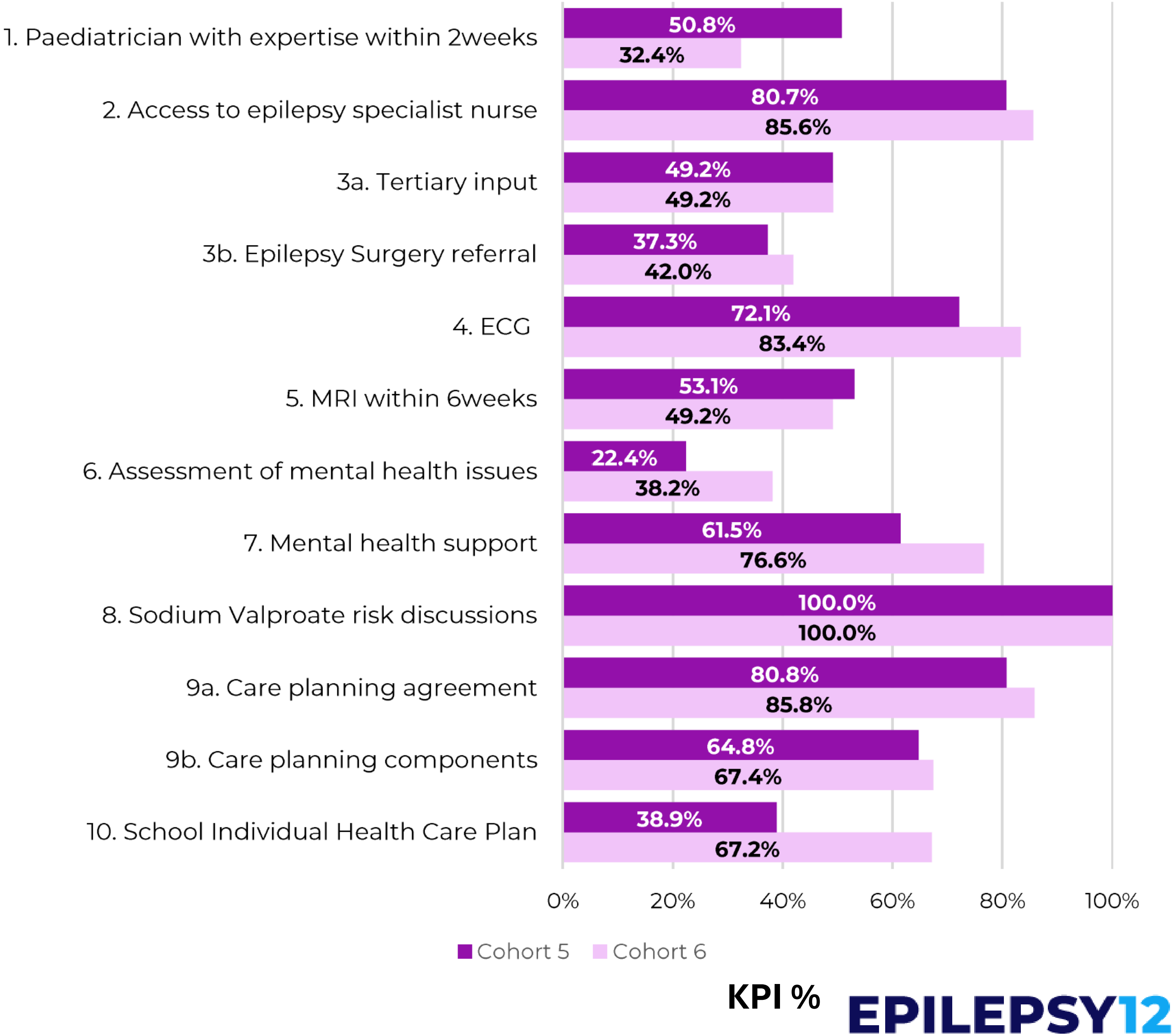


	National
Neurodevelopmental condition	**27.5% (854/3105)**
Autistic Spectrum Disorder	13.9% (431/3105)
Intellectual disability/global developmental delay/'learning disability'	21.9% (681/3105)
Mental health condition	**9% (278/3105)**
Anxiety disorder	3.6% (111/3105)
Emotional/behavioural	4.6% (144/3105)
Mood disorder	1% (31/3105)
Self-harm	0.9% (27/3105)
Other	1% (32/3105)

Distribution by deprivation



Summary of KPIs, cohort 6



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Contributing and participating
Key theme:

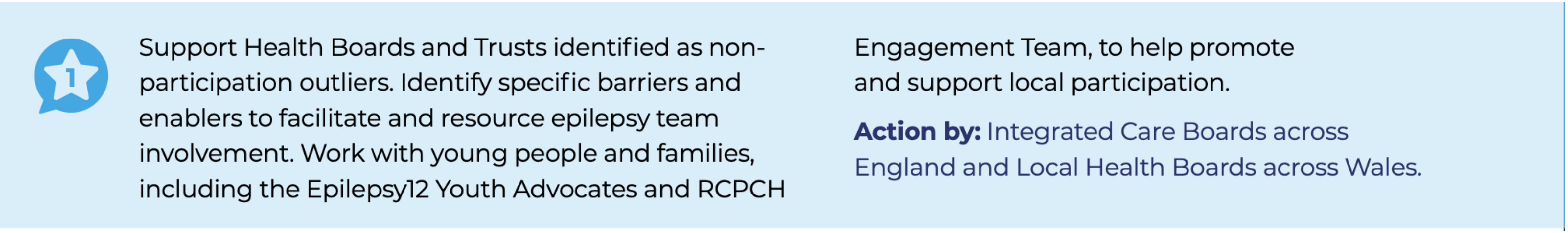
- **80%** (120/150) of registered Health Boards and Trusts registered into Epilepsy12 participated in the cohort 6 clinical audit
- **76%** (114/151) submitted organisational data to describe their service as at 1 November 2023. This now includes data from Jersey.
- **3,152** children and young people with epilepsy were registered onto the Epilepsy12 platform and allocated to cohort 6 before the January data submission deadline.
- **3,105** had fully completed first year of care forms and were included in analyses.

Contributing and participating
Key theme:

- **40%** (46/114) of Health Boards/Trusts did not have any time specified towards local epilepsy audit and quality improvement (QI) activity for teams in job plans.
- For teams with some time indicated, the median amount for audit/QI was **1 hour/week**
- **35%** (40/114) of Health Boards and Trust had no time specified for epilepsy leadership.
- For teams with some time indicated, the median amount for epilepsy leadership was **1 hour/week**

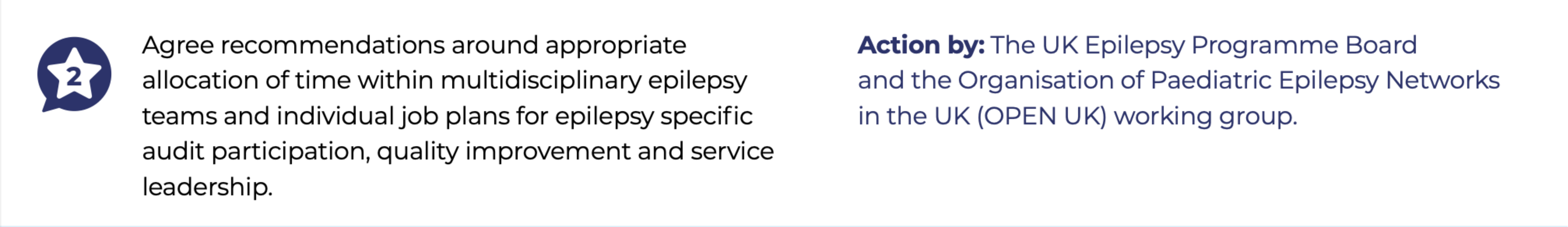
Contributing and participating

Recommendations 1&2



1 Support Health Boards and Trusts identified as non-participation outliers. Identify specific barriers and enablers to facilitate and resource epilepsy team involvement. Work with young people and families, including the Epilepsy12 Youth Advocates and RCPCH Engagement Team, to help promote and support local participation.

Action by: Integrated Care Boards across England and Local Health Boards across Wales.

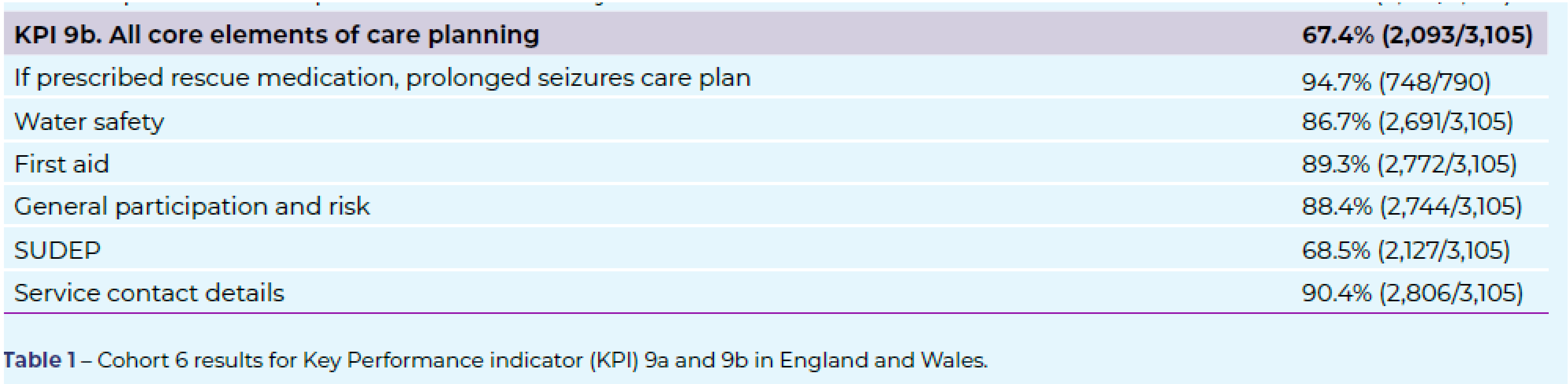


2 Agree recommendations around appropriate allocation of time within multidisciplinary epilepsy teams and individual job plans for epilepsy specific audit participation, quality improvement and service leadership.

Action by: The UK Epilepsy Programme Board and the Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK) working group.

Building community and neighbourhood provision
Key theme:

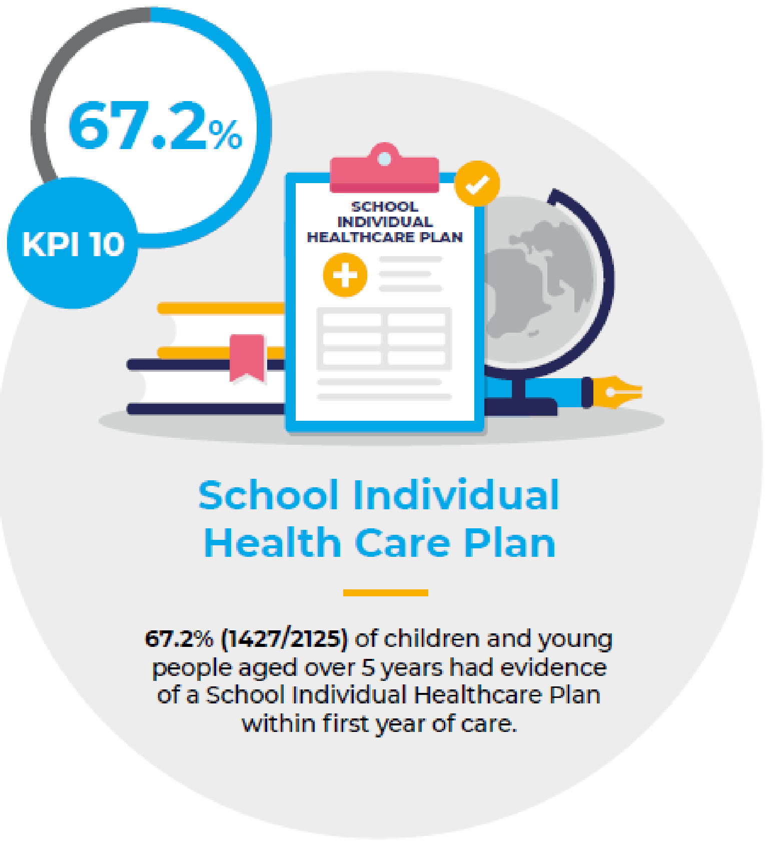
- **86%** (2,665/3,105) of children and young people with epilepsy had evidence of care planning **agreement** within the first year of care in cohort 6
- **67%** (2,093/3,105) had evidence of achieving **all core elements** of care planning



KPI 9b. All core elements of care planning	**67.4% (2,093/3,105)**
If prescribed rescue medication, prolonged seizures care plan	94.7% (748/790)
Water safety	86.7% (2,691/3,105)
First aid	89.3% (2,772/3,105)
General participation and risk	88.4% (2,744/3,105)
SUDEP	68.5% (2,127/3,105)
Service contact details	90.4% (2,806/3,105)

Table 1 – Cohort 6 results for Key Performance indicator (KPI) 9a and 9b in England and Wales.

Building community and neighbourhood provision
Key theme:



School Individual Health Care Plan

67.2% (1427/2125) of children and young people aged over 5 years had evidence of a School Individual Healthcare Plan within first year of care.

- **67% (1,427/2,125)** of children and young people with epilepsy aged over 5 years had evidence of a **School Individual Health Care Plan**
- A large increase compared to previous cohorts, eg **39% (573/1,472)** in cohort 5

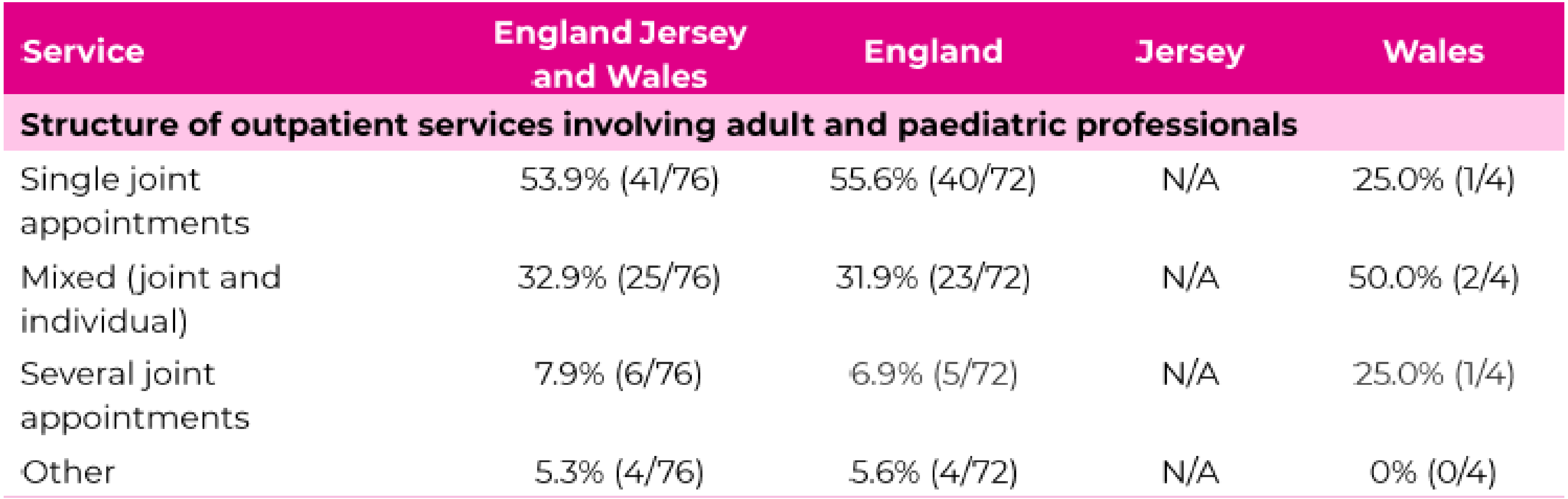
Building community and neighbourhood provision

Key theme:

- In 2024, **89% (101/114)** of participating Health Boards and Trusts had an **agreed referral pathway to adult services**, compared to 91% in 2023.
- **76% (87/114)** used **structured transition resources**
- **61% (70/114)** had clinics specifically for young people with epilepsy and **67% (76/114)** involved **both adult and paediatric professionals** in transition services.

Building community and neighbourhood provision

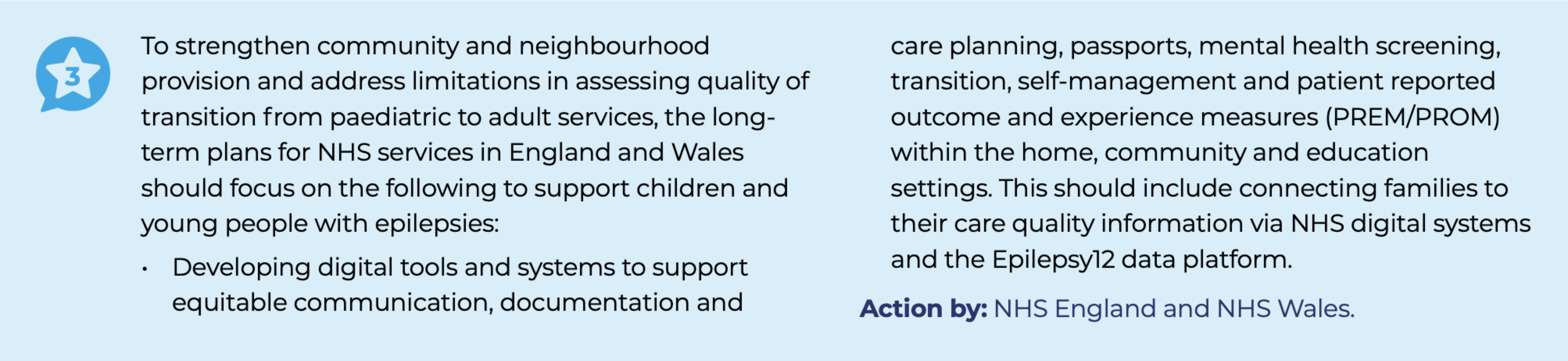
Key theme:



Service	England Jersey and Wales	England	Jersey	Wales
Structure of outpatient services involving adult and paediatric professionals				
Single joint appointments	53.9% (41/76)	55.6% (40/72)	N/A	25.0% (1/4)
Mixed (joint and individual)	32.9% (25/76)	31.9% (23/72)	N/A	50.0% (2/4)
Several joint appointments	7.9% (6/76)	6.9% (5/72)	N/A	25.0% (1/4)
Other	5.3% (4/76)	5.6% (4/72)	N/A	0% (0/4)

Building community and neighbourhood provision

Recommendation 3:



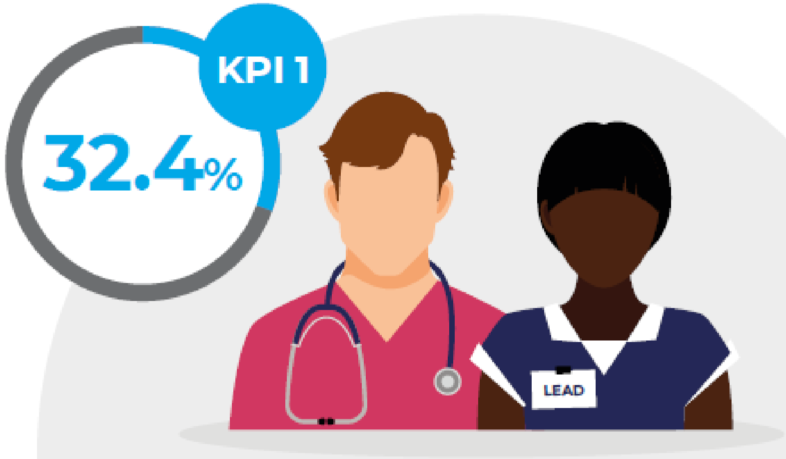
To strengthen community and neighbourhood provision and address limitations in assessing quality of transition from paediatric to adult services, the long-term plans for NHS services in England and Wales should focus on the following to support children and young people with epilepsies:

- Developing digital tools and systems to support equitable communication, documentation and care planning, passports, mental health screening, transition, self-management and patient reported outcome and experience measures (PREM/PROM) within the home, community and education settings. This should include connecting families to their care quality information via NHS digital systems and the Epilepsy12 data platform.

Action by: NHS England and NHS Wales.

Strengthening epilepsy pathways

Key theme:



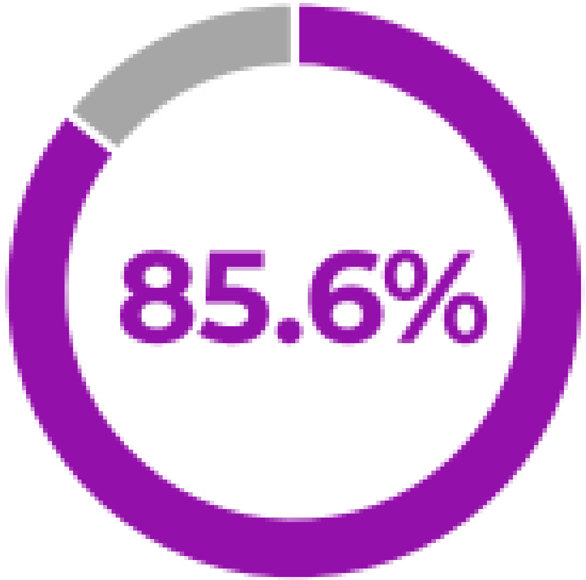
Paediatrician with expertise in epilepsy within 2 weeks

32.4% (1007/3105) of children and young people were seen by a consultant paediatrician with expertise in epilepsies within two weeks from first paediatric assessment.

- This was a decrease from **51%** (1,123/2,212) in cohort 5, probably because ‘input’ clarified as ‘direct input’
- **90%** (2,801/3,105) were seen within the first year of care
- The mean Whole Time Equivalent (WTE) in Health Boards and Trusts for ‘consultant paediatrician with expertise’ was **2.2 WTE** in 2024

Strengthening epilepsy pathways

Key theme:



- Increase compared to **81%** (1,786/2,212) in cohort 5.
- **97%** (110/114) of Health Boards/Trusts had some ESN provision
- **1.8 WTE** in 2024 mean per health board/trust (1.6 in 2023)

86% (2,659/3,105) of children and young people with epilepsy were seen by an ESN within the first year

Strengthening epilepsy pathways

Key theme:

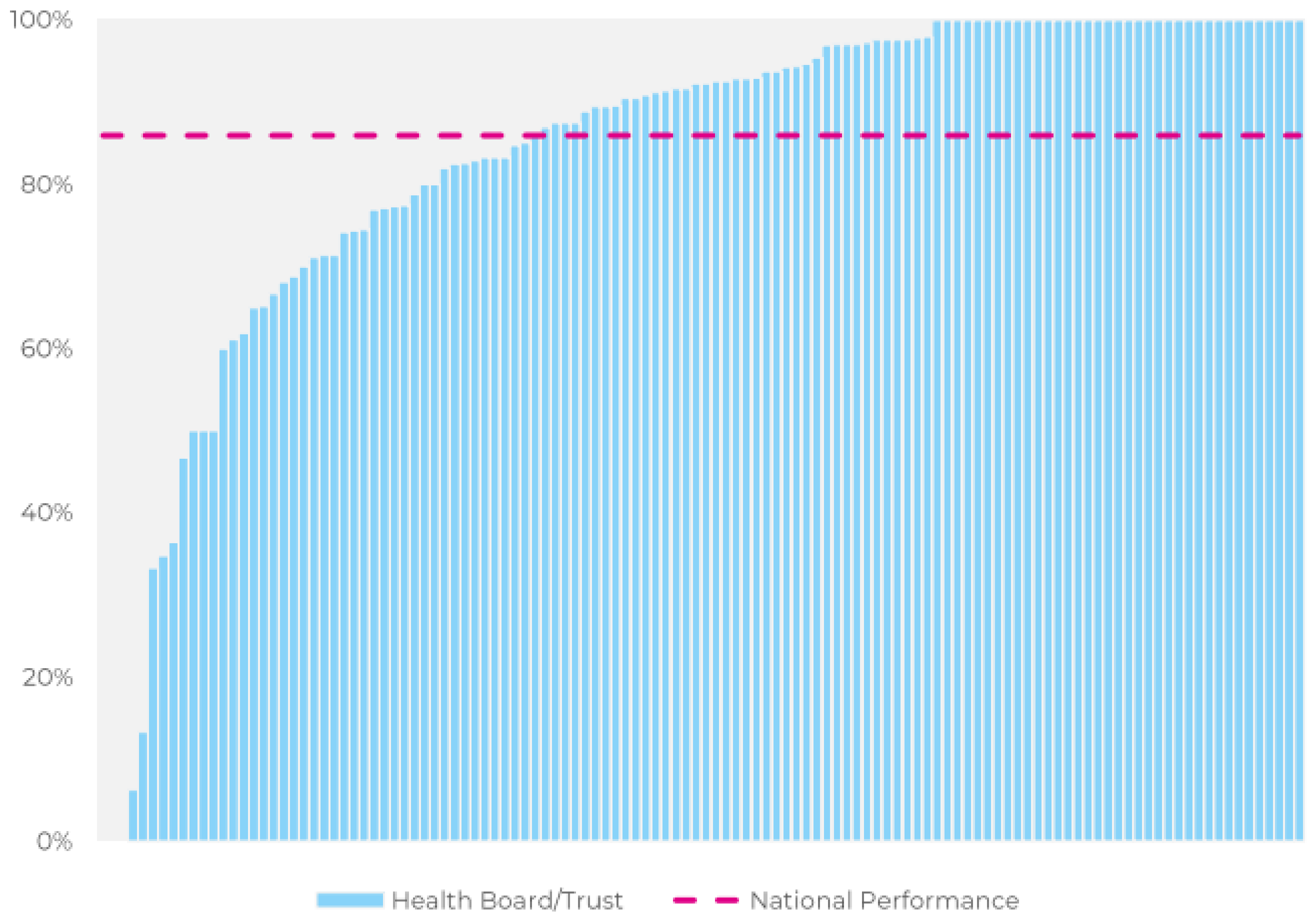
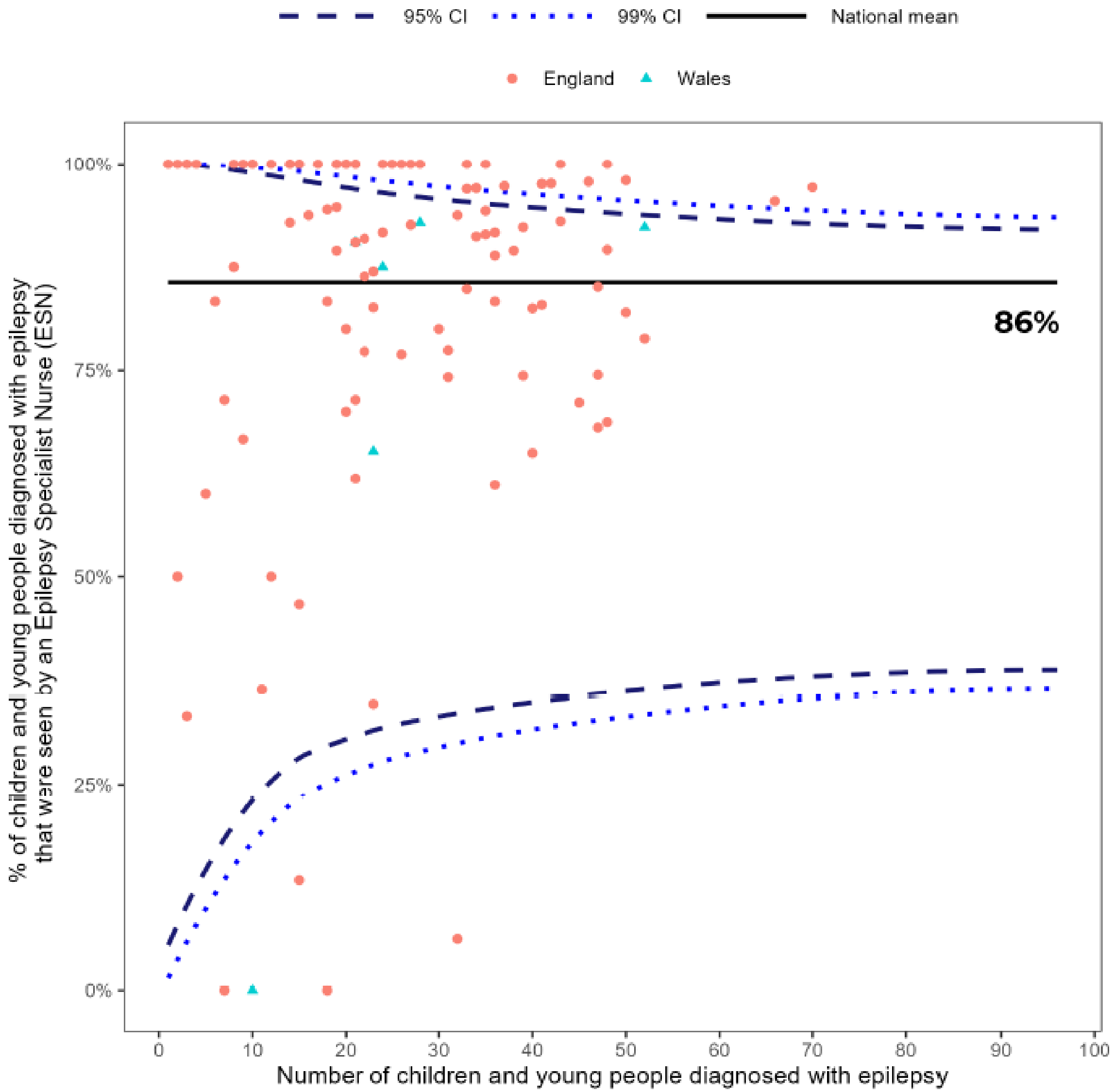


Figure 13: Access to Epilepsy Specialist Nurse by Health Board and Trust, cohort 6. Each participating Health Board or Trust is represented by a vertical bar in the order of the percentage score, including those scoring 0% in this graph.

Funnel plot showing ESN access outliers…



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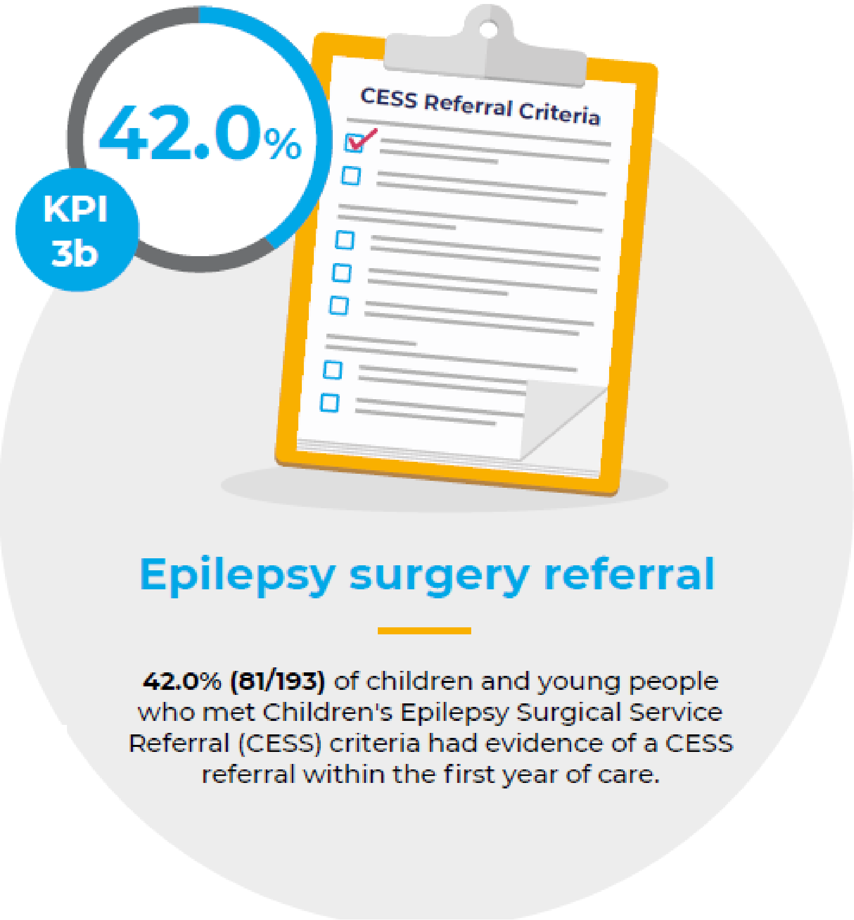
Strengthening epilepsy pathways

Key theme:

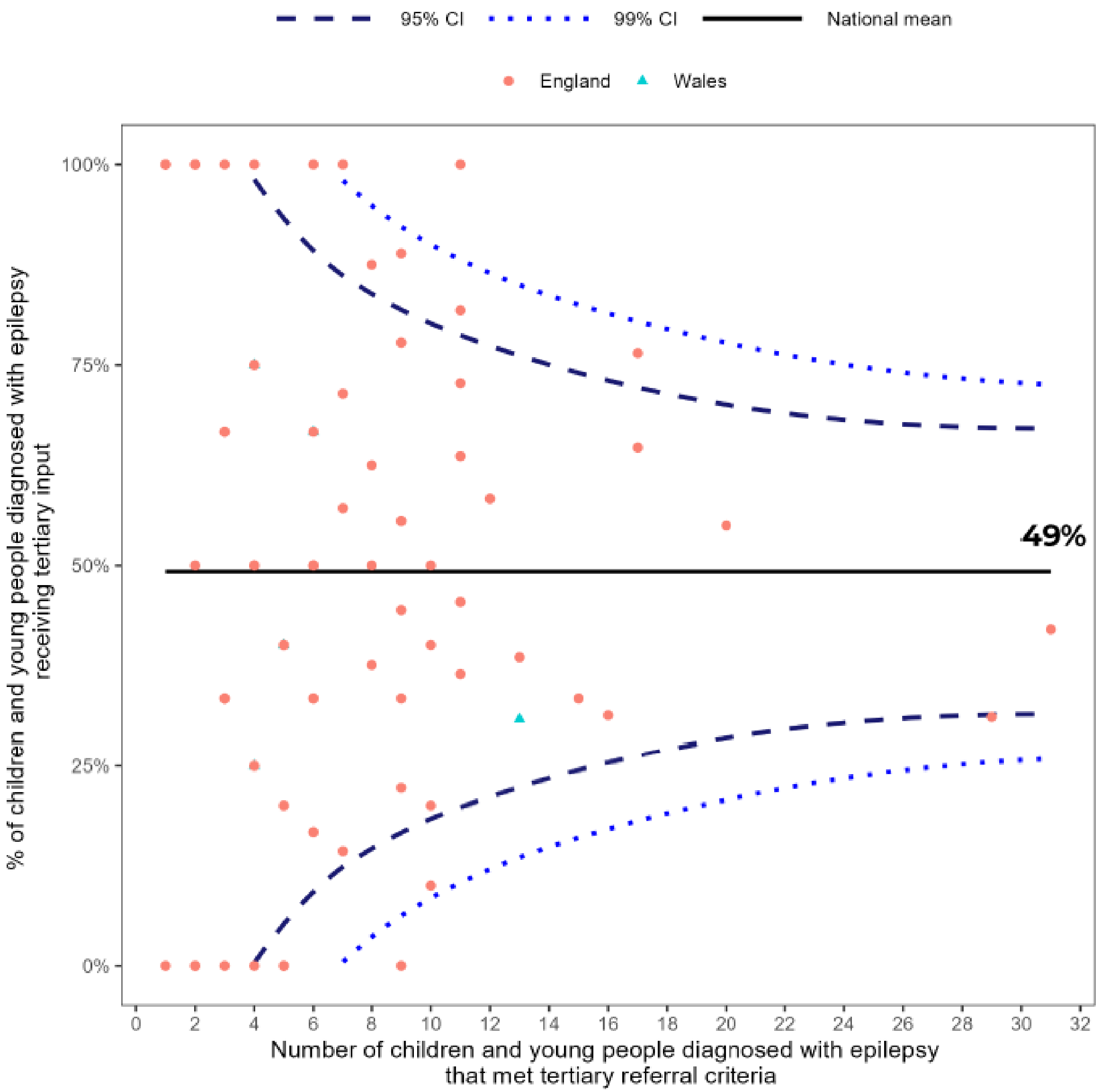


Epilepsy surgery referral

42.0% (81/193) of children and young people who met Children's Epilepsy Surgical Service Referral (CESS) criteria had evidence of a CESS referral within the first year of care.

- This was an increase compared to **37%** (41/110) in cohort 5.
- **49.2%** (388/788) of children and young people with epilepsy meeting defined criteria for tertiary input, received input of tertiary care. This appears static.

Funnel plot showing Tertiary input outliers…



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Strengthening epilepsy pathways

Recommendation 4:

4

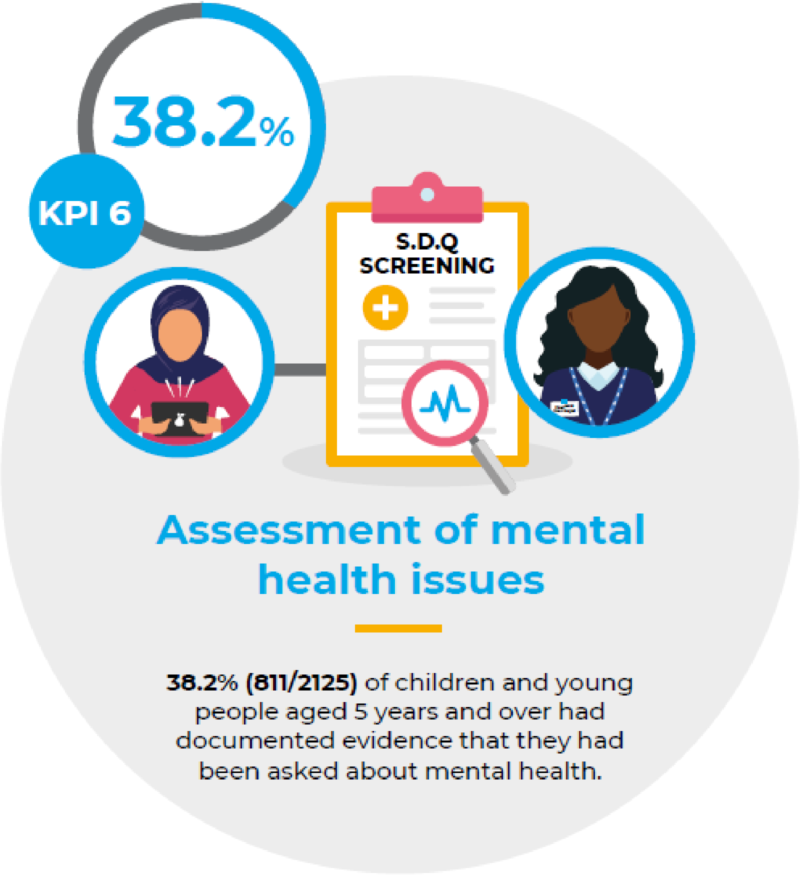
Improve timely and equitable access to tertiary and epilepsy surgery services by:

- Reviewing and updating referral criteria and pathways for epilepsy surgical evaluation, ensuring ongoing consistency between the evidence base, national recommendations and regional and local practices.
- Reviewing the specification of tertiary neuroscience services to ensure commissioning towards a sustainable workforce and capacity to meet the needs of local populations.

Action by: NHS England, the Children's Epilepsy Surgery Service (CESS) in England and Integrated Care Boards across England. The Welsh Government and Local Health Boards across Wales.

Supporting mental health and wellbeing

Key theme:



Assessment of mental health issues

38.2% (811/2125) of children and young people aged 5 years and over had documented evidence that they had been asked about mental health.

- This increased from **22%** (330/1472) in cohort 5.
- Only **9%** (278/3,105) of children and young people in cohort 6 had a mental health condition identified, suggesting under-diagnosis of mental health.
- **77%** (213/278) of children and young people with epilepsy that had an identified mental health problem, also had evidence of receiving mental health support. This increased from **62%** (83/135) in cohort 5.

Mental health screening...

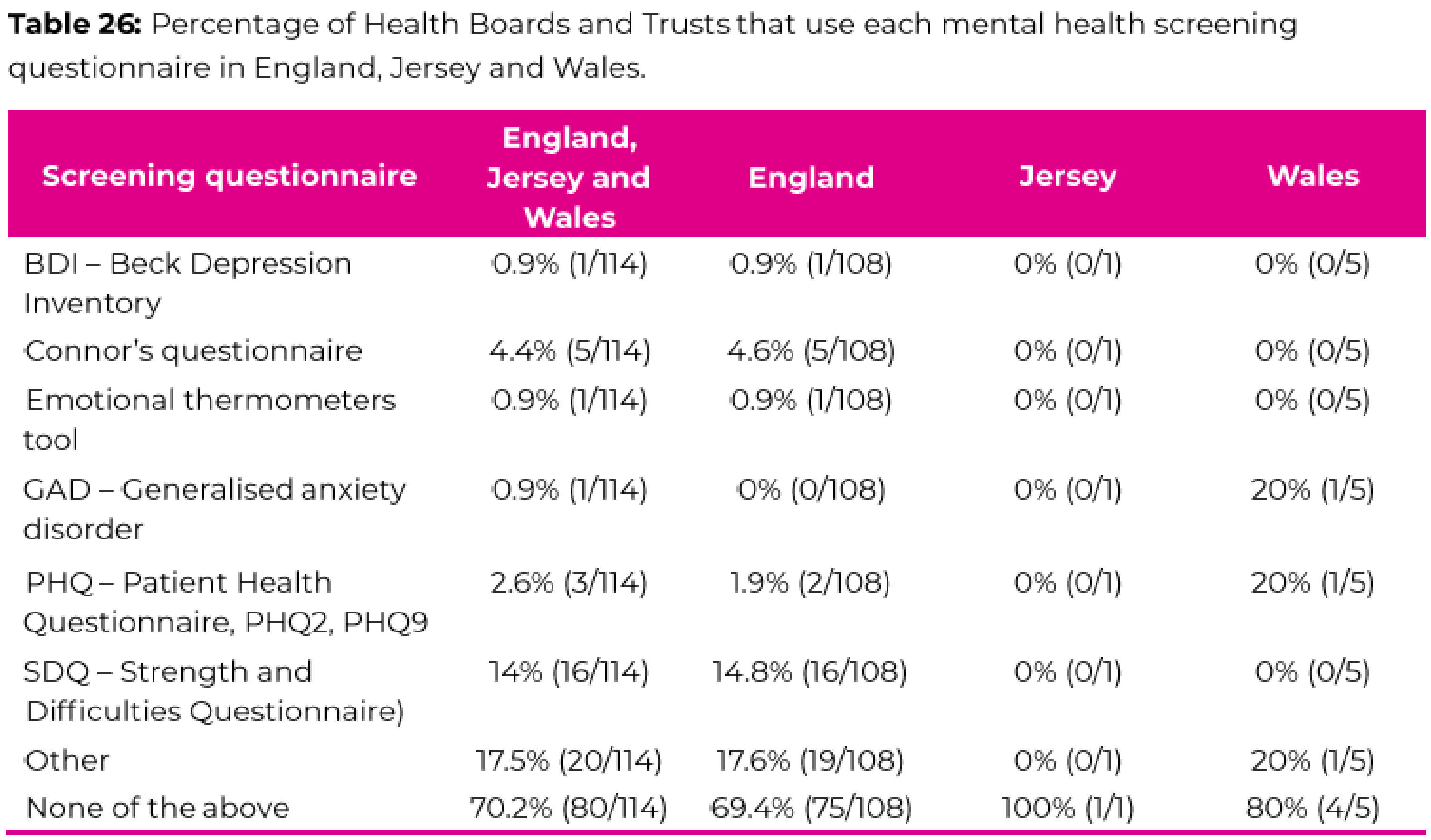
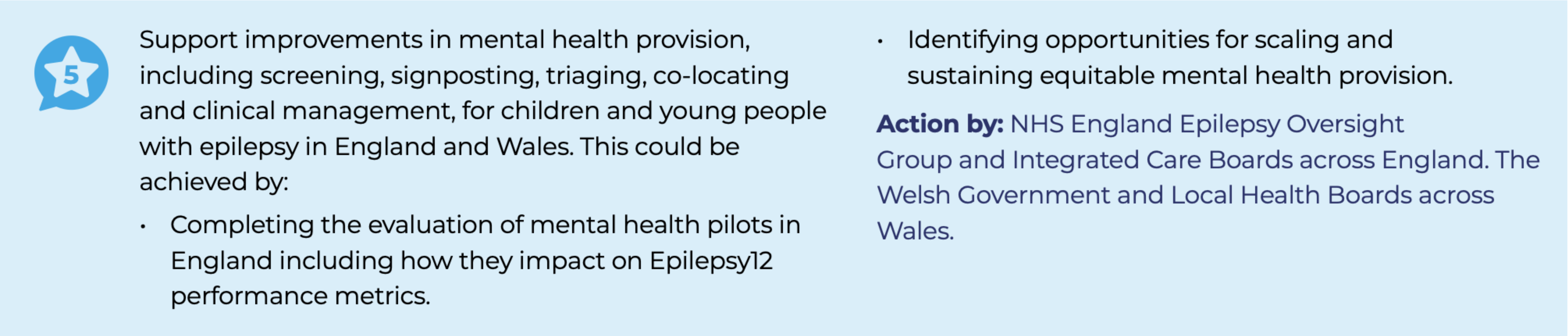


Table 26: Percentage of Health Boards and Trusts that use each mental health screening questionnaire in England, Jersey and Wales.

Screening questionnaire	England, Jersey and Wales	England	Jersey	Wales
BDI – Beck Depression Inventory	0.9% (1/114)	0.9% (1/108)	0% (0/1)	0% (0/5)
Connor's questionnaire	4.4% (5/114)	4.6% (5/108)	0% (0/1)	0% (0/5)
Emotional thermometers tool	0.9% (1/114)	0.9% (1/108)	0% (0/1)	0% (0/5)
GAD – Generalised anxiety disorder	0.9% (1/114)	0% (0/108)	0% (0/1)	20% (1/5)
PHQ – Patient Health Questionnaire, PHQ2, PHQ9	2.6% (3/114)	1.9% (2/108)	0% (0/1)	20% (1/5)
SDQ – Strength and Difficulties Questionnaire)	14% (16/114)	14.8% (16/108)	0% (0/1)	0% (0/5)
Other	17.5% (20/114)	17.6% (19/108)	0% (0/1)	20% (1/5)
None of the above	70.2% (80/114)	69.4% (75/108)	100% (1/1)	80% (4/5)

Supporting mental health and wellbeing

Recommendation 5:

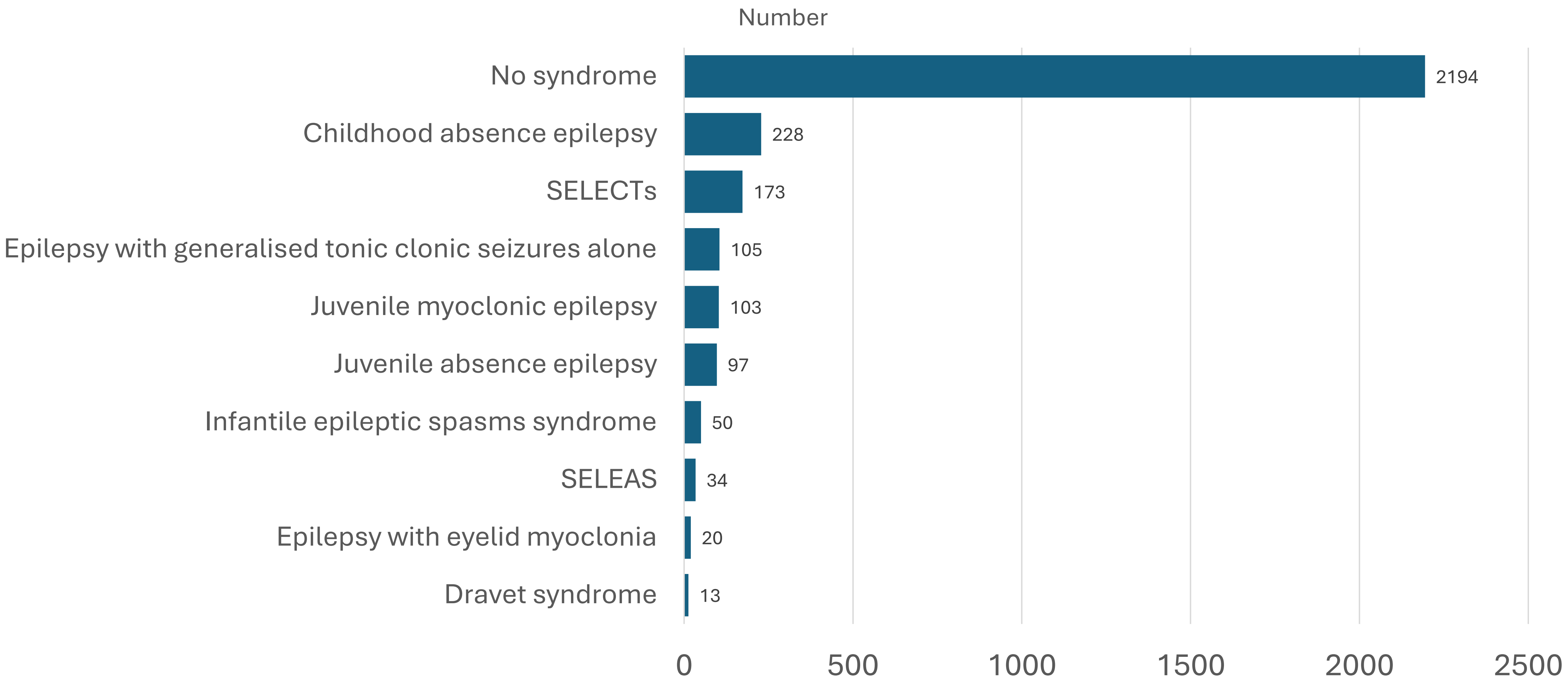


Support improvements in mental health provision, including screening, signposting, triaging, co-locating and clinical management, for children and young people with epilepsy in England and Wales. This could be achieved by:

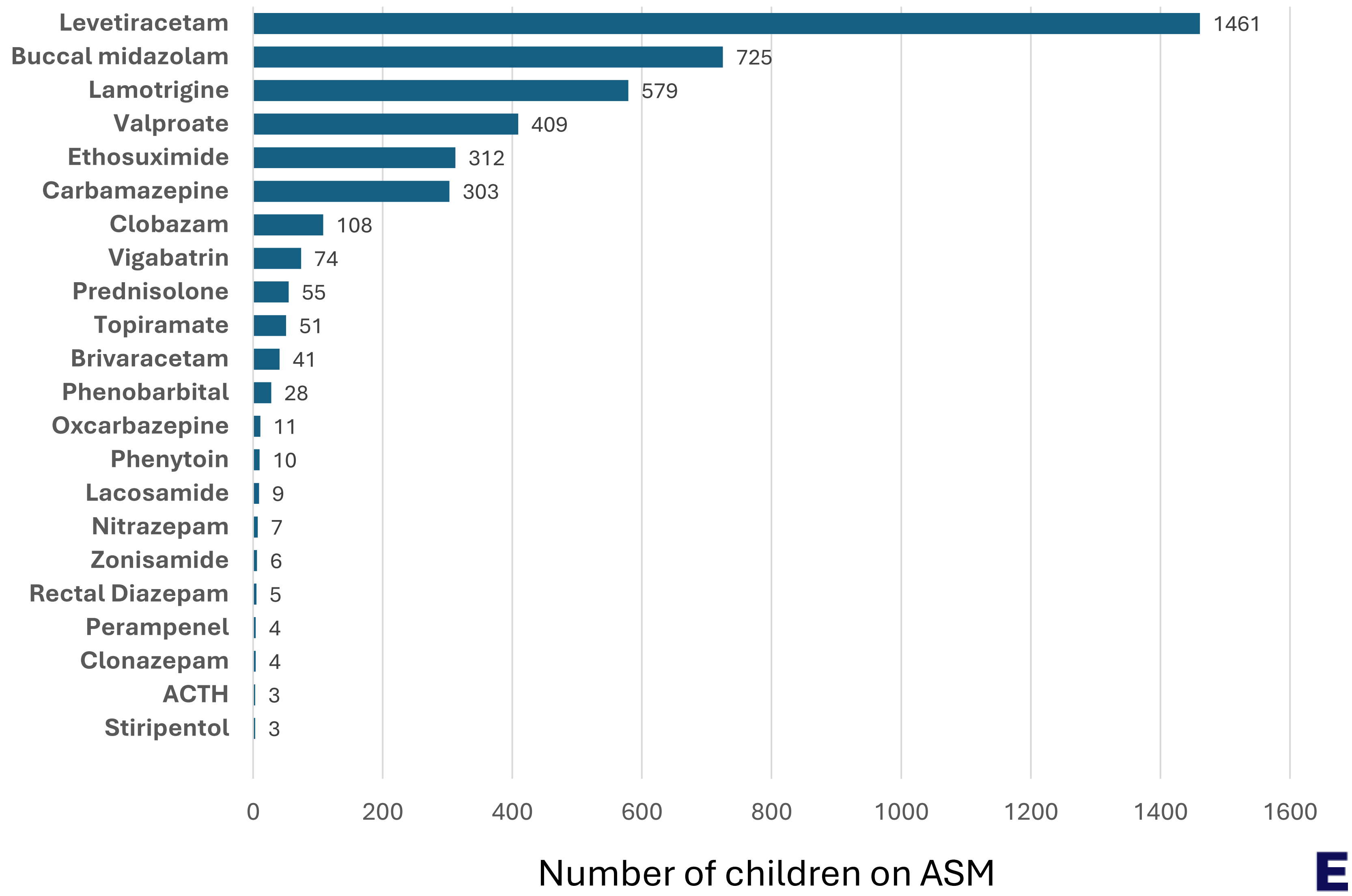
- Completing the evaluation of mental health pilots in England including how they impact on Epilepsy12 performance metrics.
- Identifying opportunities for scaling and sustaining equitable mental health provision.

Action by: NHS England Epilepsy Oversight Group and Integrated Care Boards across England. The Welsh Government and Local Health Boards across Wales.

Epilepsy syndromes– Top 10



Anti-seizure medication



Valproate

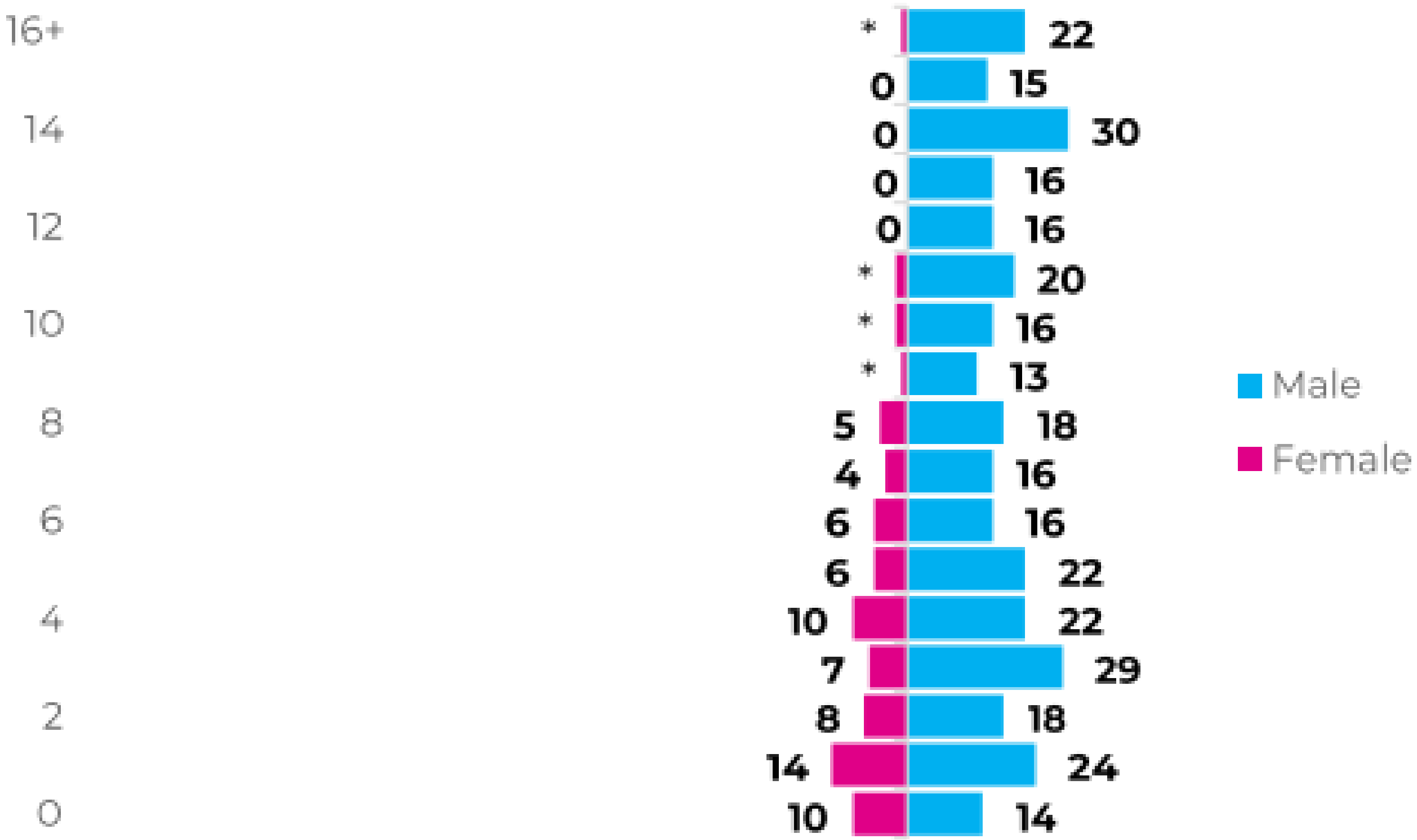
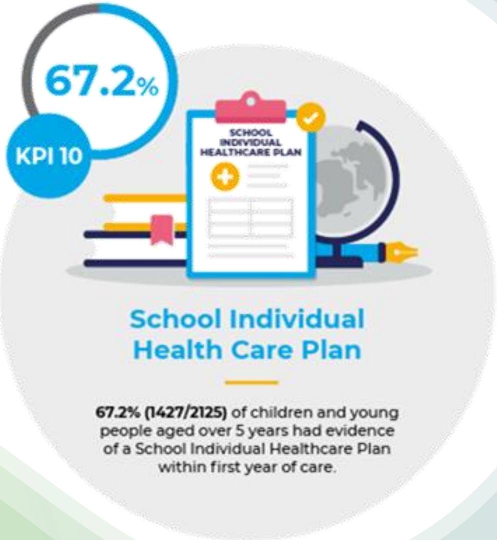


Figure 28: Number of males and females on sodium valproate by age.



School Individual Health Care Plan

67.2% (1427/2125) of children and young people aged over 5 years had evidence of a School Individual Healthcare Plan within first year of care.

HQIP / News / HQIP-Commissioned Audit Sees 72.8% Increase in School Healthcare Plans for Young People with Epilepsy

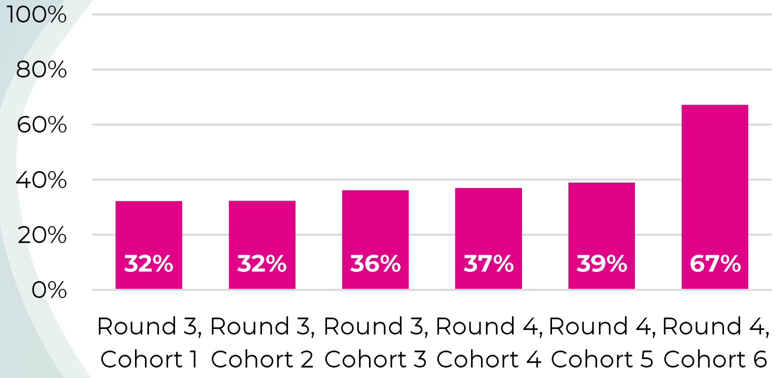
NATIONAL AUDIT SEES **72.8% INCREASE** IN SCHOOL HEALTHCARE PLANS FOR YOUNG PEOPLE WITH EPILEPSY

HQIP-Commissioned Audit Sees 72.8% Increase in School Healthcare Plans for Young People with Epilepsy

Published: 17 Sep 2025

https://www.hqip.org.uk/news/increase-in-epilepsy-school-health-plans/

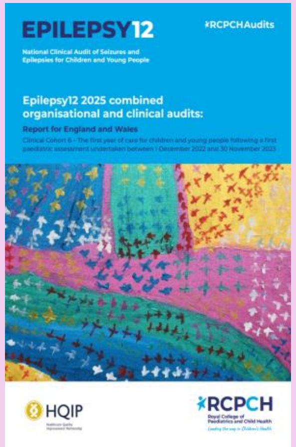
KPI 10. School Individual Health Care Plan



Epilepsy12 reporting

*Confidential data shared only with clinical/regional teams

Annual report



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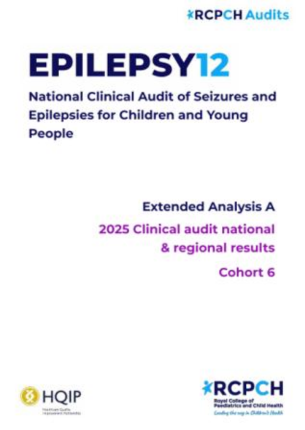
HQIP

RCPCH Royal College of Paediatrics and Child Health

Extended Analyses



RCPCH Audits

EPILEPSY12

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

Extended Analysis A

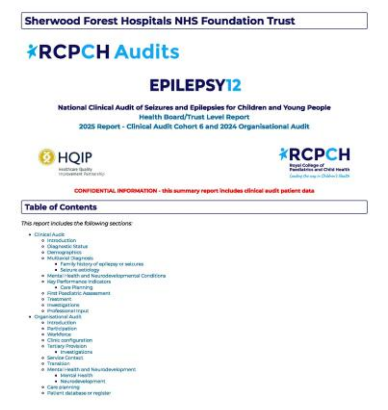
2025 Clinical audit national & regional results

Cohort 6

HQIP

RCPCH Royal College of Paediatrics and Child Health

Health Board/Trust level reports*



Sherwood Forest Hospitals NHS Foundation Trust

RCPCH Audits

EPILEPSY12

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

Health Board/Trust Level Report

2025 Report - Clinical Audit Cohort 6 and 2024 Organisational Audit

HQIP

RCPCH Royal College of Paediatrics and Child Health

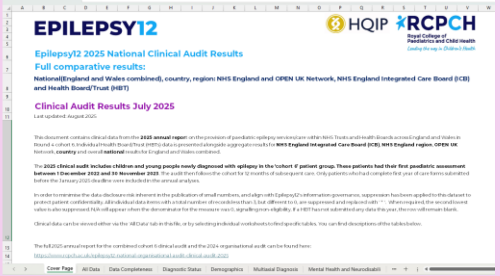
CONFIDENTIAL INFORMATION - this summary report includes clinical audit patient data

Table of Contents

This report includes the following sections:

- Clinical Audit
  - Introduction
  - Diagnostic Status
  - Demographics
  - Multiaxial Diagnosis
    - Family history of epilepsy or seizures
    - Seizure aetiology
  - Mental Health and Neurodevelopmental Conditions
  - Key Performance Indicators
    - Care Planning
  - First Paediatric Assessment
  - Treatment
  - Investigations
  - Professional Input
- Organisational Audit
  - Introduction
  - Participation
  - Workforce
  - Clinic configuration
  - Tertiary Provision
    - Investigations
  - Service Contact
  - Transition
  - Mental Health and Neurodevelopment
    - Mental Health
    - Neurodevelopment
  - Care planning
  - Patient database or register

Clinical/ organisational data files



EPILEPSY12

HQIP RCPCH Royal College of Paediatrics and Child Health

Epilepsy12 2025 National Clinical Audit Results

Full comparative results:

National(England and Wales combined), country, region: NHS England and OPEN UK Network, NHS England Integrated Care Board (ICB) and Health Board/Trust (HBT)

Clinical Audit Results July 2025

Last updated: August 2025

This document contains clinical data from the **2025 annual report** on the provision of paediatric epilepsy services/care within NHS Trusts and Health Boards across England and Wales in Round 4 cohort 6. Individual Health Board/Trust (HBTs) data is presented alongside aggregate results for **NHS England Integrated Care Board (ICB), NHS England region, OPEN UK** Network, **country** and overall **national** results for England and Wales combined.

The **2025 clinical audit includes children and young people newly diagnosed with epilepsy in the 'cohort 6' patient group. These patients had their first paediatric assessment between 1 December 2022 and 30 November 2023**. The audit then follows the cohort for 12 months of subsequent care. Only patients who had complete first year of care forms submitted before the January 2025 deadline were included in the annual analyses.

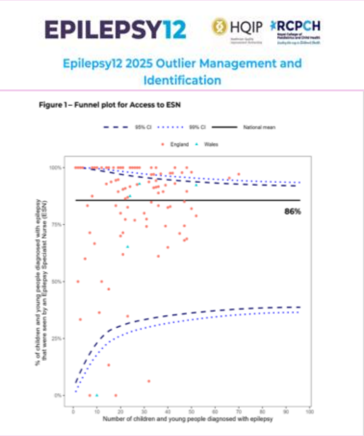
In order to minimise the data disclosure risk inherent in the publication of small numbers, and align with Epilepsy12's information governance, suppression has been applied to this dataset to protect patient confidentiality. All individual data items with a total number of records less than 3, but different to 0, are suppressed and replaced with ' * '. When required, the second lowest value is also suppressed. N/A will appear when the denominator for the measure was 0, signalling non-eligibility. If a HBT has not submitted any data this year, the row will remain blank.

Clinical data can be viewed either via the 'All Data' tab in this file, or by selecting individual worksheets to find specific tables. You can find descriptions of the tables below.

The full 2025 annual report for the combined cohort 6 clinical audit and the 2024 organisational audit can be found here:

https://www.rcpch.ac.uk/epilepsy12-national-organisational-audit-clinical-audit-2025

Outlier reporting



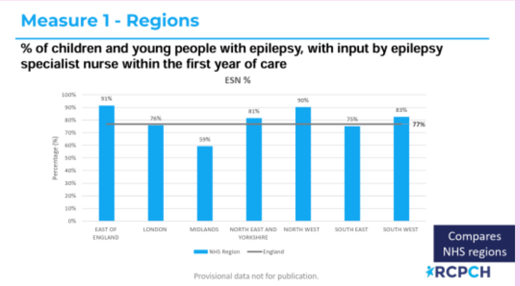
EPILEPSY12

HQIP RCPCH

Epilepsy12 2025 Outlier Management and Identification

Figure 1 – Funnel plot for Access to ESN

NHS England data packs*



Measure 1 - Regions

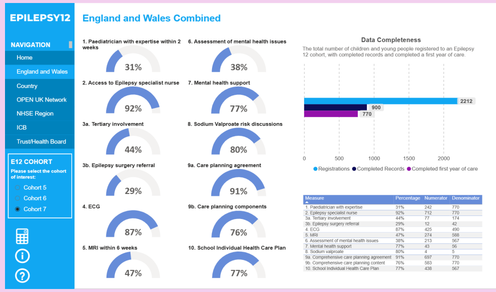
% of children and young people with epilepsy, with input by epilepsy specialist nurse within the first year of care

Provisional data not for publication.

Compares NHS regions

RCPCH

Monthly dashboard



England and Wales Combined

Data Completeness

The total number of children and young people registered to an Epilepsy 12 cohort, with completed records and completed a first year of care.

Measure	Percentage	Numerator	Denominator
1. Paediatrician with expertise	31%	242	770
2. Epilepsy specialist nurse	92%	712	770
3a. Tertiary involvement	44%	77	174
3b. Epilepsy surgery referral	29%	12	42
4. ECG	87%	425	490
5. MRI	47%	274	588
6. Assessment of mental health issues	38%	213	567
7. Mental health support	77%	43	56
8. Sodium valproate	80%	4	5
9a. Comprehensive care planning agreement	91%	697	770
9b. Comprehensive care planning content	76%	583	770
10. School Individual Health Care Plan	77%	438	567

Live dashboard*

Real-time Key Performance Indicator (KPI) Metrics for Cohort 7

Clinical Team

Indicator	Organisation (13)	Trust (13)	Integrated Care Board (44)	NHS Region (198)	OPEN UK Region (74)	England (946)	National (965)
1. Paediatrician with expertise in Epilepsy within 2 weeks	15% (13)	15% (13)	39% (44)	30% (198)	34% (74)	33% (946)	32% (965)
2. Access to Epilepsy Specialist Nurse	92% (13)	92% (13)	91% (44)	92% (198)	92% (74)	94% (946)	93% (965)
3a. Tertiary Input	**100% (1)**	**100% (1)**	**71% (7)**	**43% (47)**	**75% (12)**	**46% (219)**	**46% (222)**
3b. Epilepsy Surgery Referral	!	!	100% (1)	30% (10)	100% (2)	32% (53)	32% (53)

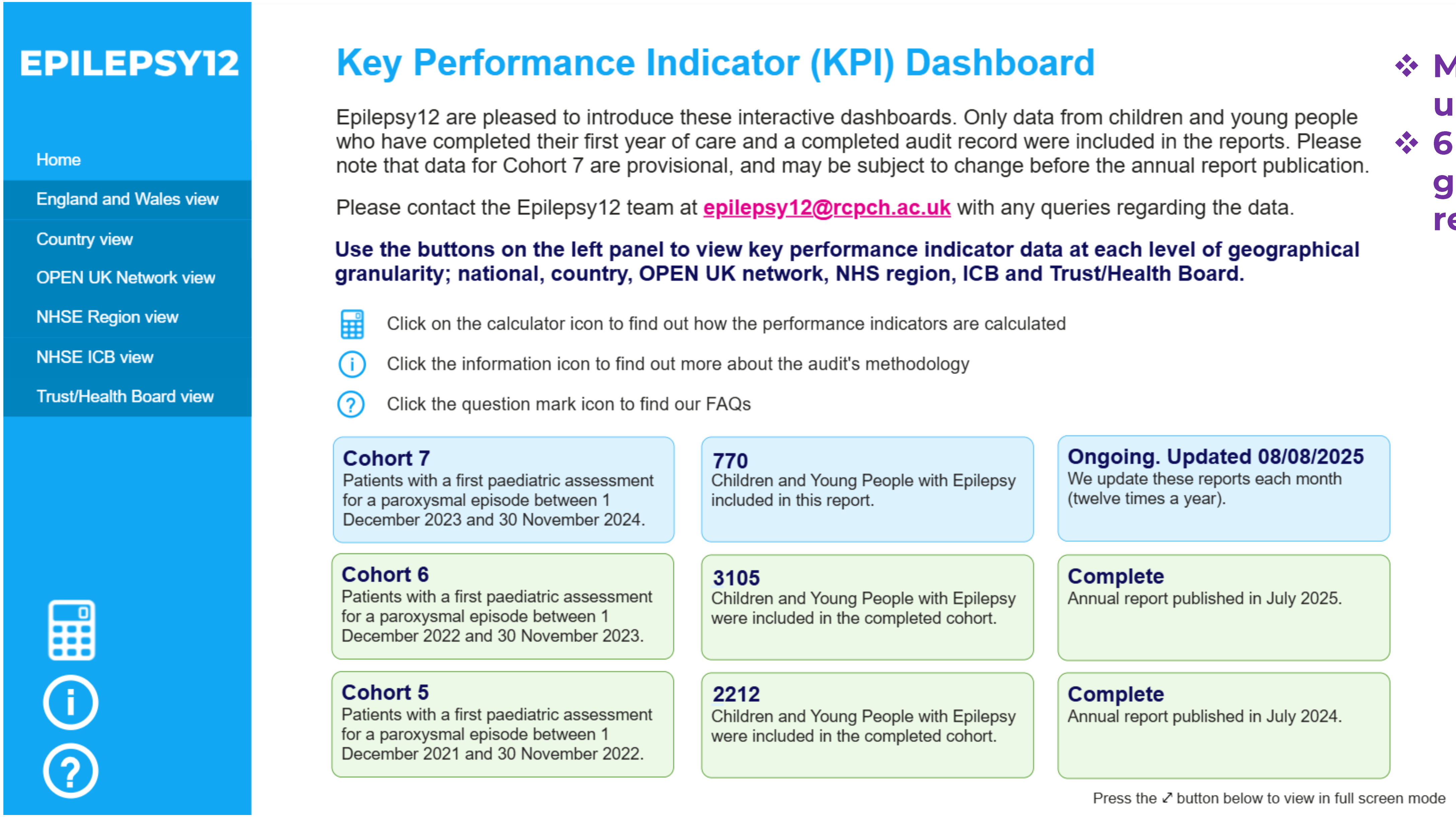
Investigations

Indicator	Organisation (13)	Trust (13)	Integrated Care Board (44)	NHS Region (198)	OPEN UK Region (74)	England (946)	National (965)
4. ECG	100% (10)	100% (10)	100% (25)	94% (126)	93% (43)	88% (607)	87% (617)
5. MRI within 6 weeks	82% (11)	82% (11)	67% (36)	49% (173)	70% (56)	46% (737)	46% (751)

Mental Health

Indicator	Organisation (13)	Trust (13)	Integrated Care Board (44)	NHS Region (198)	OPEN UK Region (74)	England (946)	National (965)
6. Assessment of Mental Health Issues	100% (11)	100% (11)	47% (34)	44% (140)	39% (59)	37% (680)	37% (696)
7. Mental Health Support	100% (2)	100% (2)	100% (4)	100% (8)	86% (7)	81% (73)	81% (74)

Frequent Reporting Dashboard



Key Performance Indicator (KPI) Dashboard

Epilepsy12 are pleased to introduce these interactive dashboards. Only data from children and young people who have completed their first year of care and a completed audit record were included in the reports. Please note that data for Cohort 7 are provisional, and may be subject to change before the annual report publication.

Please contact the Epilepsy12 team at epilepsy12@rcpch.ac.uk with any queries regarding the data.

Use the buttons on the left panel to view key performance indicator data at each level of geographical granularity; national, country, OPEN UK network, NHS region, ICB and Trust/Health Board.

Click on the calculator icon to find out how the performance indicators are calculated

Click the information icon to find out more about the audit's methodology

Click the question mark icon to find our FAQs

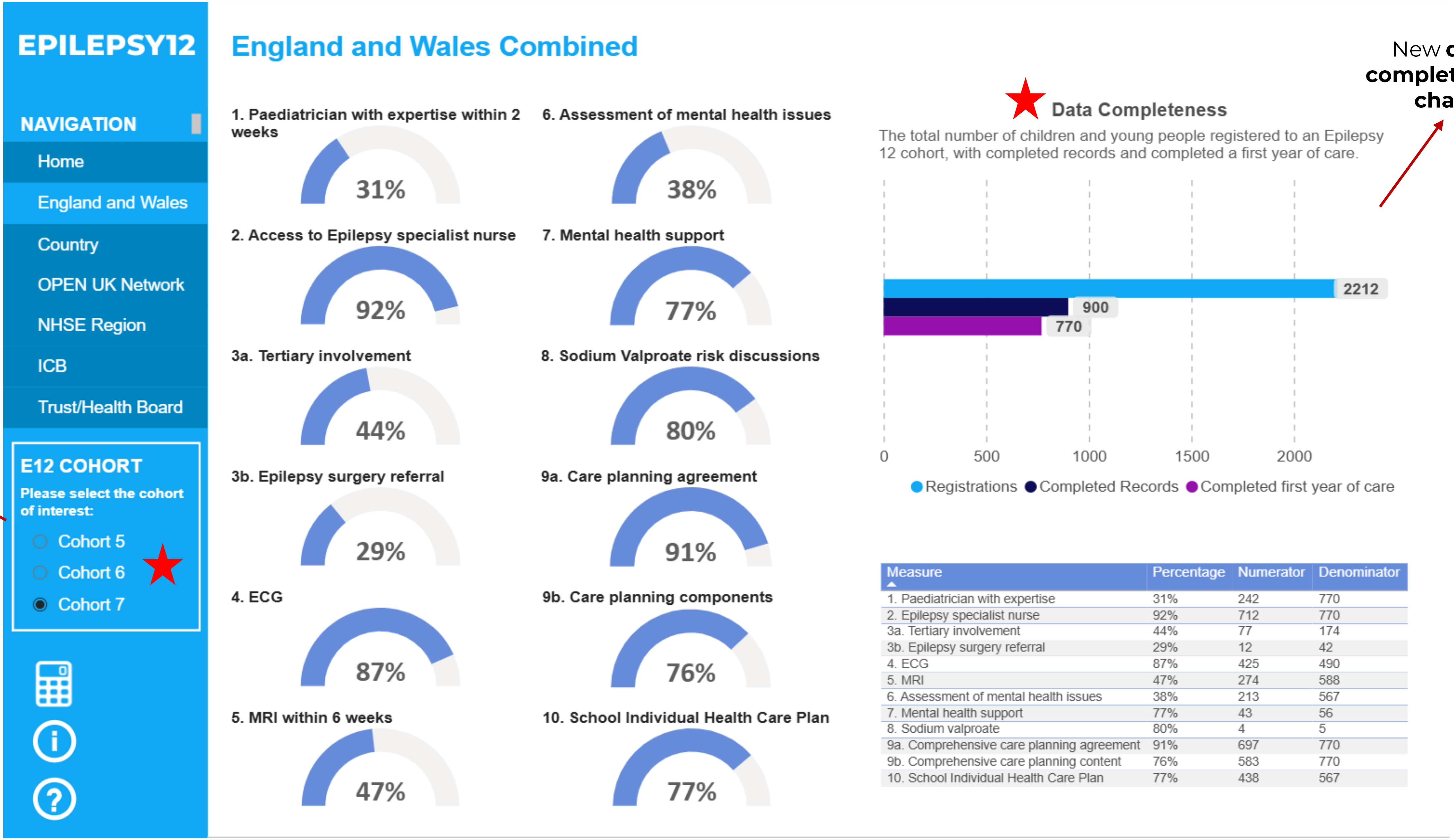
Cohort 7 Patients with a first paediatric assessment for a paroxysmal episode between 1 December 2023 and 30 November 2024.	**770** Children and Young People with Epilepsy included in this report.	**Ongoing. Updated 08/08/2025** We update these reports each month (twelve times a year).
Cohort 6 Patients with a first paediatric assessment for a paroxysmal episode between 1 December 2022 and 30 November 2023.	**3105** Children and Young People with Epilepsy were included in the completed cohort.	**Complete** Annual report published in July 2025.
Cohort 5 Patients with a first paediatric assessment for a paroxysmal episode between 1 December 2021 and 30 November 2022.	**2212** Children and Young People with Epilepsy were included in the completed cohort.	**Complete** Annual report published in July 2024.

Press the ⤢ button below to view in full screen mode

- ❖ **Monthly updates**
- ❖ **6 levels of geographical reporting**

Frequent Reporting Dashboard – monthly updates

Users can now **select the cohort of interest**



EPILEPSY12

NAVIGATION

- Home
- England and Wales
- Country
- OPEN UK Network
- NHSE Region
- ICB
- Trust/Health Board

E12 COHORT

Please select the cohort of interest:

○ Cohort 5
○ Cohort 6
● Cohort 7

England and Wales Combined

1. Paediatrician with expertise within 2 weeks — 31%

2. Access to Epilepsy specialist nurse — 92%

3a. Tertiary involvement — 44%

3b. Epilepsy surgery referral — 29%

4. ECG — 87%

5. MRI within 6 weeks — 47%

6. Assessment of mental health issues — 38%

7. Mental health support — 77%

8. Sodium Valproate risk discussions — 80%

9a. Care planning agreement — 91%

9b. Care planning components — 76%

10. School Individual Health Care Plan — 77%

Data Completeness

The total number of children and young people registered to an Epilepsy 12 cohort, with completed records and completed a first year of care.

Measure	Percentage	Numerator	Denominator
1. Paediatrician with expertise	31%	242	770
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10. School Individual Health Care Plan	77%	438	567

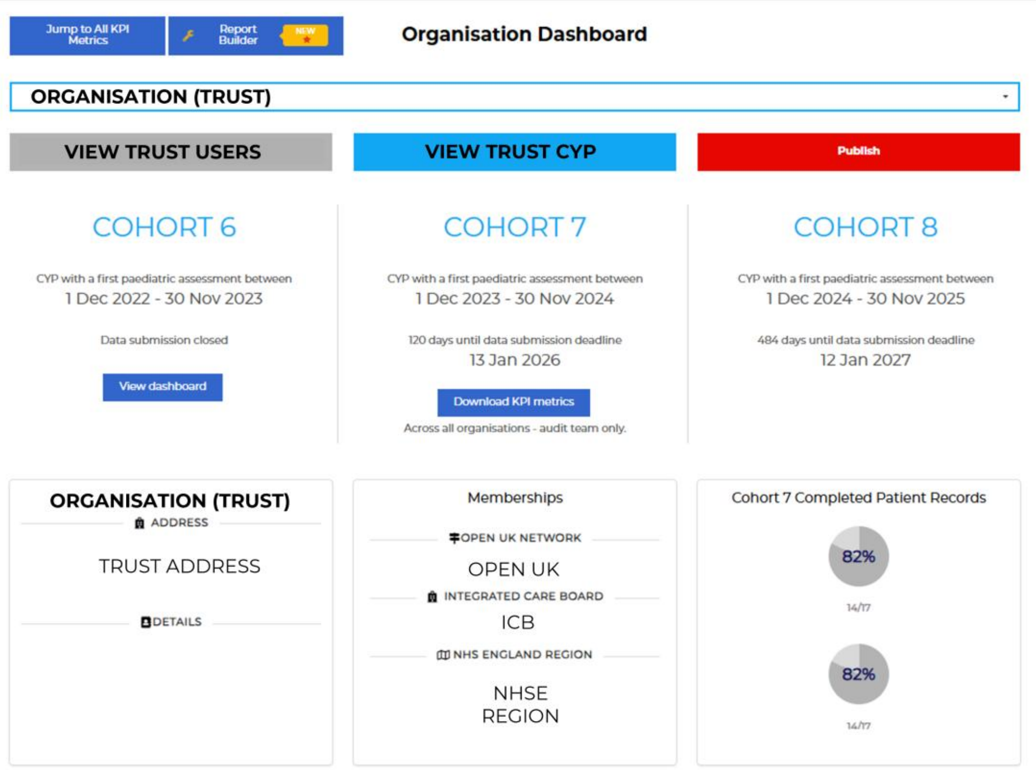
New **data completeness chart**

New Epilepsy12 data platform

*Dummy data

Aims to reduce data entry burden

- Focused case ascertainment – only confirmed epilepsy patients
- Minimised dataset – mostly Y/N questions
- Easier navigation



Organisation Dashboard

ORGANISATION (TRUST)

COHORT 6

CYP with a first paediatric assessment between
1 Dec 2022 - 30 Nov 2023

Data submission closed

COHORT 7

CYP with a first paediatric assessment between
1 Dec 2023 - 30 Nov 2024

120 days until data submission deadline
13 Jan 2026

Across all organisations - audit team only.

COHORT 8

CYP with a first paediatric assessment between
1 Dec 2024 - 30 Nov 2025

484 days until data submission deadline
12 Jan 2027

ORGANISATION (TRUST)

ADDRESS

TRUST ADDRESS

DETAILS

Memberships

OPEN UK NETWORK

OPEN UK

INTEGRATED CARE BOARD

ICB

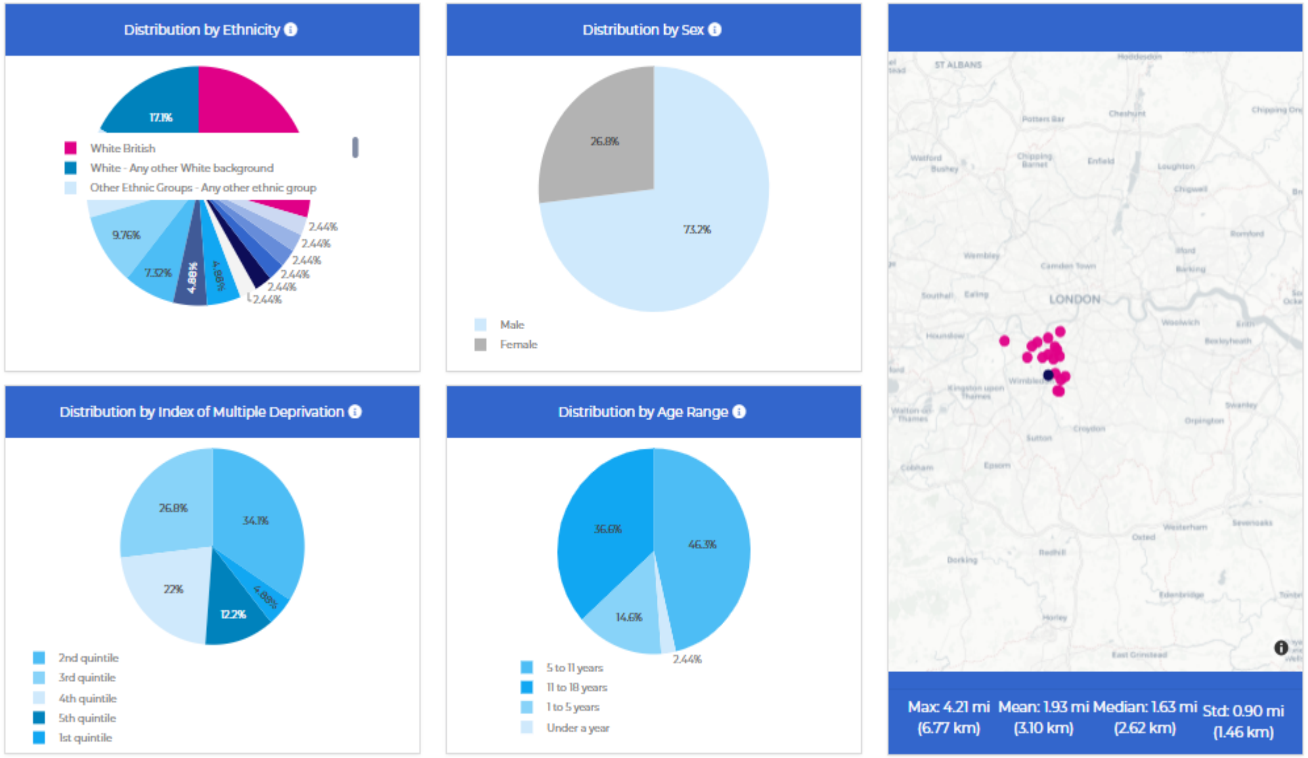
NHS ENGLAND REGION

NHSE
REGION

Cohort 7 Completed Patient Records

82%
14/17

82%
14/17

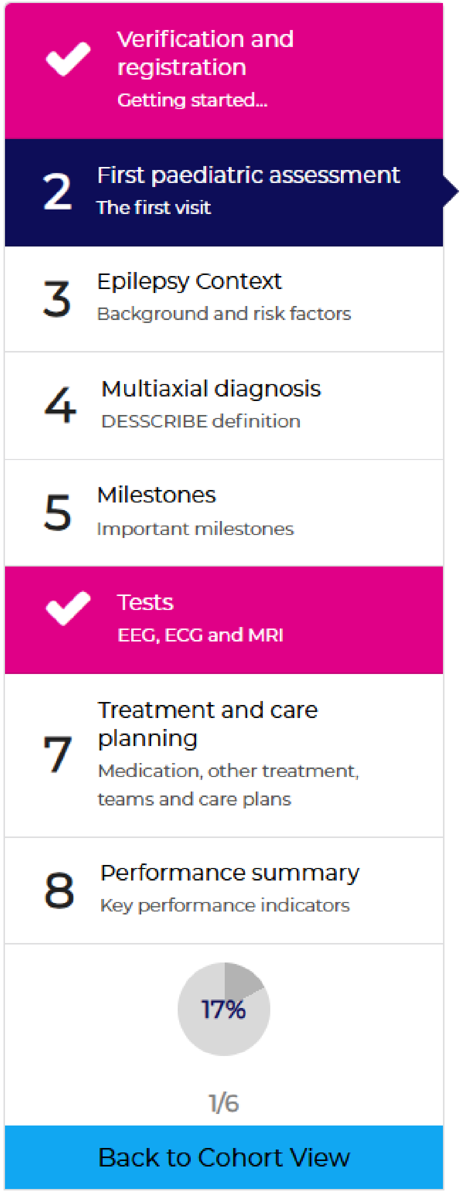


Max: 4.21 mi (6.77 km) Mean: 1.93 mi (3.10 km) Median: 1.63 mi (2.62 km) Std: 0.90 mi (1.46 km)

Patient performance summary

*Dummy data

Record progress & completeness



✓ Verification and registration
Getting started...

2 First paediatric assessment
The first visit

3 Epilepsy Context
Background and risk factors

4 Multiaxial diagnosis
DESSCRIBE definition

5 Milestones
Important milestones

✓ Tests
EEG, ECG and MRI

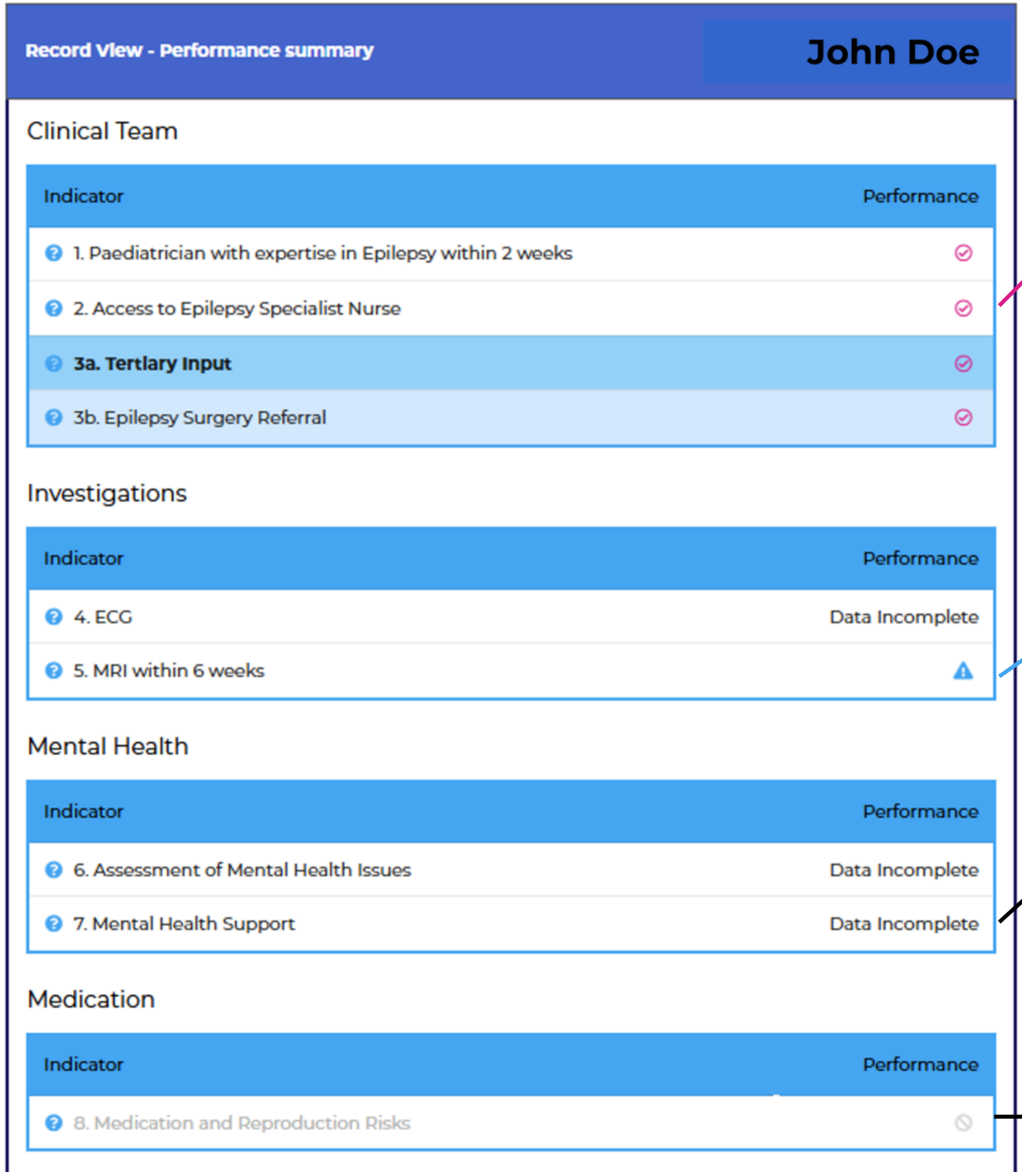
7 Treatment and care planning
Medication, other treatment, teams and care plans

8 Performance summary
Key performance indicators

17%

1/6

Back to Cohort View



Record View - Performance summary **John Doe**

Clinical Team

Indicator	Performance
1. Paediatrician with expertise in Epilepsy within 2 weeks	✓
2. Access to Epilepsy Specialist Nurse	✓
3a. Tertiary Input	✓
3b. Epilepsy Surgery Referral	✓

Investigations

Indicator	Performance
4. ECG	Data Incomplete
5. MRI within 6 weeks	⚠

Mental Health

Indicator	Performance
6. Assessment of Mental Health Issues	Data Incomplete
7. Mental Health Support	Data Incomplete

Medication

Indicator	Performance
8. Medication and Reproduction Risks	⊘

KPI achieved

KPI not achieved yet

Question not answered yet

KPI not applicable

Real-time benchmarking data

*Dummy data

Real-time Key Performance Indicator (KPI) Metrics for Cohort 7

Clinical Team

Indicator	Organisation ⓘ (13)	Trust ⓘ (13)	Integrated Care Board ⓘ (44)	NHS Region ⓘ (198)	OPEN UK Region ⓘ (74)	England ⓘ (946)	National ⓘ (965)
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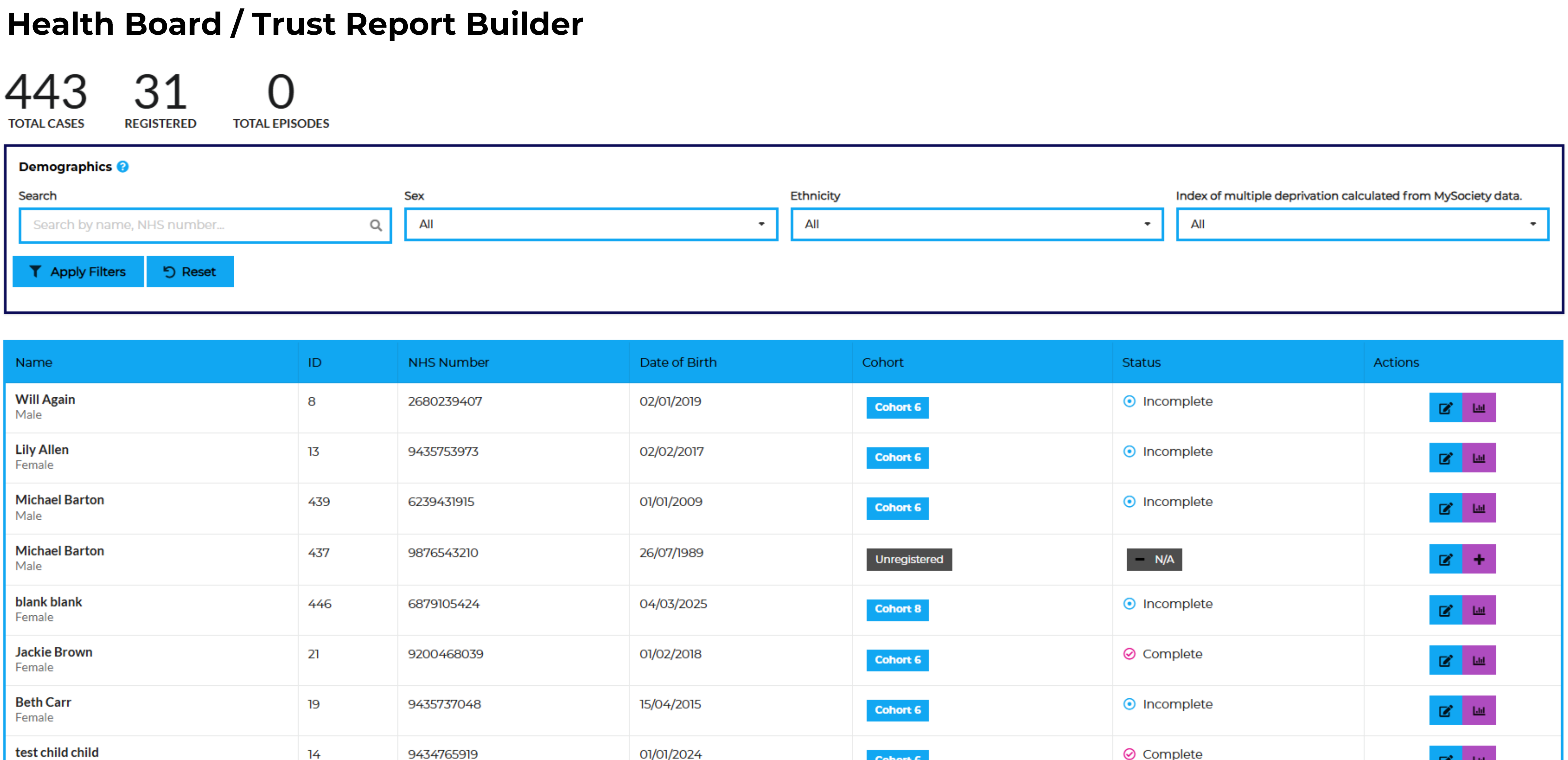
Next steps – ‘report builder’

*Dummy data



Health Board / Trust Report Builder

443 TOTAL CASES
31 REGISTERED
0 TOTAL EPISODES

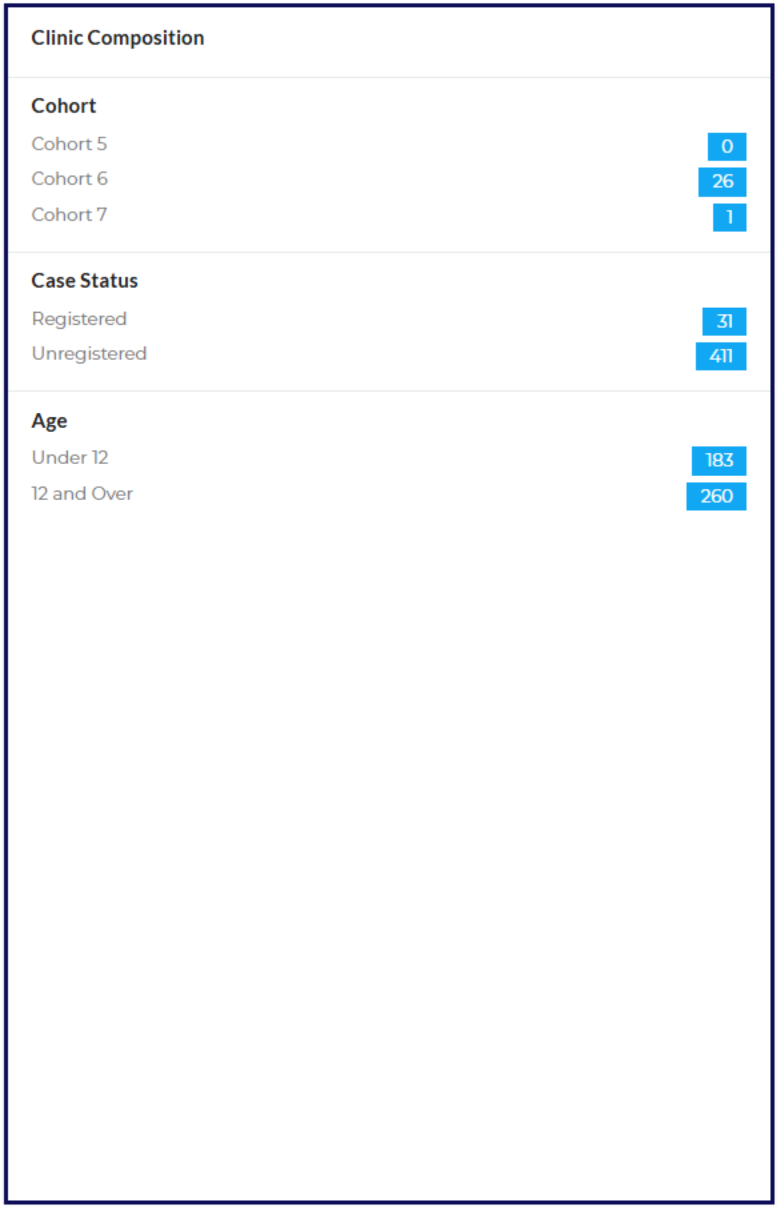
Demographics

Search	Sex	Ethnicity	Index of multiple deprivation calculated from MySociety data.
Search by name, NHS number...	All	All	All

Name	ID	NHS Number	Date of Birth	Cohort	Status	Actions
Will Again Male	8	2680239407	02/01/2019	Cohort 6	⊙ Incomplete	✎ 📊
Lily Allen Female	13	9435753973	02/02/2017	Cohort 6	⊙ Incomplete	✎ 📊
Michael Barton Male	439	6239431915	01/01/2009	Cohort 6	⊙ Incomplete	✎ 📊
Michael Barton Male	437	9876543210	26/07/1989	Unregistered	− N/A	✎ +
blank blank Female	446	6879105424	04/03/2025	Cohort 8	⊙ Incomplete	✎ 📊
Jackie Brown Female	21	9200468039	01/02/2018	Cohort 6	✓ Complete	✎ 📊
Beth Carr Female	19	9435737048	15/04/2015	Cohort 6	⊙ Incomplete	✎ 📊
test child child	14	9434765919	01/01/2024		✓ Complete	

‘Report builder’ – filter options

*Dummy data



Clinic Composition

Cohort

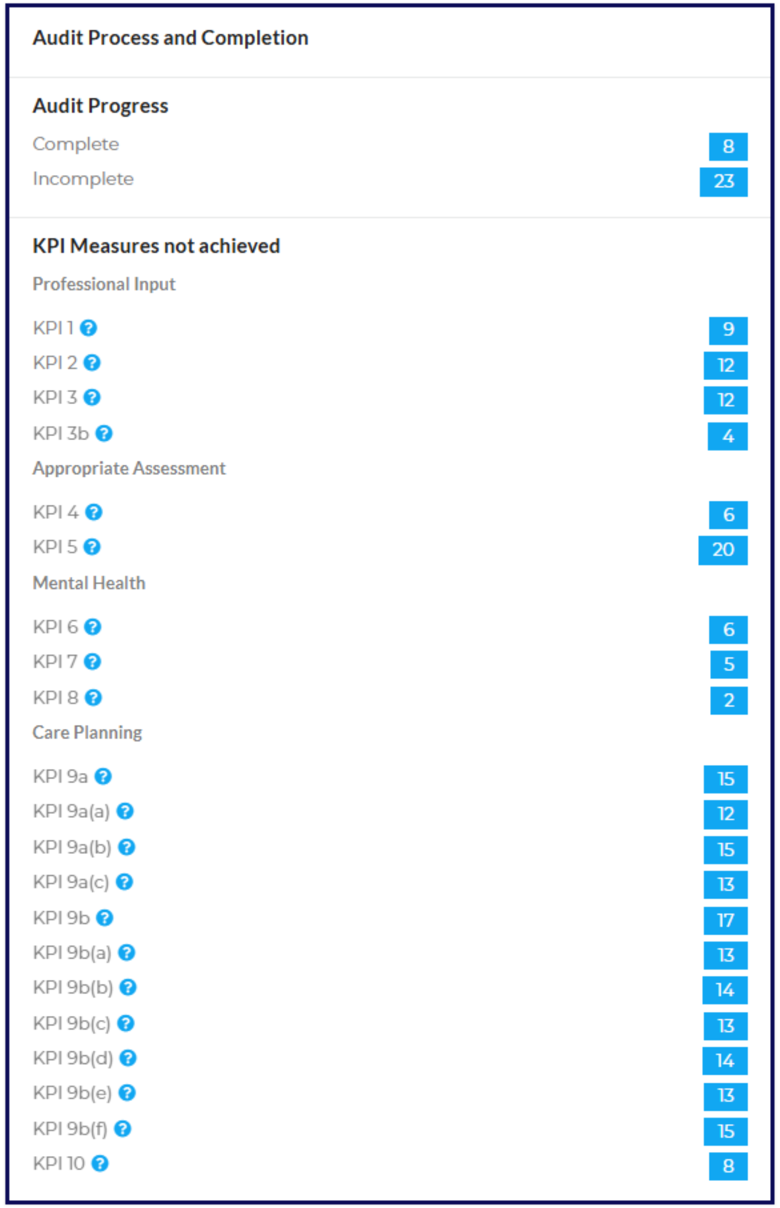
Cohort 5	0
Cohort 6	26
Cohort 7	1

Case Status

Registered	31
Unregistered	411

Age

Under 12	183
12 and Over	260



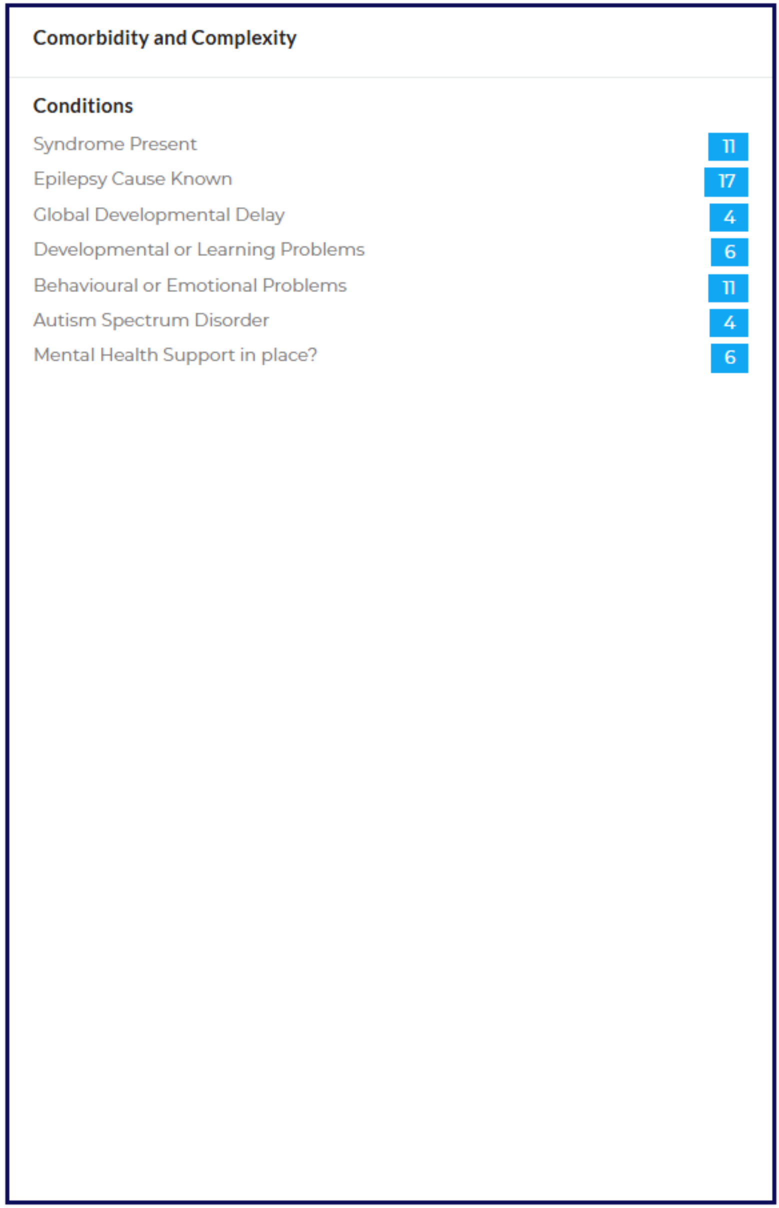
Audit Process and Completion

Audit Progress

Complete	8
Incomplete	23

KPI Measures not achieved

Professional Input	
KPI 1 ?	9
KPI 2 ?	12
KPI 3 ?	12
KPI 3b ?	4
Appropriate Assessment	
KPI 4 ?	6
KPI 5 ?	20
Mental Health	
KPI 6 ?	6
KPI 7 ?	5
KPI 8 ?	2
Care Planning	
KPI 9a ?	15
KPI 9a(a) ?	12
KPI 9a(b) ?	15
KPI 9a(c) ?	13
KPI 9b ?	17
KPI 9b(a) ?	13
KPI 9b(b) ?	14
KPI 9b(c) ?	13
KPI 9b(d) ?	14
KPI 9b(e) ?	13
KPI 9b(f) ?	15
KPI 10 ?	8



Comorbidity and Complexity

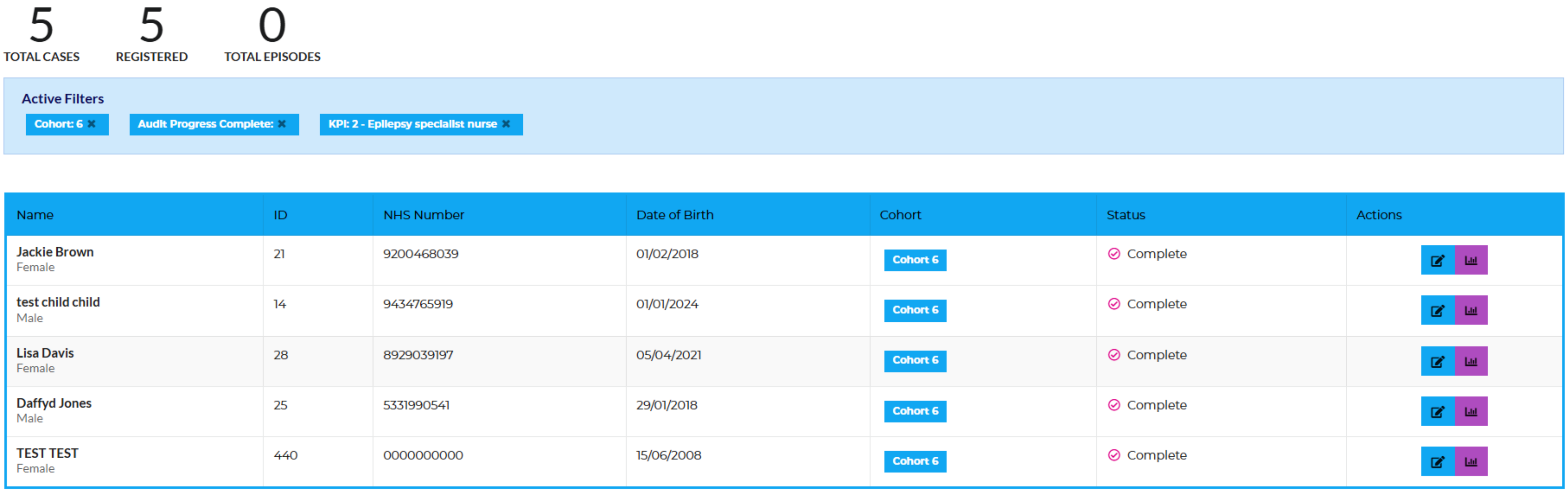
Conditions

Syndrome Present	11
Epilepsy Cause Known	17
Global Developmental Delay	4
Developmental or Learning Problems	6
Behavioural or Emotional Problems	11
Autism Spectrum Disorder	4
Mental Health Support in place?	6

*Dummy data

‘Report builder’

→ Filtered list of CYP



5 TOTAL CASES

5 REGISTERED

0 TOTAL EPISODES

Active Filters

Cohort: 6 ✖ | Audit Progress Complete: ✖ | KPI: 2 - Epilepsy specialist nurse ✖

Name	ID	NHS Number	Date of Birth	Cohort	Status	Actions
Jackie Brown Female	21	9200468039	01/02/2018	Cohort 6	✓ Complete	
test child child Male	14	9434765919	01/01/2024	Cohort 6	✓ Complete	
Lisa Davis Female	28	8929039197	05/04/2021	Cohort 6	✓ Complete	
Daffyd Jones Male	25	5331990541	29/01/2018	Cohort 6	✓ Complete	
TEST TEST Female	440	0000000000	15/06/2008	Cohort 6	✓ Complete	

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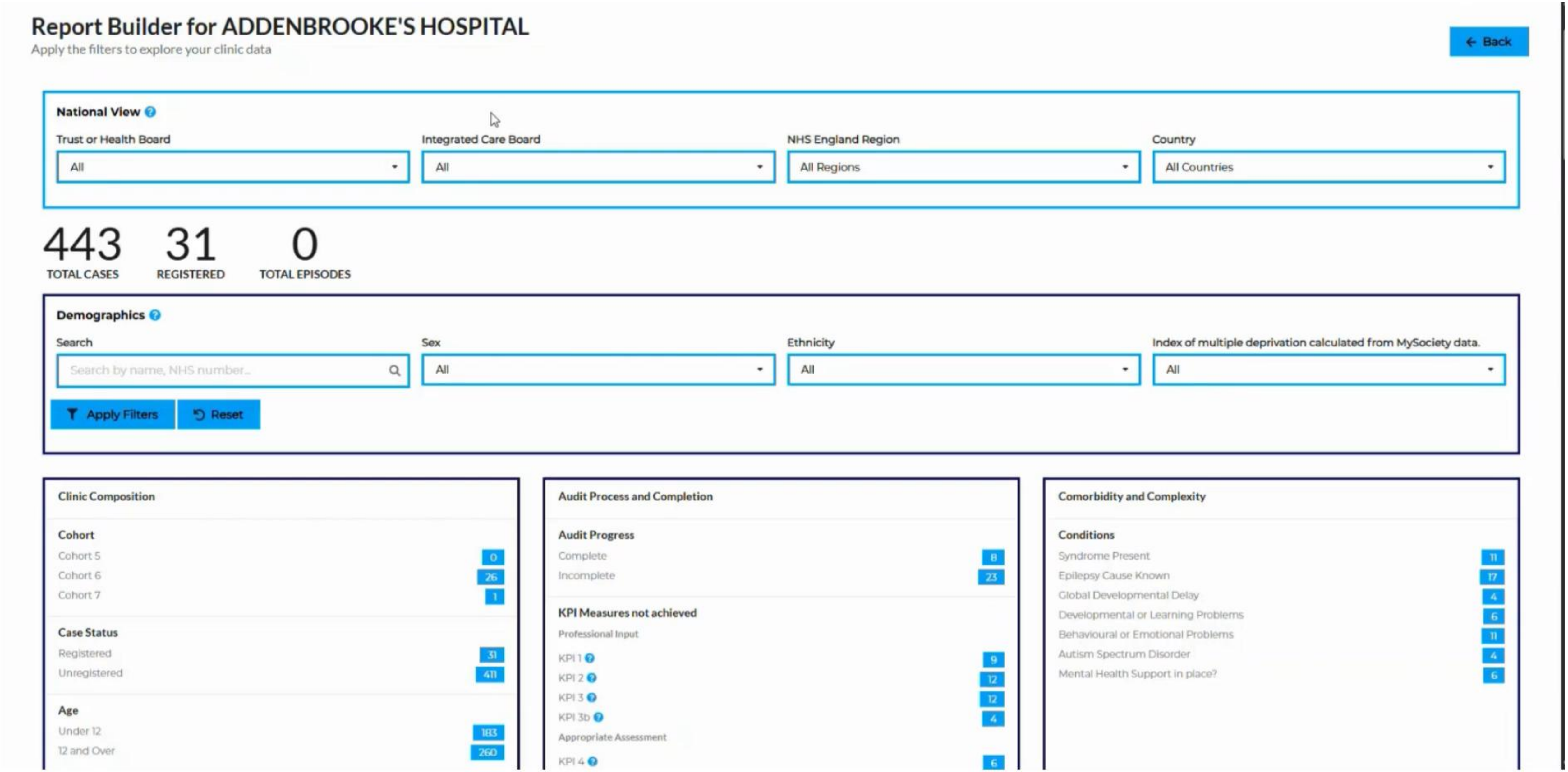
EPILEPSY12

Report Builder Demo

*Dummy Data



Report Builder for ADDENBROOKE'S HOSPITAL

Apply the filters to explore your clinic data

National View

Trust or Health Board: All
Integrated Care Board: All
NHS England Region: All Regions
Country: All Countries

443	31	0
TOTAL CASES	REGISTERED	TOTAL EPISODES

Demographics

Search: Search by name, NHS number...
Sex: All
Ethnicity: All
Index of multiple deprivation calculated from MySociety data.: All

Clinic Composition

Cohort	
Cohort 5	0
Cohort 6	26
Cohort 7	1
Case Status	
Registered	31
Unregistered	411
Age	
Under 12	183
12 and Over	260

Audit Process and Completion

Audit Progress	
Complete	8
Incomplete	23
KPI Measures not achieved	
Professional Input	
KPI 1	9
KPI 2	12
KPI 3	12
KPI 3b	4
Appropriate Assessment	
KPI 4	6

Comorbidity and Complexity

Conditions	
Syndrome Present	11
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Behavioural or Emotional Problems	11
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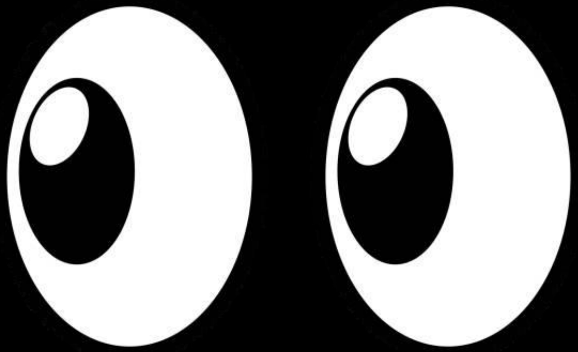
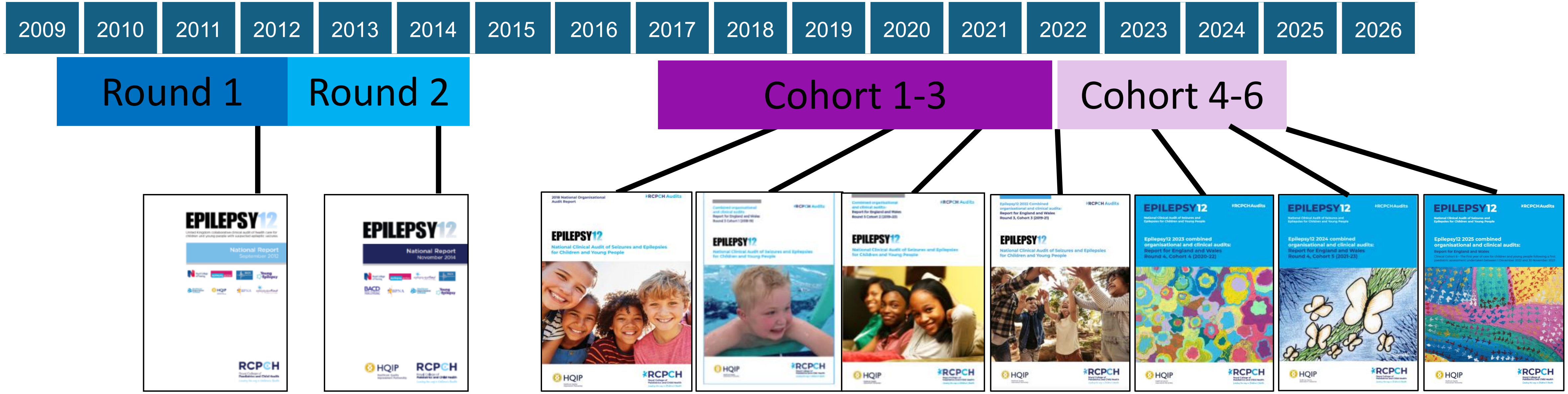
Mental Health Support in place?	6



Looking back…

Since 2009…



2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025	2026

Round 1

Round 2

Cohort 1-3

Cohort 4-6

Aims

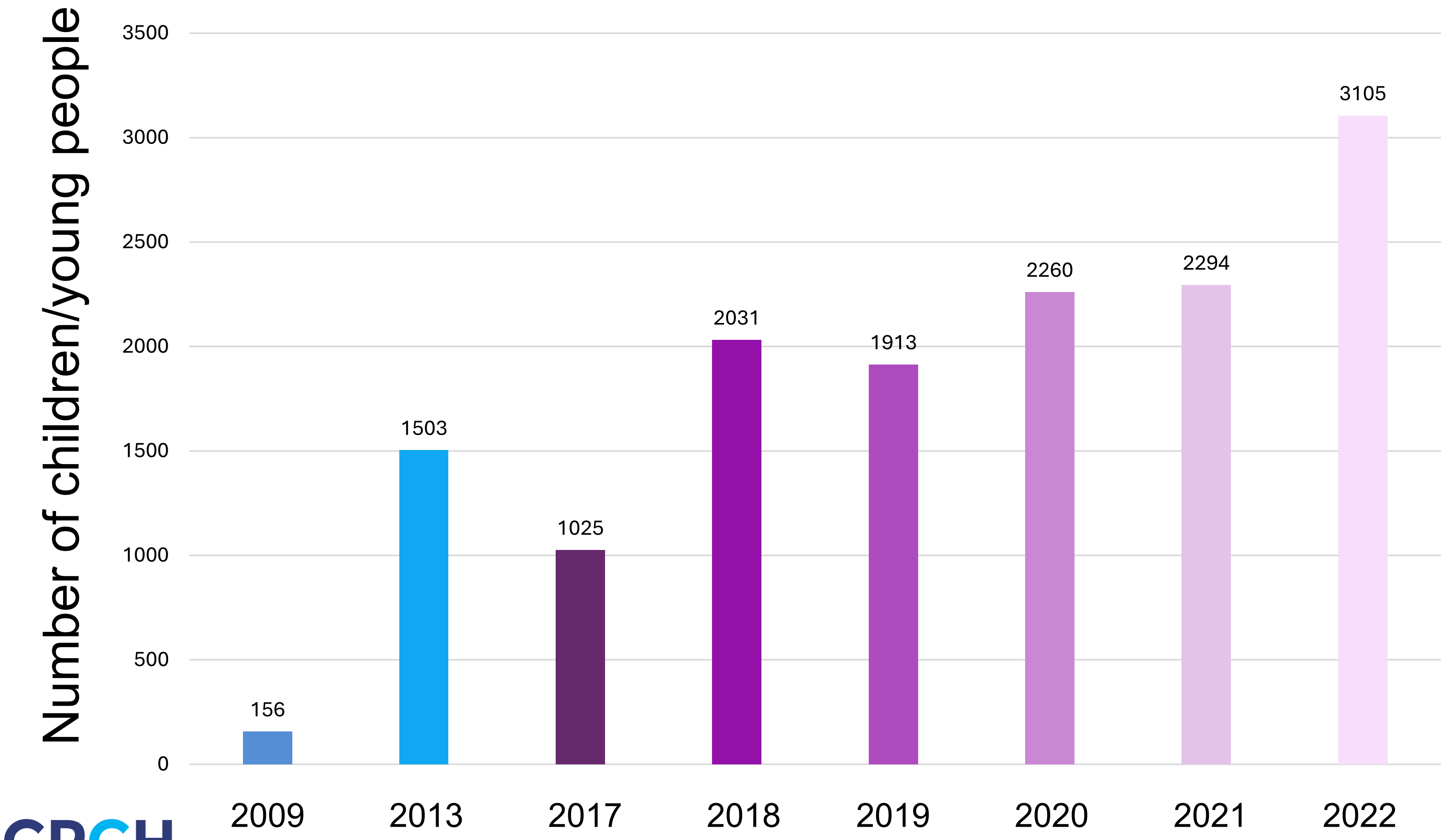
To describe longitudinal trends in quality of care across England/Wales since the commencement of the Epilepsy12 in 2009

Methods

- All 8 cohorts since 2009 reviewed
- All KPIs reviewed to facilitate longitudinal comparison
- National levels presented

- 🟦 Round 1 (2009-2010)
- 🟦 Round 2 (2013-2014)
- 🟪 Cohort 1 (2017-2018)
- 🟪 Cohort 2 (2018-2019)
- 🟪 Cohort 3 (2019-2020)
- 🟪 Cohort 4 (2020-2021)
- 🟪 Cohort 5 (2021-2022)
- 🟪 Cohort 6 (2022-2023)

Results - Cohort size



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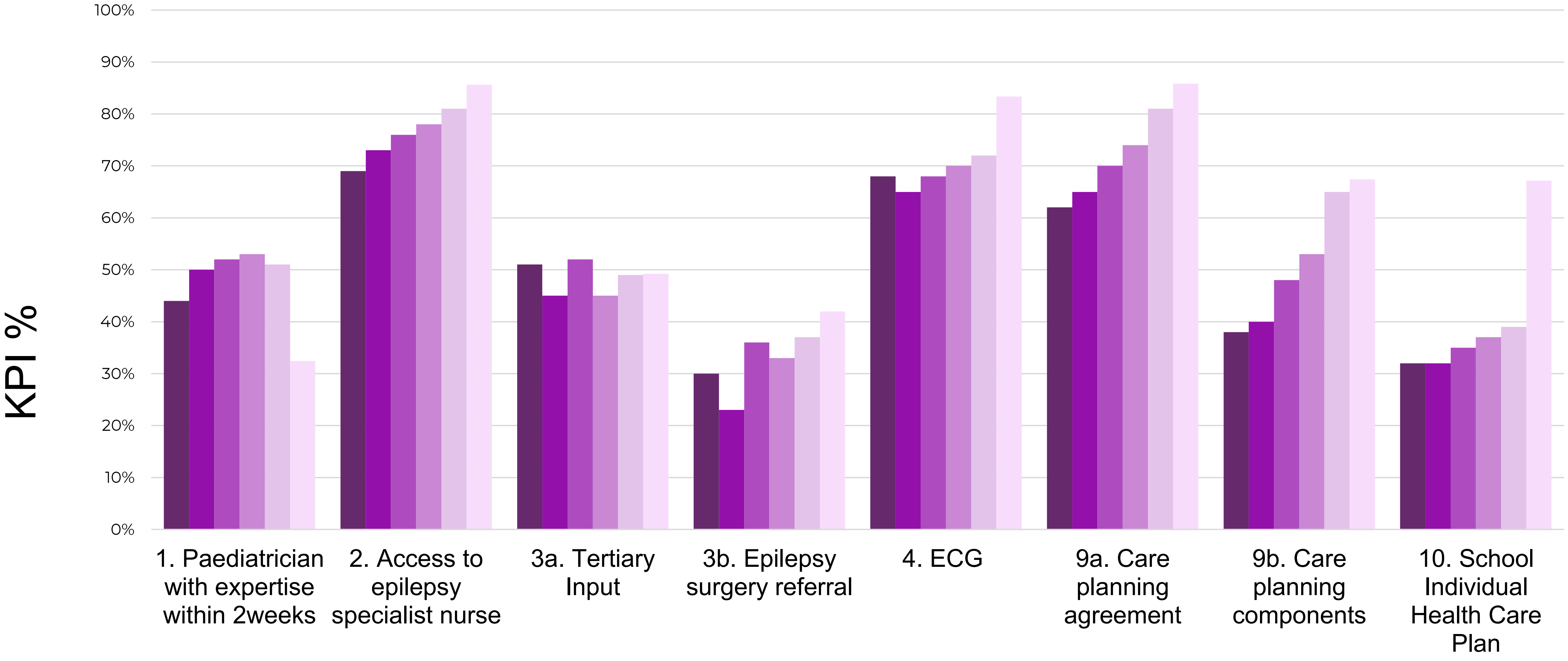
EPILEPSY12

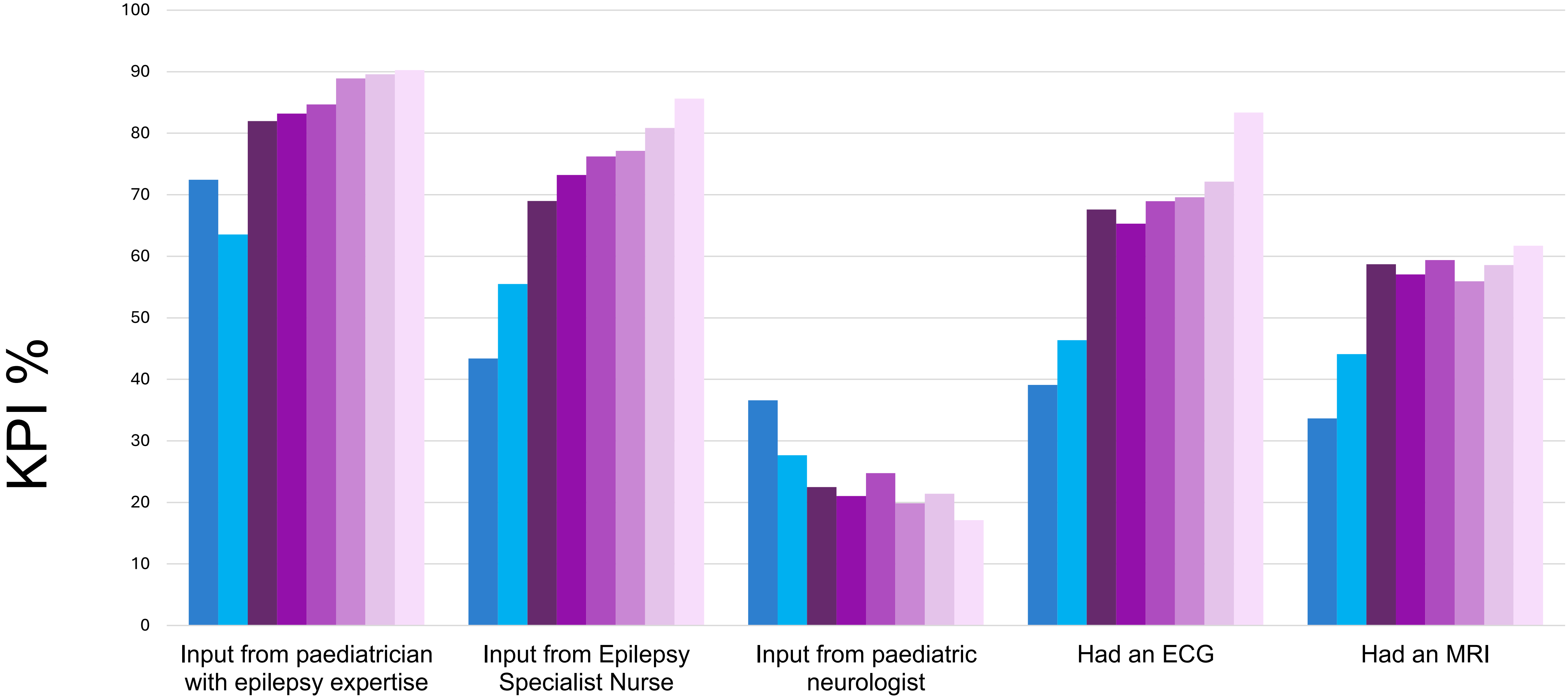
8 KPIs over 6 cohorts from 2017

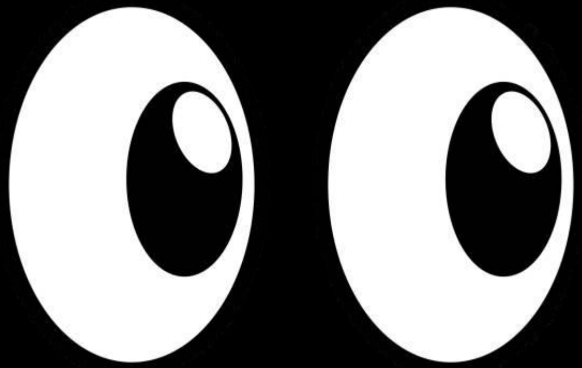


RCPCH

EPILEPSY12

5 KPIs over 8 cohorts from 2009





Looking forward…

A bit about the 10 year plan...

- No mention of epilepsy....however...

UK Government

NHS

FIT FOR
THE FUTURE

10 Year Health Plan
for England

Executive Summary

July 2025

A bit about the 10 year plan…

- From sickness to prevention
- From hospital to neighbourhood
- From analogue to digital
- Equitable

UK Government

NHS

FIT FOR
THE FUTURE

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for England

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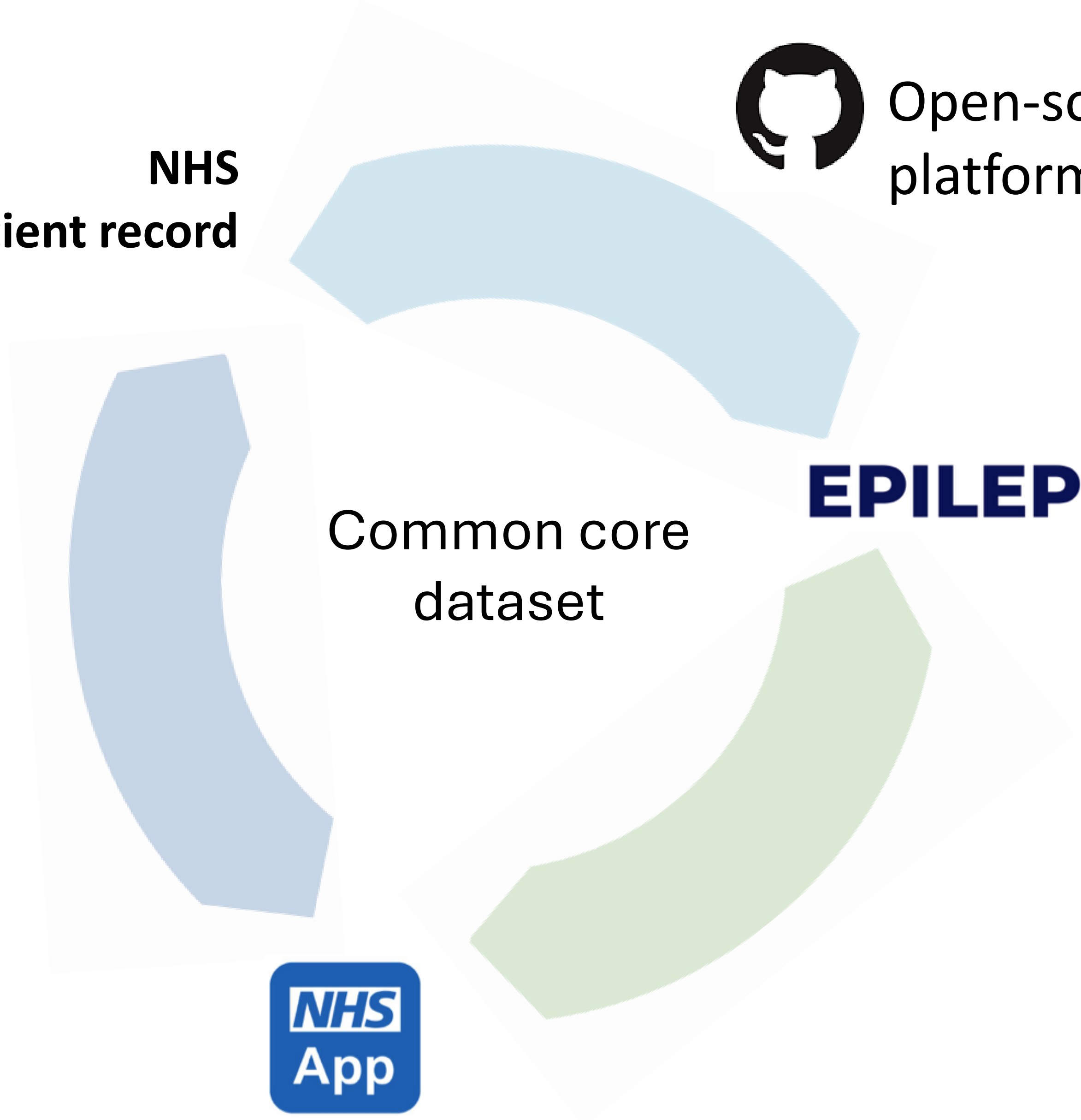
July 2025

Creating data fit to flow…



NHS
Health Records/Single patient record

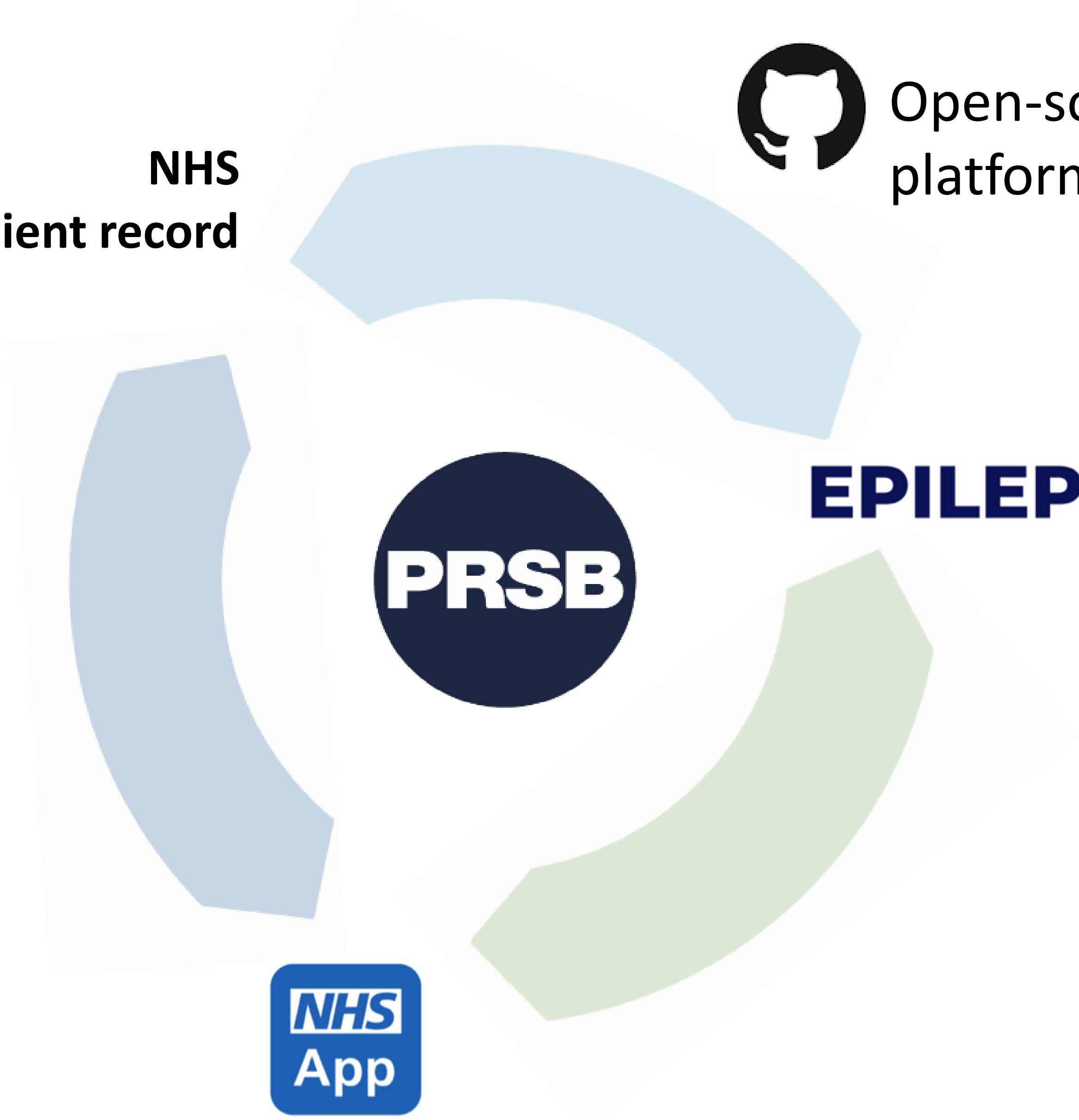
Open-source RCPCH audit platform

Common core dataset

EPILEPSY12

NHS App

Standardising the Data to flow…



NHS
Health Records/Single patient record

Open-source RCPCH audit platform

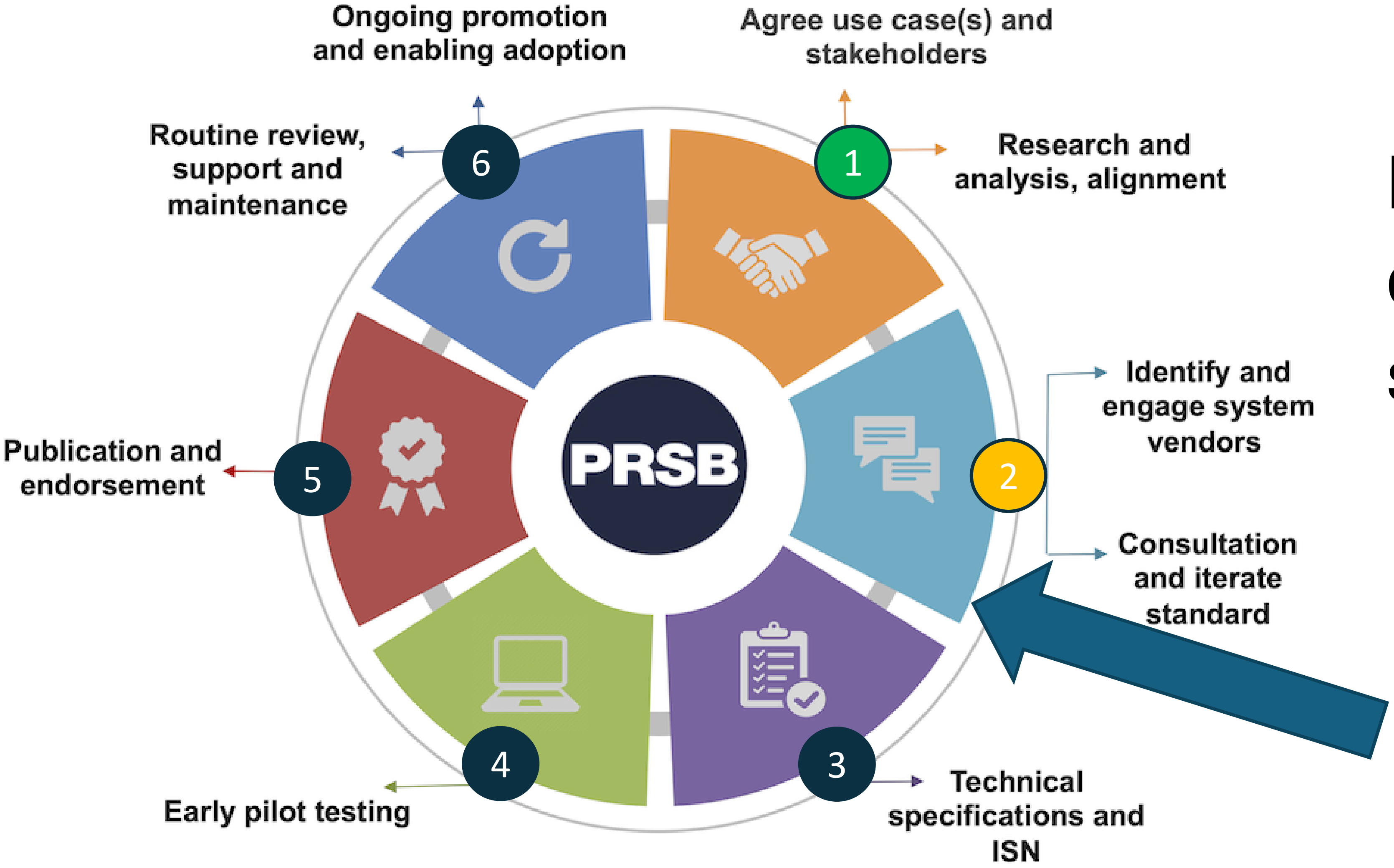
PRSB Professional Record Standards Body

UK NHS Epilepsies Data Standard

- Commenced 2022 with PRSB
- UK wide, whole health, whole lifetime
- NHS funded via Epilepsy12 and now NHSE
- A 6-stage cycle co-created, vendor-neutral
- To facilitate and mandate interoperability across the NHS and social care digital landscape

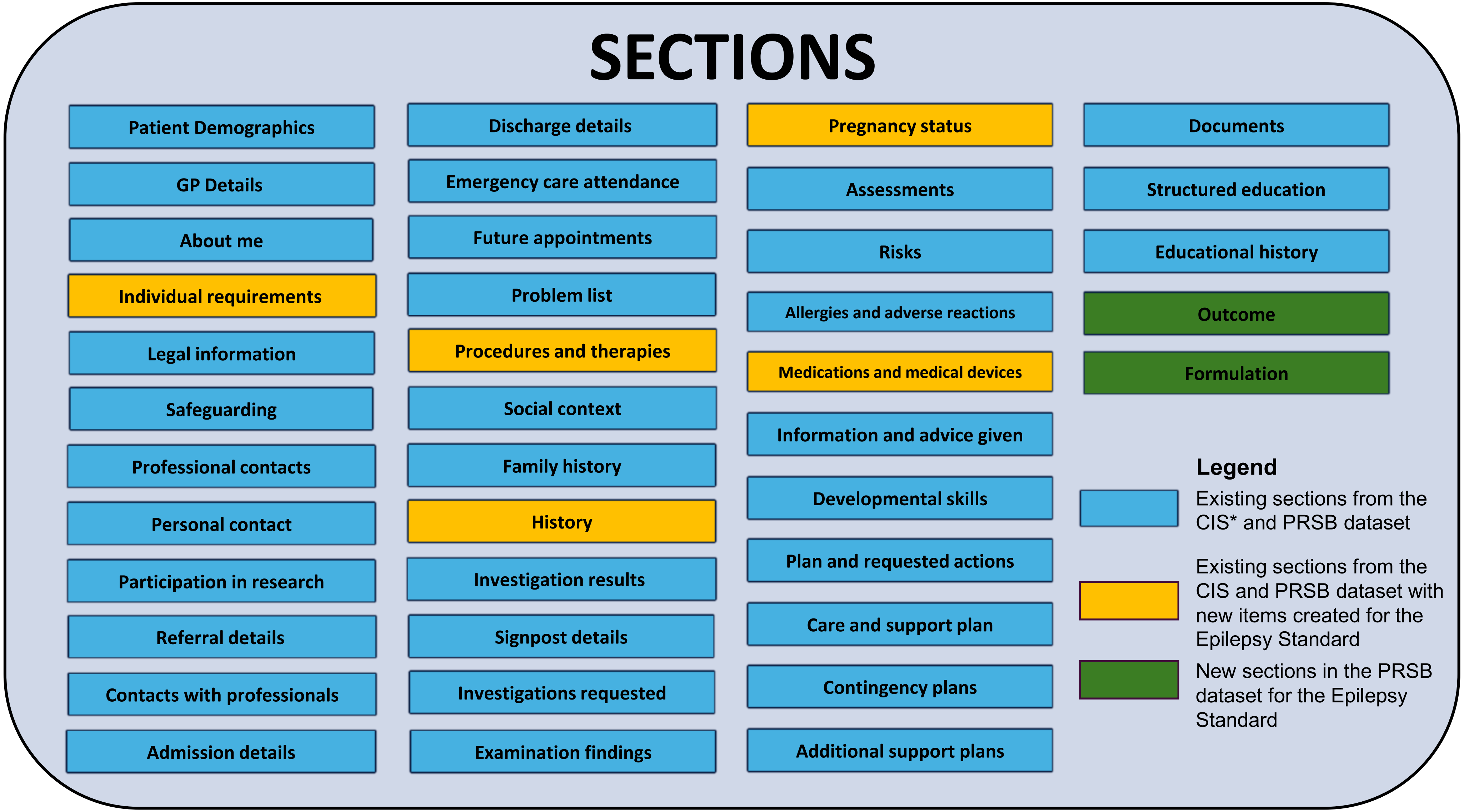
RCPCH EPILEPSY12 THE NEUROLOGICAL ALLIANCE Young Epilepsy EPILEPSY RESEARC INSTITUTE UK ILAE BRITISH BRANCH

Now completing stage 2…



Published 1st draft data standard, 2024

EPILEPSY FRAMEWORK



SECTIONS

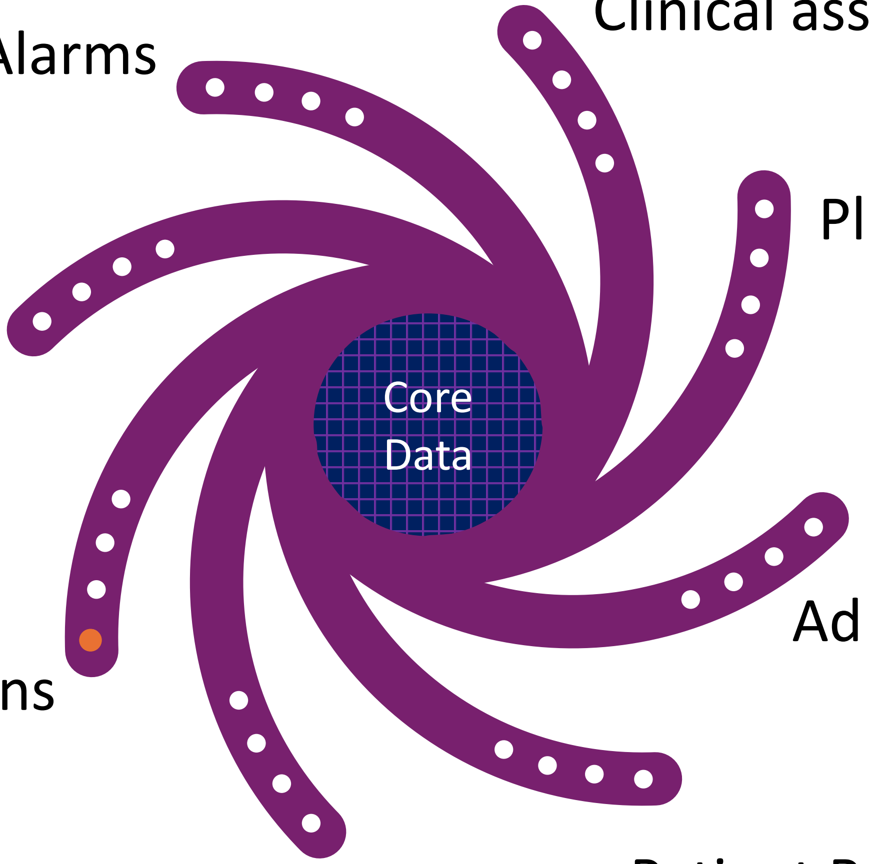
- 🟦 Patient Demographics
- 🟦 GP Details
- 🟦 About me
- 🟨 Individual requirements
- 🟦 Legal information
- 🟦 Safeguarding
- 🟦 Professional contacts
- 🟦 Personal contact
- 🟦 Participation in research
- 🟦 Referral details
- 🟦 Contacts with professionals
- 🟦 Admission details
- 🟦 Discharge details
- 🟦 Emergency care attendance
- 🟦 Future appointments
- 🟦 Problem list
- 🟨 Procedures and therapies
- 🟦 Social context
- 🟦 Family history
- 🟨 History
- 🟦 Investigation results
- 🟦 Signpost details
- 🟦 Investigations requested
- 🟦 Examination findings
- 🟨 Pregnancy status
- 🟦 Assessments
- 🟦 Risks
- 🟦 Allergies and adverse reactions
- 🟨 Medications and medical devices
- 🟦 Information and advice given
- 🟦 Developmental skills
- 🟦 Plan and requested actions
- 🟦 Care and support plan
- 🟦 Contingency plans
- 🟦 Additional support plans
- 🟦 Documents
- 🟦 Structured education
- 🟦 Educational history
- 🟩 Outcome
- 🟩 Formulation

Legend

🟦	Existing sections from the CIS* and PRSB dataset
🟨	Existing sections from the CIS and PRSB dataset with new items created for the Epilepsy Standard
🟩	New sections in the PRSB dataset for the Epilepsy Standard

**Core Information Standard (CIS) defines a set of information that can potentially be shared between systems in different sites and settings, among professionals and people using services.*

Connecting inputs...



Wearables/Implantables/Alarms

Clinical assessment

Planned epilepsy reviews

Seizure videos

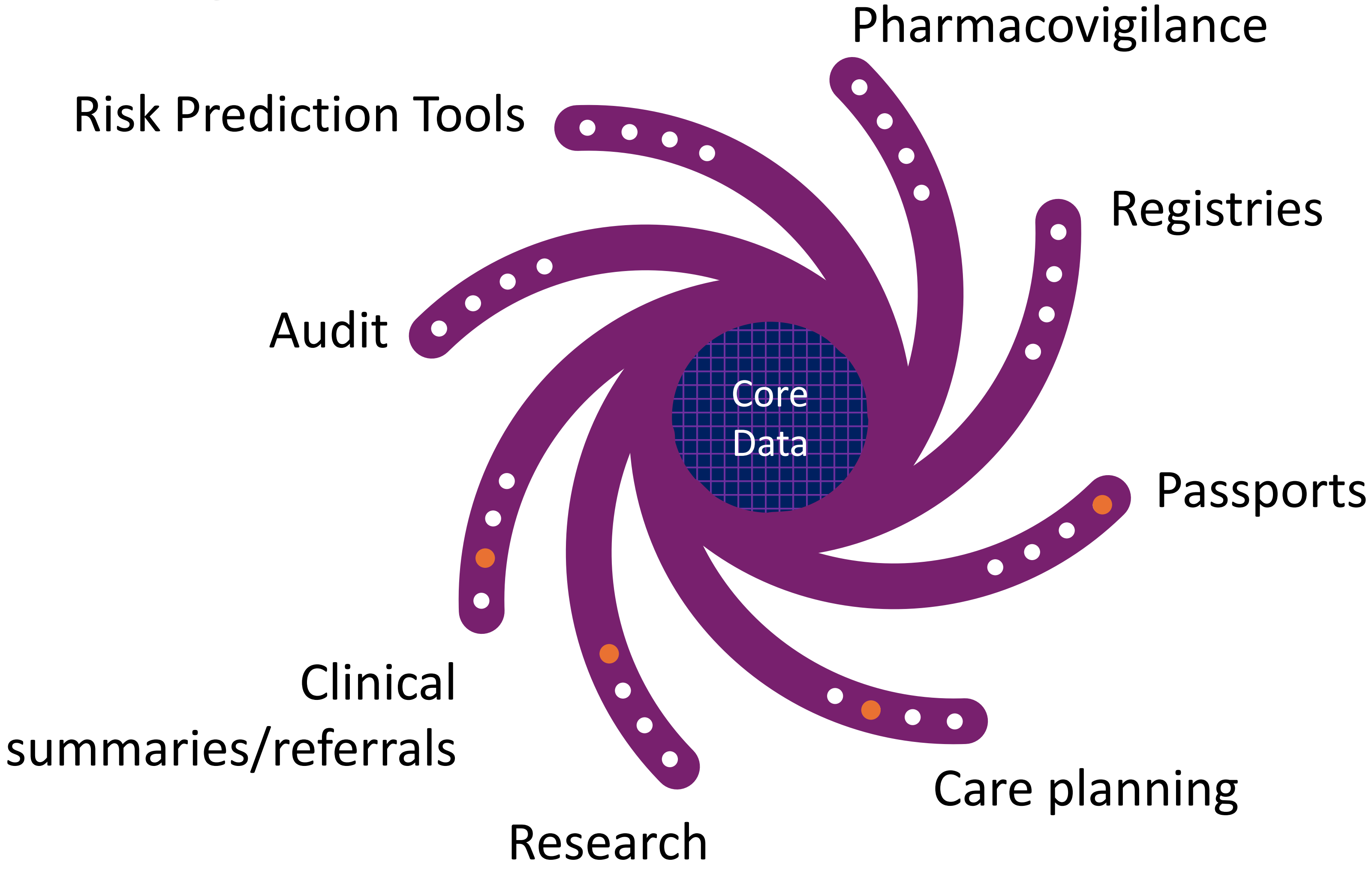
Ad hoc epilepsy review

Seizure descriptions

'Seizure diary'

Patient Reported Outcome Measures

Connecting outputs...



Conclusions…

- There are **notable improve**ments this year in the areas of ascertainment, ESN provision, epilepsy surgery referrals, ECGs, mental health screening/support and school individual health care plans
- There is **statis** in terms of tertiary neurology input for children with complex epilepsies and overall mental health provision is insufficient
- In the longer term there is good evidence of **reducing gaps in care** for children with epilepsies across England and Wales
- We can be increasingly focussed on the effects of different **individual attributes** and potential service factors enablers

Next steps…

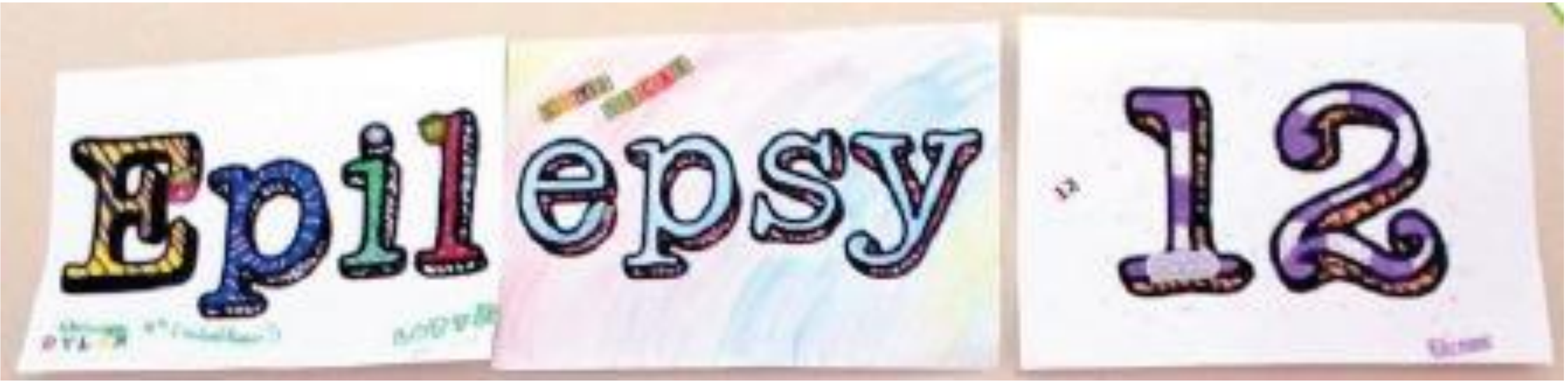
- Opportunities for further enhancing **Epilepsy12 participation** and **job planned time**, managing **flow and capacity** within tertiary and surgical provision and embedding **mental health** provision
- Plan to **map Epilepsy12 data** to clinical outcomes, health service activity and health economics
- Translate the data standard work from theory into **connected health records and tools**
- Plan for **big data and AI opportunities** using structured population health data encompassing **clinical, audit, research and strategic** benefits

Thank you…

- All paediatric epilepsy teams submitting data in participating NHS Health Boards and Trusts
- Epilepsy12 Youth advocates and the RCPCH& Us team
- Epilepsy12 Project Team, Methodology & Dataset group, Project Board
- RCPCH, epilepsy charities and key stakeholder organisations
- HQIP (Healthcare Quality Improvement Partnership), NHS England, Welsh Government and Jersey

Let knit good connections…

…into the 'real world'!



www.rcpch.ac.uk/epilepsy12

RCPCH EPILEPSY12