

EPILEPSY12

@drcolindunkley
10.09.20

How do we escape from here?!

Acknowledgements

Epilepsy12 Project Board

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All Epilepsy12 Youth Advocates

All participating health professionals



PUBLIC BRIDLEWAY



| | |
|--------------|----------|
| KIRKCLINGTON | 3 miles |
| FARNSFIELD | 5½ miles |
| BILSTHORPE | 7½ miles |



SOUTHWELL TOWN COUNCIL

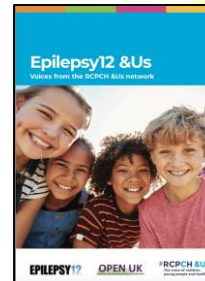
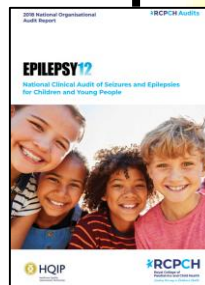
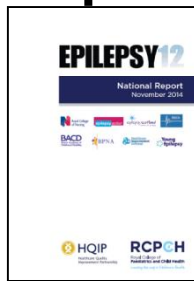
Timeline



Round 1

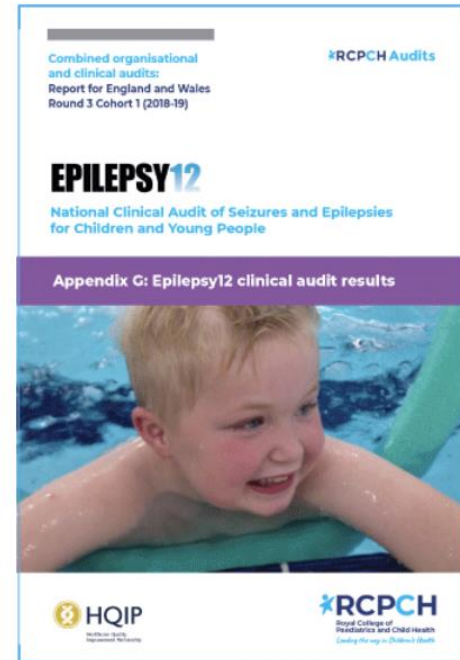
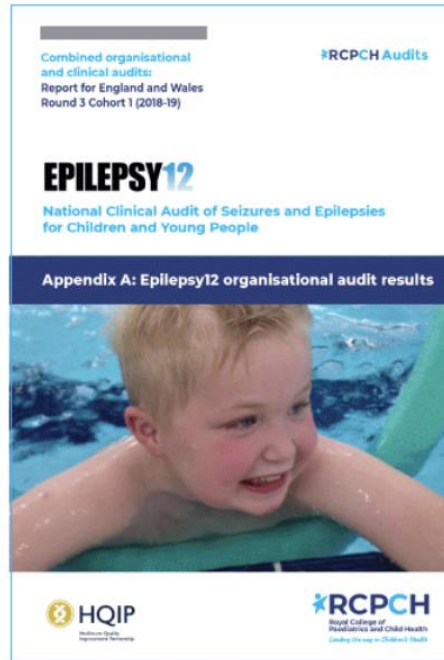
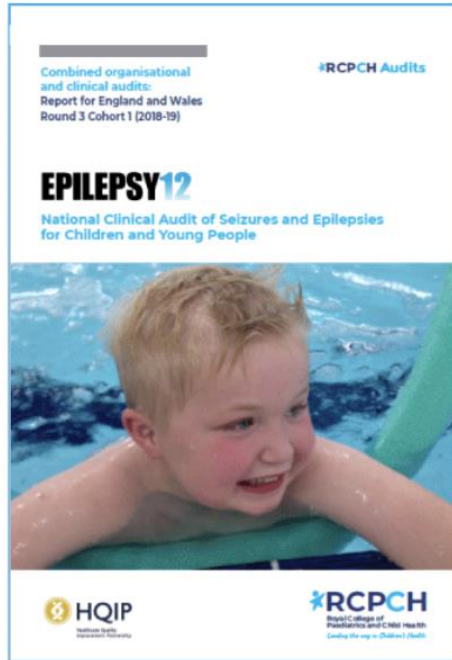
Round 2

Rounds 3+



Full Report

Published today...



<https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-clinical-audit-2019>



Method

All Trusts/Health Boards (T/Hb) England/Wales invited to register

Organisational audit: Snapshot Nov 2019; Epilepsy12 Leads

Clinical audit: 12 defined performance indicators applied to the first 12 months of care for all children and young people meeting inclusion criteria with a 1st paediatric assessment between July-Dec 2018 submitted by Jan 2020.

Results

All 149 T/Hbs England/Wales registered (4 merged = 145)

Organisational audit: 136/145 T/Hbs (94%)

Clinical audit 113/149 T/Hbs (76%)

Results

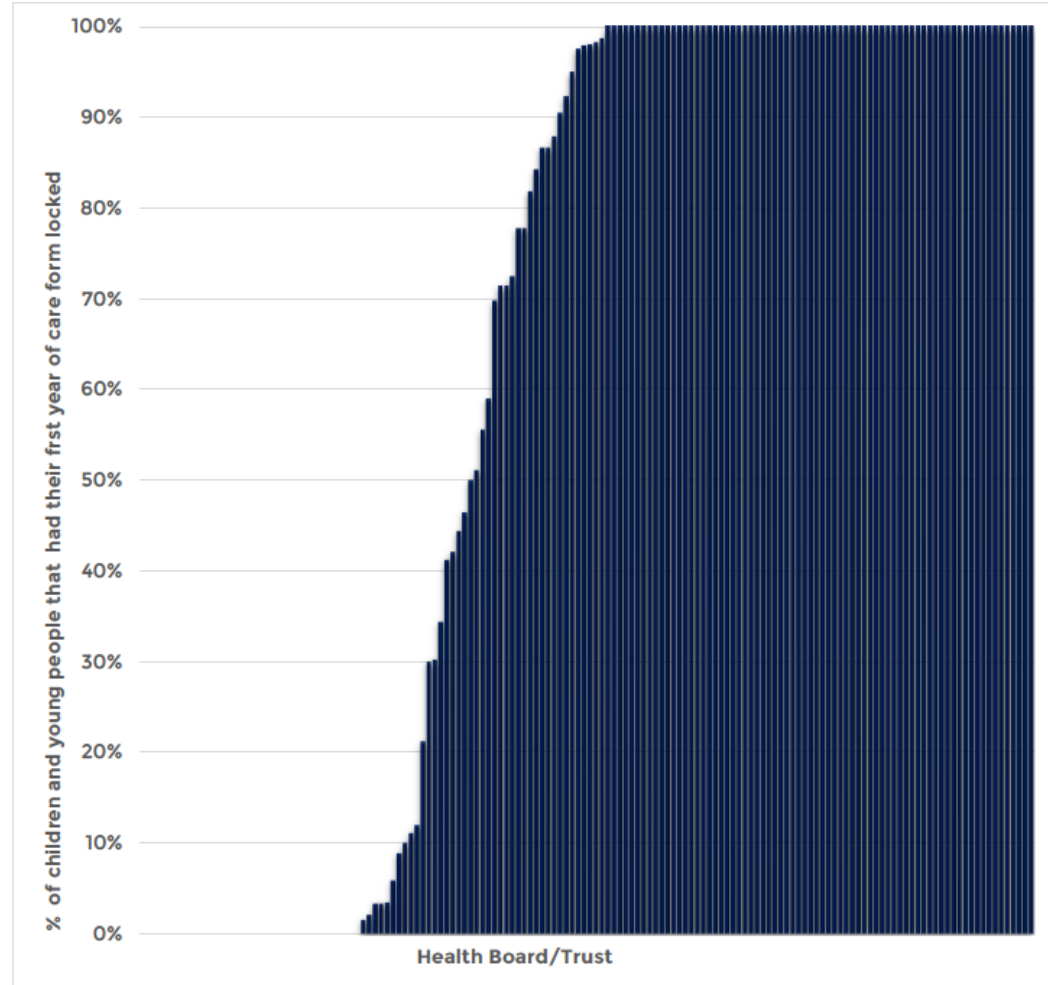
By Jan 2020:

| | |
|-------------------|--------------|
| Registered | 14591 |
| Verified Cohort 1 | 4684 |
| Complete data | 3318 (70.8%) |

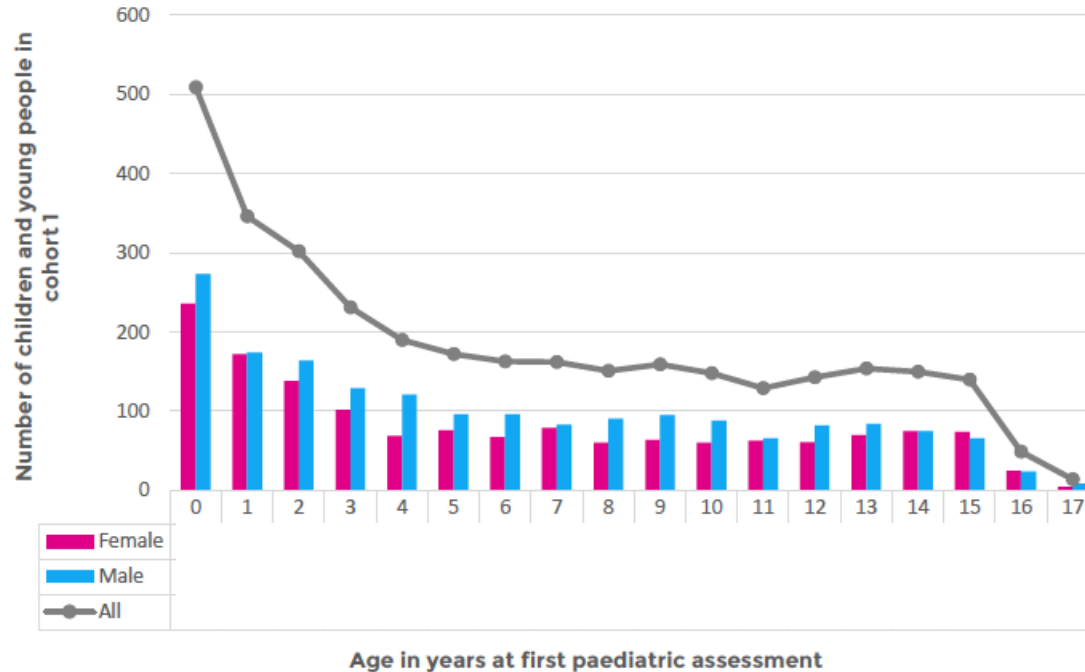
n= 3318

Epilepsy at 1 year = 1112

EPILEPSY12



Age and sex



Deprivation

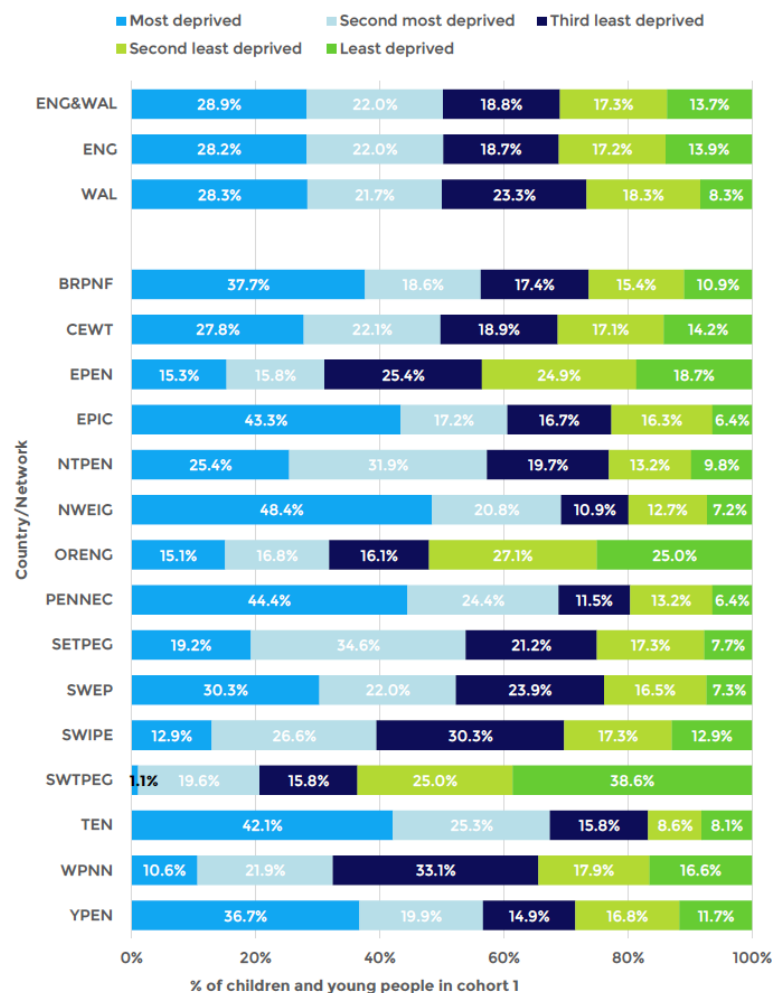


Figure 36: Percentage of children and young people in cohort 1 by deprivation by country/network.

Diagnostic status

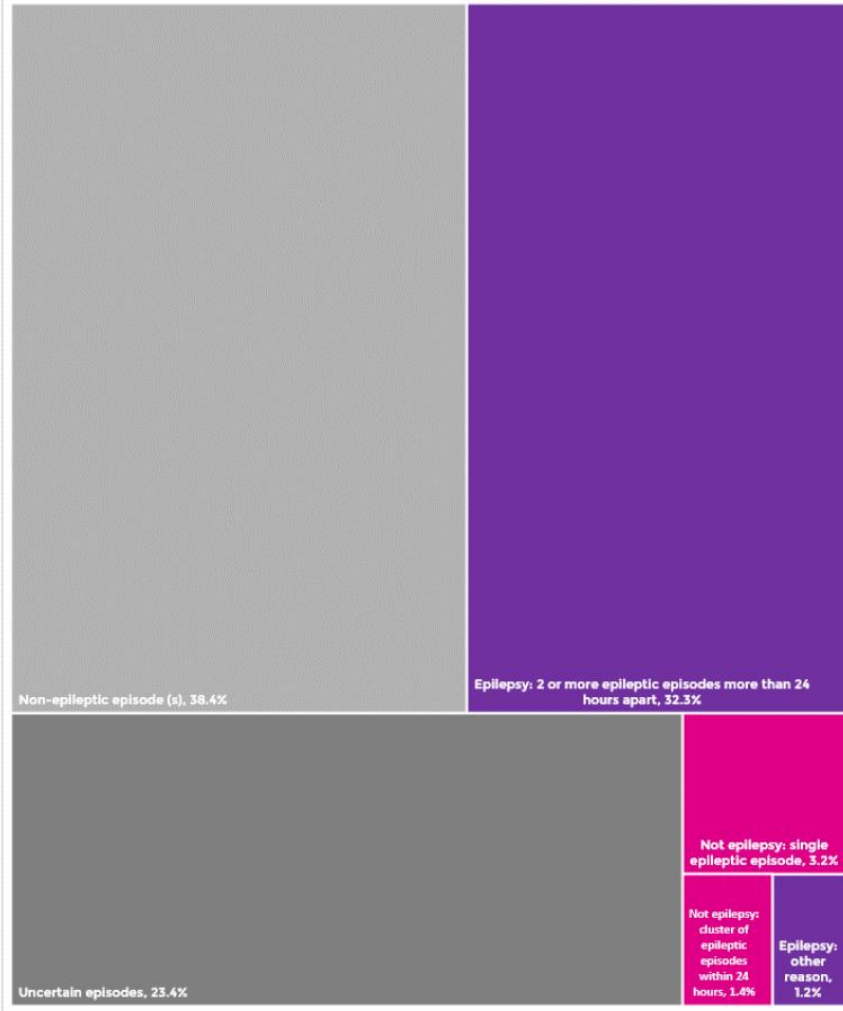


Figure 38: Percentage of children and young people in Cohort 1 by diagnostic status at first year of care, in England and Wales.

Epilepsy: age & gender

Epilepsy = 1112/3318 (33.5%)

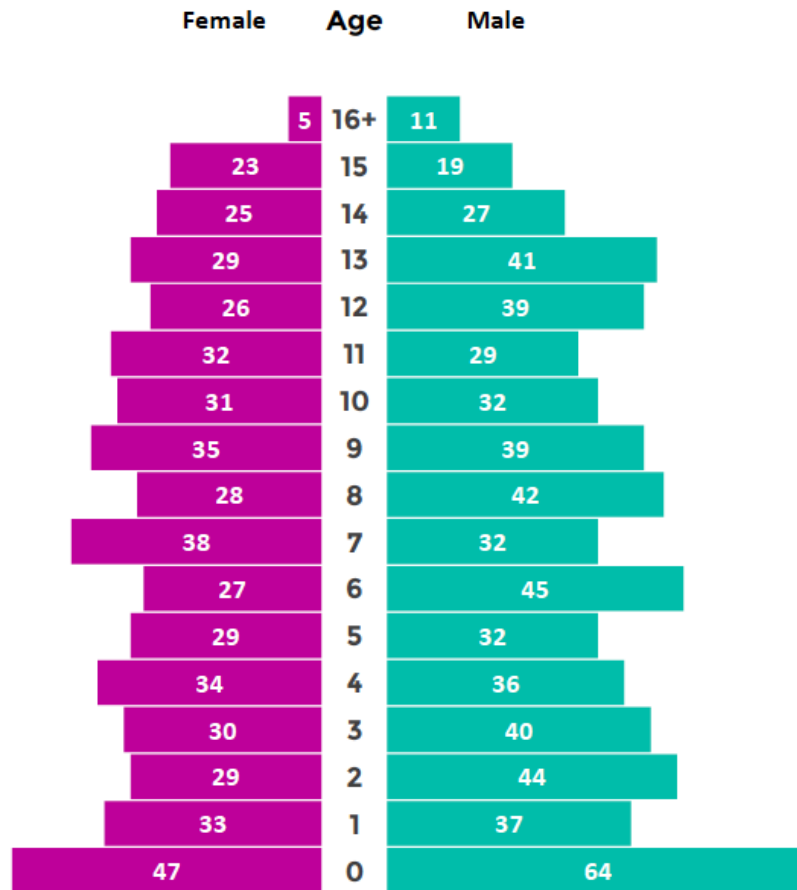


Figure 43: Numbers of children and young people diagnosed with epilepsy by age in years at first paediatric assessment and gender in England and Wales. (This figure excludes 2 children with unknown gender).

Epilepsy Syndrome

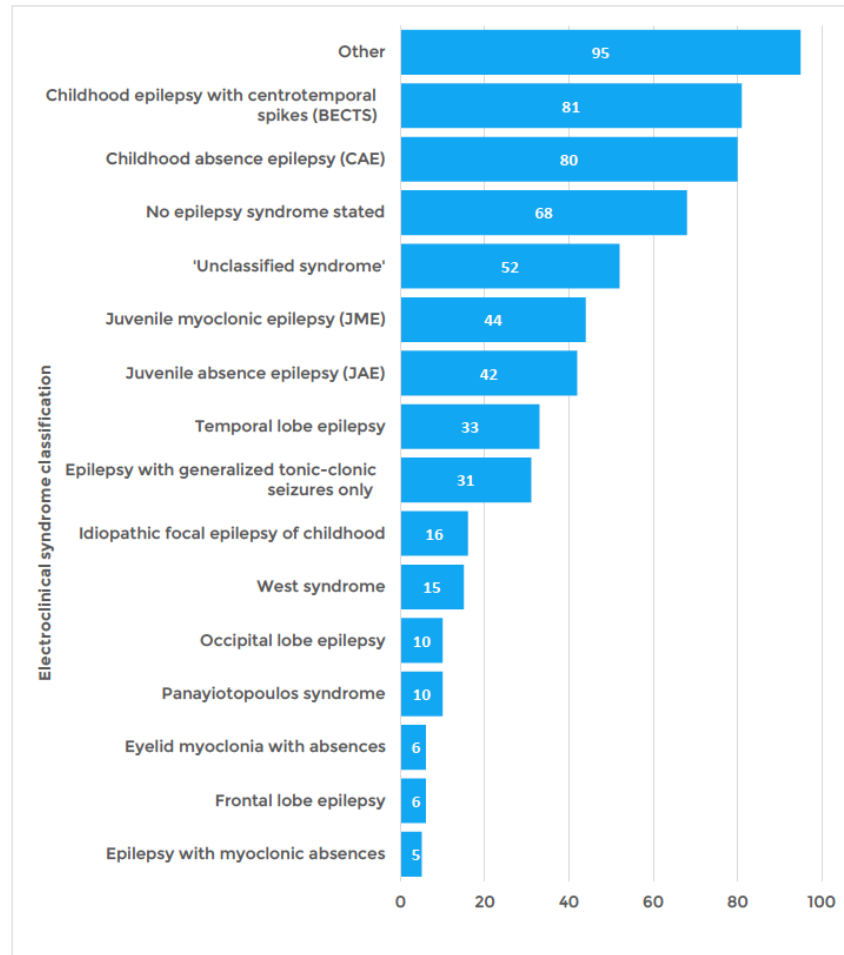


Figure 50: Number of children and young people diagnosed with epilepsy by electroclinical syndrome in England and Wales.

Performance Indicator 1 – Consultant Paediatrician with Expertise Input

| Audit Round | England and Wales |
|-------------|-------------------|
| Round 1 | 78.0% (1183/1516) |
| Round 2 | 86.1% (938/1090) |
| Round 3 | 87.9% (977/1112) |

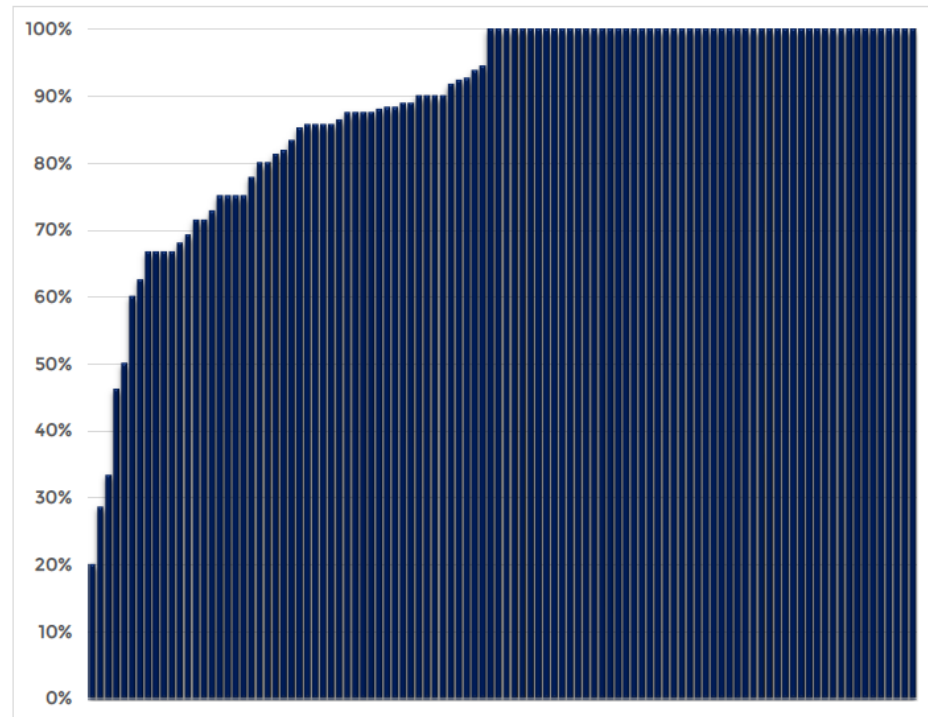


Figure 75: Paediatrician with expertise in epilepsies by Health Board and Trust, Round 3, cohort 1.

Performance Indicator 2 – Epilepsy Specialist Nurse Input

| Audit Round | England and Wales |
|-------------|-------------------|
| Round 1 | 43.4% (658/1516) |
| Round 2 | 55.5% (605/1090) |
| Round 3 | 69.0% (767/1112) |

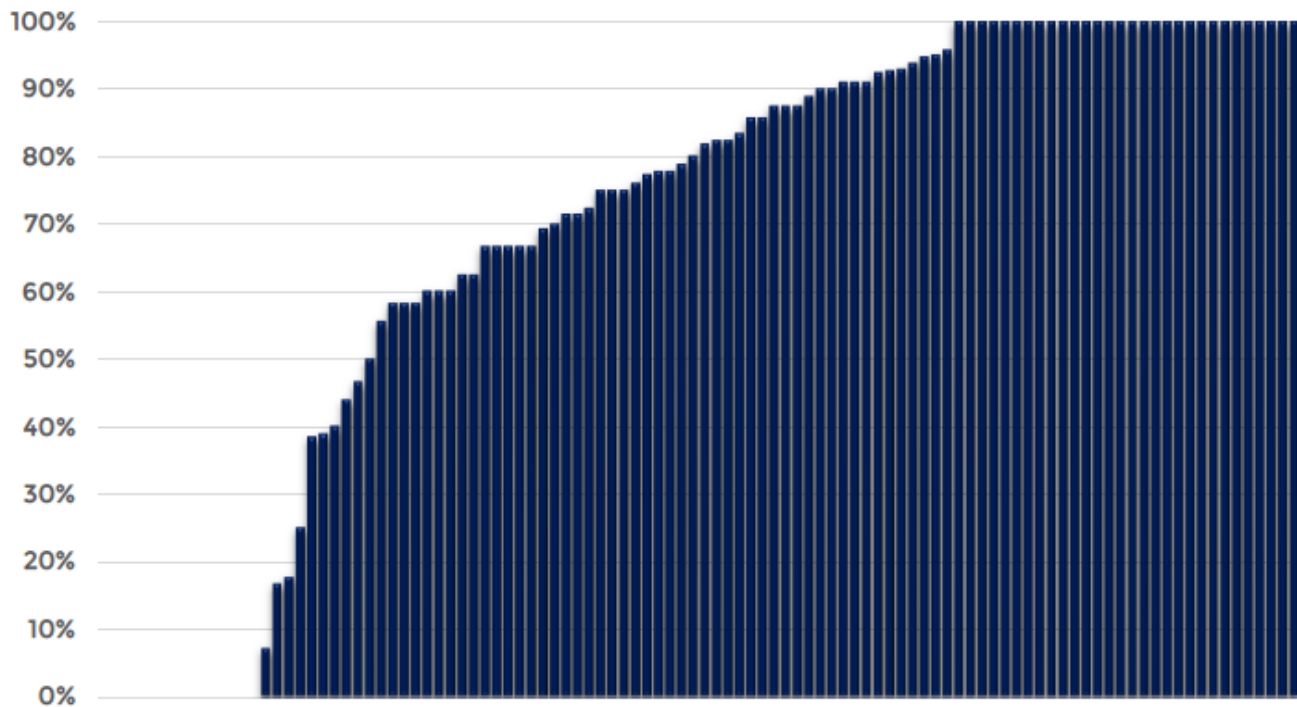


Figure 76: Input from an ESN by Health Board and Trust, Round 3, cohort 1.

No. of Epilepsy Specialist Nurses

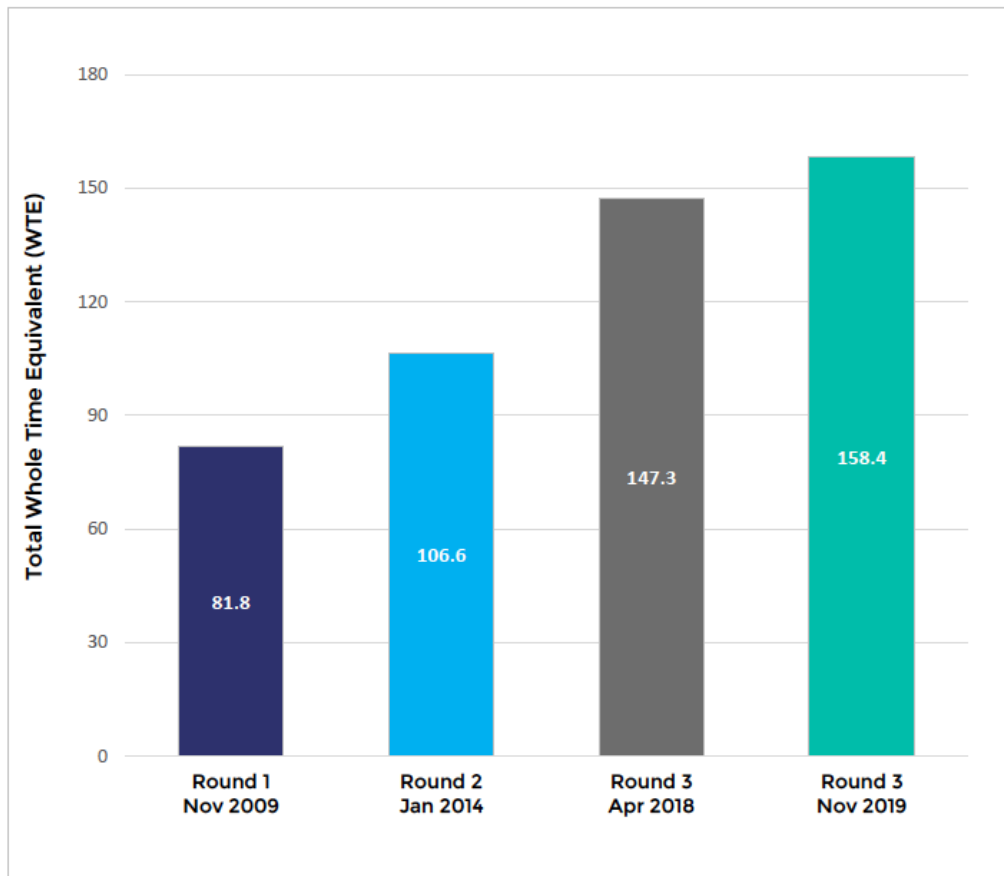


Figure 2: Total Whole Time Equivalent epilepsy specialist nurses employed in England and Wales in Round 1, Round 2, Round 3 April 2018 and November 2019.

Performance Indicator 3 – Tertiary Input

| Audit Round | England and Wales |
|-------------|-------------------|
| Round 1 | 59.1% (205/347) |
| Round 2 | 54.1% (119/220) |
| Round 3 | 59.3% (150/253) |

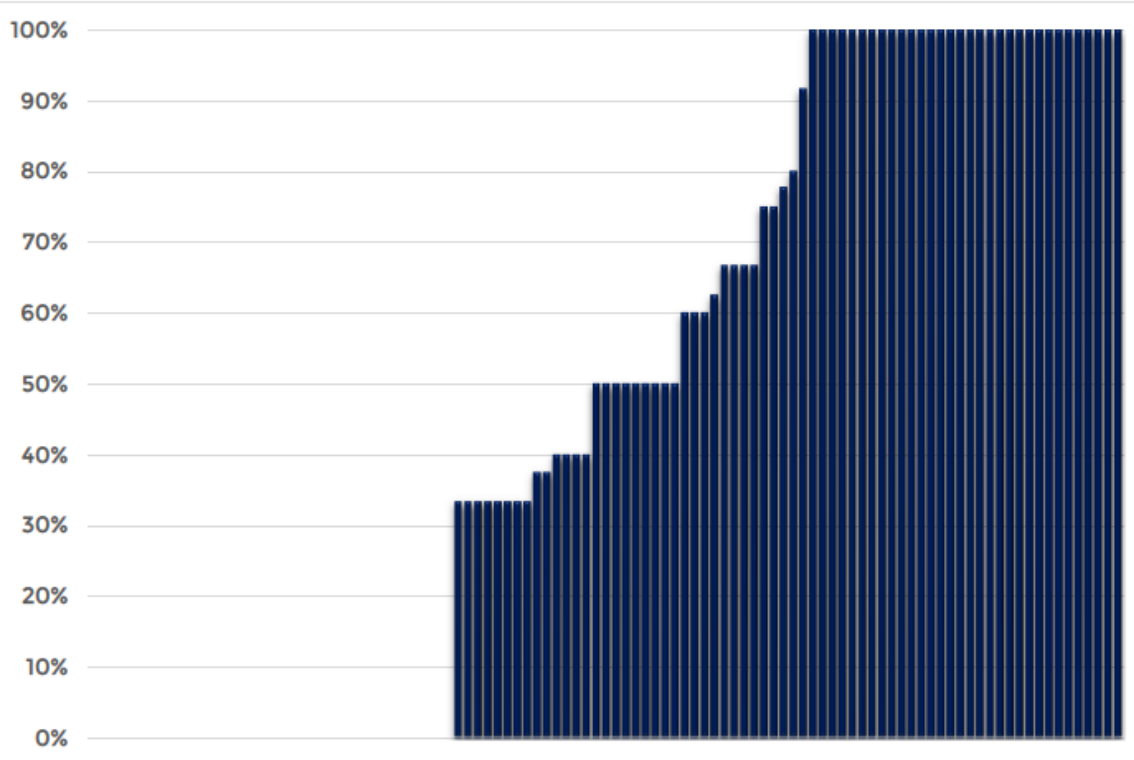


Figure 77: Tertiary input by Health Board and Trust, Round 3, cohort 1.

Performance Indicator 4 – Appropriate first paediatric assessment

| Audit Rounds | England and Wales |
|--------------|-------------------|
| Round 3 | 61.6% (685/1112) |

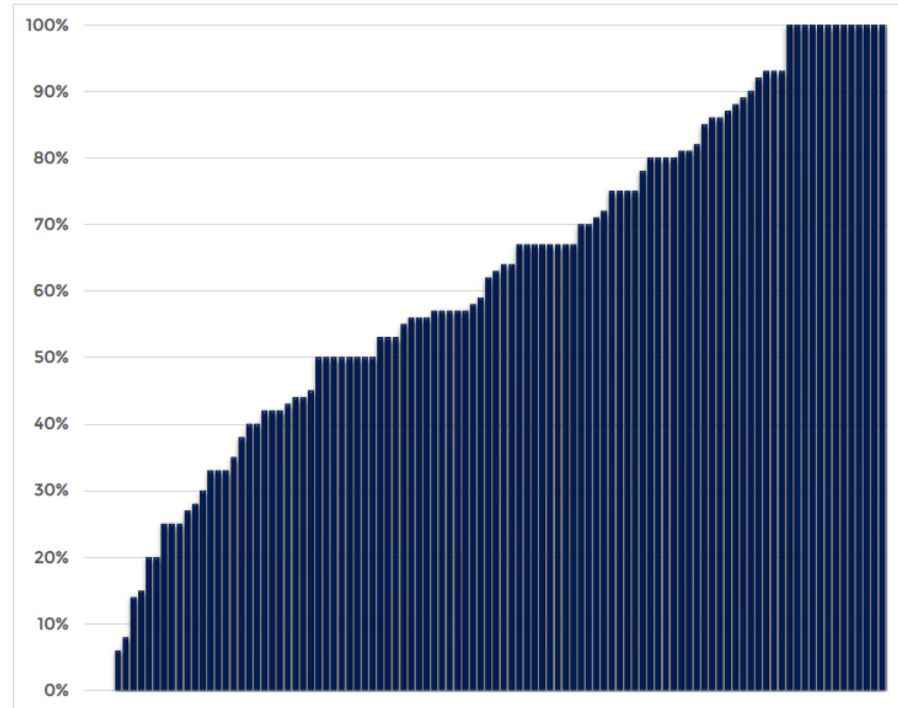


Figure 45: Appropriate first paediatric assessment by unit, Round 3, cohort 1

Performance Indicator 5 – Seizure formulation

| Audit Round | England and Wales |
|-------------|-------------------|
| Round 1 | 86.9% (1318/1516) |
| Round 2 | 94.9% (1040/1096) |
| Round 3 | 88.0% (979/1112) |

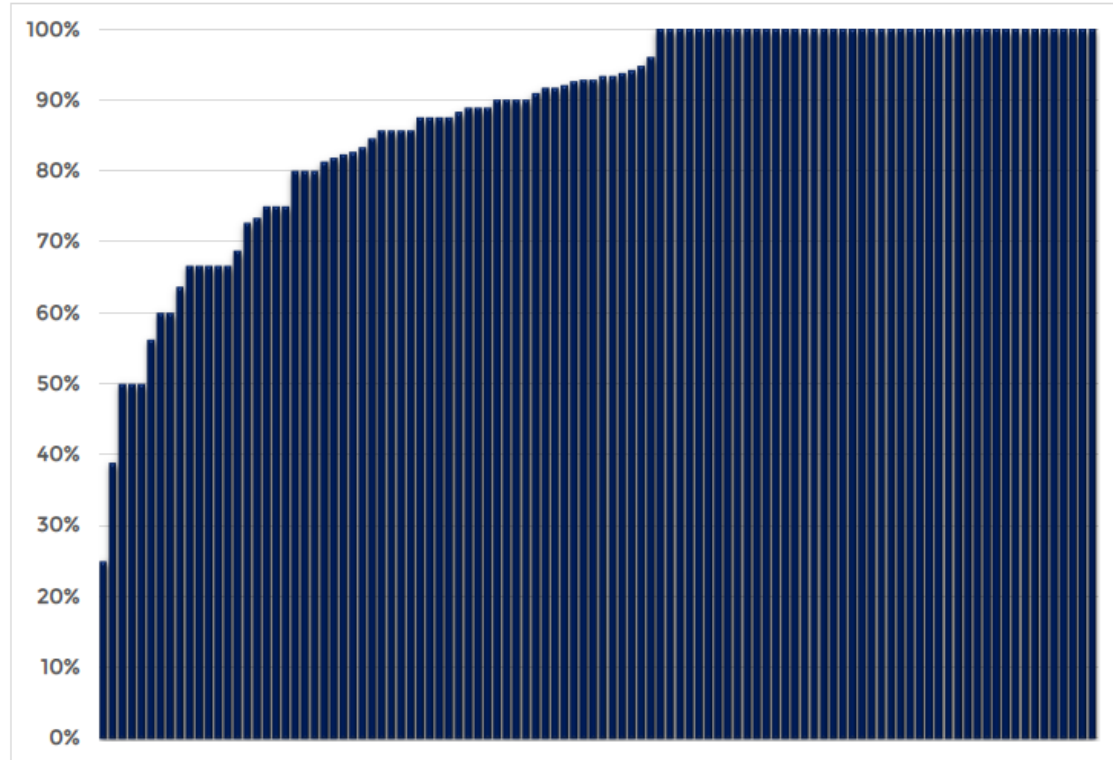


Figure 51: Seizure formulation, by Health Board and Trust, Round 3, cohort 1.

Performance Indicator 6 - ECG

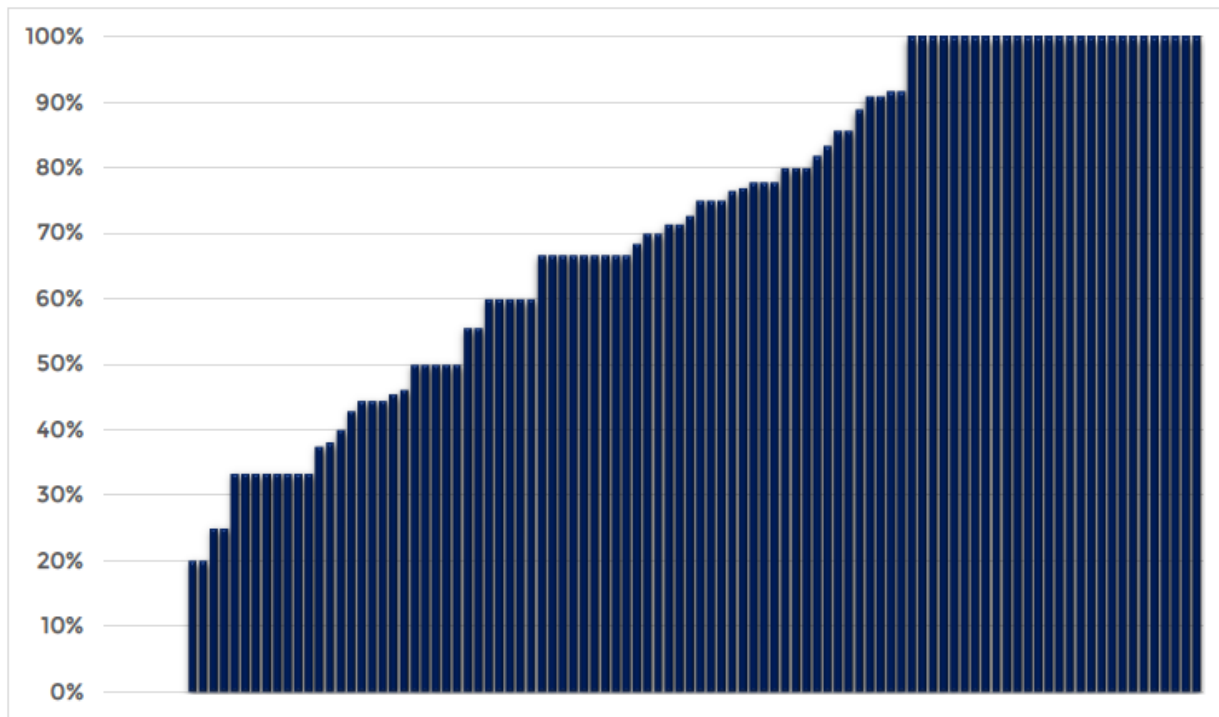
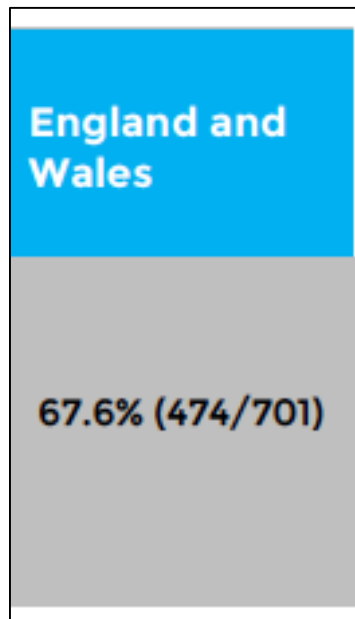


Figure 60: Percentage of children and young people with convulsive seizures and epilepsy, with an ECG at first year by Health Board and Trust, Round 3, cohort 1.

Performance Indicator 7 - MRI

| Audit Round | England and Wales |
|-------------|-------------------|
| Round 1 | 63.5% (602/948) |
| Round 2 | 72.2% (481/666) |
| Round 3 | 68.6% (317/462) |

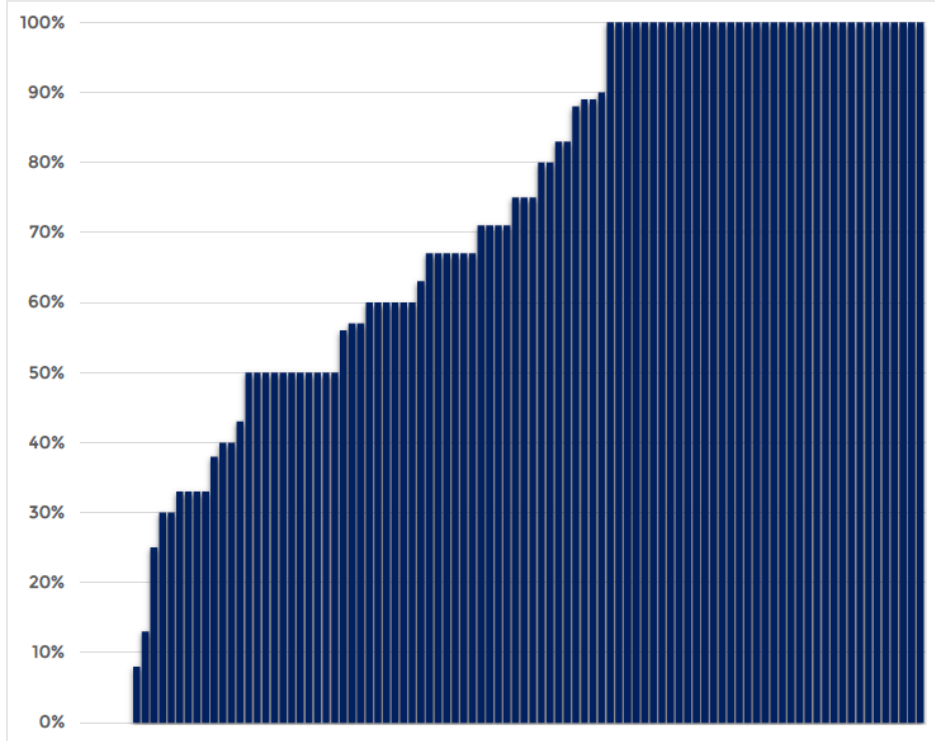


Figure 61: Percentage of children and young people with defined indications for an MRI, who had MRI by first year by Health Board and Trust, Round 3, cohort 1.

Performance Indicator 8 – Accuracy of Diagnosis

| Audit Round | England and Wales |
|-------------|-------------------|
| Round 1 | 88.1% (1516/1721) |
| Round 2 | 93.2% (1077/1156) |
| Round 3 | 97.2% (1093/1124) |

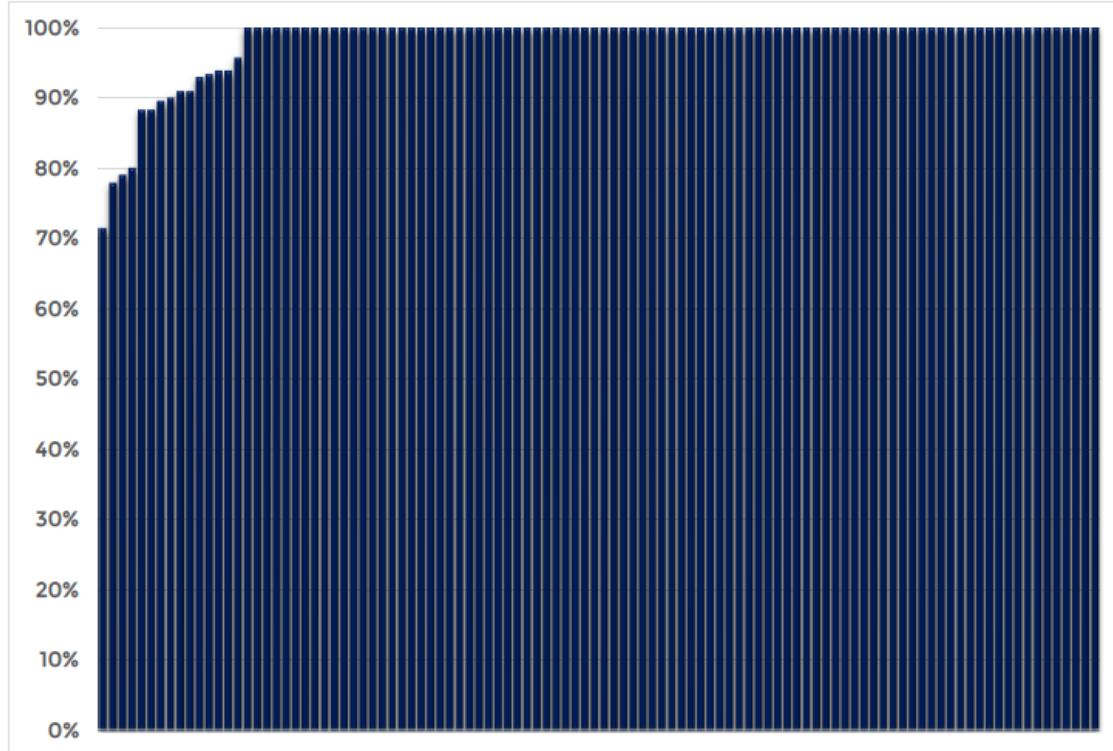


Figure 79: Accuracy of diagnosis by Health Board and Trust, Round 3, cohort 1.

Performance Indicator 9 – Sodium Valproate discussion

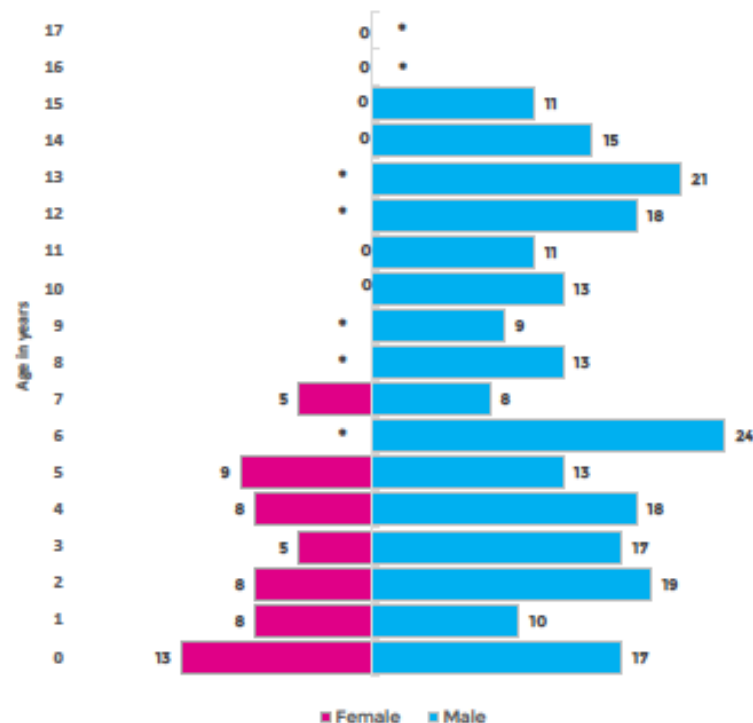


Figure 63: Number of children and young people diagnosed with epilepsy on sodium valproate by gender in England and Wales, Round 3 cohort 1.

Performance Indicator 10 – Comprehensive Care Planning agreement

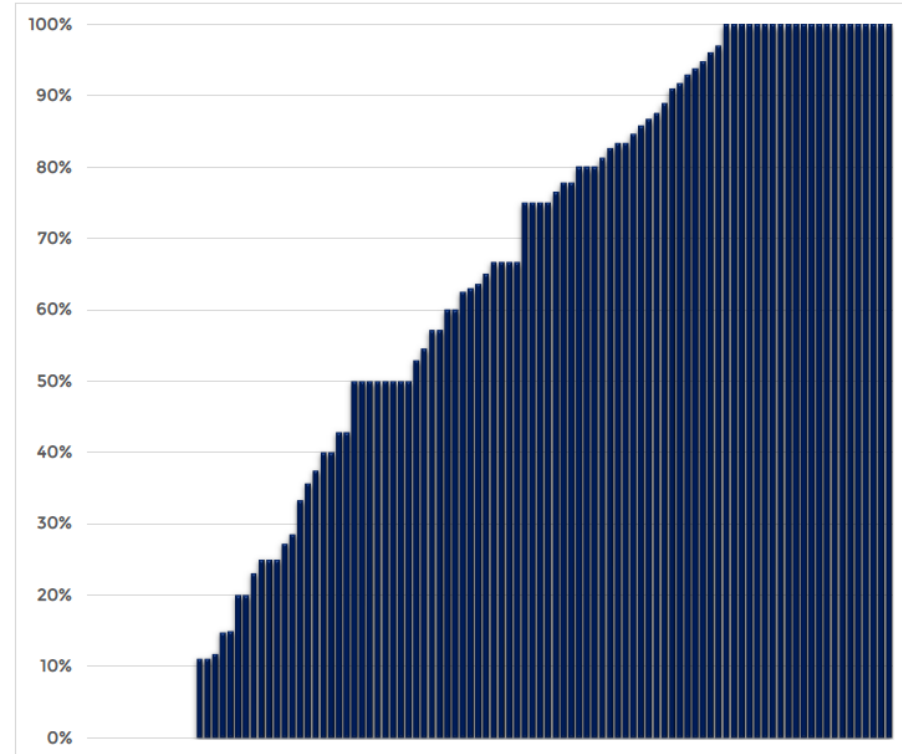
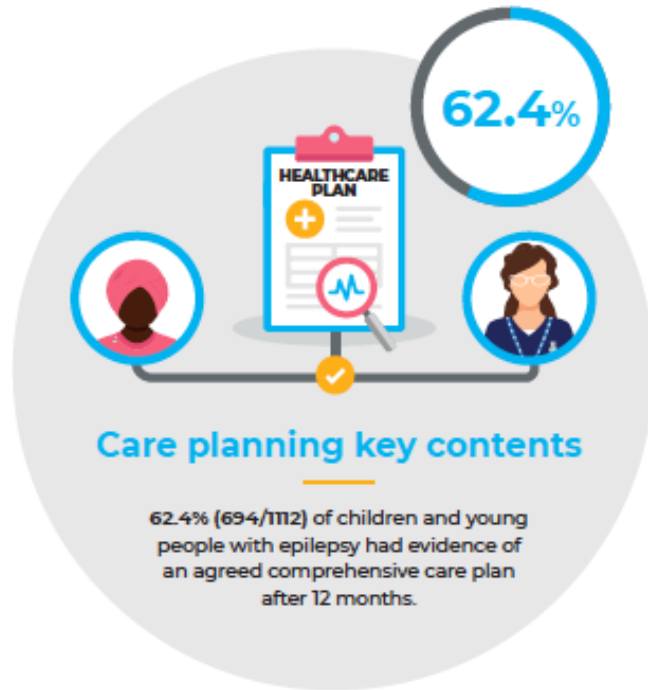


Figure 69: Comprehensive Care Planning agreement, Round 3

Performance Indicator 11 – Comprehensive Care Planning Content

| Audit Round | England and Wales |
|-------------|-------------------|
| Round 3 | 70.1% (779/1112) |

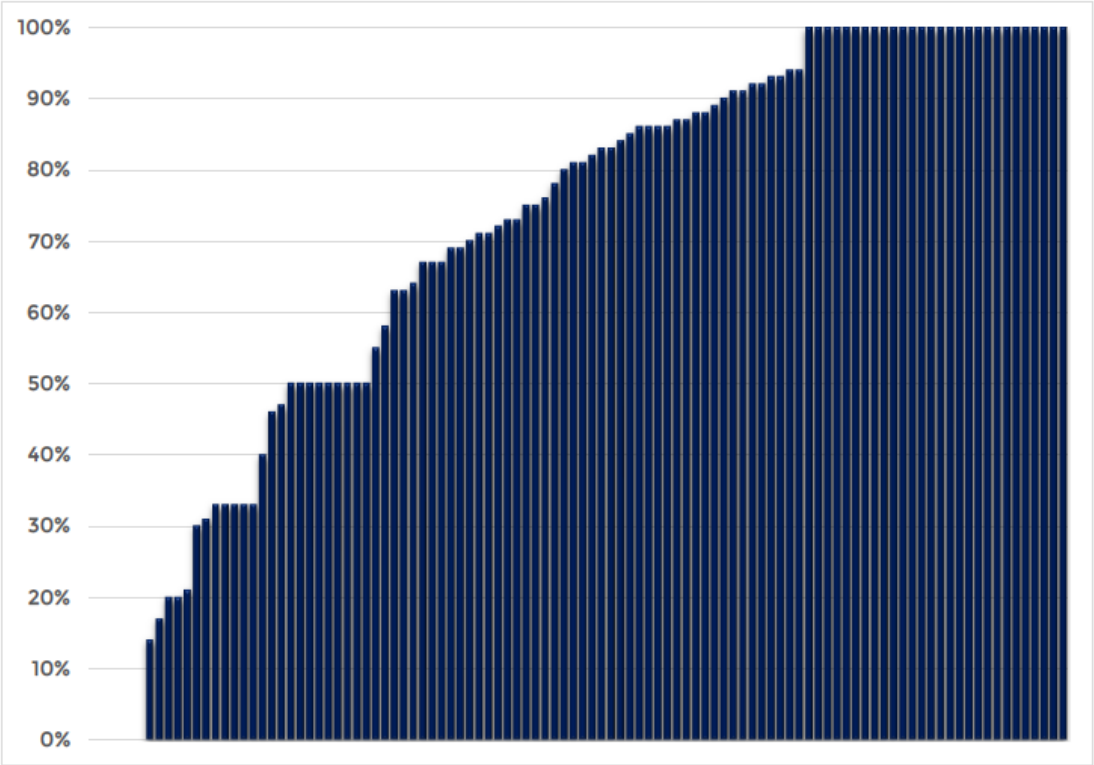


Figure 70: Comprehensive Care Planning content by Health Board and Trust, Round 3.

Performance Indicator 12 – School Individual Health Care Plan

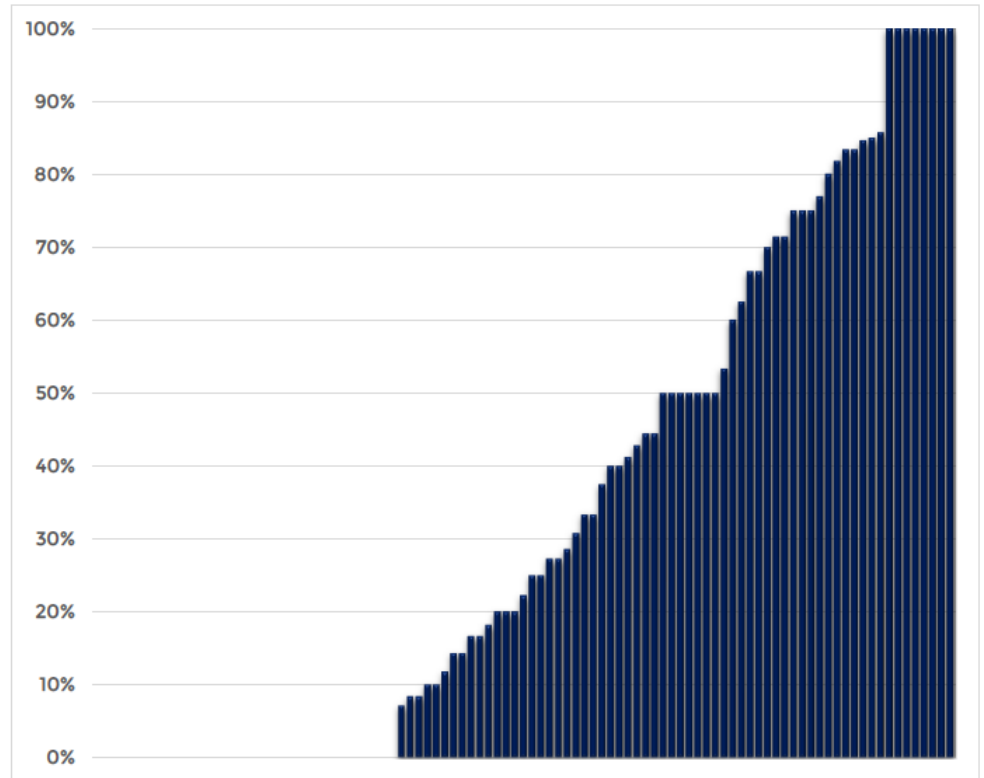
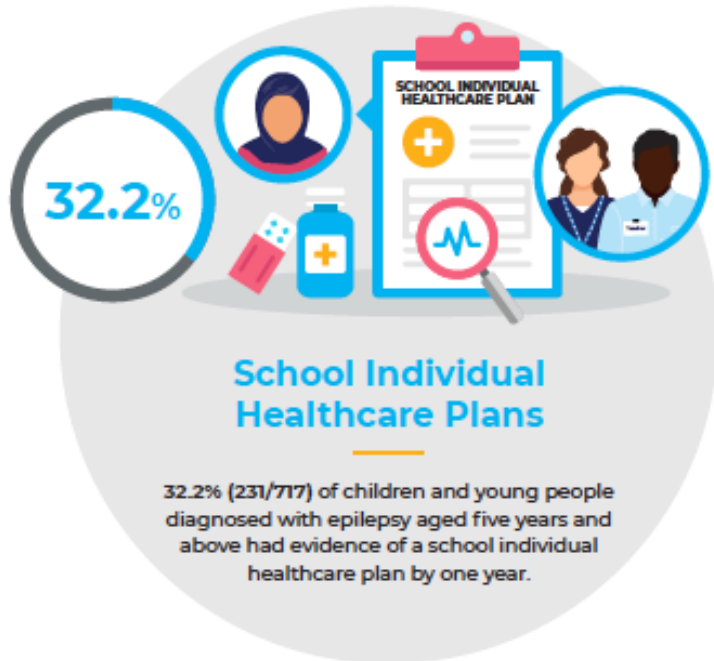


Figure 71: School Individual Healthcare Plan, by Health Board or Trust, Round 3, cohort 1

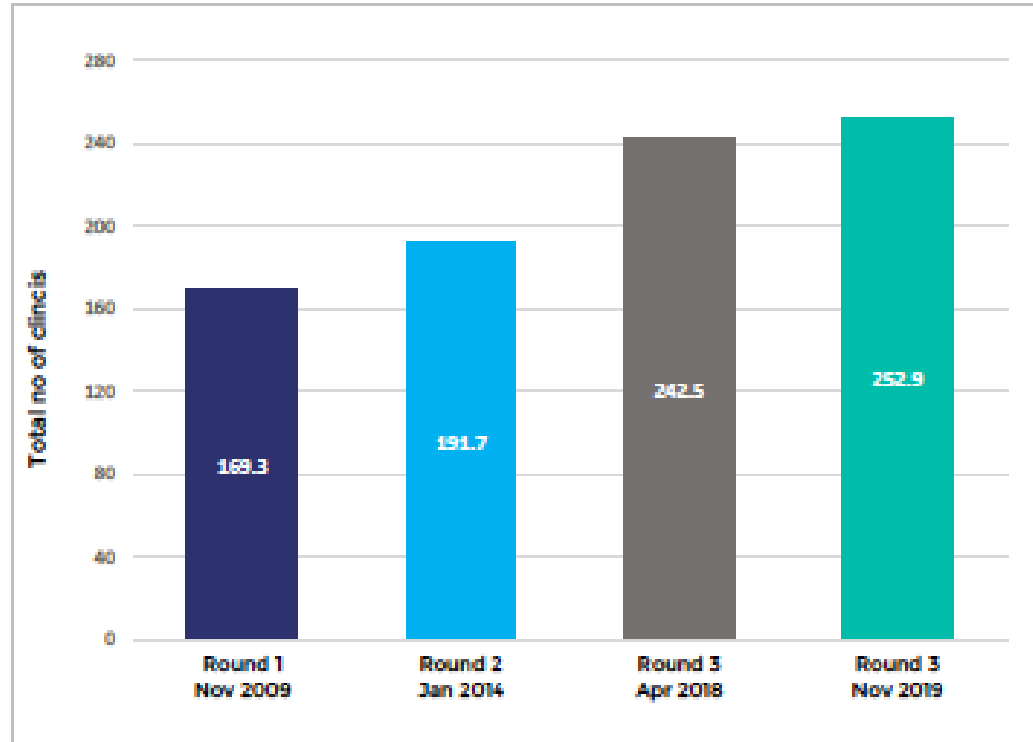
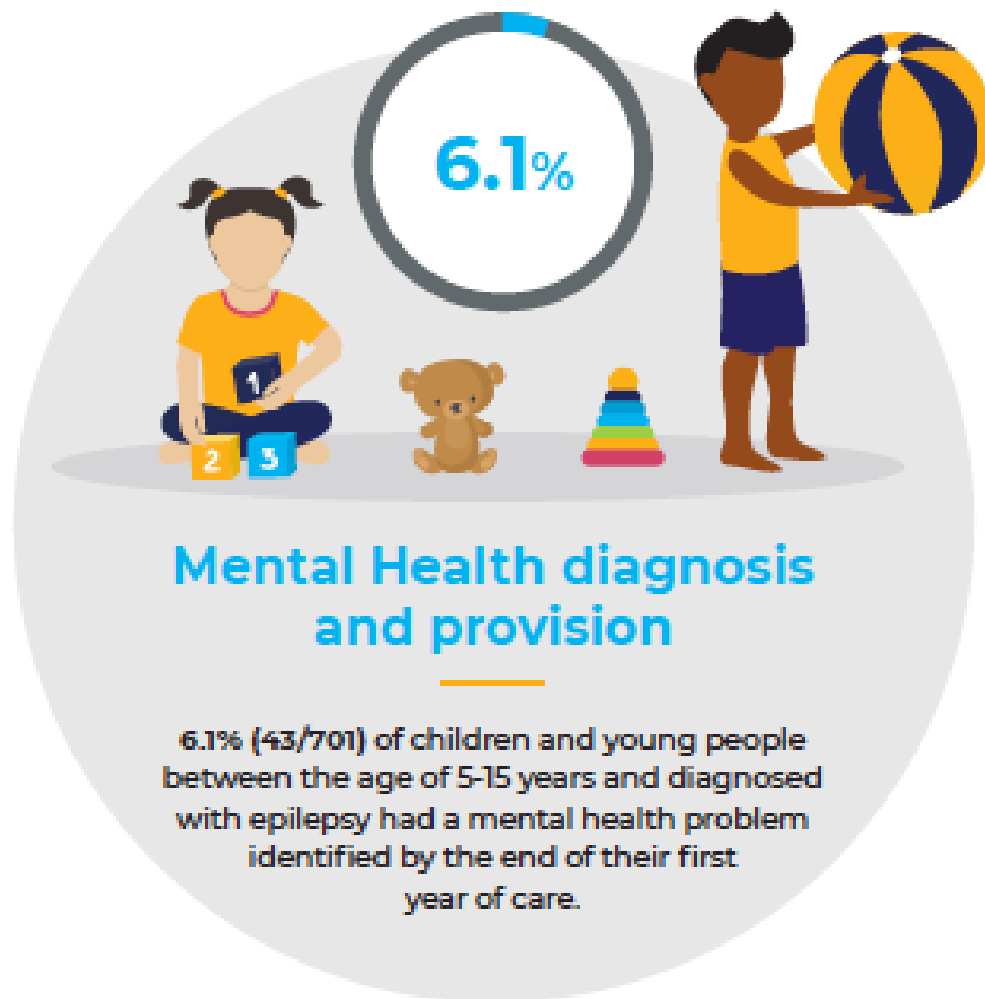
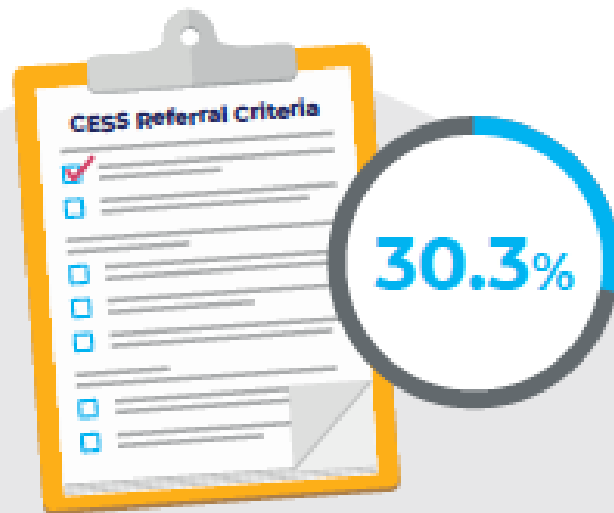


Figure 5: Total number of consultant or associate specialist led secondary level epilepsy clinics in Round 1, Round 2, Round 3 April 2018 and November 2019.





Children's Epilepsy Surgical Service (CESS)

30.3% (27/89) of the children and young people who met CESS referral criteria had CESS referral by one year.



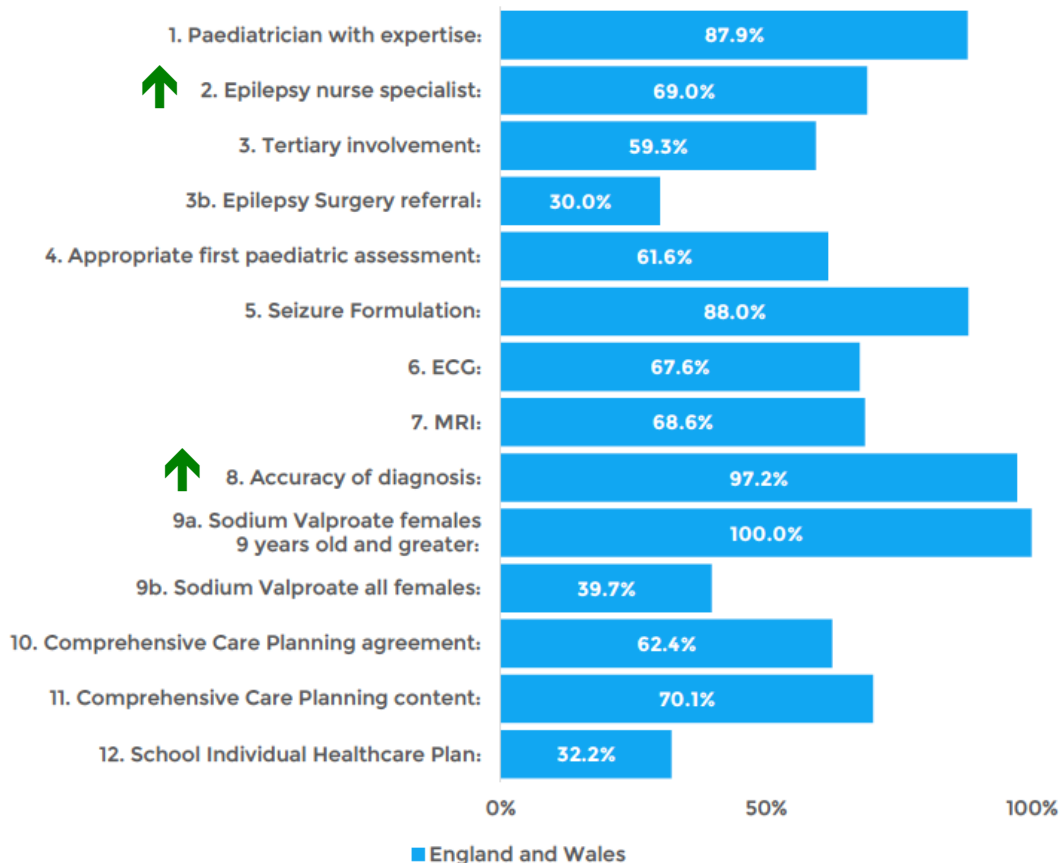
Providing specialist advice

47.7% (62/130) of Health boards/Trusts reported typical response times for specialist advice of 3 or more days.



All

Epilepsy12 Performance indicators in England and Wales, Round 3



Next steps...

Look at national report:

- What are relevant recommendations for you?

Look at your local reports:

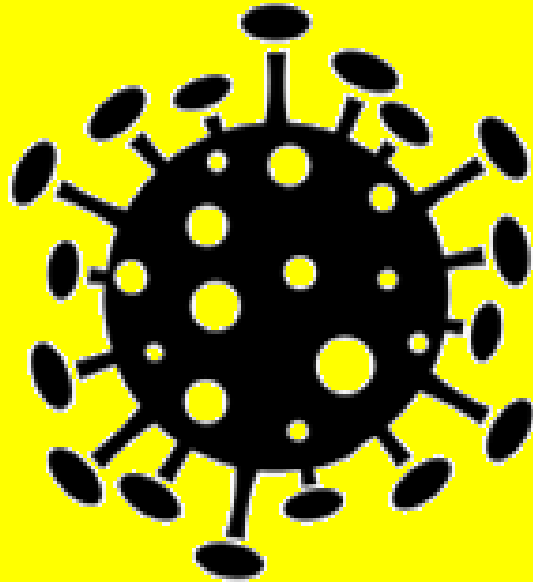
- Which vertical bar were you?
- Consider whether issues need a personal, local team, trust, regional or national response

• Agree some actions with your trust

Next steps...

- Nurture your local team and service
- Keep entering cohort 2 and 3
- Do the best you can!
- Share the work
- Engage with your regional network, EQIP and youth advocate work
- Contribute to our feedback survey

But what about COVID-19?





Learning from...

What a child says..

NHS

Sherwood Forest Hospitals
NHS Foundation Trust

...ABOUT CORONAVIRUS

What is Coronavirus?

It's very bad!

What can we do to get rid of coronavirus?

Attack it!
(doing punches with his fists in the air)

Who will you hug first?

Everyone!!



Where would you like to go first?

Alton Towers

If coronavirus was an animal what would it be?

A shark!

What clothing would protect you?

Football clothes!

How did the coronavirus start?

In a bad place

Causes for hope...

‘Contactability’ has been ‘shaken up’

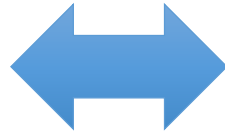
‘Co-location’ for transition, mental health,
multi-agency working may be easier to
achieve now!

A large, solid yellow circle is centered on a black background. Inside the circle, the text "is there light at the end of the tunnel?" is written in a bold, black, sans-serif font, split across two lines.

**“is there light
at the end of the tunnel?”**



Patient-Facing



**Electronic
Health
Records**



EPILEPSY12



Unsuitable
for motor

In the pipeline...


Usability changes

Live Performance Indicator display

Change in ascertainment targets: expected epilepsy incidence for a trust population



...find good tunnels!

A photograph of a dirt path winding through a dense forest. Sunlight filters through the green leaves of the trees, creating a dappled light effect on the path and foliage. The path leads into the distance, where a brighter area suggests an opening or a 'tunnel' of light.

keep **pedalling**
keep our **balance**
know we're **appreciated!**

light on the way
lighten the data
...find **good** tunnels!

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