

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

✧RCPCH Audits

EPILEPSY12

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



Epilepsy12

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

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

The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies.

www.hqip.org.uk/national-programmes

© 2022 Healthcare Quality Improvement Partnership (HQIP)

Published by RCPCH 2022.

The Royal College of Paediatrics and Child Health is a registered charity in England and Wales (1057744) and in Scotland (SCO38299).

Acknowledgements

The Epilepsy12 Project Board would like to thank the administrators, clinical audit department staff, data analysts, doctors, nurses and others within participating Health Boards and Trusts.

These teams have put time and effort into collecting information for the audit and working to improve paediatric epilepsy services in what have been incredibly challenging circumstances. We would like to give additional thanks to the Epilepsy12 designated clinical leads and EEG service leads in each Health Board or Trust, and the Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK) for their continued support.

Epilepsy12 Clinical lead

Dr Colin Dunkley, Consultant Paediatrician and Epilepsy12 Clinical Lead, Sherwood Forest Hospitals NHS Foundation Trust

Epilepsy12 Project Board members

Dr Sarah Aylett, Consultant Paediatric Neurologist, Chair of British Paediatric Epilepsy Group, British Paediatric Neurology Association (BPNA)

Prof Nicholas Bishop, Vice President for Science & Research, Royal College of Paediatrics and Child Health and Chair of the Epilepsy12 Project Board

Ann Brown, Clinical Nurse Specialist Paediatric Epilepsies, Royal College of Nursing

Dr Richard Brown, Consultant Paediatrician, Cambridge University Hospitals NHS Foundation Trust & Chair of the OPEN UK Working Group

Vivien Dunne, Project Manager, Healthcare Quality Improvement Partnership (HQIP)

Dr Katherine Martin, Consultant Paediatrician, British Academy of Childhood Disability (BACD)

Rosemarie Pardington, Director of Integrated Care, Young Epilepsy

Angie Pullen, Epilepsy Services Manager, Epilepsy Action

Mirek Skrypak, Associate Director for Quality and Development, Healthcare Quality Improvement Partnership (HQIP)

Epilepsy12 project team

Nicholas Bui, Epilepsy12 Data Analyst, Royal College of Paediatrics and Child Health

Fridah Calvin-Mwingirwa, Epilepsy12 Data Analyst, Royal College of Paediatrics and Child Health

Calvin Down, Head of Audits, Royal College of Paediatrics and Child Health

Simon Duncan, Audit Administrator, Royal College of Paediatrics and Child Health

Tom Keiller, Audit Administrator, Royal College of Paediatrics and Child Health

Niky Raja, Epilepsy12 Co-ordinator, Royal College of Paediatrics and Child Health

Helen Stacey, Epilepsy12 Manager, Royal College of Paediatrics and Child Health

Epilepsy12 Methodology and Dataset Group members

Dr Sophie Bennett, Clinical Psychologist, Great Ormond Street Hospital (GOSH)

Dr Richard Brown, Consultant Paediatrician, Cambridge University Hospitals NHS Foundation Trust & Chair of the OPEN UK Working Group

Jill Conium, Children's Epilepsy Specialist Nurse, East and North Hertfordshire NHS Trust

Dr Trupti Dhorajiwala, Consultant Paediatrician, Tameside and Glossop Integrated Care NHS Foundation Trust

Diane Flower, Lead Children's Epilepsy Specialist Nurse, University Hospitals Bristol NHS Foundation Trust

Robert Grant, Chartered Statistician at BayesCamp & statistical advisor to Epilepsy12

Dr Ramesh Kumar, Consultant Paediatrician, South Tees Hospitals NHS Foundation Trust

Dr Jeya Natarajan, Consultant Paediatrician, Cym Taf Morgannwg University Health Board

Millie Power, Patient & Nurse representative

Dr Colin Reilly, Educational Psychologist

Dr Robert Robinson, Consultant Paediatric Neurologist, GOSH

Dr Sara L. Shavel-Jessop, Clinical Paediatric Neuropsychologist, GOSH

Lisa Thurston, Parent and Young Epilepsy Representative

Special thanks

Melanie David-Feveck, EQIP Project Manager, Royal College of Paediatrics and Child Health

Emma Hosking, Engagement & Participation Youth Worker, Royal College of Paediatrics and Child Health

Emma Sparrow, Head of Children, Young People & Engagement, Royal College of Paediatrics and Child Health

Epilepsy12 Youth Advocates

EQIP Faculty & Advisory groups

Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK) Working Group



Contents

Foreword	8
Executive summary	9
1. Introduction	13
Clinical audit of 'cohort 3'	14
Organisational audit of November 2021	14
Quality improvement	15
2. Key findings and recommendations	16
Epilepsy12 Performance Indicators	17
Rescue medication usage variation	21
Sodium valproate in girls and young women	23
Care planning	25
Waiting times	28
Mental health and psychological support	31
Transition to adult services	34
Tertiary care and surgery	37
3. Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK)	39
OPEN UK Working Group 2021-22	39
OPEN UK and Epilepsy12 user survey	40
4. Epilepsy12 Youth Advocates improvement activities	42
5. Epilepsy Quality Improvement Programme (EQIP) 2021-22	45
Lessons learnt	50
6. Quality improvement in University Hospitals of Derby & Burton NHS Trust (UHDB)	52
One stop Epilepsy-EEG service for Children's Epilepsy Clinics	53
Epilepsy service review at Royal Derby Hospital	54
Improving patient information about the epilepsy service	55

The full audit results and additional information are listed below.

These appendices are available to download from rcpch.ac.uk/epilepsy12.

Appendix A: Epilepsy12 Round 3, 2021 Organisational audit

Full results:

- Participation
- Workforce
- Clinic configuration
- Tertiary provision
- Investigations
- Service contact
- Transition
- Mental health
- Neurodevelopmental support
- Care planning
- Patient database or registry
- Findings by OPEN UK regional networks

Appendix B: Epilepsy12 Round 3, Cohort 3 Clinical audit

Full results:

- Participation and case ascertainment
- Description of cohort
- Diagnostic status
- Initial referral and examination
- Description of episodes
- Convulsive seizures
- Neurodisability or neurodevelopmental problems
- Mental health conditions
- Investigations
- Treatment
- Care planning
- Professionals and services involved in care
- Overview of performance indicators

Appendix C

- Glossary of terms and abbreviations
- Useful resources

Foreword

Hi from the Epilepsy12 Youth Advocates!

We have been working on the audit for the last 3 years and were really pleased to see the positive changes that the audit has made to epilepsy care over the years.

One thing we are really proud of is the difference over the years in being able to see an epilepsy specialist nurse. Having access to their support really can change your life and make such a big difference to how we feel as young people with epilepsy. It's now really important that we get this figure up as high as possible in paediatrics, but that we make sure that there is always an Epilepsy Specialist Nurse waiting for you in adult services so that you have their support as you go forward as a young adult.

We think there is still more to do when it comes to support for worries and anxieties linked to your epilepsy, including mental health support, as well as with school care plans. We were all quite surprised to see that the numbers of children and young people getting support with their mental health in their first year is so low – this could be we think because their epilepsy is the first focus, or that it takes longer now to be referred due the pandemic.

We would like there to be more of a focus on emotional wellbeing from the start when you have your first seizure, with questions on the audit helping people to keep track of the best way to provide this help like through a youth worker, a specialist play worker or other early help services.

When it comes to school individual healthcare plans, we really want to make sure that this figure keeps getting higher each year but in much bigger steps. Only 36% of children and young people in their first year had a school care plan recorded by their epilepsy team.

In your first year of having epilepsy you could be feeling scared, worried, unsure and really want to have all the people around you, including in school, feeling confident that they have the right information to be able to support you, so that you and your family feel reassured. We need to do more work to support schools, doctors, patients and families so that the school care plan is in place – there is still a long way to go.

We've loved our time working with the Epilepsy12 Audit and hope that you enjoy reading our update in our chapter! Thanks for all you are doing with patients and their families to improve their lives and epilepsy experiences.

The Epilepsy12 Youth Advocates



Executive summary

Epilepsy12 is the national clinical audit of seizures and epilepsies in children and young people for England and Wales.

The audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and includes NHS services in England and Wales.

This report focuses on 'cohort 3': children and young people who had a first paediatric assessment for a suspected seizure between 1 December 2019 and 30 November 2020. The audit then follows the patients for 12 months of subsequent care. There are 12 'Performance Indicator' measures for the audit which are derived from national guidelines and recommendations; results from the last three cohorts are shown below.

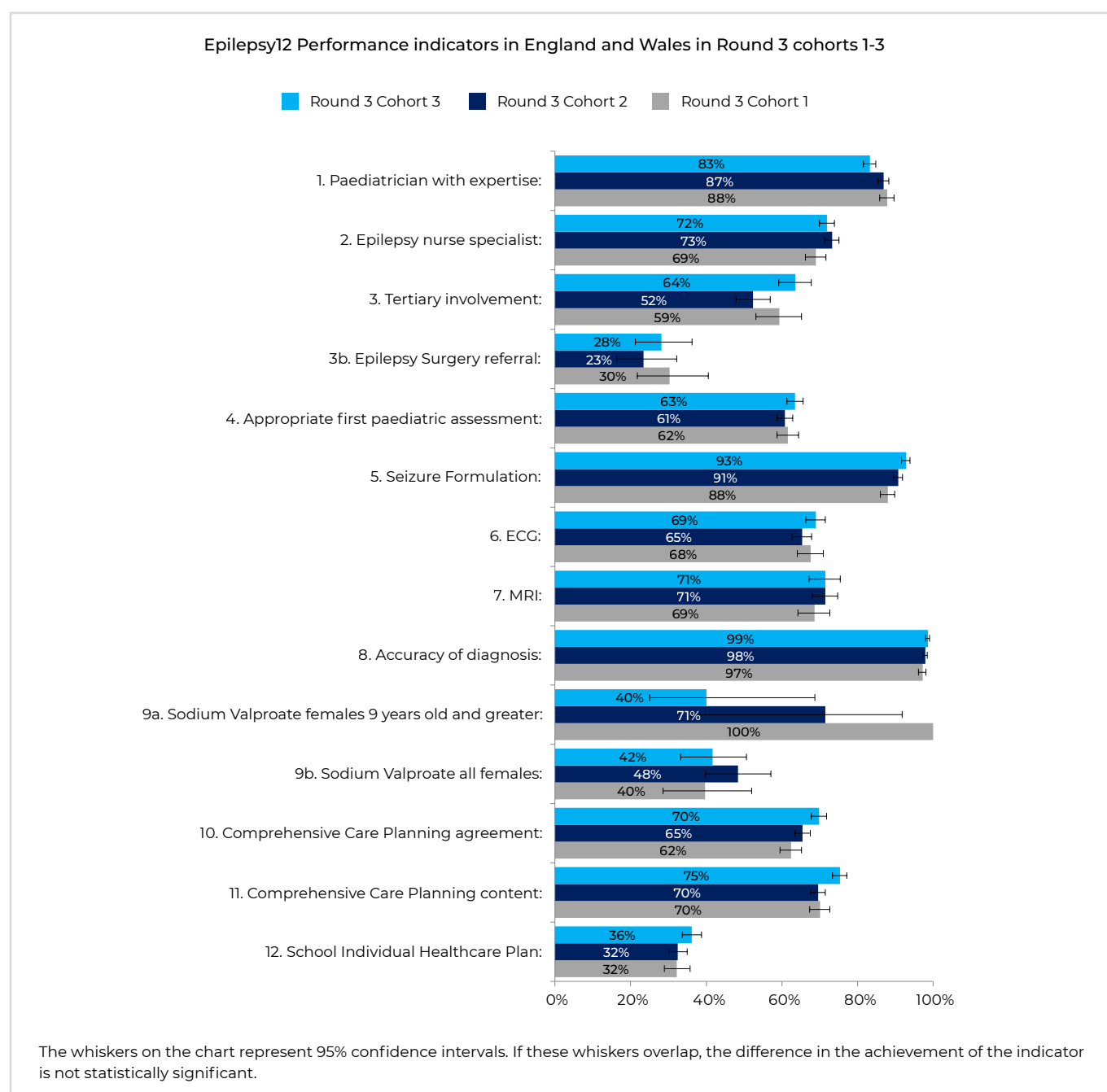
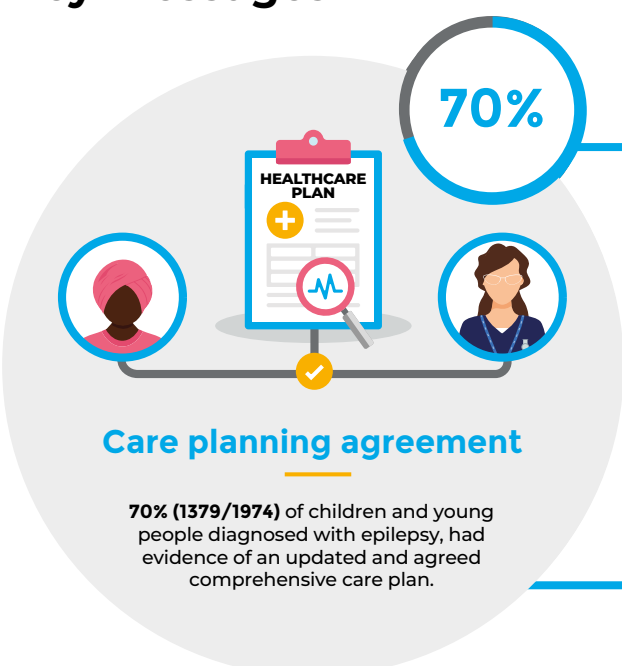


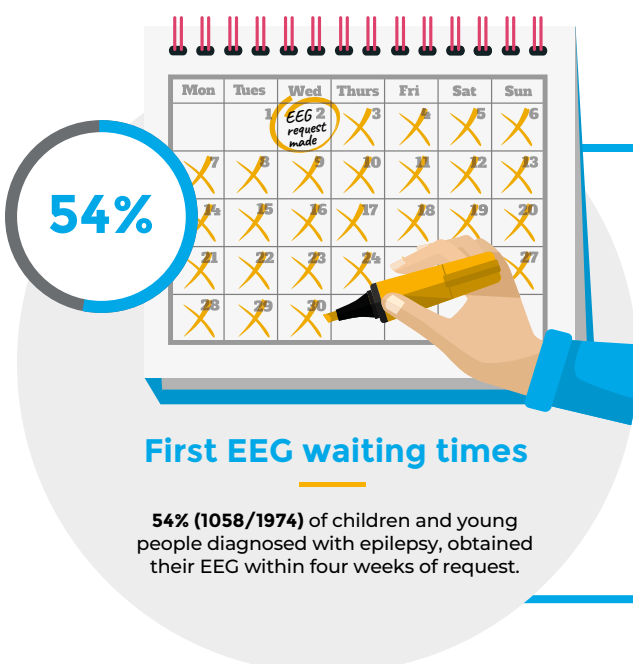
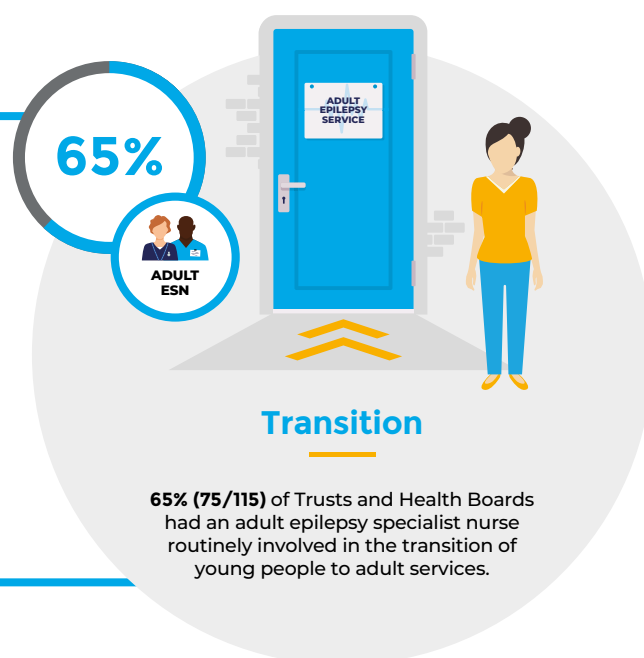
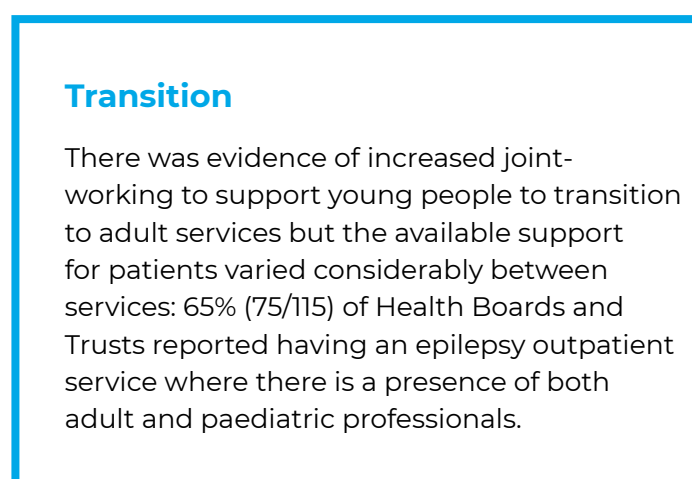
Figure 1: Epilepsy12 Performance indicators in England and Wales in Round 3 cohorts 1-3.

Key messages



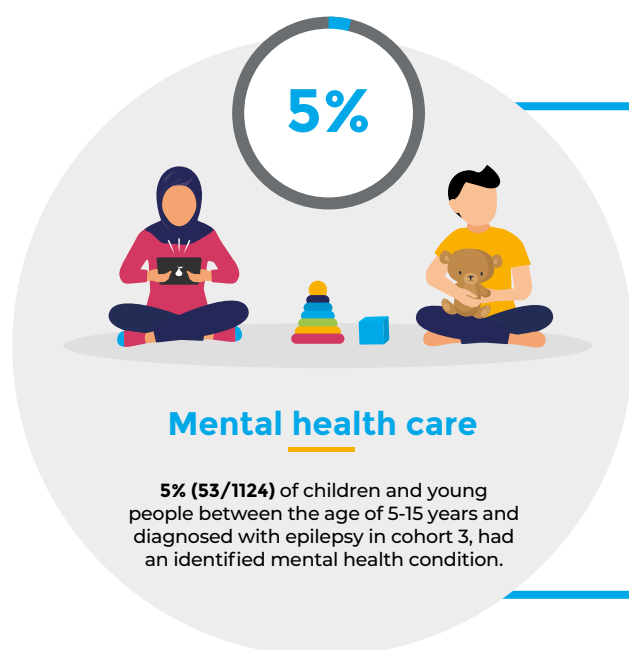
Care planning

There was evidence of wide-spread use of comprehensive, individual care planning for children with epilepsy. Most care plans were agreed and updated. The proportion of plans which contained all the required elements also increased to 75% (1487/1974) in cohort 3.



First EEG waiting times

There was an increase in children and young people waiting more than 16 weeks for an initial Electro-encephalogram (EEG) in cohort 3 (10%, 191/1974). NICE Quality Standard 27 (statement 2) states that children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of being requested.

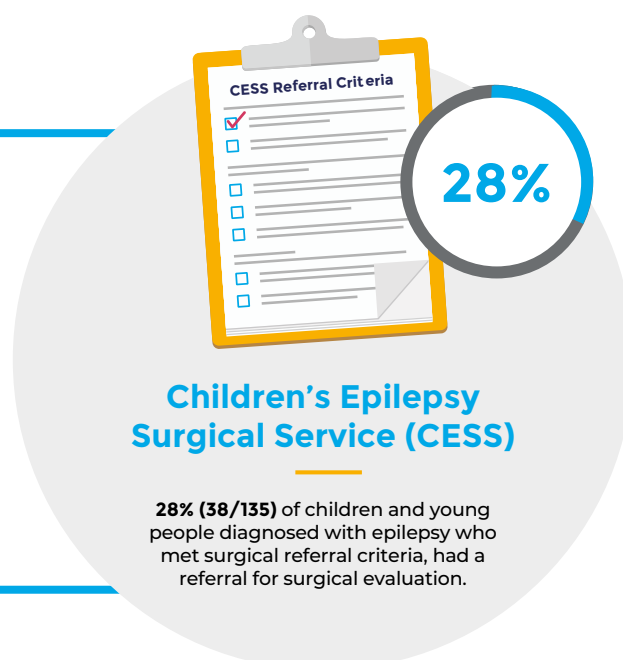


Mental health care

Research suggests there is a higher incidence of mental health problems among children and young people with long term conditions, but very few of the epilepsy patients had an identified mental health condition (5%, 53/1124). Few epilepsy services could provide co-located mental health provision as recommended within the Best Practice Criteria (18%, 12/115).

Children's Epilepsy Surgical Service (CESS)

Some children and young people with epilepsy may be missing out on, or having delayed referral to, epilepsy surgery assessments. 28% (38/135) of children and young people diagnosed with epilepsy who met surgical referral criteria had a referral for surgical evaluation during their first year of care.



Recommendations for improvement



EEG and epilepsy services continued to submit their data to Epilepsy12 despite significant challenges of the pandemic. We want to recognise the dedication to children with epilepsy that this shows.

The recommendations made in the report focus on areas for improvement, however the overall consistency of the results with those from pre-pandemic cohorts is a testament to how hard teams and individuals have worked to maintain services and care.

There were four new recommendations made:



1

Recommendation 1

Epilepsy clinical teams, OPEN UK, the Welsh Government and the NHS England Regional teams should review the Epilepsy 12 data, and the criteria and implementation of, prescription of rescue medications for prolonged convulsive seizures in children and young people.

2

Recommendation 2

All females of child-bearing potential prescribed Sodium Valproate should have ongoing documentation regarding their status within the valproate Prevent Programme.

3

Recommendation 3

OPEN UK regions, and Health Boards and Trusts should ensure there is a process in place to ensure discussion of Sudden Unexpected Death in Epilepsy (SUDEP), and care planning for risks and participation, is achieved for children and young people with epilepsy.

4

Recommendation 4

All Health Board and Trusts, OPEN UK, and ICSs should review the waiting times for standard EEG in their services; ensuring sufficient capacity and pathways in place to achieve EEG within four weeks of referral.

Several of the previous recommendations made by Epilepsy12 remain relevant and require improved implementation. These recommendations are highlighted by theme in our '**Key findings and recommendations**' section. This section also includes a summary of the audit evidence underpinning both the new and repeated recommendations; full results are found in appendices A and B.

Further **sections** of the report include different quality improvement activities taking place within the audit, by children and young people, and within NHS epilepsy services.

1. Introduction

Epilepsy12 was established in 2009 and has the continued aim of helping epilepsy services, and those who commission health services, to measure and improve the quality of care for children and young people with seizures and epilepsies.

The audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and is delivered by the Royal College of Paediatrics and Child Health (RCPCH).

Epilepsy is the most common significant long-term neurological condition of childhood and affects an estimated 112,000 children and young people in the UK. Epilepsy12 seeks to help improve the standard of care for children and young people with epilepsies.

To do this, the audit collects and processes patient data. This information is used by the audit to highlight areas where services are doing well, and also identify areas in which they need to improve.

In 2022, a further contract was awarded to the RCPCH to deliver the audit up to 31 March 2025.

All current and previous publications from Epilepsy12 are available at www.rcpch.ac.uk/epilepsy12

There are three main elements to Epilepsy12 which are included in this report:

- 1.** A clinical audit of children and young people newly diagnosed with epilepsy in the 'cohort 3' patient group.
- 2.** An organisational audit of epilepsy services as at November 2021.
- 3.** Quality improvement activities and projects related to the audit.

The measures and analysis used in Epilepsy12 audits are directed by our Epilepsy12 Methodology and Dataset Group, which brings together a range of clinical, patient and parent, and statistical experts. The measures were developed to align to national standards and guidelines, including:

- Epilepsies: diagnosis and management (2012) NICE guideline CG137.
- Epilepsy in children and young people (2013) NICE Quality Standard 27.

Full details of the Epilepsy12 Round 3 datasets can be viewed on the [Epilepsy12 website](http://www.rcpch.ac.uk/epilepsy12)

Clinical audit of 'cohort 3'

The clinical audit focuses on care provided to patients with a new diagnosis of epilepsy. Clinical audit data entry is prospective, with eligible patients grouped into cohorts based on when they are first assessed by the paediatric service. During 2020 and 2021 the guidance from NHS England was that clinical services should protect and prioritise their clinical activity, and services could pause other activities (including the mandatory submission of audit data) when necessary. The pandemic has, by necessity, limited the audit data available.

This report focuses on 'cohort 3' which is the third group of patients in Round 3 of Epilepsy12. Cohort 3 includes children and young people who had a first paediatric assessment for a 'paroxysmal episode' (or episodes) between 1 December 2019 and 30 November 2020. Paroxysmal episodes are any epileptic seizures, non-epileptic seizures, or seizures of uncertain origin.

Epilepsy12 follows patients for twelve months of care following their first assessment; we refer to this as the 'first year of care'. Depending on when they had entered the audit, children and young people in cohort 3 completed their first year of care between 1 December 2020 and 30 November 2021.

There were 147 registered Health Boards and Trusts for cohort 3 of Epilepsy12. The number of participating Health Boards and Trusts has changed over time due to changes in the configuration of the Health Boards and Trusts. Of these, 105 Health Boards and Trusts were able to submit a full first year of care clinical record for one or more children and young people in cohort 3. First year of care records were submitted for 5501 children and young people in cohort 3.

Organisational audit – November 2021

The Epilepsy12 audit of the organisation of paediatric epilepsy services in England and Wales focuses on services and workforce at Trust and Health Board level, describing a designated point in time. This report presents organisational data describing the services as they were in November 2021. At this time the NHS was dealing with a significant surge in COVID-19 cases and hospitalisations in both England and Wales.

115 Health Boards and Trusts were able to submit and lock their November 2021 organisational audit data for inclusion in this report. The data were provided to Epilepsy12 between November 2021 and February 2022.

Quality improvement

The audit supports quality improvement activities in a number of different ways:

Local: Supporting planning & quality improvement



- The **Epilepsy Quality Improvement Programme (EQIP)** 17 NHS Trusts joined 2 waves of 2021/22 EQIP. The teams implemented improvement projects in their Trust or ICS services.
- The Epilepsy12/OPEN UK **annual stakeholder meeting** brought together epilepsy teams to sharing learning and case studies on different improvement themes.
- Each Trust/Health Board receives local results with regional and national bench-marks. Results are used to develop local strategy, provide an evidence base for improvement projects, and to highlight successes and identify ongoing needs.
- The Epilepsy12 Youth Advocates published a **self-assessment tool** developed with services to improve support for patients' worries and anxieties.

Public: Involving patients & supporting the public



- Children and young people are actively involved: their views influence the areas included the audit, and improvement activities led by the 'Youth Advocates' (epilepsy experienced children, young people, families and two epilepsy specialist nurses).
- A set of '**clinic posters**' were developed which are a one-page, easy to access information of Health Board or Trust Epilepsy12 results. These have been designed to be displayed in clinics or shared digitally with patients/families.
- Publication of a **Patient and Parent/Carer guide** to the 2021 Epilepsy12 Annual Report.

National: Policy development & system management



- Epilepsy12 national reports set out recommendations developed in conjunction with system stakeholders.
- NHS England Epilepsy Oversight Group will use evidence from the audit to support policy and improvements in their 4 priority areas of epilepsy care.
- Epilepsy12 evidence was submitted to NICE as part of the consultation exercise for the update of epilepsy clinical guidelines.
- An Epilepsy12 pilot project is working to improve interoperability between the audit and NHS systems, improving data collection, reporting & use of this intelligence.
- Epilepsy12 host the OPEN UK Working Group, and sits on the RCPCH Epilepsy National Programme Board, bringing stakeholders together to support improvement in epilepsy care.

2. Key findings and recommendations

In previous rounds of Epilepsy12 there has been considerable variation in the ability of different Health Boards and Trusts in England and Wales to provide adequate workforce time and resources to participate in this national audit.

This has become even more challenging for services to manage since 2020 due to the impact of the COVID-19 pandemic on the NHS.

EEG and epilepsy services have continued to submit their data to Epilepsy12 despite significant clinical demands, staff redeployment, and sickness absences. We want to recognise the dedication to children with epilepsy that this shows.

The recommendations in this section focus on areas for improvement, however the overall consistency of the results with those from pre-pandemic cohorts is a testament to how hard teams and individuals have worked to maintain services and care.

Health Boards and Trusts can use audit data for benchmarking practices to identify areas to focus on in service improvements, share best practice and improve care outcomes. It is essential that Health Board and Trust managers support and resource their paediatric epilepsy services to improve data completeness, ensuring an accurate reflection of their standards of care.

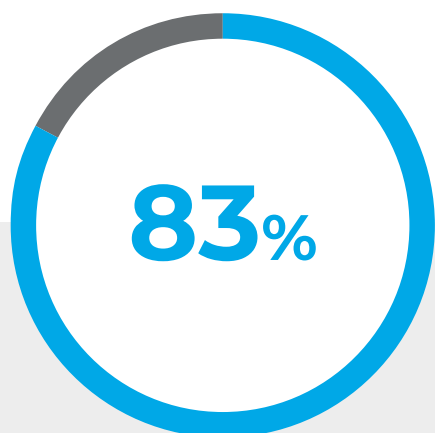
The full audit results highlight several areas of strength, including that children and young people continued to access appropriate investigations for their epilepsy. During their first year of care 98% (1931/1974) of children with epilepsy received an EEG and an MRI was achieved for 71% (328/459) of the patients meeting the defined indications for this measure.

The proportion of patients with a comprehensive care plan also improved: 75% (1458/1918) had a plan which included every core element of content. Elements of the content, such as prolonged seizure plans, discussion of first aid, and service contact details, were provided very consistently. These were recorded for 92% (406/439), 87% (1723/1974), and 93% (1827/1974) of patients respectively.

The full results from the clinical and organisational data are available in appendices A and B. This includes the results of analysis for each Epilepsy12 audit measure, and analysis by country and regional epilepsy network areas. Trust and Health Board level results are also provided on our website, as data tables for both clinical and organisational audits.

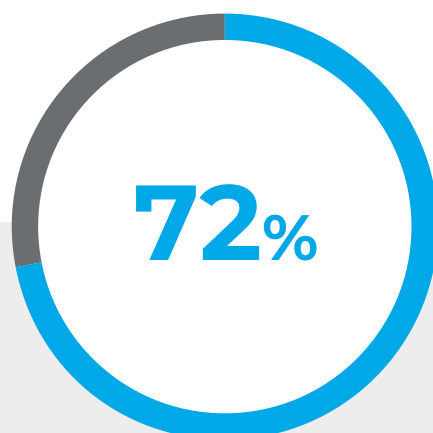
Epilepsy12 Performance Indicators

Within the clinical audit, there are 12 'Performance Indicator' measures which are derived from national guidelines and recommendations.



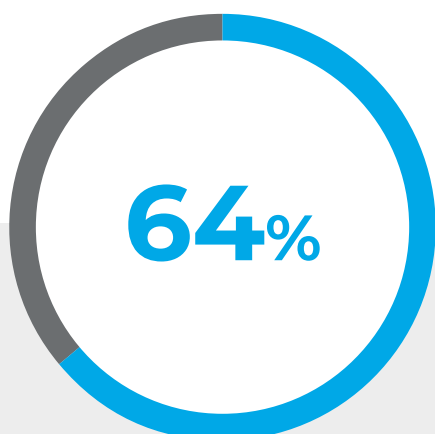
1. Paediatrician with expertise in epilepsies

In Round 3, cohort 3, **83%** (1643/1974) of children and young people diagnosed with epilepsy, had input from a paediatrician with expertise in epilepsies in their first year of care. This was slightly lower than the previous two cohorts.



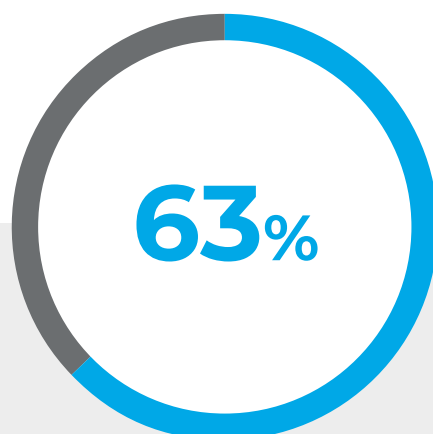
2. Epilepsy specialist nurse (ESNs)

72% (1420/1974) of children and young people diagnosed with epilepsy, had input from an ESN in their first year of care. After increases in previous rounds and cohorts, ESN input remained stable between cohort 2 and 3.



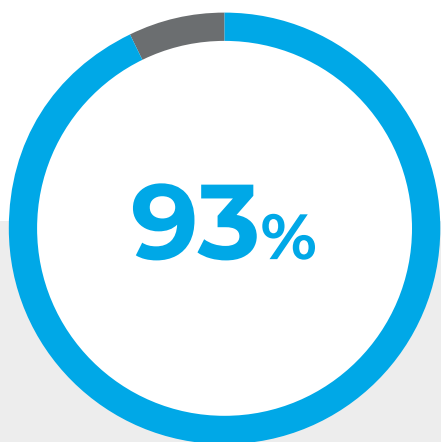
3. Tertiary services

64%, (305/480) of patients meeting the criteria received tertiary input into their epilepsy care; an increase compared to the previous cohorts. However, few of the patients (**28%**, 38/135) that met the surgery criteria were referred to the epilepsy surgery service for assessment within the first year of care.



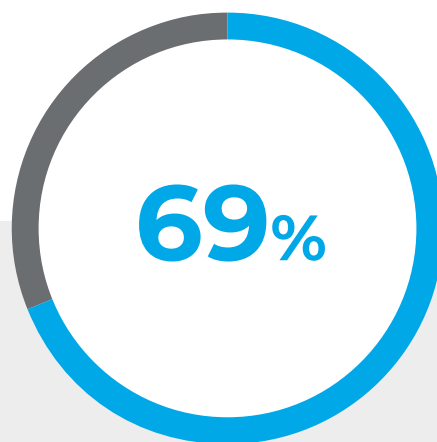
4. First paediatric assessment

Similar to the previous cohorts, **63%** (1253/1974) of children and young people diagnosed with epilepsy had all the key elements of the first paediatric assessment completed.



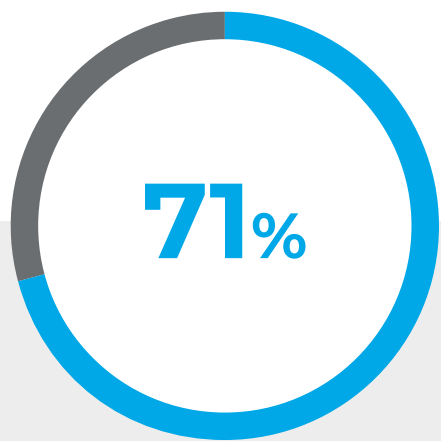
5. Seizure formulation

This was consistently achieved with **93%** (1780/1974) of children and young people diagnosed with epilepsy for whom an International League Against Epilepsy (ILAE) seizure classification was recorded in their first year of care.



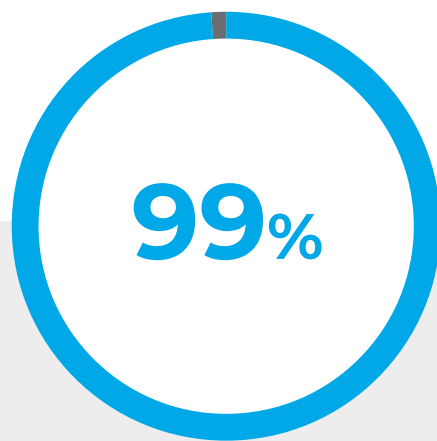
6. Electrocardiogram (ECG)

The proportion of children and young people with epilepsy and convulsive seizures that obtained a 12 lead ECG was **69%** (840/1218); which was consistent with pre-pandemic rates in cohort 1 (68%, 474/701).



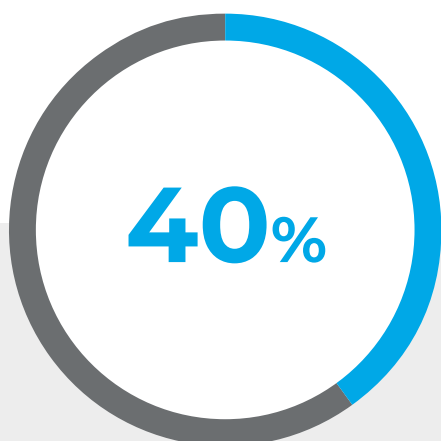
7. Magnetic resonance imaging (MRI)

The proportion of children and young people diagnosed with epilepsy who had an MRI, remained stable across all three cohorts. In Cohort 3, MRI was achieved for **71%** (328/459) of the patients meeting the defined indications for an MRI.



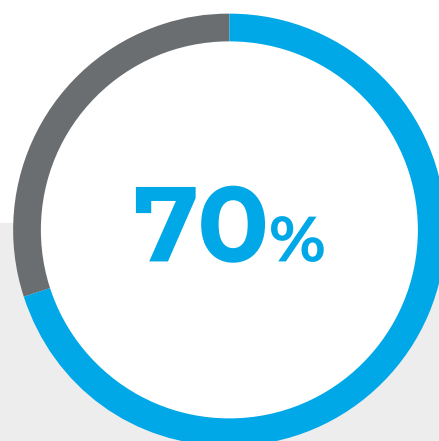
8. Accuracy of diagnosis

In Round 3, cohort 3, **99%** (1953/1980) of children and young people initially diagnosed with epilepsy retained the diagnosis at one year of care. This proportion has been increasing in every audit round.



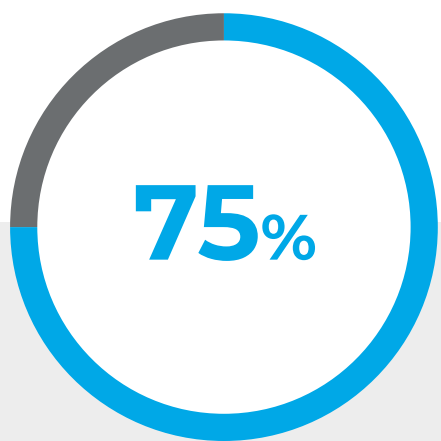
9. Sodium valproate

Few girls and young women were prescribed sodium valproate compared to boys. Although a very small number were aged over nine, of these **40%** had a record of discussion of the associated risks during pregnancy and it is important this is achieved consistently.



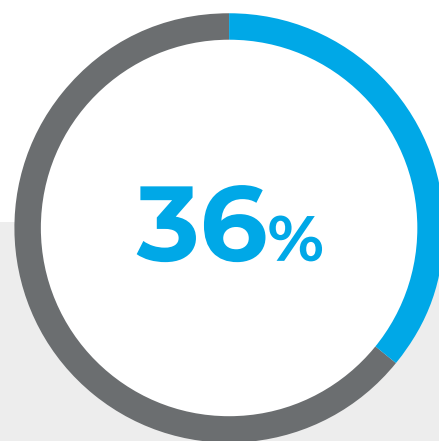
10. Care planning agreement

70% (1379/1974) of children and young people diagnosed with epilepsy, had evidence of a comprehensive care plan that had been agreed between the patient, their family and care providers, and was updated where necessary.



11. Comprehensive care planning

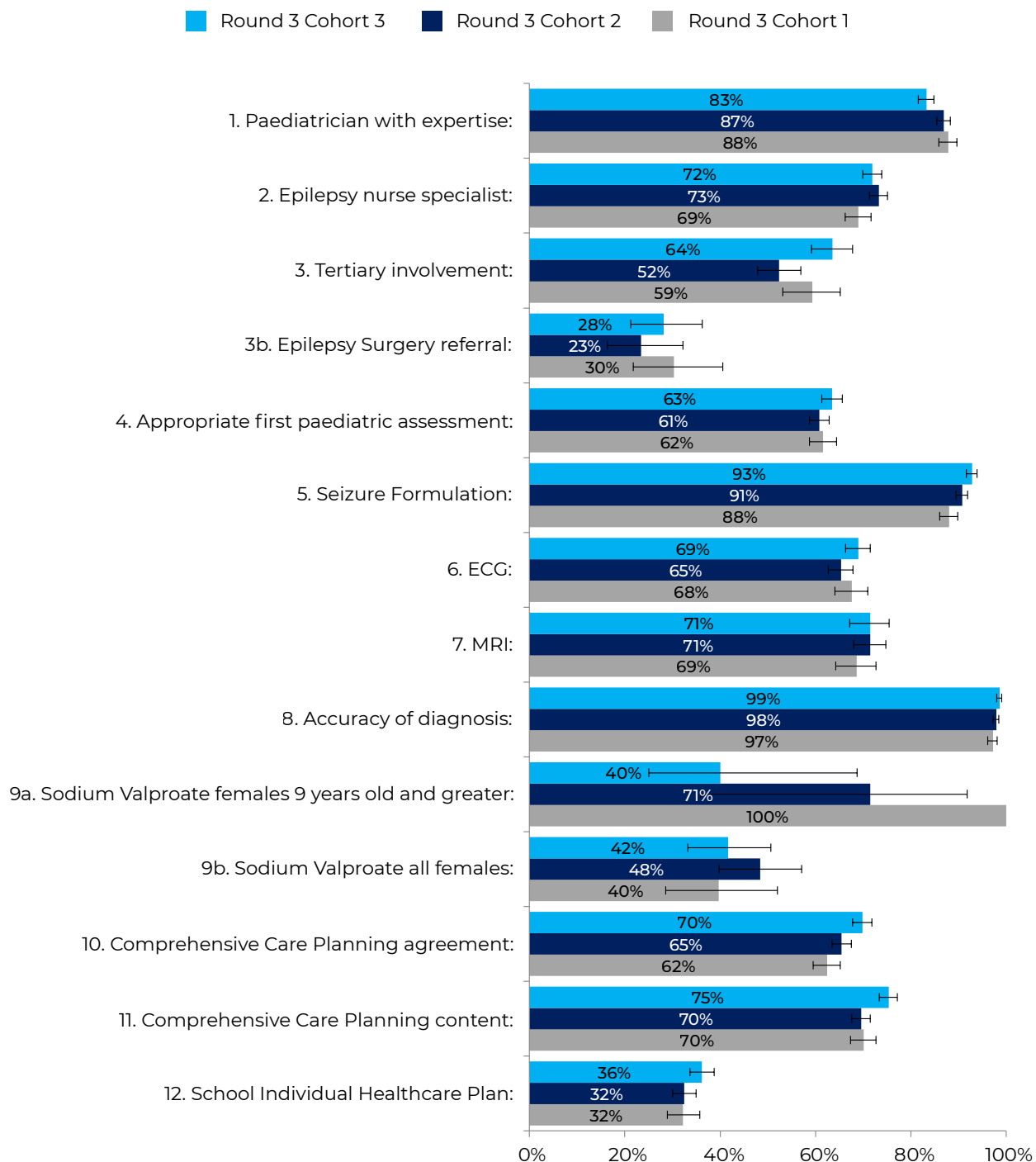
There was an increase in patients receiving all core elements of care planning; **75%** (1458/1918) of children and young people had evidence of all elements completed, compared to 70% in cohorts 1 and 2.



12. A school individual healthcare plan

For **36%** (499/1381) of children and young people diagnosed with epilepsy (aged five years and above), their epilepsy service had evidence of a school individual healthcare plan being in place.

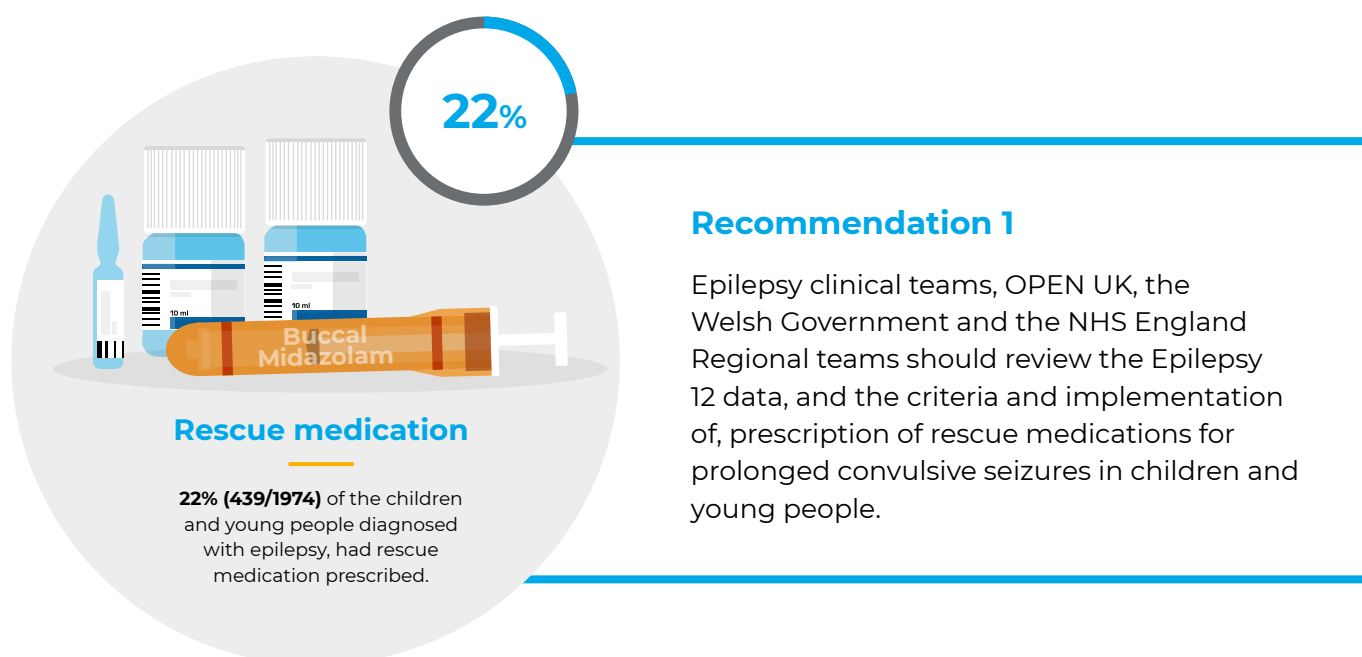
Epilepsy12 Performance indicators in England and Wales in Round 3 cohorts 1-3



The whiskers on the chart represent 95% confidence intervals. If these whiskers overlap, the difference in the achievement of the indicator is not statistically significant.

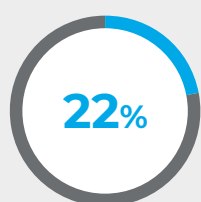
Figure 2: Epilepsy12 Performance indicators in England and Wales in Round 3 cohorts 1-3.

Rescue medication usage variation



Key findings

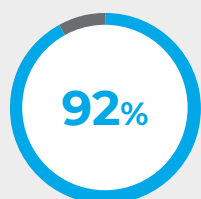
The proportion of patients prescribed rescue medication to help manage their epilepsy was relatively consistent across cohorts 1 to 3, at around a fifth of children and young people with epilepsy. However, there is considerable regional and local variation in the provision of rescue medication, which requires further consideration.



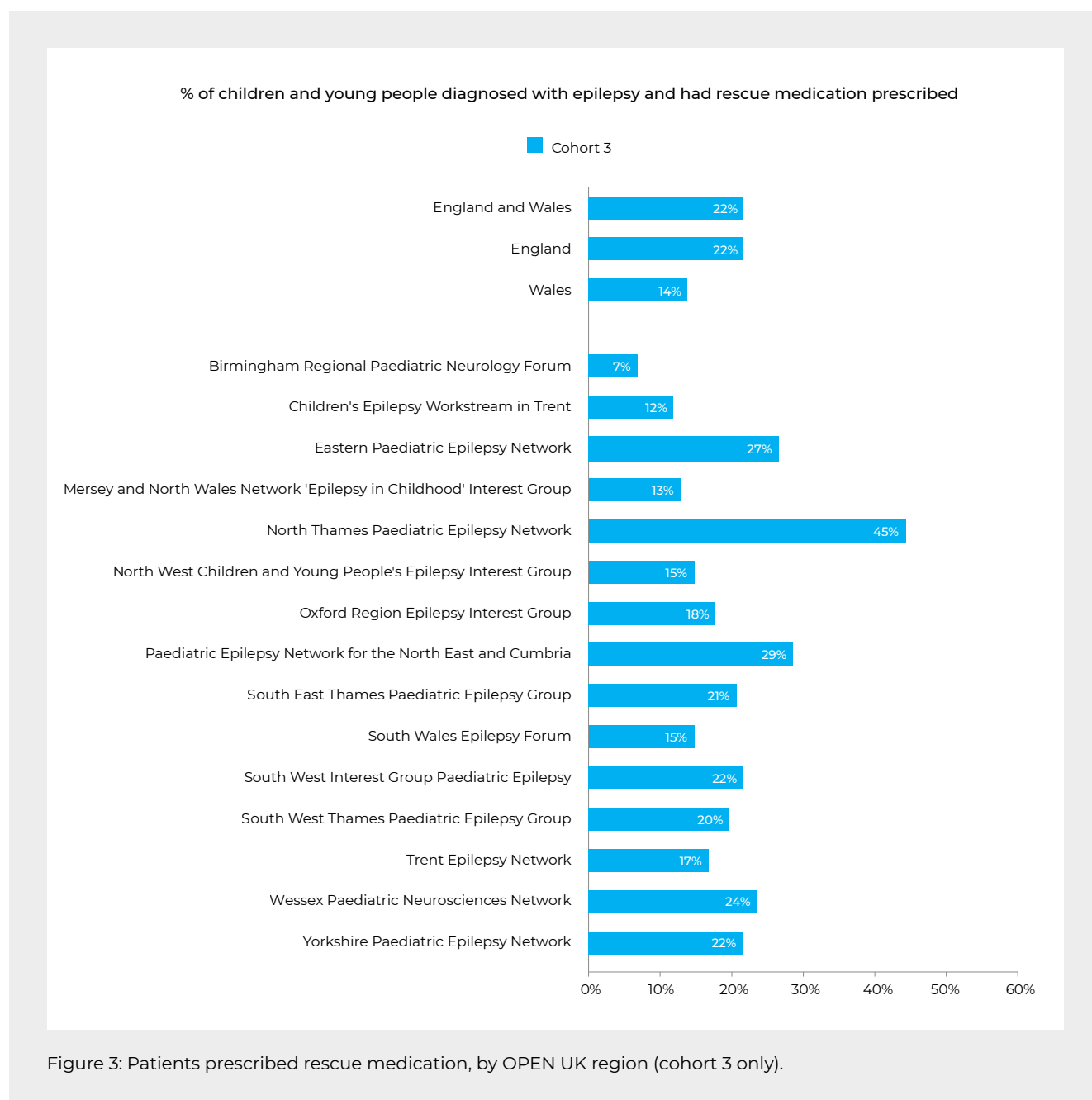
22% (439/1974) of the children and young people diagnosed with epilepsy, had rescue medication prescribed in England and Wales in Cohort 3. This was relatively consistent across cohorts; with 22% for cohort 2 and 20% for cohort 1.



Analysis at a regional level indicates a wide variation in prescribing practices, with rescue medication prescribed for a range of between 7% and 45% of children and young people with epilepsy across the regional networks in England and Wales.



92% (406/431) of children and young people diagnosed with epilepsy and on rescue medication, had a parental prolonged seizure care plan. This had increased from 89% of cohort 1 and 90% of cohort 2.



National guidelines and standards

- NICE guidelines Quality Standard 27 (statement 6) state that children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan.

Epilepsy12 audit measure

- Percentage of the children and young people diagnosed with epilepsy, prescribed rescue medication.

Target audiences

- Epilepsy clinical teams, OPEN UK, the Welsh Government and the NHS England Regional teams.

Sodium valproate in girls and young women

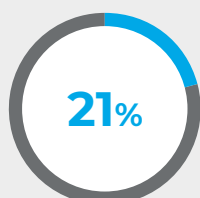


Recommendation 2

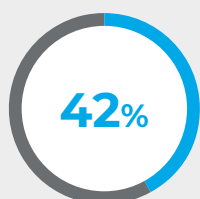
All females of child-bearing potential prescribed Sodium Valproate should have ongoing documentation regarding their status within the valproate Prevent Programme.

Key findings

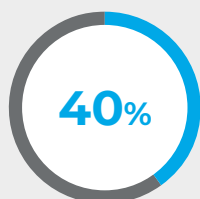
All females able to have children must be enrolled in a pregnancy prevention programme (PPP) to be prescribed sodium valproate but there were a small number of patients in Cohort 3 where this was not recorded.



There was a clear gender difference in sodium valproate prescribing: **21% (120/584)** of children and young people receiving it were female.



42% (50/120) of females prescribed Sodium Valproate had evidence of discussion of risk regarding the risks of birth defects and/or neurodevelopmental outcomes.



This proportion was similar when including only the females aged 9 and above, where **40%** had evidence of discussion of the risks recorded. This was lower than previous cohorts (71% of cohort 2 and >95% of cohort 1). For patient privacy, we do not report the exact small numbers of patients in this group.

National guidelines and standards

- Medicines and Healthcare products Regulatory Agency (MHRA) guidance requires that valproate must no longer be used in any woman or girl able to have children, unless she has a pregnancy prevention programme in place.

Epilepsy12 indicators

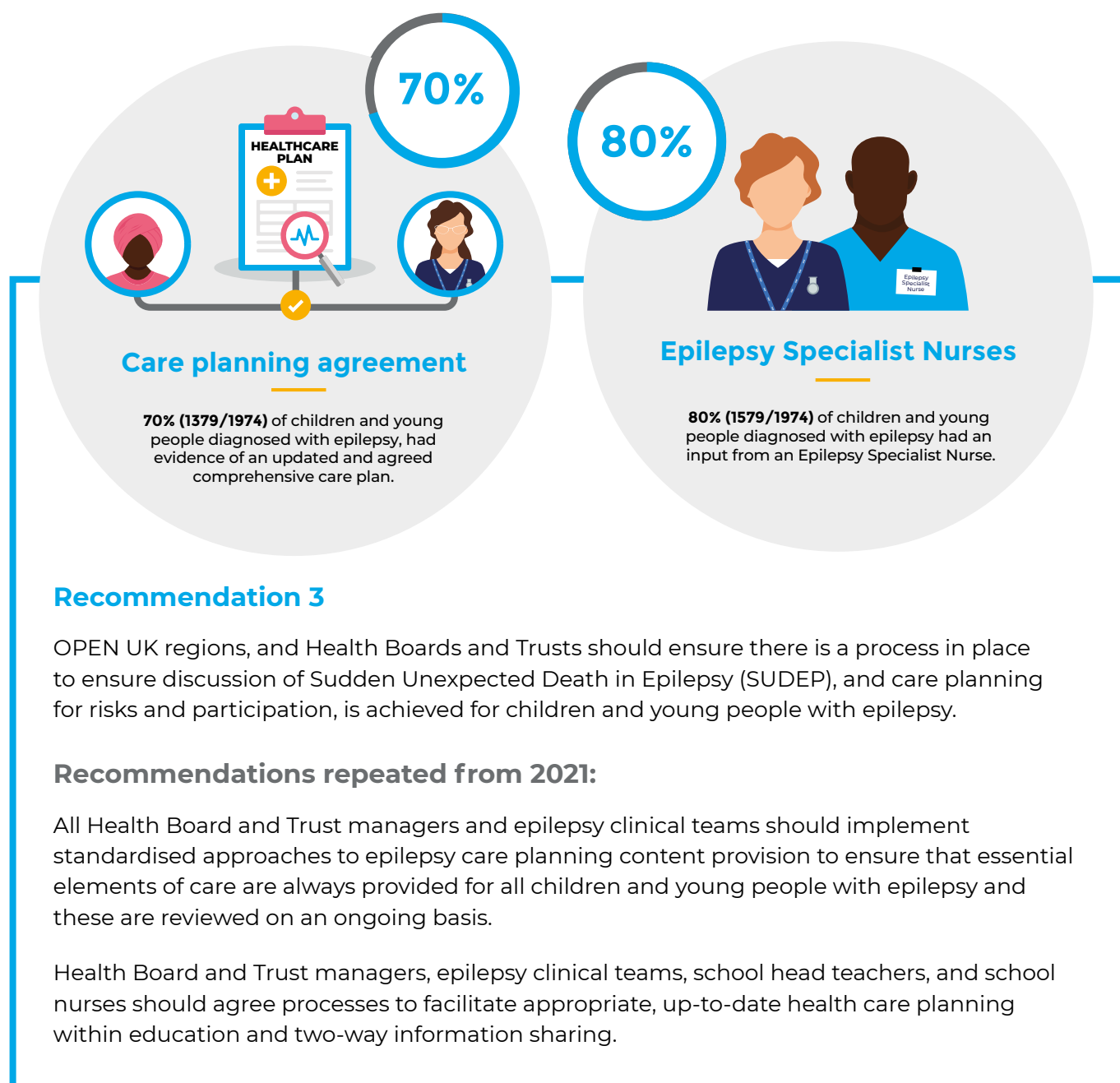
- Performance indicator 9a: Percentage of females aged 9 and above currently on valproate treatment with evidence of discussion of foetal risk.
- Performance indicator 9b: Percentage of all females currently on valproate treatment with evidence of discussion of foetal risk.

Target audiences

- Epilepsy clinical teams, the Welsh Government and the NHS England Regional teams.



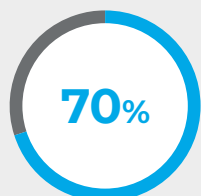
Care planning



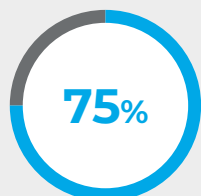
Key findings

There was evidence of wide-spread use of comprehensive, individual care planning for children with epilepsy. Core elements of content were present in most care plans and the proportion of care plans which contained all the required elements increased in cohort 3. Epilepsy teams rarely had record of a school individual healthcare plan for the children and young people whose care they manage.





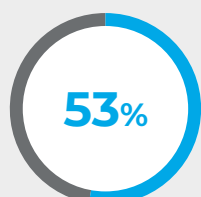
70% (1379/1974) of children and young people diagnosed with epilepsy, had evidence of a care plan that had been both updated as needed and agreed between the child, their family and their healthcare provider. This had increased from 65% (1378/2106) in cohort 2.



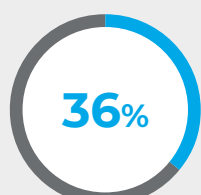
75% (1487/1974) of children and young people with epilepsy had a comprehensive care plan which contained all the core elements of content. This had increased from 70% (1464/2106) in cohort 2.



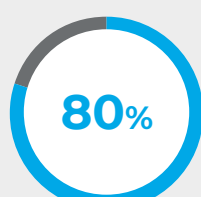
One of the care planning contents elements is for planning and discussion of 'general participation and risks'. This had been achieved in an increasing proportion of care plans over the three cohorts from 80% (890/1112) in cohort 1 to 85% (1686/1974) in cohort 3; but it continued to be achieved less than other elements of content.



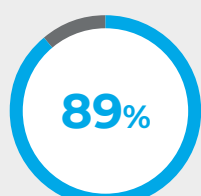
53% (1049/1974) of children and young people diagnosed with epilepsy, had evidence of information on SUDEP in England and Wales in Cohort 3.



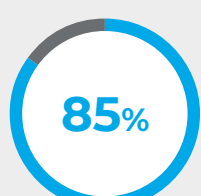
36% (499/1381) of school-aged children and young people with epilepsy were identified as having a school Individual Healthcare Plan. This had been similar in cohort 2 (32%, 455/1402).



80% (1579/1974) of children and young people diagnosed with epilepsy had an input from an ESN. This is similar to cohort 2 (78%, 1644/2106), and an increase compared to cohort 1 (72%, 798/1112) and the two earlier rounds of the audit in 2009 and 2014.



89% (102/115) of Health Boards and Trusts employed some ESN provision within their paediatric service. In most services ESNs facilitate the care planning process and updates, (in 85%, 98/115, of the Health Boards and Trusts).



ESNs are also an important link to schools in many epilepsy services; in **85% (98/115)** of Trusts and Health Boards the ESNs support school meetings and school rescue medication training (77%, 89/115).

National guidelines and standards

- NICE Quality Standard 27 (statement 4) states that children and young people with epilepsy have an agreed and comprehensive care plan.
- NICE Quality Standard 27 (statement 5) states that children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Epilepsy12 indicators

- Performance indicator 10: Percentage of children and young people diagnosed with epilepsy where there is evidence of a comprehensive care plan that is agreed between the person, their family and/or carers, and primary and secondary care providers, and the care plan has been updated where necessary.
- Performance indicator 11: Percentage of children diagnosed with epilepsy with documented evidence of communication regarding relevant core elements of care planning.
- Performance indicator 12: Percentage of children and young people with epilepsy aged 5 years and above with evidence of a school individual healthcare plan by 1 year after first paediatric assessment.

Target audiences

- Health Board and Trust managers, commissioning organisations, epilepsy clinical teams, ESNs, school head teachers, and school nurses.



East Sussex Healthcare
NHS Trust



Quality improvement at East Sussex Healthcare NHS Trust

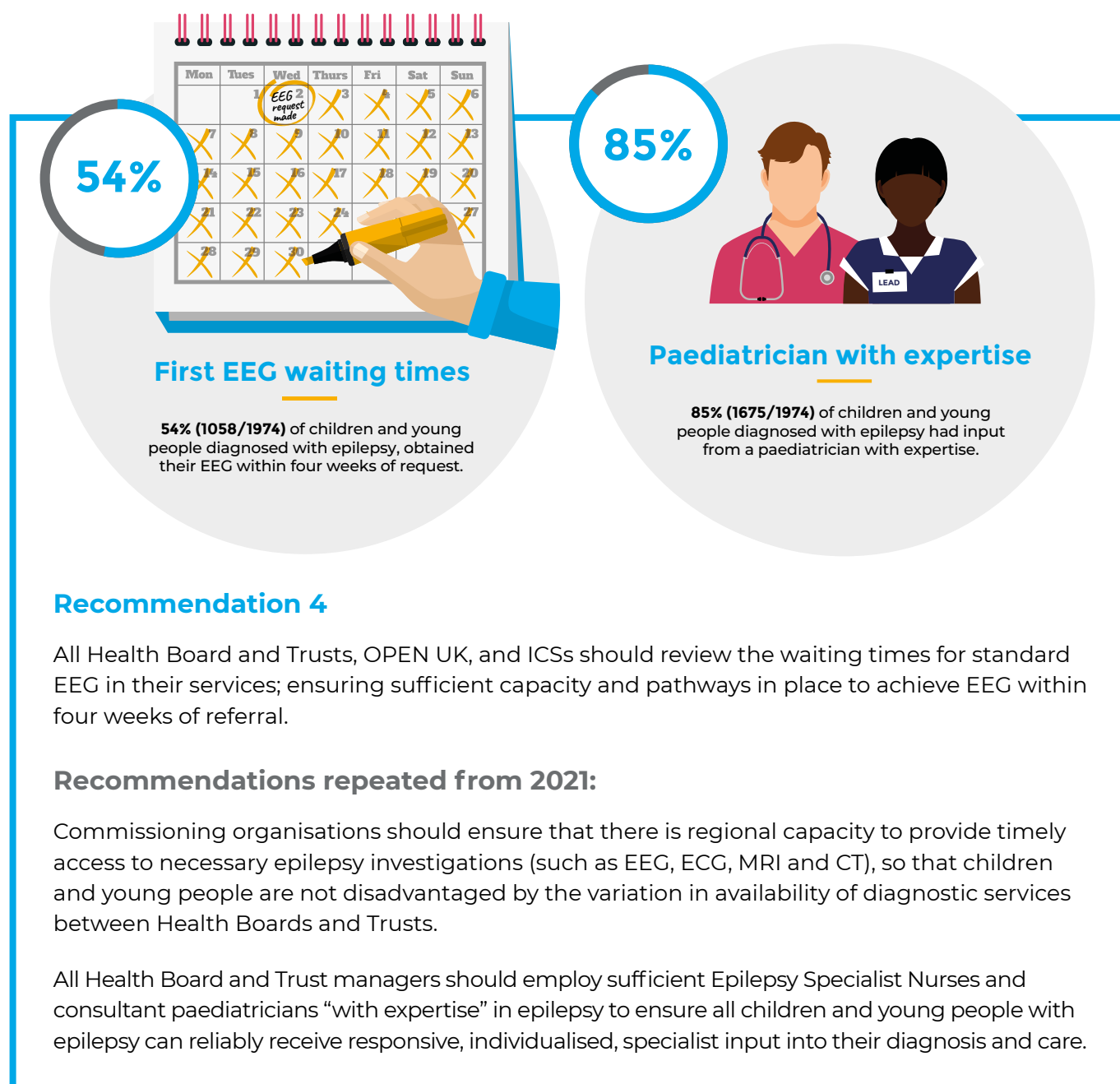
The clinical team at the Trust are aiming to improve the communication with, and information given to, patients and their families.

The team has implemented the use of video in their diagnostic process. This has been through use of the 'vCreate Neuro' platform which allows secure communication and file sharing between clinicians and the children and young people (or their parents and guardians). The service has also worked to improve the verbal and written information given to patients about SUDEP, increased the multi-disciplinary elements of their epilepsy clinics, and have recently initiated mental health screening tools within clinics.

This has helped to:

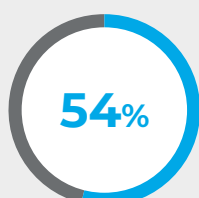
- Improve the accuracy of diagnoses with sharing of video between the family and epilepsy service.
- Increase the input from ESNs into children's and young people's care.
- Improved patient information and awareness of SUDEP.

Waiting times



Key findings

The proportion of patients receiving a timely EEG was consistent with previous cohorts (national guidance states this should be within 4 weeks of referral). However there was a concerning increase in children waiting over 16 weeks for a first EEG.



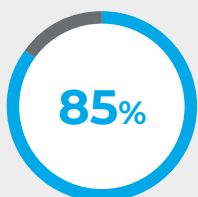
54% (1058/1974) of children and young people diagnosed with epilepsy, obtained an EEG within four weeks of request. This had been similar in cohort 2 (53%, 1117/2106).



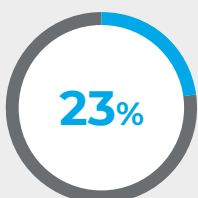
There was an increase in children and young people waiting more than 16 weeks for an EEG in cohort 3 10% (191/1974) compared to cohort 2 5% (95/2106.)



There is considerable variation in available services at Trust and Health Board level: 64% (74/115) (2020: 61%, 72/119) of Trusts and Health Boards could provide a standard EEG within their location; 95% (109/115) (2020: 96%, 114/119) could provide a 12-lead ECG; 95% (109/115) (2020: 94%, 112/119) an 'awake' MRI or 66% (76/115) (2020: 63%, 75/119) 'with sedation'.



85% (1675/1974) children and young people diagnosed with epilepsy had input from a paediatrician with expertise in epilepsy during their first year of care.



23% of (457/1974) children and young people diagnosed with epilepsy were seen by a paediatrician with expertise in epilepsy within 2 weeks of first referral. This had increased compared to previous cohorts: from 16% (172/1112) in cohort 1 and from 19% (392/2106) in cohort 2.

National guidelines and standards

- NICE Quality Standard 27 (statement 2) states that children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of being requested.
- NICE Quality Standard 27 (Statement 3) states that children and young people who meet the criteria for neuroimaging for epilepsy should have magnetic resonance imaging (MRI).
- Current British Paediatric Neurology Association (BPNA) PET (Paediatric Epilepsy Training) teaching curriculum, states that all children with a convulsive seizure should have a 12-lead ECG.
- NICE Quality Standard 27 (statement 1) states that children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Epilepsy12 indicators

- Performance indicator 1: Percentage of children and young people with epilepsy, with input by a 'consultant paediatrician with expertise in epilepsies' within the first year of care.
- Performance indicator 6: Percentage of children and young people with convulsive seizures and epilepsy, with an ECG by the first year.
- Performance indicator 7: Percentage of children and young people with defined indications for an MRI, who had MRI by first year.

Target audiences

- Health Board and Trust managers, EEG teams, and commissioning organisations.



St George's University Hospitals NHS Foundation Trust



Quality improvement at St. George's University Hospitals NHS Trust

The clinical team at the Trust are aiming to decrease their referral waiting times for a first seizure clinic; improve seizure management outcomes for patients; and reduce patient distress. They began the process by reviewing which factors were leading to long waiting times, and identifying possible strategies for elements they could change.

They then put in place a number of changes, including setting up a shared team email address, developing a new standard referral form, and defining a clear system to process the referrals.

The outcomes so far have been:

- Improved communication between different teams.
- Improved understanding of the referral process.
- Better awareness of the epilepsy team's workload.
- Tracking has shown reduced waiting times (although the change was not statistically significant).

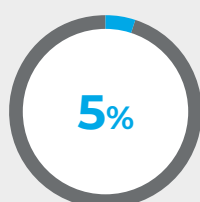


Mental health and psychological support



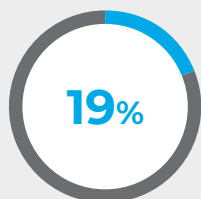
Key findings

Research¹ suggests there is a high incidence of mental health problems among children and young people with long term conditions, yet very few of the epilepsy patients had an identified mental health condition. Few epilepsy services use formal screening tools.

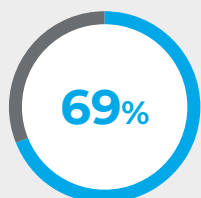


5% (53/1124) of children and young people between the age of 5-15 years and diagnosed with epilepsy had an identified mental health condition; this was the same proportion as in cohort 2 (5%, 68/1358).

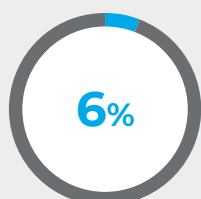
¹ Buelow JM, et al. (2003) Behavior and mental health problems in children with epilepsy and low IQ. Dev Med Child Neurol



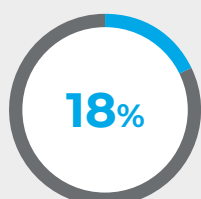
19% (22/115) of Health Boards and Trusts used formal screening for mental health disorders in 2021. This was a slight increase from 2020 (17%, 20/119). Similar proportions formally screen for autism spectrum disorder and/or ADHD.



69% (79/115) of Health Boards and Trusts have agreed referral pathways for children with mental health conditions.



6% (7/115) of Health Boards and Trusts could not refer to mental health assessment services, either in or outside of their Health Board or Trust. In 2020 this was 7% (8/119).



18% (12/115) of Health Boards and Trusts had co-located mental health provision within their epilepsy service, compared to 15% (18/119) in 2020.

National guidelines and standards

- NHS Best Practice Criteria (2019) states that there should be some co-located mental health provision within epilepsy clinics.
- NICE Clinical Guideline 137 states that children and young people should have access to: written and visual information; counselling services; information about voluntary organisations; epilepsy specialist nurses.

Epilepsy12 indicator

- Percentage of children and young people between the age of 5 to 15 years, diagnosed with epilepsy and an identified mental health condition.

Target audiences

- Health Board and Trust managers, epilepsy clinical leads, and commissioning organisations.



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Cwm Taf Morgannwg

Cwm Taf Morgannwg
University Health Board



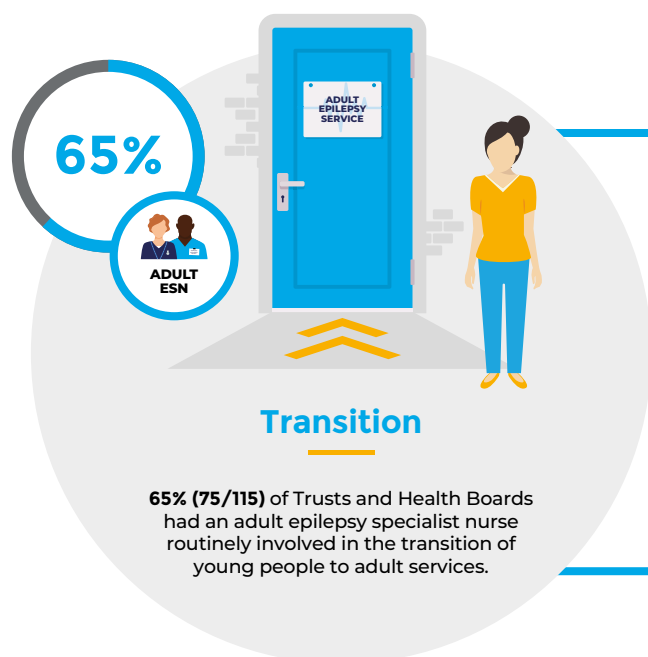
Quality improvement at Cwm Taf Morgannwg University NHS Health Board

The clinical team have worked to improve routine mental health screening and co-located mental health support in their epilepsy service. They began by identifying and reviewing different mental health screening tools and approaches.

The team then agreed a set of screening protocols for their outpatient clinics. They worked with psychology and CAMHS to establish referral pathways for patients, and to integrate elements of mental health support into the epilepsy service. Data is still being collected on the outcomes of this pilot project. However, the initial feedback from staff, patients and families has been positive.



Transition to adult services

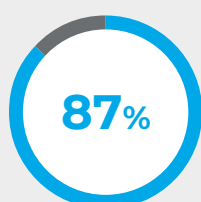


Recommendations repeated from 2021:

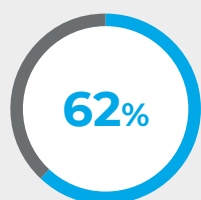
All Health Board and Trust managers and commissioning organisations should ensure that adult and paediatric epilepsy teams have time allocated in job plans and are resourced to allow joint transition-related clinical appointments and quality improvement work.

Key findings

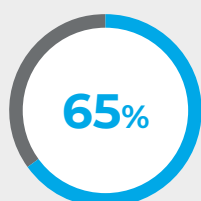
There was positive evidence of increased joint-working to support young people to transition to adult services. However, the available support and pathways for patients to transition to adult care varies considerably between services.



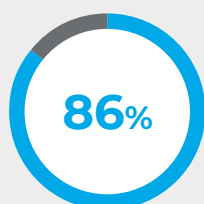
Most (**87%, 100/115**) Trusts and Health Boards had an agreed referral pathway for young people to transition to adult care.



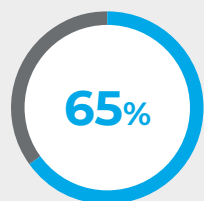
62% (71/115) of Health Boards and Trusts, used structured resources (for example Ready, Steady, Go) to support patients' transition to adult services.



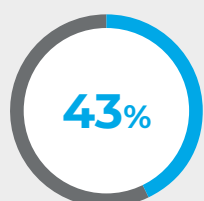
65% (75/115) of Health Boards and Trusts reported having an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals, compared to 60% (71/119) in 2020.



After increasing 2018-2020, there was a sustained level of adult specialist involvement in transition services for young people. In 2021, **86% (99/115)** of Health Boards and Trusts adult neurologists were routinely involved in transition to adult services, compared to 85% (101/119) in 2020, 84% (114/136) in 2019, and 78% (116/148) in 2018.



Adult ESNs were routinely involved in the transition services at **65% (75/115)** of Health Boards and Trusts, compared to 63% (75/119) in 2020, 54% (74/136) in 2019 and 51% (76/148) in 2018.



43% (49/115) of Trusts and Health Boards had an outpatient clinic specifically for young people with epilepsies. The median age at which these clinics typically accepted young people was from shortly before their 15th birthday.

National guidelines and standards

- NICE Quality Standard 140 (Statement 1) Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.
- NICE Quality Standard 140 (Statement 2) Young people who will move from children's to adults' services have an annual meeting to review transition planning.
- NICE Quality Standard 140 (Statement 4) Young people who will move from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer.

Epilepsy12 indicator(s)

- Percentage of Health Boards and Trusts reported having an outpatient service for epilepsy where there is a presence of both adult and paediatric professionals.

Target audience(s)

- Health Board and Trust managers and commissioning organisations.



**Hull University
Teaching Hospitals**
NHS Trust



Quality improvement at Hull University Teaching Hospitals NHS Trust

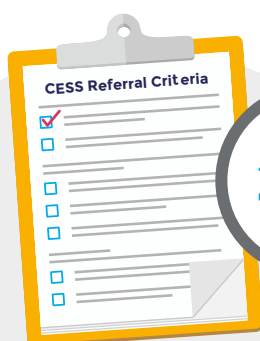
The clinical team have used their Epilepsy12 data to support their planned improvement activity in the service. They are aiming to improve patient's transition to adult services, particularly for those with learning difficulties, and to integrate mental health support into care plans.

Working towards those goals, the epilepsy service has:

- Updated their patient information folder.
- Developed a bespoke transition tool.
- Created a second version of the tool for children with moderate to severe learning disabilities.
- Integrated mental health screening and psychological support within their ESN-led clinics.



Tertiary care and surgery



28%

Children's Epilepsy Surgical Service (CESS)

28% (38/135) of children and young people diagnosed with epilepsy who met surgical referral criteria, had a referral for surgical evaluation.

Recommendations repeated from 2021:

OPEN UK regional networks and commissioning organisations should work together to review the Epilepsy12 findings in their area and ensure there is sufficient capacity for paediatric neurologists to provide timely assessment and ongoing management.

The specialist CESS centres should collectively:

- Review the referral criteria to ensure these are clear, consistent, and embedded in shared care pathways from secondary care and paediatric neurology.
- Agree a communications strategy to raise awareness of referral criteria, and encourage early referral of appropriate children and young people.

Key findings

There was evidence that some children and young people with epilepsy may not be receiving appropriate referrals to tertiary care and missing out on, or having delayed referral for, epilepsy surgery assessment.



28%

28% (38/135) of children and young people diagnosed with epilepsy who met surgical referral criteria had a referral to CESS for surgical evaluation during their first year of care. This is slightly higher than in cohort 2 (23%). Both cohorts 2 and 3 referral rates were lower than pre-pandemic (30% for cohort 1).

64%

64% (305/480) of children and young people who met paediatric neurology referral criteria had either input paediatric neurologist, or had been referred to CESS, during their first year of care. This was an increase compared to cohort 2 (52%, 243/464).

National guidelines and standards

- NICE Clinical Guideline 137 states that children, young people should have access to referrals to tertiary services, including surgery if appropriate.

Epilepsy12 indicator(s)

- Performance indicator 3: Percentage of children and young people meeting defined criteria for paediatric neurology referral, with input of tertiary care and/or CESS referral within the first year of care.
- Performance indicator 3b: Percentage of ongoing children and young people meeting defined epilepsy surgery referral criteria with evidence of epilepsy surgery referral.

Target audience(s)

- OPEN UK regional networks, commissioning organisations, NHS England and specialist CESS centres.



3. Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK)

OPEN UK is a clinical network connecting NHS Health Boards and Trusts that provide care for children with epilepsies within regional epilepsy networks across the UK and a UK Working Group.

You can find details of each regional network and learn more about OPEN UK at [OPEN UK](#).

OPEN UK Working Group 2021-22

Epilepsy12 hosts the OPEN UK Working Group meetings which bring together the regional leads from each OPEN UK epilepsy network. Their aim is to:

- Encourage collaboration and sharing of regional and national ideas, pilots, and resources.
- Be a national resource and professional UK body to which other organisations may come for information, support, data and strategic or clinical input.
- Facilitate links to local, regional and national funding bodies.

The fourth annual Epilepsy12 & Organisation of Paediatric Epilepsy Networks (OPEN UK) national conference took place on 14 September 2021. Over 150 health professionals came together to discuss improving paediatric epilepsy care. This was the second conference successfully hosted in an online format. Feedback from attendees was that the conference sessions were useful and thought provoking; without the need to travel to attend we also saw a wider range of registrations from different specialities and locations.

The event was chaired by Dr Alastair Parker, President of the British Paediatric Neurology Association, who facilitated stimulating discussions around the current state of paediatric epilepsy services and how these can be improved in future. Sessions provided updates from OPEN UK, Epilepsy12 and the Youth Advocates; each of which are also covered in this report. There were also three breakout sessions with presentation and discussion of:

- Innovative technology in paediatric epilepsy, and demonstration of the 'vCreate Neuro' platform which allows families and patients to securely communicate with, and share video recording of seizures, with the clinical teams.
- The emerging evidence from two mental health interventions for children with epilepsy. The '[MICE](#)' project is evaluating the impact of adding an additional psychological intervention for children with epilepsy and a mental health disorder. The '[PAVES](#)' pilot is testing an approach to integrating psychological services into paediatric epilepsy clinic.
- Patient engagement, led by the Epilepsy12 Youth advocates, to share approaches to engagement and important themes for epilepsy teams to consider in their services.

During 2021-22 the OPEN UK working group have:

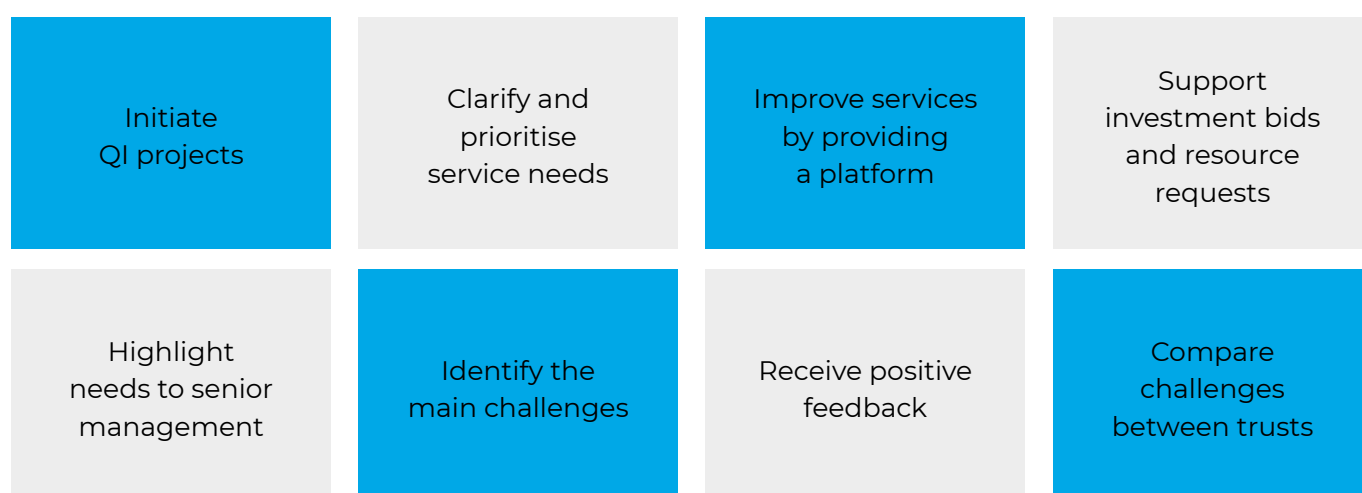
- Held regular national network meetings sharing learning and collaborating on cross-regional changes such as genomic testing services for paediatric epilepsy, shared learning from local improvement projects and how services were responding to pandemic pressures, building links to new Integrated Care Systems (ICS) and NHS England regional teams.
- Supported Epilepsy12 in developing a user survey to understand more about the uses of, and requirements for, the audit in epilepsy services across the UK. More detail about what we learned from this below.
- Fed back to Epilepsy12 about experiences of EQIP pilot, and shared ideas for the new 2021/22 collaboratives.
- Reviewed their regional Epilepsy12 results and other regional or local plans.

OPEN UK and Epilepsy12 user survey

Epilepsy12 and OPEN UK collaborated on a user survey in summer 2021 to capture feedback from those participating in the national audit. The survey aimed to highlight audit strengths, identify common problems and guide future plans to improve user experience. The survey received an encouraging response, with almost one hundred users leaving their feedback and fourteen of the seventeen OPEN UK regions being represented. Most people scored all aspects of the audit highly on usefulness.

Key Survey Findings

Reviewing and sharing Epilepsy12 results helped clinical teams to:



Two thirds of epilepsy teams reviewed their audit results at national, regional and Trust or Health Board level. However, only 38% had developed action plans in response to the audit.

76% of respondents found their Trust or Health Board audit reports useful and most also felt Epilepsy12 was useful for future peer review, bench marking and quality improvement activities.

In response to Epilepsy12 results, services across the country undertook several quality improvement activities in 2020. Examples of these projects include:

- Improved care pathways between services - Established good links between epilepsy care and psychology, mental health, tertiary transition and community services.
- New services and investment – Rewrote business cases, ran local epilepsy audits, investigated links to sleep deprivation and set-up First Fit Clinics.
- Technology – Initiated telephone/video clinics, electronic letters and prescriptions, novel databases and a wider needs screening tool.
- Records management - utilised new local Epilepsy12 data collection sheets and ECG forms for patient notes to help data submission.

When we asked users what the barriers were to using Epilepsy12 for planning and quality improvement, the common answers were surrounding the data quantity; time taken to collect and submit data; lack of protected time to participate in the audit or quality improvement activities; and IT difficulties.

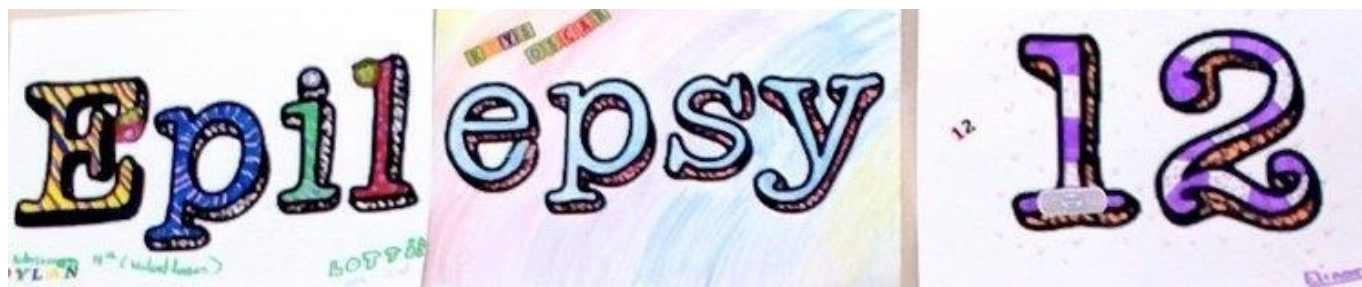
Actions and conclusions

Overall, teams were positive when discussing Epilepsy12 and appreciated the value in participating in the audit. Users were keen to highlight the benefits brought to their services, for example Epilepsy12 facilitated collaboration, bench marking and quality improvement. Audit results evidenced business cases and highlighted challenges to prioritise future plans. The survey identified common problems, with the greatest roadblocks to participation being time and data burden.

Considering the feedback, the Epilepsy12 project team are working to improve user experience by undertaking the following actions:

- Reducing the metrics currently being collected.
- Reviewing the platforms' access, functionality and speed.
- Providing more guidance and support to clinical teams on data entry.
- Recommending to senior leaders that time for audit and improvement are included in job plans.
- Providing evidence and useful resources for clinical teams to use within their Trust or Health Board; showing both about successes and where additional resource is required.
- Providing robust and timely data.
- Shortening our reports, and improving other resources including the one-page poster summaries and live dashboards.
- Continuing to consult users through OPEN UK on Epilepsy12 changes, plans and projects.

4. Epilepsy12 Youth Advocates 2021-22



“Despite everything, we did it.”

Hi everyone! If you don't know who we are, we're a group of volunteers aged 13-25 who have experience or an interest in epilepsy. We are supported by an epilepsy specialist nurse and staff from RCPCH to work together to improve epilepsy care and experience for patients.

The way our project works is by meeting online and having discussions about different topics that we have chosen linked to the Epilepsy12 Audit or on questions that the audit team would like our views on.

Despite lockdowns, the pandemic, having COVID, working online and everything thing else, we've been really busy. Since April 2021 when we last wrote to you, we have:



Won an RCPCH &Us Volunteer Award



Published articles and resources on our experience, findings and project



Published our templates so units can do their own clinic chat checklists



Spoken at the RCPCH Annual Conference and the Epilepsy12 OPENUK Conference



Started a new project on care plans to provide examples to schools



Recorded a podcast on the experience of being diagnosed



Agreed to continue working on mental health



Celebrated our 3rd birthday!

Told you it's been busy! We looked at the audit findings together, and decided that improving school individual healthcare plans was something that we wanted to get involved in. We could see that there weren't huge numbers of school care plans in place (about 32%) and we had really mixed experiences ourselves. We had a think about what makes a good school, college or work care plan for us and looked at examples from around the world.



Our tips are:

Keep it
personal

Keep it
relevant

Keep it
visual

Keep it
up to date

Keep it
**short but
useful!**

Things to include:

- Seizure care – what to do, who to call, how to help
- Information about me before and after a seizure
- Contact details for me, my chosen contact, my specialist health team
- Links to charities that support epilepsy, mental health, and other areas of our life
- Reassurance for me and those supporting me about what is my normal
- Clear information in plain English

We think that it would be good to have different versions for different reasons. You might need a really complete health care plan full of your medicine information, diagnosis, treatment plans if you are staying away for the night or your epilepsy needs more support. We think it would be good to have a small card version with an easy to follow flowchart for our friends and extended family to have when we visit, and a short but personal version that we can carry with us or give to people we see regularly.

You'll have your own school care plans, seizure management plans, individual health plan, education health care plan, epilepsy plan, epilepsy passport.... (so many different names for the same thing!). Have a look and see if it is visual, easy to understand and looks like it talks about a real person with likes, dislikes, hopes and dreams. Or does it just look like another impersonal form full of boxes?

It would be good to see if we can increase the numbers of children and young people talking with confidence about their school, college or work care plan. We think that there is more to be done in school to raise awareness of epilepsy. Sometimes it helps us to be involved and it empowers us to talk in assembly and tell people our experiences, other times it would be nice if it was done without everyone knowing about our diagnosis – so always ask us first if we want to be involved.

Don't forget, there are lots of examples out there like the [Young Epilepsy Guide for Schools](#), examples of school training by [Epilepsy Action](#), and experiences shared on [The Channel](#) and [The Epilepsy Space](#) that you can learn from too. We will be sharing our experiences and examples of a good care plan for you to use – keep an eye on our webpage for more details!

We were also really pleased to be able to celebrate our 3rd birthday and all the work that has gone on over the last few years.

Our standout moments over the 3 years have included:



- Winning 2 awards from HQIP and 1 from RCPCH &Us for our volunteering.
- Speaking at annual conferences each year about our projects.
- How we have started conversations about mental health in different ways with doctors.
- Planning our visits to hospitals before the pandemic, then changing everything to do them online.
- Lots of games, fun, laughter, and time together over the years.
- Seeing our information published.
- Feeling really proud that epilepsy units want to work with us, or are interested and inspired by our work.

We just wanted to say a big thank you to all the 130+ children, young people and families who have been involved over the last 3 years, to all the units and staff that took part in our project and all the young people, parents, carers and workers that have helped us as part of the Epilepsy12 Youth Advocates. We are really looking forward to the next 3 years!

For more information about the Epilepsy12 Youth Advocates please visit our [webpage](#) or contact and_us@rcpch.ac.uk.



5. Epilepsy Quality Improvement Programme (EQIP) 2021-22



Epilepsy12 quality improvement programme

The RCPCH EQIP pilot programme delivered in 2019-20 involved multi-disciplinary paediatric epilepsy teams from 11 NHS Trusts in England and one Health Board in Wales, (*Epilepsy12 Combined organisational and clinical audits: Report for England and Wales, Round 3 Cohort 2 (2019-2020)*, pg. 39). Their response to the emerging COVID-19 pandemic demonstrated their commitment to improving the care provided to children and young people within NHS paediatric epilepsy services.

Following the success of the 2019-20 pilot, the programme was extended in 2021. The second cohort of teams involved 17 new multi-disciplinary paediatric epilepsy teams – 11 from individual NHS Trusts and one Integrated Care System (ICS) network structure of six NHS Trusts. Over a seven-month period between August 2021 and April 2022, online practical training and support helped teams identify local areas of improvement, see table 1.

EQIP teams were provided with high quality QI training by distance learning in a virtual format. This was co-designed and delivered with an expert QI trainer/facilitator and offered flexible remote learning options which were adaptable to the pace of individual teams. Team members could attend live training webinars and access digital pre-course materials, case studies and real-world training examples through a dedicated online microsite. A framework of support was offered to each identified team champion. Additional one-hour monthly support calls were offered to all teams, alongside 1:1 team meetings with QI facilitators to support them in achieving their project aims.

The 2021-2022 programme was designed to offer more flexibility and work around the current capacity of participant teams. The programme encouraged a multi-disciplinary whole-team approach to service improvement, with a particular focus on children and young people's engagement and measurement for improvement. It was recommended that teams devoted at least 1-2 hours per week towards the projects.

Visit the RCPCH EQIP website <https://eqip.rcpch.ac.uk> or Twitter [#RCPCHEQIP](https://twitter.com/RCPCHEQIP) to learn more and to watch the teams present their projects from an EQIP learning event on 17 March 2022. Posters of their EQIP project interventions are also available.

Table 1: The 2021/2022 participant EQIP teams and their QI project aims.

Team	Project aim
Developing Mental health pathways	
Epsom and St Helier University NHS Trust	Identify and implement a mental health screening tool for CYP with epilepsy to identify those at risk.
North-West Anglia Foundation Trust	Improving mental health pathways using signposting.
Warrington and Halton Teaching Hospitals NHS Foundation Trust	Engage with families to improve the mental health care pathway for young people with epilepsy.
Improve and adapt the transition process to adult services	
Croydon Health Service NHS Trust	Improve and adapt the transition process for young people with epilepsy.
East Lancashire Hospital NHS Trust	Develop the transition service for young people with epilepsy.
Developing an integrated care pathway and increasing specialist input	
North Tees & Hartlepool NHS Foundation Trust	Reduce referrals from 12 to 4 weeks for 50% of patients following first epilepsy seizure.
Salisbury NHS Foundation Trust	75% of CYP with first afebrile seizure will be seen in clinic within 2 weeks of referral.
Improving patient engagement processes	
Barts Health NHS Trust	Obtain meaningful feedback on our service from 50% of children, young people and families by March 2022.
Doncaster and Bassetlaw NHS Foundation Trust	By March 2022, 70% of children aged 11-19 Years with Epilepsy will have Digital feedback forms offered in clinics (Consultant and Nurse led) and on acute wards.
SUDEP risk	
Oxford University Hospitals NHS Foundation Trust	Develop a patient standardised toolkit for clinicians to use to provide information on SUDEP to families, enabling a personalised annual discussion on SUDEP for at least 80% of children with epilepsy.

Table 1: The 2021/2022 participant EQIP teams and their QI project aims.

Team	Project aim
Digitalisation of Epilepsy passports	
University hospitals of Morecambe Bay NHS Foundation Trust	Produce epilepsy passports electronically for 50% of our patients with epilepsy and complex comorbidities.
Improving the First year of care	
West Yorkshire & Harrogate Health and Care Partnership (ICS team including six NHS Trusts)	Establish a standardised first year of care pathway for patients with epilepsy diagnosis (sub-projects include the areas of Transition, Mental health and reducing waiting times for first referral).



Table 2: Service-level outcomes of the EQIP

Status pre-EQIP	Changes and benefits post-EQIP
Participant teams initially focused on the negative barriers they faced, in comparison to the successes they achieved as a service.	<p>By using QI methodology, service teams gained skills in how to break down challenges and find solutions. Trusts were therefore able to achieve outcomes meeting their specific service goals.</p> <p>For example, the successful development of an integrated digital Epilepsy Passport - co-designed with patients and their families - shows the barriers that can be overcome when working with multi-faceted teams.</p>
Few teams had prior knowledge of quality improvement methods.	All teams have now been trained in the use of QI tools to help diagnose and test solutions when making service improvements. This resulted in multiple teams reporting a reduction in new patient referral waiting times, for example, above 16 weeks to within 6 weeks or 12 weeks to 4 weeks.
<p>Some service teams struggled to communicate effectively; especially when working across different sites within their NHS Trust, or across multiple Trusts in ICS structures.</p> <p>Many were unsure what an effective epilepsy service team looked like beyond the roles of the consultant and ESN.</p>	<p>The ICS team have increased their outputs by working on improving effective communication methods across six sites. The group shared knowledge in developing pathways in mental health support, establishing effective transition clinics and reporting on a reduction in waiting times for first seizure referrals.</p> <p>Further examples of incremental changes to services has led to the implementation of new ED patient referral processes to paediatric epilepsy clinics. These have been embedded within Trust guidelines.</p>
Some of the service teams were not participating in Epilepsy12.	All teams on the programme participated in the Epilepsy12 audit by the end of the programme cycle. They had a greater understanding of its value, and how to use the data in local QI activity.
Services lacked clear processes to meet national standards, measured in Epilepsy12's key indicators.	Teams used the audit data to review areas for improvement and help plan their projects. Several projects focused on building new processes, for example to: ensure discussion of SUDEP risk with patients and their families, establish a new mental health care pathway, developing screening tools and methods of signposting information or services.

Table 2: Service-level outcomes of the EQIP

Status pre-EQIP	Changes and benefits post-EQIP
Some teams were not able to effectively engage with children and young people, or to include them in the co-design of services.	All teams have reported an increase in regular patient and family engagement, using tools and techniques they have learnt. Teams focusing on transition to adult services have worked with children and young people on capturing their needs and wants. This helped to structure and establish an efficient referral pathway for young children aged from 14 years old onwards.
All teams wished to improve aspects of their culture and clinical services.	All teams experienced a transformation in terms of the skills learnt from expert trainers and each other. Teams benefited from the knowledge provided through monthly coaching and support. All teams experienced incremental changes within team interactions and improvements in how they deliver their service to children and young people.



Lessons learnt

1

Team working and communication – Services need the time and space to define what makes an effective team and agree a shared purpose when developing service improvements. It is important the teams strengthen their team building and improve communication processes to see significant improvement and meet national standards.

2

QI training and support – NHS Trusts should incorporate time within job plans for teams to deliver quality improvement in their services and share learning within the organisation; whether through programmes such as EQIP or independently. In EQIP, teams found the monthly coaching and support crucial; helping to keep momentum through incremental changes as well as providing guidance to help resolve barriers.

3

Patient and family engagement – EQIP's new training and structure placed a greater emphasis on patient engagement, and for many of the 2021/22 teams this was at the centre of their project interventions. Teams had a better understanding of how to include patients and families in service redesign. EQIP teams were able to identify where assumptions made about patient preferences were unproductive. They tested and quickly abandoned practices where these did not result in engagement.

4

Overcoming challenges – Due to the COVID-19 pandemic, at times some of the improvement projects lost momentum when the service or the wider NHS were under significant pressures. In challenging conditions, the teams and individuals demonstrated dedication to their continued efforts to improve the care for children and young people.

The pandemic also prompted significant change, and teams found the importance of using data to evidence and understand change, with both local and national data providing insights into variation between and within services.

5

Network links and sharing of good practice – There is a need for platforms, such as OPEN UK, where service teams can share best practice across different Trusts, ICSs or regions. These connections may assist in reducing variation in practice and develop standardised processes and procedures to improve the quality of care.

Acknowledgements

We would like to say a huge thanks to all the participant teams. It has been a pleasure supporting their QI journey and seeing the teams' growth. We would like to acknowledge a special thanks also to the advisors and faculty for their valuable input for this programme.

ESN advisors: Alison Mollett, Amanda Tomlin, Carolyn McAskil, Christine Bennett, Debbie Dean, Emma Hassan, Jill Conium, Laura Neely,

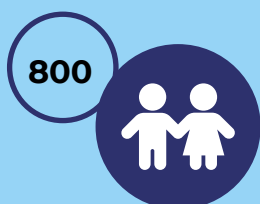
QI Trainer: Dr Patricia O'Connor, CEO QI Discovery.

Faculty team: Angie Pullen, Dr Colin Dunkley, Emma Sparrow, Dr Megan Peng, Mirek Skrypak, Dr Richard Brown, Rosemarie Pardington, Dr Sreenivasa Tekki-Rao.

6. Quality improvement in University Hospitals of Derby & Burton NHS Trust (UHDB)

Presented by: Dr Sally Moss (Associate Specialist in Paediatrics), Dr Sumant Kumar (Consultant Paediatrician), Dr Rusia Manuel (Consultant Paediatrician), Dr Heather Carswell (Speciality Doctor), Mrs Amanda Cholerton (Clinical Physiologist/EEG Lead), Miss Rachael Wheway (Senior Children's Epilepsy Specialist Nurse), Mrs Carly Sladen (ESN), Mrs Laura Churm (Paediatric Lead Nurse), Dr Gisela Robinson (Consultant Paediatrician & Clinical Director Paediatrics), Mrs Rachael Jerram (General Manager, Paediatrics).

The epilepsy services in UHDB



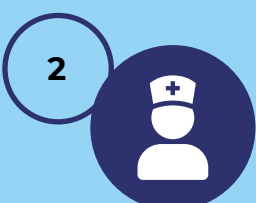
A combined population of more than 800 children and young people with epilepsy.



2 sites: Royal Derby Hospitals (RDH) and Queen's Hospital Burton (QHB).



2.7 whole time equivalent (WTE) Consultant Paediatricians/Associate Specialists with expertise in epilepsy.



2 WTE Epilepsy Specialist Nurses (ESN).

Figure 4: About the epilepsy services and workforce in UHDB NHS Trust

Over the past year, our Epilepsy team have worked hard to continue to improve the quality of our epilepsy care for children, young people and families. We are pleased to share with you three quality improvement activities we have successfully developed.

One stop Epilepsy-EEG service for Children's Epilepsy Clinics

In March 2020, the coronavirus pandemic halted almost all outpatient services at our hospital.

As most of our consultations became telephone or video consultations, we started exploring new ways of working. We initiated a new one-stop service to reduce foot-traffic within RDH and QHB Hospitals.

Our aims were to:

- Enable patients to receive diagnosis, and potentially treatment, the same day as their initial consultation.
- Provide same day standard EEG testing, which will reduce footfall within the hospital and prevent patients returning on multiple days for tests.
- Reduce EEG waiting times for all other patients attending the main department.
- Reduce COVID-19 risks to visitors, patients and staff.

Three epilepsy clinics are run on Tuesday mornings at RDH and supported by epilepsy specialist nurses. As there were lower outpatient EEG demands during the pandemic, we were able to spare an EEG machine. We could therefore dedicate a separate room for EEGs near to the clinics. New or clinically urgent patients are seen by the paediatrician and if an EEG is clinically indicated, we can perform this in the clinic. The advanced clinical physiologist leads on this, performing the EEG and providing a provisional report.

The outcomes included:

- 68 EEGs were performed in the clinic over 6 months from May 2020.
- 20 EEGs were abnormal and supported an epilepsy diagnosis.
- 10 of the children were newly diagnosed with epilepsy and started on medication on the same day, and one other child started medication within a week.
- Other children treated for non-convulsive seizures, had their medication doses increased or received confirmation that their clinical events were non-epileptic.

We have been able to reduce our waiting times for routine standard EEGs from 6 weeks to 2 weeks, in line with NICE guidance, as well as outpatient EEG waiting times. Performing EEGs and obtaining verbal provisional reports in the outpatient department during a clinic session has benefitted children, families and our epilepsy service. We were able to provide definitive epilepsy diagnoses, and in many instances, start treatment on the same day. This has reduced the number of hospital visits needed for patients.

These outcomes, along with the positive patient experiences highlighted in our service reviews, have supported a business case to purchase more equipment and improve the service further. Following the success of the one stop EEG clinic in Royal Derby, we have now initiated a similar service at Queen's Burton Hospital.

Epilepsy service review at Royal Derby Hospital

In October 2020, we conducted a service review of children attending the RDH epilepsy clinics to identify our total epilepsy case load and audited this against NICE guidelines on epilepsies. We used our results to support business cases and request more resource:

Tertiary neurology input - We identified a case load of 652 epilepsy children from RDH, out of which 303 (46.5%) met the criteria for review by a Neurologist and 85 (13.2%) were identified as 'complex patients' who need to be under shared care with a tertiary centre. The service review was focused on RDH, where the tertiary paediatric neurology input is provided by Nottingham University Hospital NHS trust (QHB has a separate tertiary pathway with input from Birmingham Children's Hospital NHS trust).

Only a small proportion of patients received the appropriate level of tertiary input. We identified this as a clinical risk at our clinical governance meeting, which led to discussions with our commissioners and local tertiary paediatric neurology services. We are pleased to receive increased capacity from our joint paediatric neurology clinics in RDH, to allow visiting Paediatric Neurologists to review patients, and be entering a shared care system with the local tertiary centre to treat our most complex children.

Epilepsy Specialist Nurses - Epilepsy12 recommends 1 WTE Epilepsy Specialist Nurse per 250 patients. We had 2 WTE ESN working across both sites, with over 800 patients under the care of the Epilepsy Team. The ESNs were also regularly supporting general paediatricians, children's emergency staff, community paediatricians, schools, social workers, GPs and ambulance crews. This was alongside attending consultant/ESN clinics and providing regular epilepsy training sessions to parents, schools, nursery staff and hospital colleagues.

It was clear that this was unsustainable. A business plan was subsequently agreed by the Trust to appointment the epilepsy team dedicated administrative support and employ another 1 WTE ESN.

Speciality Doctor in Paediatrics - We were delighted that our service review and subsequent business plan enabled us to appoint a Speciality Doctor who will be able to provide clinics and care for children with epilepsy across both Burton and Derby sites.

Another service review at the end of the year will further track our progress and lead to more improvements.

Improving patient information about the epilepsy service

It is our usual practice to provide children, young people and families with a range of written information on various topics when they come to clinic. We have developed an easily accessible webpage for families to introduce our service and team, explain how the service is run, and provide contact details for the Children's Epilepsy Service and the outpatient department.

We provide information on investigations which may be recommended, for example EEGs, MRI brain scans, and links to general information about epilepsy, such as the Epilepsy Action and Epilepsy Society websites. We also provide advice on seizure management, including the RCPCH First Seizure advice leaflet, epilepsy first aid and safety as well as reducing risk, SUDEP, medication, the ketogenic diet, Vagal Nerve Stimulation, and the Children's Epilepsy Surgical Service.

There is specific information available for teenagers and young people about our teenage clinics as well as useful links and documents from Young Epilepsy. The Epilepsy12 audit continues to highlight a significant gap in the provision of support for children and young people's emotional wellbeing. Whilst we try to address this in our clinics, the website also signposts to local and national resources for this support.

Final reflections and plans for the future

Our team are proud of what we have achieved this year. We have felt well supported by our managers and the Trust, with more paediatric neurology expertise to improve the care of our children with epilepsy. We are delighted to have been able to expand our dedicated team and will continue to strive to improve our service.

Our future projects will be the continued development of our new Ketogenic Diet service, and extending the ESN training sessions to education settings to further include parents/carers. Additionally, we want to develop strategies to identify and support children and young people with epilepsy who have difficulties with emotional wellbeing.

Epilepsy12

Combined organisational and clinical audits:

Report for England and Wales Round 3 Cohort 3 (2019-21)

Published by the RCPCH July 2022



**Healthcare Quality
Improvement Partnership (HQIP)**

Dawson House, 5 Jewry Street,
London EC3N 2EX



**Royal College of Paediatrics
and Child Health**

5-11 Theobalds Road,
London, WC1X 8SH

The Royal College of Paediatrics and Child Health (RCPCH) is a registered charity in England and Wales (1057744) and in Scotland (SC038299).