Professional Record Standards Body

Better records for better care

EPILEPSY

DISCOVERY REPORT

May 2023

[DATE]

Document Management

Revision History

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Project Board		02-05-23	0.2
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Glossary of Terms

Term / Abbreviation	What it stands for
ABN	Association of British Neurologists
AEDs	Antiepileptic Drugs
BPNA	British Paediatric Neurology Association
CCG	Clinical Commissioning Group
CESS	Children's Epilepsy Surgery Service
CHOICE	Core Health Outcomes in Childhood Epilepsy
CIS	Core Information Standard
COPD	Chronic Obstructive Pulmonary Disease
COS	Core Outcome Set
CYP	Children and Young People
DGH	District General Hospital
E12	Epilepsy12
ED	Emergency Department
EEG	Electroencephalography
EHR	Electronic Health Record
EPR	Electronic Patient Record
EQIP	Epilepsy Quality Improvement Programme
ERUK	Epilepsy Research UK
GIRFT	Getting It Right First Time
GP	General Practice
HES	Hospitals Episodes Statistics
HQIP	Healthcare Quality Improvement Partnership
ILEA	International League Against Epilepsy
NASH	National Audit of Seizure Management in Hospitals
NCAPOP	National Clinical Audit and Patient Outcomes Programme
NEAD	Non-Epileptic Attack Disorder
OPEN UK	Organisation of Paediatric Epilepsy Networks in the UK
PCO	Primary Care Organisations
PCSP	Personalised Care and Support Plan
PRSB	Professional Records Standard Body
QOF	Quality And Outcomes Framework
RCPCH	Royal College of Paediatrics and Child Health
SUDEP	Sudden Unexpected Death in Epilepsy
TLoC	Transient Loss of Consciousness
WHO	World Health Organisation

Contents

1 Executive Summary

Use Case: Marie

Marie is a 23-year-old university student living in Edinburgh. She was diagnosed with epilepsy when she was 17 and living at home in Manchester. In the period between her first seizure and being seen by the first seizure clinic (about 7 weeks) she was seen by paramedics and ED staff almost weekly. Once diagnosed she had regular contact with a neurologist and the Manchester epilepsy nurse whilst trying to get her head around epilepsy, seizures, medication, and pacing.

After about 6 months of being diagnosed with epilepsy she moved to Edinburgh for university. In order to be on the waiting list for neurology in Edinburgh she had to be discharged from Manchester neurology's care, and have an address in Edinburgh. A long waiting list for Edinburgh neurology meant that for her first year and a half in Edinburgh she was not under the care of a neurology service. During this time she had contact with paramedics, was admitted to hospital (but never a neurology ward), and the GP. When seen by these services they were all reliant on Marie to provide the information about her medical history, due to the separation between NHS England and NHS Scotland health records.

When Marie was seen by neurology they seemed to have no record of the admissions of the last year and a half, on top of not yet having her records from Manchester, meaning she had to recall the past two years as best she could. Her epilepsy is now much more stable, and she has a call from a neurologist twice a year, and a video call with an epilepsy nurse twice a year. However, she is due to graduate and move away from Edinburgh this summer and is nervous about the prospect of having to navigate the period of being between services again.

Background

Epilepsy is one of the most common neurological conditions in the world. Its impact can vary considerably from person to person depending on which part of the brain is affected. Epilepsy can affect anyone of any age, gender, race or ethnicity, but is most commonly diagnosed in childhood and in people over the age of 60.

Epilepsy12 is the national clinical audit of seizures and epilepsies in children and young people for England and Wales. Epilepsy12 is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and the current Round 4 contract is being delivered by the Royal College of Paediatrics and Child Health (RCPCH) from April 2022 to March 2025.

The Epilepsy12 (E12) project team have identified the need for an agreed epilepsy information standard to facilitate sharing of data relating to a patient's epilepsy care between health and care settings, and for secondary use such as the national clinical audit.

Further, whilst the audit is undertaken by RCPCH, it is also recognised that any information standard must also meet the requirements of adults with epilepsy.

Scope

The scope of the project covers both children and adults with epilepsy. Scope includes data relating to epilepsy which:

- might be required at the point of care
- might be shared between different settings
- a patient might wish to share
- might be required for national audit and approved research or quality improvement purposes
- might be required to support care planning

Objectives

The overall aim of the project is to support the integrated and continuous care of epilepsy across settings by developing an information standard for epilepsy data items which can be utilised across all settings to facilitate sharing of data between these settings.

The key objectives are to:

- Agree a consensus definition of epilepsy data items
- Develop an information standard defining epilepsy data items
- Facilitate reduction in the inconsistency of data through a standard that will enable interoperability

Evidence review

An extensive evidence review has been undertaken including:

- National guidance
- Professional bodies
- Third sector
- Existing standards
- General evidence review
- Hospital epilepsy proforma review

Conclusions

Health inequalities

A number of health inequalities exist:

- Misdiagnosis of epilepsy is common. According to the evidence base, the rate of misdiagnosis of epilepsy in the UK is around 20-30%.
- Although overall UK age standardised mortality is decreasing, mortality attributed to epilepsy is on the increase, including SUDEP, and there are significantly higher mortality rates in the most deprived areas of England, in people with learning disabilities and epilepsy, and in pregnant women.
- The incidence and prevalence of epilepsy is at least a third higher in the most deprived areas of the UK than the least deprived, and people are three times more likely to die from their condition.
- Epilepsy accounts for 40% of all emergency admissions in people with a learning disability.
- People with learning disability are at higher risk of dying from epilepsy with factors increasing risk including severity of the learning disability

Comorbidities

The burden of comorbidity in people with epilepsy is high. Several diseases, including depression, anxiety, dementia, migraine, heart disease, peptic ulcers, and arthritis are up to eight times more common in people with epilepsy than in the general population.

One in every four people newly diagnosed with epilepsy is over the age of 65. These factors mean that people with epilepsy are likely to receive treatment and care from different specialities across multiple settings.

Range of pathways and settings

The complexity and heterogeneity of the disease means that there are a wide range of pathways and settings (as evidenced by the Getting it Right First Time (GIRFT) Neurology report patient journeys) which people with epilepsy might experience which would greatly benefit from information being automatically available in the right place at the right time.

Currently most professionals only have access to their own organisations electronic systems (and these may not currently be well integrated).

Patient experience and safety

People need to record information relating to their epilepsy, such as seizure diaries and care plans and may also use apps or a monitoring tool. There is a significant opportunity to make better use of this information and share it with healthcare professionals.

The wide ranging health inequalities identifies that patient safety is quite severely compromised.

Whole system transformation
There is a need for whole system transformation to address the challenges of managing long term conditions and 'joined-up care'. This should encompass multiple different IT systems spanning primary, community, secondary and tertiary service providers, together with information that people with epilepsy use to self-manage and which they might wish to share.

Whilst the standard is only one element of the jigsaw in terms of whole system change and it is not just technology but people and process, it is a fundamental building block to enable interoperability which will in turn enable transformation.

Research
The research trajectory for epilepsy is increasingly dependent on larger multi-centre population cohorts. Opportunities to invite specific subgroups to participate in research at various stages in the care pathway or undertake approved research studies using data derived from routine clinical care are paramount for the step changes required to improve outcomes. ERUK (Epilepsy Research UK) has recently identified 'big data analysis' as a key research priority amongst 10 key research priorities.

Existing standards
There is a significant overlap between the diabetes standard and that required for epilepsy. Alternative data sources have identified elements more specific to epilepsy. It is likely that there would be significant overlap in the management of most long-term conditions.

Prioritisation
Within the NHS Rightcare epilepsy toolkit, a saving of £12.1 million could be saved on non-elective spend for epilepsy if Clinical Commissioning Groups (CCGs) achieved the rate of their best 5 peers.

In their comment on the NHS Long Term Plan, Epilepsy Action note that the plan does mention epilepsy but disappointingly, epilepsy and other neurological conditions do not seem to be a priority for the NHS.

They go on to say:

The proposals to improve the care for children with epilepsy are encouraging. It is however disappointing that the Long Term Plan does not mention services for adults with epilepsy. It also makes no mention of the move from children to adult services (transition). These services are in need of drastic improvement. In addition, there is very little detail in the plan about wider neurology services.
Overall, it is disappointing that epilepsy is not given more priority in the Long Term Plan. Epilepsy and neurology services in the NHS are already under pressure. It is very concerning that these services are not given the focus they need. We have seen that when services for specific conditions are included in NHS strategic plans, huge improvements can be made to the care that people receive.
NASH also observe that:
Despite being the most common serious neurological condition (with around 600,000 people in the UK having the diagnosis), epilepsy is not high on the commissioning agenda – and indeed is often ignored behind the higher profiles of heart disease, chronic obstructive pulmonary disease (COPD), diabetes and stroke.

Charity organisations
The charity organisation resources reviewed in this report provide breadth of outstanding support in terms of information about epilepsy and living with epilepsy for both people with epilepsy and their family or carers, together with excellent resources to support individuals such as seizure diaries, care plans etc.

What did become obvious when reviewing many organisations for resources was that there was a significant amount of overlap in many of these areas.

Recommendations

Epilepsy SMI Information Standard
The draft standard should undergo full and extensive consultation to gain consensus from all stakeholders on the content of the information model. System suppliers should be engaged from the outset.

Comprehensive implementation support should be developed to facilitate successful implementation of the standard.

NHS England priorities
Given the health inequalities, the burden of comorbidities and the range of pathways and settings which a person with epilepsy might have to endure, together with the potential savings of £12.1 million identified by the NHS rightcare toolkit, NHSE might like to consider the opportunity to invest in a pilot implementation as a 'proof of concept' for this long term condition, in a similar fashion to diabetes.

Charitable organisations
Given the outstanding support and resources provided by charitable organisations, it appears there may be an opportunity to provide even more support by reducing duplication and freeing up resource. This might be done by working under the umbrella of one organisation, such as the Neurological Alliance, to set up an overarching board to agree allocation of work to be undertaken between parties.

Supplier engagement
Suppliers should be engaged throughout the process of development of the standard.

2 Background

2.1 Background

Epilepsy Research UK (ERUK) define epilepsy as:

A neurological condition characterised by seizures which are caused by excessive electrical activity within networks of neurons in the brain.

It is one of the most common neurological conditions in the world. Its impact can vary considerably from person to person depending on which part of the brain is affected. Epilepsy can affect anyone of any age, gender, race or ethnicity, but is most commonly diagnosed in childhood and in people over the age of 60.

There are over 40 different types of seizure, but the International League Against Epilepsy (ILAE) have identify 3 main types:

- *generalised onset*
- *focal onset*
- *seizures of unknown onset*

Seizures of generalised onset involve large areas on both sides of the brain and often result in loss of consciousness. Focal onset seizures affect a specific region in one side of the brain where consciousness may be altered but is not lost. Seizures of unknown onset are where the origin of the seizure is unclear.

The major challenge for all developed health and care systems is that of aging, lifestyle and long-term conditions. In the UK, we have a health and care system that was established primarily for delivering acute interventions, and we are now undergoing system-wide transformation to address this challenge.

There is consensus that all long-term conditions need more and better self-management. In addition, there are policy drives to move the health and care system to greater integration and to delivering population health.

2.2 Epilepsy12

Epilepsy12 is the national clinical audit of seizures and epilepsies in children and young people for England and Wales. Epilepsy12 is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and the current Round 4 contract is being delivered by the Royal College of Paediatrics and Child Health (RCPCH) from April 2022 to March 2025.

Epilepsy12 has seen considerable variation in the ability of different Health Boards and Trusts in England and Wales to provide adequate workforce time and resources to participate and manually enter data into the national audit. This has been particularly challenging throughout the COVID-19 pandemic.

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

- A clinical audit describing the care provided to children and young people newly diagnosed with epilepsy during their first year of care. Patients are split into cohorts according to the date of their first paediatric assessment and are followed for the subsequent 12 months of care.
- An organisational audit of paediatric epilepsy services, focusing on services and workforce at Trust/Health Board level, as they were in November of each year.
- Quality improvement activities and projects related to the audit. The annual report contains case study examples from NHS Trusts/Health Boards, the Epilepsy Quality Improvement Programme (EQIP) and the Epilepsy12 Youth Advocates, showing ways services have been working together to make lasting improvements in care.

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 in England and Wales.

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.

The latest RCPCH National Clinical Audit of Seizures and Epilepsies for Children and Young People Annual combined report[1] was published in November 2022. This report described clinical data for cohort 3 patients, who had their first paediatric assessment between 1 December 2019 and 30 November 2020, and organisational data from November 2021. These data cover the care provided to children and young people during the COVID-19 pandemic and a time where the NHS was dealing with a significant surge in COVID-19 cases and hospitalisations in England and Wales.

The Epilepsy12 (E12) project team have identified the need for an agreed epilepsy information standard to facilitate sharing of data relating to a patient's epilepsy care between health and care settings, and for secondary use such as the national clinical audit.

Further, whilst the audit is undertaken by RCPCH, it is also recognised that any information standard must also meet the requirements of adults with epilepsy.

2.3 Drivers

There are many other drivers for the epilepsy community to agree and embed data standards for epilepsy. The RCPCH passport is an example of a patient facing resource that was published in 2015 to support families having up to date copies of their epilepsy health details. Implementation was difficult because there were no established routes to update and derive that information from Electronic Health Records (EHRs). This issue is also problematic for many types of epilepsy care planning as updating accurate and consistent information about a person's diagnosis is a key component. E12 2022 reported 77% (91/119) of Trusts/Health Boards having some type of local database or registry for their epilepsy patients. There is no evidence these describe epilepsy diagnoses and care in consistent ways or are linked to EHRs. The multi-axial nature, complexity and heterogeneity of epilepsy diagnosis, its relationship with other co-morbidities and its evolution over time means, that the interoperability and aggregation of datasets are particularly difficult.

Within primary care or Trust/Health Board EHRs the diagnosis of epilepsy is not consistently recorded. This limited system-wide visibility of those with epilepsy and the consistency with which that diagnosis and care is recorded within EHRs constrains a number of key activities. Examples include

- The coding of admissions and Emergency Department (ED) attendances for people with or because of epilepsy, is not systematically recorded within Hospital Episodes Statistics (HES) data.
- National activity and outcome epilepsy dashboards to inform service commissioning have limited options to visualise epilepsy-related diagnoses, activity and outcomes and are reliant on admission data.
- The research trajectory for epilepsy is increasingly dependent on larger multi-centre population cohorts. Opportunities to invite specific subgroups to participate in research at various stages in the care pathway or undertake approved research studies using data derived from routine clinical care are paramount for the step changes required to improve outcomes. ERUK (Epilepsy Research UK) has recently identified 'big data analysis' as a key research priority amongst 10 key research priorities.
- Core20plus5 for children states epilepsy, particularly those with learning disability and/or autism as a key priority for reducing inequities.

[1] Epilepsy12 2022 Combined organisational and clinical audits: Report for England and Wales Round 3, Cohort 3 (2019-21) Version 2.0: Updated November 2022: RCPCH Audits

2.4 Scope

2.5 In scope

The scope of the project covers both children and adults with epilepsy. Scope includes data relating to epilepsy which:

- might be required at point of care
- might be shared between different settings
- a patient might wish to share
- might be required for national audit and approved research or quality improvement purposes
- might be required to support care planning

2.6 Exclusions from scope

Project scope does not include the development of integrated personalised care and support plans (PCSPs).

Project scope does not include wearable devices.

Work required to:

- undertake consultation
- finalise the standard and supporting documentation
- commission development of corresponding technical messages from NHS Digital
- complete the process of endorsement by members.

2.7 Objectives

The overall aim of the project is to support the integrated and continuous care of epilepsy across settings by developing an information standard for epilepsy data items which can be utilised across all settings to facilitate sharing of data between these settings.

The key objectives are to:

- Agree a consensus definition of epilepsy data items
- Develop an information standard defining epilepsy data items
- Facilitate reduction in the inconsistency of data through a standard that will enable interoperability

The objectives of the Discovery Phase are to:

- Identify Use Case(s)
- Gather evidence from research and a literature review
- Map to existing standards
- Obtain expert input to develop a first draft standard
- Set out the plan, approach, costs, and recommendations for taking the work forward into delivery

3 Method

3.1 Project Advisory Group

At an early stage in the project, PRSB identified clinical and citizen advisors who can provide expert advice and guidance:

Ally Lloyd	Citizen Lead	
Colin Dunkley	Clinical Lead	Consultant Paediatrician, Clinical Lead for Epilepsy12 audit RCPCH, Short Course Content Manager for British Paediatric Neurology Association and member of the Implementation Task Force for the International League Against Epilepsy.
James Mitchell	Clinical Adviser	Association of British Neurologists (ABN) Clinical Research Fellow and neurology registrar

Regular meetings are held with the advisors during the Discovery Phase to review findings, provide expert advice and inform recommendations.

3.2 Evidence Review

3.2.1 NICE Guidance

NICE guidance on epilepsy includes:

NG217 Epilepsies in children, young people and adults. Published: 27 April 2022

CG 109 Transient loss of consciousness ('blackouts') in over 16s. Published: 25 August 2010 Last updated: 01 September 2014

NG 150 Supporting adult carers. Published: 22 January 2020

CG76 Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence. Published: 28 January 2009

NG5 Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes. Published: 04 March 2015

CG91 Depression in adults with a chronic physical health problem: recognition and management. Published: 28 October 2009

NG54 Mental health problems in people with learning disabilities: prevention, assessment and management. Published: 14 September 2016

QS26 Epilepsy in adults Published: 28 February 2013

QS27 Epilepsy in children and young people Published: 28 February 2013

3.2.2 Health Improvement Scotland SIGN

SIGN guidance on epilepsy includes:

SIGN159 Epilepsies in children and young people: Investigative procedures and management May 2021

SIGN143 Diagnosis and management of epilepsy in adults updated September 2018

3.2.3 NHS England Service Specifications

NHS England service specifications relating to epilepsy include:

E09/S/b Paediatric Neurosciences - Neurology

E09/S/c Paediatric Neurosciences: Neurodisability

E09/S/e Children's Epilepsy Surgery Service (CESS)

3.2.4 NHS RightCare: Epilepsy Toolkit

NHS England identify that in England, people living with epilepsy and the systems supporting them are experiencing challenges including high misdiagnosis rates; inaccurate epilepsy population estimates; increasing mortality attributed to epilepsy and a lack of optimal management strategies that could reduce unnecessary emergency care for people living with epilepsy.

The NHS RightCare: Epilepsy Toolkit was developed in partnership with Epilepsy Action, SUDEP Action and Young Epilepsy, this Epilepsy Toolkit will support systems to understand the priorities in epilepsy care and key actions to take. It provides opportunity to assess and benchmark current systems to find opportunities for improvement. It is produced with reference to an expert group of stakeholders and is supported by NICE.

Wider consultation took place with patient representatives, clinicians, social care organisations, professional bodies and other key stakeholders.

3.2.5 Professional bodies resources

3.2.5.1 Royal College of Paediatrics and Child Health

RCPCH resources were reviewed.

3.2.5.2 OPEN UK

Organisation of Paediatric Epilepsy Networks in the UK (OPEN UK) is a clinical network connecting NHS Health Boards and Trusts that provide care for children with epilepsies with regional epilepsy networks and a UK Working Group.

OPEN UK aims to unite children's regional and national epilepsy networks to improve integrated care for children and young people with epilepsies and has representation from all regional epilepsy networks.

It also aims 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

OPEN UK members were requested to send or signpost to empty templates, proformas, care plans, passports that they may currently use to capture epilepsy care.

3.2.5.3 International League Against Epilepsy

The International League Against Epilepsy (ILEA) is the world's preeminent association of health care professionals and scientists working toward a world where no person's life is limited by epilepsy.

3.2.6 Third sector resources

The resources from the following third sector organisations were reviewed:

- Epilepsy Research UK
- SUDEP *Action*
- Young epilepsy
- Epilepsy society
- Epilepsy action
- Epilepsy Scotland

3.2.7 GIRFT

Getting It Right First Time (GIRFT) is a national programme designed to improve the treatment and care of patients through in-depth review of services, benchmarking, and presenting a data-driven evidence base to support change.

The programme undertakes clinically-led reviews of specialties, combining wide-ranging data analysis with the input and professional knowledge of senior clinicians to examine how things are currently being done and how they could be improved.

GIRFT is part of an aligned set of programmes within NHS England. The programme has the backing of the Royal Colleges and professional associations.

The Neurology GIRFT Programme National Specialty Report (September 2021) has been reviewed.

3.2.8 Existing Standards

3.2.8.1 PRSB

PRSB's Core Information Standard (CIS) sets out the requirements of a person-centred care record. All other PRSB information standards are developed by reference to the CIS, and many are incorporated within it. The proposed Epilepsy Information Record Standard will be similarly integrated with the CIS ensuring a consistent clinical model and enabling interoperability.

It is anticipated that the development of the new information standard will draw on fields from existing PRSB Information Standards. In particular the Diabetes Information Standard, which will be used as a foundation as

it is also a standard for a long-term condition with monitoring requirements, medications, medical devices and care planning.

In addition to drawing on fields from these existing standards, the Epilepsy Information Record Standard project work may identify the need to include additional fields in these existing standards.

3.2.8.2 Alternative data sources

The following data sources were reviewed:

- International Consortium for Health Outcomes Measurement ICHOM Patient-Centred Outcomes Measures Epilepsy.
- A Core Outcome Set specific to adults with epilepsy EPSET
- The Core Health Outcomes In Childhood Epilepsy CHOICE
- NASH

PRSB would like to gratefully acknowledge the contributions by the following organisations:

- Gloucestershire Hospitals NHS Foundation Trust InfoFlex - Paediatric Epilepsy Data Dictionary

3.2.9 General Evidence Review

A general review was undertaken using key words ‘epilepsy information standard’, ‘epilepsy record’, ‘SUDEP’ and ‘international epilepsy record’. Relevant guidelines and research papers are referenced through the report.

3.2.10 Hospital Epilepsy Proforma Review

Blank proformas relating to epilepsy were received from hospitals in the UK to assess what information is currently being recorded by healthcare professionals. PRSB would like to gratefully acknowledge the contributions by the following organisations:

- St George’s Healthcare
- Chelsea and Westminster Hospital NHS Foundation trust
- University Hospital Lewisham
- Somerset NHS Foundation Trust
- Harrogate and District NHS Foundation Trust
- University Hospitals of Derby and Burton NHSFT
- Paediatric Epilepsy Service Ayrshire and Arran
- North West Anglia NHS Foundation Trust
- Princess Royal University Hospital
- Warrington And Halton Teaching Hospitals NHS Foundation Trust
- Royal Berkshire Hospital
- Royal Aberdeen Children's Hospital
- York and Scarborough Teaching Hospitals NHS Foundation Trust
- Warwick Hospital
- NHS Borders
- County Durham and Darlington NHS Foundation Trust
- Sheffield, Chesterfield and Rotherham Epilepsy Liaison Service
- The Newcastle Upon Tyne Hospitals NHS Foundation Trust

4 Findings

4.1 NICE Guidance

NICE guidance was reviewed and the information requirements identified were used to develop the draft information model.

4.1.1 NG217 Epilepsies in children, young people and adults

NG217 guideline covers diagnosing and managing epilepsy in children, young people and adults in primary and secondary care, and referral to tertiary services. It aims to improve diagnosis and treatment for different seizure types and epilepsy syndromes, and reduce the risks for people with epilepsy.

NG217 guideline includes recommendations on:

- referral, assessment and diagnosis
- information and support
- principles of treatment, treating epileptic seizures and treating childhood-onset epilepsies
- non-pharmacological treatments
- status epilepticus, repeat or cluster seizures, and prolonged seizures
- managing comorbidities
- reducing the risk of epilepsy-related death
- referral to tertiary services
- epilepsy specialist nurses and transition from children's to adults' services

The visual summary of the recommendations for people with epilepsy and a learning disability is shown at Appendix A.

4.1.2 CG109 Transient loss of consciousness ('blackouts') in over 16s

CG109 guideline covers assessment, diagnosis and referral for people over 16 who have had a transient loss of consciousness (TLoC; also called a blackout). It aims to improve care for people with TLoC by specifying the most effective assessments and recommending when to refer to a specialist.

CG109 guideline includes recommendations on:

- initial assessment
- further assessment and referral
- specialist cardiovascular assessment and diagnosis
- assessment when the cause of transient loss of consciousness is still uncertain
- information for people with transient loss of consciousness

4.1.3 NG150 Supporting adult carers

NG150 This guideline covers support for adults (aged 18 and over) who provide unpaid care for anyone aged 16 or over with health or social care needs. It aims to improve the lives of carers by helping health and social care practitioners identify people who are caring for someone and give them the right information and support. It covers carers' assessments, practical, emotional and social support and training, and support for carers providing end of life care.

NG150 is not considered to be within the scope of this project.

4.1.4 CG76 Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence

CG76 guideline covers medicines adherence in people aged 18 and over. It recommends how to encourage adherence to medicines by supporting and involving people in decisions about their prescribed medicines. It aims to ensure that a person's decision to use a medicine is an informed choice.

CG76 guideline includes recommendations on:

- patient involvement in decisions about medicines
- supporting adherence
- reviewing medicines
- communication between healthcare professionals

4.1.5 NG5 Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes

NG5 guideline covers safe and effective use of medicines in health and social care for people taking 1 or more medicines. It aims to ensure that medicines provide the greatest possible benefit to people by encouraging medicines reconciliation, medication review, and the use of patient decision aids.
NICE has also produced a guideline on medicines adherence.

NG5 guideline includes recommendations on:

- systems for identifying, reporting and learning from medicines-related patient safety incidents
- medicines-related communication systems for when patients move from one care setting to another
- medicines reconciliation and medication review
- self-management plans
- patient decision aids

Whilst safe and effective use of medications is critical within epilepsy and recording relevant medication is in scope, **NG5 is not considered to be within the scope of this project.**

4.1.6 CG91 Depression in adults with a chronic physical health problem: recognition and management.

CG91 This guideline covers identifying, treating and managing depression in people aged 18 and over who also have a chronic physical health problem such as cancer, heart disease or diabetes. It aims to improve the care of people with a long-term physical health problem, which can cause or exacerbate depression. This has the potential to increase their quality of life and life expectancy.
NICE has also produced a guideline on depression in adults: treatment and management.

CG91 guideline includes recommendations on:

- care of all people with depression
- stepped care
- recognition, assessment and initial management
- persistent subthreshold depressive symptoms or mild to moderate depression
- persistent subthreshold depressive symptoms, mild to moderate depression with inadequate response to initial interventions or moderate and severe depression
- complex and severe depression

Whilst it is acknowledged that people with epilepsy are at a higher risk of mental health problems and that it is important to record depression, **the scope of this project is to include the information in the record, not to address recognition and management.**

4.1.7 NG54 Mental health problems in people with learning disabilities: prevention, assessment and management

NG54 guideline covers preventing, assessing and managing mental health problems in people with learning disabilities in all settings (including health, social care, education, and forensic and criminal justice). It aims to improve assessment and support for mental health conditions, and help people with learning disabilities and their families and carers to be involved in their care.

NG54 guideline includes recommendations on:

- organising and delivering care
- involving people in their care
- prevention, including social, physical environment and occupational interventions
- annual GP health checks
- assessment
- psychological interventions, and how to adapt these for people with learning disabilities
- prescribing, monitoring and reviewing pharmacological interventions

Whilst it is acknowledged that people with epilepsy are at a higher risk of learning disabilities and mental health problems and that it is important to record learning difficulties, **the scope of this project is to include the information in the record, not to address recognition and management.**

4.1.8 QS26 Epilepsy in adults

Note: QS26 is currently being updated in line with updated guidance

QS26 covers the diagnosis and management of the epilepsies in adults (aged 18 years and older). For more information see the scope for this quality standard.

Introduction

Epilepsy is a common neurological disorder characterised by recurring seizures. It is estimated that 320,000 adults in England with a diagnosis of epilepsy are currently receiving anti-epileptic drugs. There are more than 40 different types of epilepsy, with 40 different associated seizure types. The nature of epilepsy means that it can be difficult to diagnose accurately. NICE clinical guideline 137 estimates that in 5–30% of people diagnosed with epilepsy the diagnosis is incorrect. A diagnosis of epilepsy can have a wide-ranging impact on a person's health and lifestyle. A key part of this quality standard is therefore focused on improving the diagnosis of epilepsy and ensuring that diagnosis and treatment are confirmed and reviewed as necessary.

For many adults diagnosed with epilepsy the seizures can be controlled through treatment with an anti-epileptic drug or other interventions. Optimal management improves health outcomes and can help to minimise other, often detrimental, impacts on social, educational and employment activity. This quality standard therefore includes a focus on tailoring treatment to the individual circumstances and needs of people with epilepsy so that they are offered the most suitable treatment.

List of quality statements

Statement 1. Adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.
Statement 2. Adults having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.
Statement 3. Adults who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.
Statement 4. Adults with epilepsy have an agreed and comprehensive written epilepsy care plan.
Statement 5. Adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.
Statement 6. Adults with a history of prolonged or repeated seizures have an agreed written emergency care plan.
Statement 7. Adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

Statement 8. Adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services.
Statement 9. Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

4.1.9 QS27 Epilepsy in children and young people

Note: QS27 is currently being updated in line with updated guidance.

QS27 covers the diagnosis and management of the epilepsies in children and young people (aged up to 18 years).

Introduction

Epilepsy is a common neurological disorder characterised by recurring seizures. It is estimated that 34,000 children and young people in England with a diagnosis of epilepsy are currently receiving anti-epileptic drugs. There are more than 40 different types of epilepsy, with 40 different associated seizure types. The nature of epilepsy means that it can be difficult to diagnose accurately. NICE's guideline on epilepsies: diagnosis and management estimates that in 5–30% of people diagnosed with epilepsy the diagnosis is incorrect. The Joint Epilepsy Council (2011) reported that up to 40% of children referred to tertiary epilepsy clinics do not have epilepsy. A diagnosis of epilepsy can have a wide ranging impact on a child or young person's health and lifestyle. A key part of this quality standard is therefore focused on improving the diagnosis of epilepsy and ensuring that diagnosis and treatment are confirmed and reviewed as necessary.

For many children and young people diagnosed with epilepsy the seizures can be controlled through treatment with an anti-epileptic drug or other interventions. Optimal management improves health outcomes and can help to minimise other, often detrimental, impacts on social, educational and employment activity. This quality standard therefore includes a focus on tailoring treatment to the individual circumstances and needs of children and young people with epilepsy so that they are offered the most suitable treatment.

List of quality statements

Statement 1 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.
Statement 2 Children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.
Statement 3 Children and young people who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.
Statement 4 Children and young people with epilepsy have an agreed and comprehensive written epilepsy care plan.
Statement 5 Children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.
Statement 6 Children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan.
Statement 7 Children and young people who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.
Statement 8 Children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually.
Statement 9 Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

4.2 Health Improvement Scotland SIGN

SIGN guidance was reviewed and as would be expected from evidence-based guidance aligns closely with NICE.

4.2.1 SIGN143

In the introduction to SIGN143 Diagnosis and management of epilepsy in adults [2]identifies why the guidance is needed:

"Since the publication of SIGN 70 in 2003 there has been an expansion in the number of epilepsy specialists, and improved and faster access to clinics devoted to epilepsy and first seizures. The number of drugs available to treat epilepsy has increased and the range of imaging, surgical and interventional techniques has risen.

Collectively, these changes have helped to bring about the improvements in care highlighted as necessary in the previous guideline. Despite these improvements, however, the scale and scope of the need for a guideline should not be underestimated. In Scotland there are 54,000 people with active epilepsy affecting all ages, and there will be between 2,000 and 3,500 new diagnoses each year.

The low number of epilepsy specialists in previous decades means that many people with epilepsy across the UK have been diagnosed and treated by non-specialists in both primary and secondary care. Up to a quarter of patients referred for specialist management of apparent drug-resistant epilepsy do not have epilepsy and around 50% of referrals to first seizure clinics result from events which are not epileptic. There is evidence that management can sometimes be suboptimal,(3-5) and with some intervention, readily improved.(3, 5) Epilepsy carries a small but significant risk of mortality which is increased where seizure control is incomplete. Specific concerns surround initial diagnosis, drug treatment, management of pregnant women with epilepsy and the provision of patient information. It is likely that the incidence of sudden unexpected death in epilepsy (SUDEP) could be reduced if antiepileptic treatment was always optimised and patients made aware of the importance of adherence. There is room for improvement in the diagnosis and management of status epilepticus and in the care and advice provided for women of reproductive age. People with epilepsy often report inadequate provision of information and advice. Such needs were highlighted in the previous guideline and, over ten years on, there remains scope for the development of better epilepsy services in both primary and secondary care."

Summary recommendations are shown at Appendix B.

4.2.2 SIGN159

In the introduction to SIGN159 Epilepsies in children and young people: Investigative procedures and management[3] identifies why the guidance is needed:

"Epilepsy is the most common serious neurological disorder in children. The epilepsies are a heterogeneous group of conditions that have differing diagnostic criteria, management and widely differing outcomes, not only of seizure control but also in terms of implications for learning and behaviour. It is therefore important to identify the specific epilepsy syndrome and aetiology wherever possible to refine the choice of treatment in order to maximise benefit and minimise adverse effects. Children and their parents will also benefit from information appropriate to their particular type of epilepsy.

The number of antiepileptic drugs (AEDs) has rapidly increased in recent years. Owing to a lack of pharmaceutical research in paediatric epilepsy, some of these medications are unlicensed, holding no current marketing authorisation, or are used outside the indication or age range for which they are licensed (off-label use). This makes selecting an appropriate AED even more complex (see section 1.3.2 and Annex 2).

Teenagers with epilepsy often have specific needs that are not well addressed by paediatric and adult services. Some of these are covered in SIGN 143: Diagnosis and management of epilepsy in adults. Epilepsy is associated

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[2] Grinspan, Z. M., Patel, A. D., Shellhaas, R. A., Berg, A. T., Axeen, E. T., Bolton, J., Clarke, D. F., Coryell, J., Gaillard, W. D., Goodkin, H. P., Koh, S., Kukla, A., Mbwana, J. S., Morgan, L. A., Singhal, N. S., Storey, M. M., Yozawitz, E. G., Abend, N. S., Fitzgerald, M. P., … Buchhalter, J. (2021). Design and implementation of electronic health record common data elements for pediatric epilepsy: Foundations for a learning health care system. Epilepsia, 62(1), 198–216. https://doi.org/10.1111/epi.16733

[3] Donahue, M. A., Herman, S. T., Dass, D., Farrell, K., Kukla, A., Abend, N. S., Moura, L. M. V. R., Buchhalter, J. R., & Fureman, B. E. (2021). Establishing a learning healthcare system to improve health outcomes for people with epilepsy. Epilepsy and Behavior, 117. https://doi.org/10.1016/j.yebeh.2021.107805

with significant comorbidities and increased incidence of neurodevelopmental disorders (see section 7.1). Recognition and management of coexisting psychiatric comorbidities can be challenging.

Within NHS Scotland, referral, diagnosis and management of childhood epilepsy occur in primary, secondary and tertiary care settings. A guideline specifically addressing the key areas of care in the management of epilepsy in children helps enable a standardised service to be provided across all of these settings.

Taking all of the above into consideration, there is a clear need for evidence-based guidance to enable healthcare professionals to:

- appropriately investigate children presenting with seizures
- consider correct management
- provide appropriate information about epilepsy, morbidity, risks of mortality and comorbidities
- recognise those who do not respond to initial treatment and consider prompt further treatment
- identify neurodevelopmental and psychiatric comorbidities early, for further management, and
- create a clear transition plan for those children who continue to have epilepsy into their adult life.

Summary recommendations are shown at Appendix C.

4.3 NHS England Service Specifications

4.3.1 E09/S/b Paediatric Neurosciences – Neurology

It has been estimated that 2-3% of the child population will have some level of special needs and/ or disability. 0.3-0.5% will have severe learning disabilities. The vast majority of disabilities are neurological in origin. Paediatric epilepsy is the most common neurological disorder with an overall childhood incidence of 50-70 cases per 100,000 per year and a childhood prevalence of 5-10 cases per 1,000 population. This affects about 0.7% of all children as shown in the table below.

Non-traumatic acute encephalopathy has an incidence of approximately 50 per 100,000 per year. Metabolic disorders may present either as an acute encephalopathy or as long term neurological illness. Individual conditions are rare (e.g. phenylketonuria (PKU), 8.5 per 100,000. Many of the neuromuscular conditions are rare but all lead to significant morbidity. The overall prevalence of an inherited neuromuscular disease may well exceed 33/100,000 and a large proportion of these will be in the paediatric age group. 4 per 100,000 children aged 0-16 years will be diagnosed with a tumour of the central nervous system.

Condition	Prevalence	Estimated number in PCO
Cerebral Palsy	3/1000 live births	110
Autistic spectrum Disorder	1/100	500
Epilepsy	0.7/100	350
Severe Learning disabilities	0.3/100	150
Acquired brain injury	18/100,000	9
Muscular dystrophy	0.3/1000 male births	5

Information requirements mainly relate to investigations and procedures and are covered by NICE guidance.

4.3.2 E09/S/c Paediatric Neurosciences: Neurodisability

Neurodisability is an umbrella term for conditions associated with impairment involving the nervous system and includes conditions such as cerebral palsy, autism and epilepsy; it is not uncommon for such conditions to co-occur. Children with a neurodisability have a range of impairments but many have complex and continuing need and as a result are frequent users of the health service at all levels, community, primary care inpatient and outpatient settings.

Information requirements mainly relate to investigations and procedures and are covered by NICE guidance.

4.3.3 E09/S/e Children's Epilepsy Surgery Service (CESS)

The Children's Epilepsy Surgery Service (CESS) centre is commissioned to provide specialist epilepsy pre-surgical evaluation and surgery to children in specialised CESS centres, for the population of England.

Epilepsy surgery is increasingly recognised as beneficial in selected children. There is also evidence that children should be considered earlier rather than later in view of the consequence of ongoing seizures on brain development. Emerging evidence suggests there are significant advantages with early surgery (especially in children under 5).

When examining the current activity for epilepsy surgery in England against international benchmarks, less than half the numbers of procedures are performed each year that would be considered to be beneficial for the population of children.

Currently there is evidence that children are taking 2 years to move through the clinical and functional assessment and evaluation process to surgery and more urgency is needed where neuro-development can be compromised through delay in operation beyond one year of onset. A recent audit (2008) demonstrated that only 35% of children had surgery within 2 years of the onset of symptoms.

The aim of the service is to improve the uptake and access to epilepsy surgery in those children for whom surgical control or amelioration for their epilepsy is a possibility.

In terms of data the specification identifies that referrals to the CESS must include a minimum of:

- Clinical history, including perinatal history, seizure onset, seizure types, medication history / treatment history, neurodevelopmental progress, family history, other medical problems, investigation history, neurological examination
- MRI using specified protocols in line with national protocols
- EEG including period of sleep in line with national protocols

For children where specialist treatment is indicated, a comprehensive specialist in-patient assessment and pre–surgical evaluation will be required following preliminary review. The pre-surgical assessment will incorporate:

- Interictal sleep EEG recording
- Video EEG recording of seizures
- MRI with specified protocol including serial scans if appropriate
- Functional imaging as required
- Age-appropriate neuropsychology or neurodevelopmental assessment, diagnosis and advice on educational interventions/treatment
- Neuropsychiatry assessment and treatment

Guidance on information to be provided to patients and family or carers is covered within NICE guidance.

4.4 NHS Rightcare Epilepsy Toolkit

This NHS RightCare system toolkit will support systems to understand the priorities in epilepsy care and key actions to take. It provides opportunity to assess and benchmark current systems to find opportunities for improvement. It is produced with reference to an expert group of stakeholders and is supported by NICE. Wider consultation has taken place with representatives of people living with epilepsy, clinicians, social care organisations, professional bodies and other key stakeholders.

The National Challenges:

- *Mortality attributed to epilepsy (~1200 deaths per year) is increasing even though overall U.K. mortality is decreasing. In people with learning disabilities epilepsy mortality is higher (5%) than the general population (<1%).*
- *20-30% of people are misdiagnosed with epilepsy in the U.K. suggesting unclear pathways for people with Non-epileptic Attack Disorder (NEAD) or other causes for seizures.*

- *There is a lack of optimal management of epilepsy leading to unnecessary emergency care for people with epilepsy.*
- *The true epilepsy population in England is not accurately known as the only register of patients with epilepsy is recorded through the Quality and Outcomes Framework (QOF), and this only records "Patients aged over 18 and who are receiving drug therapy".*

The National RightCare Opportunity:

- *Around £12.1m* could be saved on non-elective spend for epilepsy if CCGs achieved the rate of their best 5 peers†*
- *Nearly 5,300 fewer adults, and around 3,700 fewer children, admitted non-electively for epilepsy if CCGs achieved the rate of their best 5 peers†*

**The approaches outlined within the toolkit should contribute to delivery of efficiency opportunities outlined within RightCare packs, however the impact at a local level may differ based upon system configuration, capacity and contractual arrangements and potential need to invest in alternative services, where these do not currently exist.*

†Potential national opportunities represent the sum of potential opportunities for all CCGs, if all CCGs with significantly worse (higher or lower, dependent on outcome measure) values reduce or increase these values to the average of the 'Best' 5 of their nearest 10 CCGs.

The toolkit provides useful background information relating to epilepsy[4].

Overall prevalence in England according to 2017-18 Quality Outcomes Framework data is 0.8% where 362,000 to 415,000 people in England have been affected by epilepsy and 30% of people with epilepsy who receive care in any setting will have a learning disability. However this figure only captures those over 18 years old and who are on anti-epileptic drugs (AEDs). Accurate estimates of incidence and prevalence are difficult to predict as it is challenging to identify people who may have epilepsy including children, young people and the elderly. Therefore, understanding the true epilepsy population of England and how it differs in different geographic areas will provide a focus for improving systems tailored to the local needs of the epilepsy population.

Misdiagnosis of epilepsy is common. According to the evidence base, the rate of misdiagnosis of epilepsy in the UK is around 20-30%. The majority of these occur when the diagnosis is made by a non-epilepsy specialist. Clinicians making the diagnosis may not have sufficient training or experience in epilepsy and may not have easy access to the full range of appropriate investigations. Epilepsy has a large differential diagnosis, with a widespread lack of understanding about non-epileptic seizures amongst non-epilepsy specialist clinicians.

Although overall UK age standardised mortality is decreasing, mortality attributed to epilepsy is on the increase. There are approximately 1200 epilepsy-related deaths a year in the U.K. where 50% of those are attributable to Sudden Unexpected Death in Epilepsy (SUDEP). There is significantly higher mortality rates in the most deprived areas of England are almost three times higher than in lesser deprived areas. The overall life expectancy for people living with epilepsy is 70 years whereas the mean peak age for SUDEP is 20-40 years. Additionally, there have been higher deaths in people with learning disabilities and epilepsy (5%) compared to the general population who also live with epilepsy (<1%).

Support for children and young people

Epilepsy is the most common neurological disorder in childhood, affecting 112,000 children and young people in the U.K. The quality of care for children and young people (CYP) requires improvement and a reduction in variation across the system in line with NICE guidelines. Improvements are needed in the accuracy of diagnoses and adequate communication and care planning including comorbidity diagnosis management and school support. Epilepsy can have a significant impact on children's cognition and behaviour. This can affect their educational progress and consequently their life opportunities. A large proportion of children and young people's time is spent at school, under the care of school staff. Children rely on school staff to have sufficient knowledge and training to keep them safe and enable them to learn effectively. Children with neurological conditions, such

[4] NICE guidance references have been removed to avoid repetition.

as epilepsy, are known to have particularly high rates of mental health disorders. 37% of children with epilepsy have a mental health problem but only 13% of paediatric epilepsy clinics provide mental health support. Being a parent, carer or guardian of a child with epilepsy can be distressing. The biggest challenge that parents face is the fear of the unknown, therefore having some knowledge and information about the condition will increase confidence.

Support for people transitioning from child to adult services

Transitioning from child to adult services can be daunting for the patients and families. New risks may start to develop that can have an impact on the young person's condition such as lack of sleep; alcohol consumption and not taking medications or taking them regularly. The transition is often not clearly communicated and the change in service provision can have a negative impact on the person. This can cause anxiety due to fears of 'slipping through the net' during transition and dealing with unfamiliar and uncomfortable surroundings. Furthermore, there is a need to ensure that processes are efficient and timely to make sure there is adequate time to plan and implement transitions.

Support for people with learning disabilities

17.9% of patients with learning disabilities also have epilepsy and have a higher risk of unexpected death including SUDEP or dying from an accident or injury. In the learning disabilities population, 5% of all deaths are attributed to epilepsy as the primary cause of death, compared to <1% in the general population. There are 7% of gaps in provision in epilepsy care for people with learning disabilities and epilepsy is the number one reported co-morbidity long term health condition associated with the deaths (LeDeR Annual Report, 2018). Furthermore, epilepsy accounts for 40% of all emergency admissions in people with a learning disability. Therefore it is vital that adequate support is provided to healthcare professionals and also families and carers of this specific group in order to minimise the risks of injury and death and to ensure best treatment outcomes.

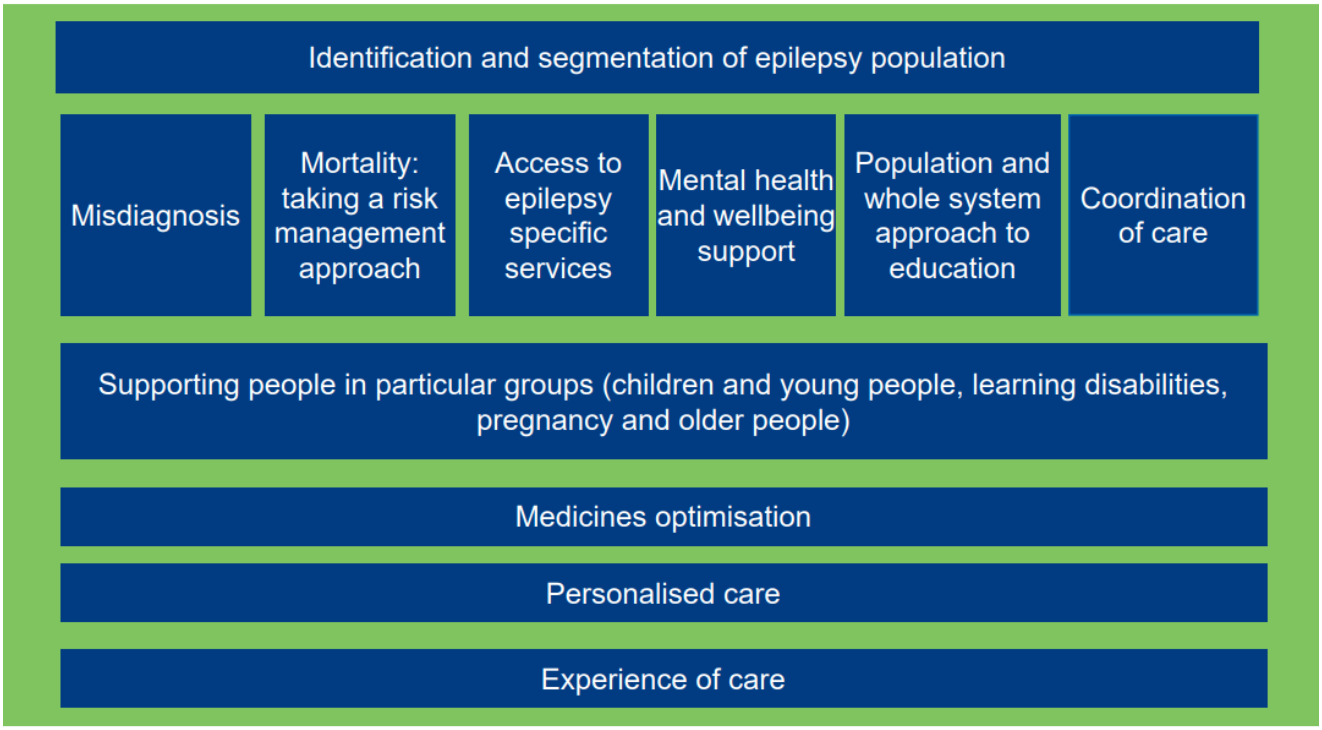
Support in pregnancy

It is vital to have an approach to support not only women with epilepsy who are pregnant but who are of childbearing age in making clear the risks of certain anti-epileptic drugs (AEDs) that are known to cause birth defects (e.g. sodium valproate). Equally, it is important to provide clear information and guidance on the risks of stopping an AED treatment (e.g. SUDEP) that is not related to causing birth defects and the risks that poses to herself and unborn baby to support balanced informed decisions on care.

Support for older people

Epilepsy is often undiagnosed, under-referred and confused with other conditions in the elderly. Due to frailty, a seizure can cause significant harm that can lead to further injuries therefore is important to develop sufficient support for this patient group

The toolkit identifies significant savings could be made in non-elective spend if improvements were realised.



Within the rightcare toolkit there are extensive epilepsy resource references, and these have been reviewed in the context of identifying relevant data.

4.5 Professional bodies resources

4.5.1 Royal College of Paediatrics and Child Health

RCPCH provide a downloadable paper record, an Epilepsy Passport (Appendix D), which gives essential up-to-date information about a child or young person's epilepsy. This includes their emergency care plan, medication history and key professional contacts.

The RCPCH Epilepsy12 national audit provides insight into the diagnosis and care of children and young people with epilepsy, and the organisation of paediatric epilepsy services in England and Wales. Established in 2009, Epilepsy12 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.

Epilepsy12 is the national clinical audit of seizures and epilepsies in children and young people for England and Wales. There are three main elements to Epilepsy12 which are included in the annual report:

- A **clinical audit** of children and young people newly diagnosed with epilepsy in the 'cohort 3' patient group. These patients had their first paediatric assessment between 1 December 2019 and 30 November 2020. The audit then follows the cohort for 12 months of subsequent care.
- An **organisational audit** of paediatric epilepsy services, focusing on services and workforce at Trust/Health Board level, as they were in November 2021. At this time the NHS was dealing with a significant surge in COVID-19 cases and hospitalisations in England and Wales.
- **Quality improvement** activities and projects related to the audit. The annual report contains case study examples from NHS Trusts/Health Board, the **Epilepsy Quality Improvement Programme** and the **Epilepsy12 Youth Advocates**, showing ways services have been working together to make lasting improvements in care.

An updated version of the 2022 Epilepsy12 annual report was published in November 2022. The executive summary is shown in Appendix E.

The Epilepsy12 dataset was reviewed against the draft standard.

4.5.2 British Paediatric Neurology Association

The British Paediatric Neurology Association (BPNA) is the professional organisation for doctors who specialise in the care of children with neurological disorders. They have produced an informatic #DESSCRIBE (Appendix F) to inform the diagnosis pathway.

4.5.3 The Neurological Alliance

The Neurological Alliance is England's leading coalition of organisations and professional bodies supporting people with neurological conditions. It is made up of over 80 organisations working together to improve neuro services and transform quality of life for people with neurological conditions.

The Neurological Alliance have provided a draft of an epilepsy resource navigator tool designed for commissioners, providers and professionals working with the epilepsy population in England. The tool identifies and directs you to the best available resources to commission, design and improve services for people with epilepsy, their families and carers. The information and resources in the tool can help local systems to deliver the NHS priorities for 2023/24 and the commitments in the NHS Long Term Plan, including addressing A&E waiting times and improving performance against the core diagnostic standard. The tool has been developed by the Neurological Alliance with support from a steering group of expert health professionals and patient organisations.

Information from this resource has been used to inform the evidence review.

4.5.4 OPEN UK

OPEN UK members were requested to send or signpost to empty templates, proformas, care plans, passports that they may currently use to capture epilepsy care. These have been tabulated within spreadsheets and analysed to establish what data is collected, and commonality across forms.

4.5.5 International League Against Epilepsy

The International League Against Epilepsy (ILAE) was founded in 1909 and is an organisation of more than 120 national chapters.

ILAE's mission is to ensure that health professionals, patients and their care providers, governments, and the public world-wide have the educational and research resources that are essential in understanding, diagnosing, and treating persons with epilepsy.

ILAE's vision is a world in which no person's life is limited by epilepsy.

The goals of the ILAE are to:

- Serve health professionals as the premier international resource for current and emerging standards and best practice
- Support health professionals worldwide to enhance their knowledge and skills in the prevention, diagnosis, treatment, and care of epilepsy
- Advocate for epilepsy as a public health imperative
- Promote research and innovation for epilepsy
- Ensure the long term financial and organizational viability of the ILAE

4.6 Third sector resources

4.6.1 Epilepsy Research UK

Epilepsy Research UK (ERUK) are exclusively dedicated to driving and enabling life changing, life saving research into epilepsy. ERUK supports a wide range of research, from experimental studies of epilepsy, including laboratory research of the cellular and molecular mechanisms of epilepsy, to novel diagnostics and treatments for the clinical management of people living with epilepsy.

4.6.2 SUDEP *Action*

SUDEP *Action* is dedicated to raising awareness of epilepsy risks and tackling epilepsy deaths including Sudden Unexpected Death in Epilepsy. SUDEP *Action* identify that epilepsy carries a mortality that is, on average, **2-3 times higher than the general population**[5], with the risk of sudden unexpected death increasing **more than 20-fold** in young people[6]. In the UK epilepsy is the 5th highest contributor to the years of potential life lost (YPLL) in men, and the 8th in women[7]. The UK National Sentinel Clinical Audit of Epilepsy Deaths found that **42% of epilepsy-related deaths were considered avoidable**[8]. A systematic review of international studies has concluded that the public health burden of Sudden Unexpected Death (SUDEP) alone, is estimated as second only to stroke among neurological conditions[9].

In a population study of deaths in Cornwall over 9 years, 80% of people with epilepsy who died suddenly had not been in contact with specialist services in the previous year. Ninety percent of people with epilepsy who died suddenly had a worsening of seizures 3-6 months before the death was reported to the coroner, but poor contact with primary or secondary care services. The study highlighted the presence of modifiable risk factors 3-6 months prior to death. These factors, when uncorrected, had a potential cumulative effect on seizure control and risk[10]. One half had a record of alcohol misuse, and a quarter had been taking drugs to treat depression or anxiety.

Research, reports and inquiries into epilepsy-related deaths have highlighted the importance of risk assessment and risk management in reducing avoidable deaths[11][12]. A common theme through these reports is the lack of awareness and the underestimation of risk. In some places epilepsy is mistakenly considered to be benign[13].

In clinical practice, especially in primary care, the lack of any tools to support risk management in epilepsy is of concern[14]. The problem requires a solution that is evidenced-based, simple to use in a clinical environment, and suitable for use across a range of settings and practices. It also needs to be flexible enough to adapt as new knowledge becomes available.

SUDEP *Action* provide for professionals a SUDEP and seizure safety checklist for adults which has been reviewed. SUDEP *Action* are working in collaboration with Young Epilepsy to produce a version for children and young people. The checklist introduction is shown in Appendix G.

SUDEP have also developed an award-winning app, EpSMon: Epilepsy Self-Monitoring, for self-monitoring and sharing information with professionals. The app content has been cross-referenced with the draft standard.

4.6.3 Young Epilepsy

Young epilepsy campaign for children's rights, deliver health services and research that improve diagnosis and treatment, support children and young people throughout school, college and university and provide information, friendly advice and practical help for living everyday life.

Young epilepsy provide a downloadable care plan, a keeping records of possible seizures guide and a witnessing a seizure record. An example of the care plan is shown in Appendix H.

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[5] Epilepsy kills: stopping epilepsy-related death *(Sander)*
[6] Are we as safe as we can be? *(Shankar)*
[7] Risk factors for SUDEP *(Tomson)*
[8] How common is SUDEP, Reconsidering the data *(Thurman)*
[9] Implications for clinical practice - SUDEP in adults with an intellectual disability *(Kerr)*
[10] SUDEP and pregnancy *(Nashef)*
[11] Risk avoidance and supervision *(Brown)*
[12] How can we translate population research into practice to avoidable death in epilepsy: a road map for the UK *(Ridsdale)*
[13] Clinical guidance for the generalist *(Smithson)*
[14] Clinical implications of SUDEP *(Johnson and Smith)*

4.6.4 Epilepsy Society

The Epilepsy Society is a UK charity transforming the lives of people with epilepsy through world-leading research, advocacy and care. Their vision is for a world where epilepsy is irrelevant and people with epilepsy lead the lives they want to lead.

The epilepsy society provide a downloadable seizure diary (Appendix I).

4.6.5 Epilepsy Action

Epilepsy Action are a national charity committed to supporting a better life for everyone affected by epilepsy.

Epilepsy Action provide a downloadable seizures diary and care plan.

Epilepsy Action's comment on the long term plan:
NHS England has published its Long Term Plan. The plan sets out the aims and priorities of the NHS for the next 10 years. The plan does mention epilepsy but disappointingly, epilepsy and other neurological conditions do not seem to be a priority for the NHS.
The plan includes proposals to create 'clinical networks' in order to improve the quality of care for children with epilepsy. There is, however, little mention of how the proposed clinical networks will work. The plan mentions "sharing best clinical practice, supporting the integration of paediatric skills across services and bespoke quality improvement projects". We need more information about these proposals. We would welcome the opportunity to work with the government and NHS to ensure the clinical networks work in the best interests of children with epilepsy.
The proposals to improve the care for children with epilepsy are encouraging. It is however disappointing that the Long Term Plan does not mention services for adults with epilepsy. It also makes no mention of the move from children to adult services (transition). These services are in need of drastic improvement. In addition, there is very little detail in the plan about wider neurology services.
The proposals on tackling inequality are encouraging. In a recent report, Public Health England (PHE) found that epilepsy-related deaths increased by 70% between 2001-14, and a link between deaths and poorer areas. It was found that people with epilepsy living in poorer areas may be at a three times higher risk of death than people in wealthier areas. It is therefore vitally important that action is taken to investigate this link so that no-one with epilepsy dies prematurely, simply because of where they live.
A 2017 report found that epilepsy was a leading cause of death in people with a learning disability. The NHS Long Term Plan commits to speeding up recommendations from this report, to identify common themes and learning points and provide targeted support to local areas. Epilepsy Action is pleased that there is recognition from the government and NHS that more work is needed. However, it is disappointing that epilepsy was not specifically mentioned in the plan. We hope to see more focus on the links between learning disabilities and epilepsy in the future and hope this plan is the start of that process.
Overall, it is disappointing that epilepsy is not given more priority in the Long Term Plan. Epilepsy and neurology services in the NHS are already under pressure. It is very concerning that these services are not given the focus they need. We have seen that when services for specific conditions are included in NHS strategic plans, huge improvements can be made to the care that people receive.

4.6.6 Epilepsy Scotland

Epilepsy Scotland's mission is to work with people living with epilepsy to ensure that their voice is heard. Their vision is that they believe that people living with epilepsy have a right to:

- Be free from stigma and discrimination
- Have access to high quality medical, social, educational, support and information services
- Be valued and included in society
- Determine their own way of life

4.7 GIRFT

Neurological disorders are common and varied, and they affect all levels of the nervous system, from the rain to nerve and muscle. Neurological conditions carry a significant burden to individuals, their families and carers, the NHS, and society as a whole. Some neurological conditions are life-threatening, and many severely affect quality of life.

There are over 600 types of neurological conditions, which can be broadly categorised into:

- *sudden-onset conditions (such as encephalitis, meningitis and Guillain-Barré syndrome);*
- *intermittent and unpredictable conditions (such as epilepsy, migraine and the early stages of multiple sclerosis);*
- *progressive conditions (such as motor neurone disease, Parkinson's disease and later stages of multiple sclerosis);*
- *stable conditions with changing need (such as cerebral palsy in adults or spina bifida).*

There are an estimated 14.7 million cases of neurological disorder in the UK, equating to one in six people having a neurological condition[15]. The annual NHS spend on care for neurological conditions is £4.4bn[16].

The report goes on to identify:

"*Comparing neurological services is challenging, as not all services are provided at all sites. Neurology services may even vary between sites within a single trust, as individual services are usually based at only one site. Given the variation between sites and between different parts of the country, our analysis assesses care for patients with neurological conditions in terms of specific sites and across broader regions.*

The size of a hospital site does not predict the neurology services available within, so we classified sites depending on the range of neurology services offered:

- *N1: Neuroscience centre with both neurology inpatients and neurosurgery*
- *N2: Neurology centre with inpatient neurology beds*
- *N3: District general hospital (DGH) neurology centre where neurologists are based but without inpatient neurology beds*
- *N4: Site with visiting neurologists only (neurologists based elsewhere)*
- *N5: Site without access to visiting neurologists*

"Given that not all services are available at all sites, we also focus on how the links between hospitals impact the availability of services within defined neuroscience regions. Neurology services have evolved to reflect local geography and history, so these 24 neuroscience regions (each of which links to a specific N1 site – a neuroscience centre) do not align with current NHS regions or other organisational structures"

Many patients with neurological disorders are not managed by neurology, especially those that are admitted acutely. To understand what happens to patients with neurological disorders who are admitted acutely as non-elective admissions, we analysed a cohort of patients with primary neurological disorders classified by discharge diagnosis. This allowed us to understand what happened at those sites without inpatient beds under neurology.

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[15] The Neurological Alliance. Neuro Numbers 2019. www.neural.org.uk/assets/pdfs/neuro-numbers-2019.pdf

[16] Ibid

We further divided this cohort into those admitted for one night or less and those admitted for more than two nights.

We further classified this cohort by diagnosis into those that would 'definitely', 'probably', 'possibly' or 'rarely' benefit from management under a neurologist.

We present our analysis and the recommendations within this report around four patient journeys:

- *Patient journey 1: a patient admitted as an emergency via the general medical take*
- *Patient journey 2: a patient referred to neurology outpatients*
- *Patient journey 3: a patient with a chronic neurological disorder*
- *Patient journey 4: a patient requiring highly specialised care"*

The summary findings of the patient journeys are shown in Appendix J. The analysis of the service, pathways and patient journeys highlights the need for information to be available at the right time in the right place. Related recommendations are shown overleaf.

Recommendations: seizure management and prescribing

Recommendation	Actions	Owners	Timescale
11. Develop pathways for management of patients with seizures and suspected seizures (including non-epileptic attack disorder) within A&E/acute medical units to link into epilepsy services.	**a** Ensure patients with suspected seizures are referred for an early assessment in an outpatient department within two weeks (as per NICE guidelines), with linked capacity for radiological and neurophysiological investigations.	Trusts, ICSs	For progress within 1 year
	b Embed systems that notify epilepsy services that patients with epilepsy have attended A&E or been admitted to hospital.	ICSs	For progress within 1 year
12. Support the Department of Health and Social Care co-ordinated response to implementation of the Independent Medicines and Medical Devices Safety Review relating to safe use of sodium valproate in women of child-bearing potential.	**a** Carry out an annual review for all women currently taking sodium valproate.	Trusts	Ongoing
	b Continue to follow guidance regarding prescribing of sodium valproate and alternatives.	Trusts	Ongoing
	c Continue to support patients' involvement in the Pregnancy Prevention Programme (PPP), including by ensuring electronic systems are compatible when the PPP moves online.	Trusts	Ongoing
	d Once established, contribute to the registry for all women on anti-epileptic drugs who become pregnant, and women with MS on disease-modifying therapies.	Trusts	Upon establishment of registry

Recommendation: disease specific networks

Recommendation	Actions	Owners	Timescale
14. Develop clinically led subspecialty regional networks, starting with epilepsy and MS, with links to local MDTs.	**a** Develop epilepsy regional networks involving neurologists and epilepsy advanced practitioner/nurses.	Trusts, Networks, ICSs	For progress within 1 year
	b Local neurology services should run virtual MDTs with team members including neurologist, specialist practitioners, neurophysiologist and neuroradiologist input for patients with epilepsy; this would provide a forum for interaction with epileptologists from regional services.	Trusts, Networks	Ongoing upon completion of 14a
	c Develop regional MS networks to facilitate virtual MDT discussions.	Trusts, Networks, ICSs	For progress within 1 year

Recommendation: neuroradiology

Recommendation	Actions	Owners	Timescale
23. Improve access and links into neuroradiology services, including through the use of digital solutions.	**a** Ensure all sites have access to a neuroradiology MDT, either in person or virtually. This would be facilitated by imaging networks. Digital solutions are required to ensure images and reports are accessible.	Trusts, Imaging networks	For progress following formation of imaging networks (i.e. from 2023)
	b Develop neuroradiology services links with all DGH sites, ideally with visits in person, to enhance imaging of the brain and spine. This would also be facilitated by the establishment of neuroimaging clinical interest groups within imaging networks.	Trusts, Imaging networks	For progress following formation of imaging networks (i.e. from 2023)
	c Ensure GPs have access to CT and MRI brain scan within appropriate guidelines. This would be enabled by Community Diagnostic Hubs.	ICSs, Imaging networks	For progress following formation of imaging networks (i.e. from 2023)

4.8 Existing standards

4.8.1 PRSB standards

The existing PRSB Diabetes standard was used as a starting point for mapping the information requirements identified for epilepsy. That project identified strategic challenge and drivers for health and care system change as shown in Figure 1.

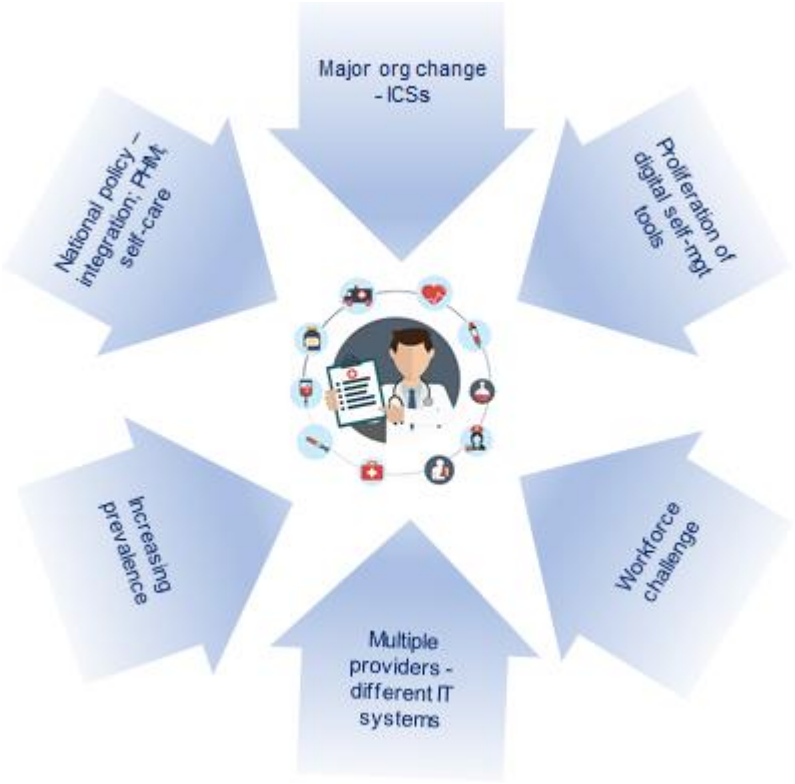


Figure 1 Health and care system challenges for long term conditions

There is a need for transformation in terms of people, process and technology to address these challenges.

4.8.2 Alternative data sources

The following data sets were reviewed against the draft standard:

4.8.2.1 ICHOM Pediatric and Adult Epilepsy

ICHOM patient-Centred Outcomes Measures Epilepsy.

ICHOM brings together patient representatives, clinician leaders, and registry leaders from all over the world to develop Sets of Patient-Centered Outcome Measures, which are comprehensive yet parsimonious Sets of outcomes and case-mix variables we recommend all providers to track.

Each Set focuses on patient-centered results, and provides an internationally-agreed upon method for measuring each of these outcomes. We do this because we believe that standardized outcomes measurement will open up new possibilities to compare performance globally, allow clinicians to learn from each other, and rapidly improve the care we provide our patients.

Our Sets include initial conditions and risk factors to enable meaningful case-mix adjustment globally, ensuring that comparisons of outcomes will take into account the differences in patient populations across not just providers, but also countries and regions. We also include high-level treatment variables to allow stratification of outcomes by major treatment types. A comprehensive data dictionary is included in the appendix.

The ICHOM Set of Patient-Centered Outcome Measures for Epilepsy is the result of hard work by a group of leading physicians, measurement experts and patients. It is our recommendation of the outcomes that matter most to patients with Epilepsy. We urge all providers around the world to start measuring these outcomes to better understand how to improve the lives of their patients.

1. *Epilepsy health-related quality of life reported with QOLIE-10 in adults, and QOLCE-16 (parent-report) or CHEQOL-25 (self-report) in children and adolescents.*
2. *Including Behavioural development, Motor development, and Cognitive development (pediatrics only), & Attention/Inattention and Memory Impairment (all patients).*
3. *Memory Impairment & Attention/Inattention reported with the PROMIS v2.0 Cognitive Function SF 4a in adults, and CHEQOL-25 in children and adolescents.*
4. *Behavioural development, Motor development, and Cognitive development measured using the mCHAT (16-48 months) or national assessment methods (>48 months).*
5. *Including Prolonged/recurrent clustered seizures requiring emergency treatment, Seizure-related injury and Incontinence. Optional patient-report with the LSSS 2.0 in adults.*
6. *Including seizure type, Seizure frequency, Seizure freedom, Emergence of new seizure type*
7. *Including impact of epilepsy on education/work and daily life activities*
8. *Depression and Suicidality reported with the PHQ-9 in adults. Depression measured with the PROMIS Pediatric Item Bank v2.0 – Depressive Symptoms/Parent Proxy Item Bank/ Early Childhood Parent Report SF 4a in children and adolescents.*
9. *Suicidality in children and adolescents reported with the ASQ. Anxiety reported with the GAD-2 in adults, and PROMIS Anxiety Item Bank SF 8a/Parent proxy SF 8a/Early Childhood Parent Report SF 4a in children and adolescents.*
10. *Including Sleep Adequacy. Reported by the PROMIS Sleep Disturbance 4a in adults, and the PROMIS Pediatric Pediatric Sleep Disturbance 4a in children and adolescents.*
11. *Including pregnancy and delivery complications, and congenital malformations in offspring. Only measured in women of a reproductive age.*

4.8.2.2 EPSET

EPSET

The University of Liverpool are leading on an international research study to find out the most important outcomes for the treatment of adults with epilepsy.

The Problem

In current epilepsy research, the choice of outcomes measured varies widely, particularly in clinical trials. This difference in outcome measurement leads to research waste and difficulty combining and comparing results from different studies. It is also unclear whether the outcomes currently being measured in research are relevant to people with epilepsy.

The EPSET study needs your help to find out what outcomes are so important that they should always be measured in studies for adults with epilepsy. We call these the Core Outcome Set (COS).

Our solution - a Core Outcome Set specific to adults with epilepsy

A Core Outcome Set (COS) is a standardised list of outcomes that should be reported as a minimum in all clinical trials assessing the effectiveness of treatments. It is developed using consensus methods to ensure that it includes what is important to patients as well as healthcare professionals and researchers from around the world.

If all future studies looking at treatments for adults with epilepsy measure these core outcomes, and measure them in similar ways, the results of the studies can be easily compared and combined. This may help new, effective treatments become available to patients more quickly. This may benefit all patients with epilepsy in the long term.

At present, no Core Outcome Set (COS) exists for adults with epilepsy.

4.8.2.3 CHOICE

CHOICE

The CASTLE research programme is about sleep and epilepsy. This summer we will launch the final part of the programme, a clinical trial to evaluate the effectiveness of an online sleep behaviour intervention (COSI) for parents of children who have epilepsy and experience a sleep problem. The trial will recruit children with rolandic epilepsy because they have seizures at night that can be triggered by sleep disturbance but we hope that if effective, then COSI will benefit many other children and their families.

The Core Health Outcomes In Childhood Epilepsy (CHOICE) study developed the first ever core outcome set for childhood epilepsy research. We reached consensus between young people, parents and professionals on which aspects of health and quality of life are most important to measure for children with epilepsy. We used established, systematic and transparent methods advocated by the COMET Initiative. We identified 38 outcomes across 10 domains that contributed toward a core outcome set for use in epilepsy research

We examined which outcomes had been measured previously in research and health and quality of life from qualitative research and patient reported outcome measures. We categorised outcome domains and conducted two rounds of a Delphi survey with young people, parents and professionals. Participants rated which outcome domains they thought were critical to measure in research. Finally we convened a face-to-face meeting that included young people with epilepsy, parents, and a variety of professionals to discuss marginal outcomes and to ratify agreement.

4.8.2.4 NASH

NASH

Epilepsy is a very worrying condition for patients and the public, but with good care, it can be better controlled and risks minimised. Many seizures presentations to Emergency Departments (EDs) could be prevented. The National Audit of Seizure management in Hospitals (NASH) examines the facilities and care available to such patients in order that it will identify how best to change services to reduce the numbers presenting at hospital.

Two rounds of NASH have previously taken place. The first round took place in 2011 with 127 hospitals entering 3755 cases onto the database. NASH2 took place in 2013, with 4,544 cases entered from 154 hospitals. St Elsewhere reports from real (but anonymised) hospital are available to download for both NASH1 and NASH2 from the "Newsletter and reports" section of our website. The NASH audits have focused upon cases presenting to EDs in the UK with a seizure.

Despite being the most common serious neurological condition (with around 600,000 people in the UK having the diagnosis), epilepsy is not high on the commissioning agenda – and indeed is often ignored behind the higher profiles of heart disease, chronic obstructive pulmonary disease (COPD), diabetes and stroke. By collecting representative data from across the UK, NASH has raised the profile of epilepsy by providing comparative data that will encourage clinicians within Trusts and commissioners within PCTs (or their successors) to include it actively when planning services.

NASH is based on the successful methods used for many of the other national audits, and has been developed with input from emergency physicians, epilepsy specialists and patient groups.

4.9 General evidence review

The resources listed in Appendix K were reviewed and informed the development of the report. Those where specifics were quoted are listed below.

Seidenberg, Pulsipher and Hermann[17] identify a number of comorbidities in epilepsy with a significantly higher rate than in the general population:

[17] Seidenberg M, Pulsipher DT, Hermann B. Association of epilepsy and comorbid conditions. Future Neurol. 2009 Sep 1;4(5):663-668. doi: 10.2217/fnl.09.32. PMID: 20161538; PMCID: PMC2802344.

Medical

- *Musculoskeletal system disorders*
- *Gastrointestinal and digestive disorders*
- *Respiratory system disorders*
- *Chronic pain disorders*
- *Cerebrovascular accidents*
- *Migraine*
- *Neoplasia*
- *Arthritis/rheumatism*
- *Obesity*
- *Diabetes*
- *Infections*
- *Fractures*
- *Allergies*

Psychiatric

- *Depression*
- *Anxiety*
- *Autism spectrum disorders*
- *Interictal dysphoric disorder*
- *Interictal behavior syndrome*
- *Psychosis of epilepsy*

Cognitive

- *Attention-deficit hyperactivity disorder*
- *Learning disability*
- *Mental retardation*
- *Alzheimer's disease/dementia*

The World Health Organisation (WHO) identify that seizures can be controlled. Up to 70% of people living with epilepsy could become seizure free with appropriate use of antiseizure medicines. Discontinuing antiseizure medicine can be considered after 2 years without seizures and should take into account relevant clinical, social and personal factors. A documented etiology of the seizure and an abnormal electroencephalography (EEG) pattern are the two most consistent predictors of seizure recurrence.

4.10 Hospital Epilepsy Proforma Review

During this phase, 60 blank epilepsy (53 child and 7 adult) related proformas were received from hospitals, which were then analysed. There was a large range in the types of proformas, they include care plans, seizure diaries, epilepsy passports, emergency care plans, checklists, and information documents.

The purpose of this analysis was to determine what information these proformas recorded about epilepsy, what was important to record for people with epilepsy and healthcare professionals, and to recognise where new data items may need to be created to accommodate this.

The results of the analysis indicated that the empty proformas typically contained a wide range of data items relating both to more general medical information and to epilepsy specific information. Some data items occurred more frequently than others, however, the majority of items provided valuable insight into what information needs to be recorded, therefore even less frequent items were still considered in developing the draft model.

A significant amount of the information in the proformas could be captured using data items in PRSB's Core Information Standard. The epilepsy specific information provides a useful starting point for inclusion in the draft standard and will help to guide future consultation.

4.10.1 Draft Information Model

The draft information Model (v0.6) overview is shown below:

PATIENT DEMOGRAPHICS	▪ Patient name, date of birth, gender, ethnic group, NHS number, address and contact details, and relevant contacts
GP DETAILS	▪ GP name/practice details
LEGAL INFORMATION	▪ Consent for treatment, information sharing and relating to a child
ABOUT ME	▪ What is important, people who are important, how I communicate, my wellness, how and when to support, what is what knowing
INDIVIDUAL REQUIREMENTS	▪ Reasonable adjustments, impairment, mobility, other individual requirements
SAFEGUARDING	▪ Safeguarding concerns, looked after child, child protection plan, unborn child protection plan
CONTACTS WITH PROFESSIONALS	▪ Professional name and role, contact type, consultation method, specialty, service, professionals present, clinical summary, outcome of contact
PROFESSIONAL CONTACTS	▪ Details of professional responsible for the care of person. Name, role, specialty, flag if keyworker, organisation, service, end and start date of service
PERSONAL CONTACTS	▪ Details of personal contact. Name, relationship, parental responsibility, contact details
REFERRAL DETAILS	▪ Name, role, grade, organisation and contact details of referrer. If not an individual, this could be e.g., GP surgery, department, specialty, sub-specialty, educational institution, mental health team etc.
SIGNPOST DETAILS	▪ Signpost to (name, role, grade, team, specialty, service), reason for signpost
SOCIAL CONTEXT	▪ Services of care, Accommodation type, Access, Household composition, occupation history, education history, smoking status, alcohol status, driving status, physical activities
FAMILY HISTORY	▪ Family history of epilepsy, family history, family history at first onset and death, relationship to person
HISTORY	▪ Personal history of seizure and epilepsy, past relevant medical, surgical and mental health history
PROCEDURES & THERAPY	▪ Surgical assessment, surgery decision, procedure done, therapy assessment, therapy decision
INVESTIGATIONS	▪ A record of investigations and procedures requested (inc. electro encephalogram) and results
ASSESSMENTS	▪ Assessment type, assessment name and result
EXAMINATION FINDINGS	▪ Weight, height, blood pressure, Occipitofrontal Circumference
PROBLEM LIST	▪ Problem, onset date, end date, severity, body site, laterality, stage of disease, problem status, problem priority, stage of disease
PREGNANCY STATUS	▪ Pregnancy state, expected state of delivery, feeding status of baby (optional), outcome of pregnancy, fertility*, attempting to conceive*
CARE AND SUPPORT PLAN	▪ Strengths, targets, need/concerns/problems, outcomes
CONTIGENCY PLAN	▪ Trigger factors, what should happen, who should be contacted, coping strategies, early warning signs
ADDITIONAL SUPPORT PLANS	▪ Any other additional support plan (Inc. education health care plan, Individual education plan)

EDUCATIONAL HISTORY	▪ Educational establishment, type of educational establishment, type of special educational need,
MEDICATIONS AND MEDICAL DEVICES	The details of and instructions for medications and medical equipment the patient is using. ▪ Medication name - generic name or brand ▪ Form – e.g., capsule, tablets, liquid ▪ Quantity supplied. ▪ Route of medication administration (may include method) ▪ Site - anatomical ▪ Method ▪ Dose directions, amount, timing descriptions ▪ Structured dose amount, timing (e.g., 20mg, 2 tablets) ▪ Dose direction duration ▪ Course status (active, discontinued, never active or completed) ▪ Start and end date/time ▪ Indication – reason for prescription ▪ Reason specific medication no prescribed* ▪ Reason for contraindication in prescribing specific medication* ▪ Comment/recommendation Medication change status (added, amended, on-hold, discontinued) ▪ Indication (reason), date of latest change, description of amendment, total dose daily quantity ▪ Medical devices entry (non dm+d). ▪ Medication discontinued on admission – status, indication, date, description ▪ Matters identified during discussion ▪ Comment
ALLERGIES AND ADVERSE REACTIONS	▪ Causative agent ▪ Reaction details – description, date recorded, severity, certainty, comments, type (allergic, intolerance), evidence, date first experienced
INFORMATION & ADVICE GIVEN	▪ Information and advice given
FUTURE APPOINTMENT	▪ Date of appointment, appointment status, reason for appointment, clinical urgency of appointment, location of future appointment, professional to see the person
PLAN AND REQUESTED ACTIONS	▪ The details of planned investigations, procedures, and treatment, and whether this plan has been agreed with the patient or their legitimate representative.
EMERGENCY CARE ATTENDANCE	▪ Date and time of attendance, attendance source, presenting complaint or issue, procedure, discharge destination, discharge status, date and time of discharge, clinical narrative, individual accompanying person
RISKS	▪ Risk start and end date, comment
DEVELOPMENTAL SKILLS	▪ Development skill, date achieved, result of observation or enquiry
ADMISSION DETAILS	▪ Responsible care professional, reason for admission, admission method, legal status on admission, source of admission, individual accompanying person, specialty
DISCHARGE DETAILS	▪ Discharging consultant, discharge method, discharging specialty, discharging department, legal status on discharge, discharge destination
DOCUMENTS	Name of document, documentation location, confidentiality, type, Image, image procedure, image procedure date, video

FORMULATION*	▪ Description of episode, seizure type, epilepsy syndrome, cause of epilepsy, co-morbidities relevant impairment, behavioural, educational, or emotional problems
STRUCTURED EDUCATION	▪ Attendance, structured education outcome
OUTCOMES*	▪ Survival, complications of treatment, seizure control and disease, neurodevelopment and cognition, Epilepsy health-related quality of life, emergency and unplanned healthcare services use, women's reproductive health

5 Conclusions

5.1 Health inequalities

A number of health inequalities exist:

- Misdiagnosis of epilepsy is common. According to the evidence base, the rate of misdiagnosis of epilepsy in the UK is around 20-30%.
- Although overall UK age standardised mortality is decreasing, mortality attributed to epilepsy is on the increase, including SUDEP, and there are significantly higher mortality rates in the most deprived areas of England, in people with learning disabilities and epilepsy, and in pregnant women.
- The incidence and prevalence of epilepsy is at least a third higher in the most deprived areas of the UK than the least deprived, and people are three times more likely to die from their condition.
- Epilepsy accounts for 40% of all emergency admissions in people with a learning disability.
- People with learning disability are at higher risk of dying from epilepsy with factors increasing risk including severity of the learning disability
- Epilepsy accounts for 40% of all emergency admissions in people with a learning disability

5.2 Comorbidities

The burden of comorbidity in people with epilepsy is high. Several diseases, including depression, anxiety, dementia, migraine, heart disease, peptic ulcers, and arthritis are up to eight times more common in people with epilepsy than in the general population.

One in every four people newly diagnosed with epilepsy is over the age of 65. These factors mean that people with epilepsy are likely to receive treatment and care from different specialities across multiple settings.

5.3 Range of pathways and settings

The complexity and heterogeneity of the disease means that there are a wide range of pathways and settings (as evidenced by the GIRFT Neurology report patient journeys) which people with epilepsy might experience which would greatly benefit from information being automatically available in the right place at the right time.

Currently most professionals only have access to their own organisations electronic systems (and these may not currently be well integrated)

5.4 Patient experience and safety

People need to record information relating to their epilepsy, such as seizure diaries and care plans and may also use apps or a monitoring tool. There is a significant opportunity to make better use of this information and share it with healthcare professionals.
The wide ranging health inequalities identify that patient safety is quite severely compromised.

5.5 Whole system transformation

There is a need for whole system transformation to address the challenges of managing long term conditions and ‘joined-up care’. This should encompass multiple different IT systems spanning primary, community, secondary and tertiary service providers, together with information that people with epilepsy use to self-manage and which they might wish to share.

Whilst the standard is only one element of the jigsaw in terms of whole system change and it is not just technology but people and process, it is a fundamental building block to enable interoperability which will in turn enable transformation.

5.6 Research

The research trajectory for epilepsy is increasingly dependent on larger multi-centre population cohorts. Opportunities to invite specific subgroups to participate in research at various stages in the care pathway or undertake approved research studies using data derived from routine clinical care are paramount for the step

changes required to improve outcomes. ERUK (Epilepsy Research UK) has recently identified 'big data analysis' as a key research priority amongst 10 key research priorities

5.7 Existing standards

There is a significant overlap between the diabetes standard and that required for epilepsy. Alternative data sources have identified elements more specific to epilepsy. It is likely that there would be significant overlap in the management of most long-term conditions.

5.8 Prioritisation

Within the NHS Rightcare epilepsy toolkit, a saving of £12.1 million could be saved on non-elective spend for epilepsy if CCGs achieved the rate of their best 5 peers.

In their comment on the NHS Long Term Plan, Epilepsy Action note that the plan does mention epilepsy but disappointingly, epilepsy and other neurological conditions do not seem to be a priority for the NHS.

They go on to say:

The proposals to improve the care for children with epilepsy are encouraging. It is however disappointing that the Long Term Plan does not mention services for adults with epilepsy. It also makes no mention of the move from children to adult services (transition). These services are in need of drastic improvement. In addition, there is very little detail in the plan about wider neurology services.
Overall, it is disappointing that epilepsy is not given more priority in the Long Term Plan. Epilepsy and neurology services in the NHS are already under pressure. It is very concerning that these services are not given the focus they need. We have seen that when services for specific conditions are included in NHS strategic plans, huge improvements can be made to the care that people receive.

NASH also observe that:

Despite being the most common serious neurological condition (with around 600,000 people in the UK having the diagnosis), epilepsy is not high on the commissioning agenda – and indeed is often ignored behind the higher profiles of heart disease, COPD, diabetes and stroke.

5.9 Charity organisations

The charity organisation resources reviewed in this report provide breadth of outstanding support in terms of information about epilepsy and living with epilepsy for both people with epilepsy and their family or carers, together with excellent resources to support individuals such as seizure diaries, care plans etc.

What did become obvious when reviewing many organisations for resources was that there was a significant amount of overlap in many of these areas.

6 Recommendations

6.1 Epilepsy SMI Information Standard

The draft standard should undergo full and extensive consultation to gain consensus from all stakeholders on the content of the information model. System suppliers should be engaged from the outset.

Comprehensive implementation support should be developed to facilitate successful implementation of the standard.

6.2 NHS England priorities

Given the health inequalities, the burden of comorbidities and the range of pathways and settings which a person with epilepsy might have to endure, together with the potential savings of £12.1 million identified by the NHS rightcare toolkit, NHSE might like to consider the opportunity to invest in a pilot implementation as a 'proof of concept' for this long-term condition, in a similar fashion to diabetes.

6.3 Charitable organisations

Given the outstanding support and resources provided by charitable organisations, it appears there may be an opportunity to provide even more support by reducing duplication and freeing up resource. This might be done by working under the umbrella of one organisation, such as the Neurological Alliance, to set up an overarching board to agree allocation of work to be undertaken between parties.

6.4 Supplier Engagement

Suppliers should be engaged throughout the process of development of the standard.

7 Appendix A NICE guidance epilepsy and learning difficulties

Epilepsy and learning disabilities

NICE National Institute for Health and Care Excellence

Learning disabilities are common in people with epilepsy. NICE's guideline on epilepsies in children, young people and adults includes recommendations to ensure that healthcare professionals:

- recognise learning disabilities in people with epilepsy
- give people with a learning disability the support they need to manage their epilepsy
- offer people with a learning disability the same treatments for their epilepsy as everyone else

This resource summarises these recommendations and provides links to other relevant guidance from NICE.

Recognising learning disabilities

- Be aware of the higher prevalence of learning disabilities in people with epilepsy
- Review neurodevelopment and learning disabilities as part of routine management of people with epilepsy

Support at all stages of care

Specialist epilepsy support

Support access to a tertiary epilepsy service for people with suspected or confirmed epilepsy and a learning disability who need additional specialist support

Support at appointments

Take into account information and support needs, for example:

- give longer appointments
- provide different formats for information, such as easy read or audio versions
- involve family members or carers or an advocate if the person wishes
- share information with those involved in their care

NICE's guideline on decision making and mental capacity also includes recommendations on supporting shared decision making

Coordinated care

- Provide coordinated care using a multidisciplinary team approach
- Be aware that children and young people with a complex childhood epilepsy syndrome may need additional support from a multidisciplinary team

NICE's guidelines on mental health problems in people with learning disabilities and challenging behaviour and learning disabilities also include recommendations on coordinating care

Regular reviews

Arrange regular monitoring reviews (at least annually) for adults with epilepsy and a learning disability

Testing at diagnosis

Consider whole genome sequencing for people with epilepsy of unknown cause who have a learning disability

Access to assessment for surgery

Do not exclude people with a learning disability from referral for epilepsy surgery assessment if indicated

Transition to adult services

Begin planning transition early for young people with epilepsy and a learning disability

NICE's guideline on transition from children's to adults' services also includes recommendations on transition planning and support

Monitoring during pregnancy

Consider more frequent monitoring reviews during pregnancy for women and girls with epilepsy and a learning disability

More guidance from NICE

- Care and support of people growing older with learning disabilities
- Challenging behaviour and learning disabilities: prevention and interventions
- Learning disabilities and behaviour that challenges: service design and delivery
- Mental health problems in people with learning disabilities: prevention, assessment and management

This is a summary of the recommendations on extra support for people with learning disabilities in the NICE guideline on epilepsies in adults, children and young people

9 Appendix B SIGN143 Diagnosis and management of epilepsy in adults

2 Key recommendations

The following recommendations were highlighted by the guideline development group as the key clinical recommendations that should be prioritised for implementation. The grade of recommendation relates to the strength of the supporting evidence on which the recommendation is based. It does not reflect the clinical importance of the recommendation.

2.1 DIAGNOSIS

C **The diagnosis of epilepsy should be made by an epilepsy specialist.**

C **A clear history from the patient and an eyewitness to the attack give the most important diagnostic information, and should be the mainstay of diagnosis.**

2.2 TREATMENT

Antiepileptic drugs should be offered after a first tonic-clonic seizure if:

B • **the patient has had previous myoclonic, absence or focal seizures**

B • **the EEG shows unequivocal epileptic discharges**

B • **the patient has a structural cerebral disorder**

D • **the patient considers the risk of recurrence unacceptable.**

C **Routine switching between different manufacturers of antiepileptic drugs should be avoided.**

C **Failure to respond to appropriate antiepileptic drugs should prompt a review of the diagnois of epilepsy and adherence to medication.**

B **Referral for assessment for neurosurgical treatment should be considered if the epilepsy is drug resistant.**

D **EEG should be used for confirming diagnosis of and monitoring treatment effects in patients with *status epilepticus*. EEG should be available as an emergency intervention for all patients with treated or suspected *status epilepticus*.**

2.3 MANAGEMENT OF PROLONGED SEIZURES INCLUDING *STATUS EPILEPTICUS*

✓ As soon as possible:

- secure airway
- give oxygen
- assess cardiac and respiratory function
- secure IV access in large veins.

B **Patients with prolonged tonic-clonic seizures that have lasted five minutes or more should be given:**

- **midazolam 10 mg buccally or intranasally, or**
- **lorazepam 4 mg IV if midazolam is unavailable, or**
- **diazepam 10 mg if midazolam and lorazepam are unavailable.**

B **Administer a repeat dose of benzodiazepine in hospital after 10 minutes if there is no response.**

2.4 EPILEPSY AND WOMEN'S HEALTH

C **To minimise the risk of contraceptive failure, a woman using any combined hormonal contraception, or a combined oral contraceptive pill, or a progesterone-only pill should be prescribed an antiepileptic drug that does not induce hepatic enzymes.**

Women with epilepsy should:

B • **receive prepregnancy counselling at the time of diagnosis and at regular intervals during their management, especially if they are taking antiepileptic drug treatment**

D • **be reassured that most will have a normal pregnancy and delivery**

C • **have their diagnosis and treatment, if appropriate, reviewed by specialist services before conception; a concerted effort should be made to optimise seizure control and rationalise antiepileptic drug therapy prior to conception**

D • **be well informed about pregnancy and epilepsy-related issues, including smoking cessation, before conception.**

2.5 PSYCHIATRIC COMORBIDITY

D **Screening for depression and suicidality should be considered in all patients with epilepsy.**

2.6 MORTALITY

B **Healthcare professionals and patients should aim for complete seizure freedom to reduce the risk of sudden unexpected death in epilepsy.**

D **Adherence to the prescribed antiepileptic drug regime should be strongly encouraged and the patient asked to report any adverse effects that might compromise adherence in order to reduce the risk of increased mortality and morbidity.**

✓ Patients with active seizures, ie who have sustained seizures, and in particular generalised tonic-clonic seizures, in the past year, should be assessed by a specialist physician and epilepsy nurse specialist.

D **Counselling about the risks of sudden unexpected death in epilepsy should be considered for patients with epilepsy at an appropriate time for the patient and by an appropriate healthcare professional** (consultant neurologist, physician with an interest in epilepsy, specialist registrar, or epilepsy nurse specialist).

2.7 MODELS OF CARE

D **A structured management system for patients with epilepsy should be established in primary care. As with other chronic diseases, an annual review is desirable.**

10 Appendix C SIGN159 Epilepsies in children and young people: investigative procedures and management

2 Key recommendations

The following recommendations were highlighted by the guideline development group as the key clinical recommendations that should be prioritised for implementation.

2.1 Investigative procedures

R **If a clinical diagnosis of epilepsy has been made, EEG is recommended for further classification of epilepsy. If standard EEG is normal, a second-line EEG that captures sleep should be carried out. This could be an ambulatory, sleep-deprived or melatonin-induced sleep EEG.**

2.2 Non-pharmacological management

R **A ketogenic diet should be offered as a treatment option in children with drug-resistant epilepsy.**

R **Children with drug-resistant epilepsy who fulfil referral criteria for assessment for surgery should be identified early.**

2.3 Cognitive, developmental and psychiatric comorbidities

R **Healthcare professionals should routinely enquire about depression and anxiety symptoms in all children and young people with epilepsy.**

2.4 Transition

R **Paediatric services providing care to children and young people should consider the use of a planned, structured, educational approach directed at both patients and carers, to help prepare young people with epilepsy for the move to adult healthcare services.**

2.5 Mortality

R **At or around the time of diagnosis healthcare professionals caring for children and young people with epilepsy should:**

- **have a face-to-face discussion about SUDEP with families/carers and young people**
- **provide written information to reinforce information provided face to face.**

11 Appendix D Epilepsy Passport

Epilepsy Passport
Communicating my condition

Please remove passport from wallet to read all 4 pages

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

PERSONAL AND BACKGROUND INFORMATION

NHS number | **Date of passport update** dd/mm/yyyy

Full name

Date of birth dd/mm/yyyy | **Gender** | **Age at diagnosis of epilepsy**

Emergency contact 1
Name, relationship & phone number

Emergency contact 2
Name, relationship & phone number

Epilepsy Seizure types (e.g. focal or complex partial, absence, myoclonic, tonic-clonic, tonic, clonic, atonic or astatic, epileptic spasms)

Epilepsy Syndromes (e.g. West, Ohtahara, Dravet, BECTS, Lennox-Gastaut, childhood-onset absence, juvenile-onset absence, juvenile myoclonic, symptomatic general, symptomatic focal, benign infantile epilepsy)

EMERGENCY CARE PLAN In the event of a seizure, do not leave the child alone

Does the child have a prescribed rescue medication If yes, state the child's rescue medication, route and dose

When should the child be given their rescue medication

Can the child be given a second dose of rescue (emergency) medication if the first dose has not stopped the seizure If yes, the minimum time after the first dose

What medication should NOT be given

When should 999 be called

Can the child be treated according to the UK APLS guideline If no, state why not

1

FURTHER INFORMATION

Cause of the epilepsy e.g. BECTS, childhood-onset absence, juvenile-onset absence and juvenile myoclonic, tuberous sclerosis, Rett syndrome – presumed genetic. Peri-ventricular haemorrhage or hypoxic-ischaemic injury – birth-related

Any additional co-morbidities or diagnoses

Current anti-epileptic medication(s) and dose(s) (give as mg/kg/day)

Is the child receiving the ketogenic diet If yes, which type of the diet

Current other regular medications

Anti-epileptic medications that were used previously but stopped because they didn't work

Anti-epileptic medications previously used that caused serious side-effects If yes, which medication(s) and which side-effects (e.g. rash, severe behaviour problems, respiratory difficulties, dramatic change in appetite)

FURTHER INFORMATION continued

Has the child received a ketogenic diet previously If yes, when was it used and which type of diet

Has the child had previous epilepsy surgery If yes, when was surgery done and what was the surgery, including the insertion of a vagal nerve stimulator (VNS)

The child's allergies, if any

Any specific safety advice e.g. participation in specific activities including swimming

DETAILS OF THE PERSON COMPLETING THIS PASSPORT

Full name

Signature written or electronic

Date dd/mm/yyyy

This passport was created by the RCPCH with support from HQIP.

PROFESSIONAL CONTACTS

Paediatrician who usually manages the child's epilepsy

Full name

Email

Phone

Hospital/Community Trust

Epilepsy Specialist Nurse

Full name

Email

Phone

Hospital/Community Trust

Tertiary Care Epilepsy Specialist the child's Paediatric Neurologist

Full name

Email

Phone

Hospital/Community Trust

General Practitioner (GP)

Full name

Email

Phone

Hospital/Community Trust

12 Appendix E Epilepsy12 Annual Report Nov 22 Executive summary

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.

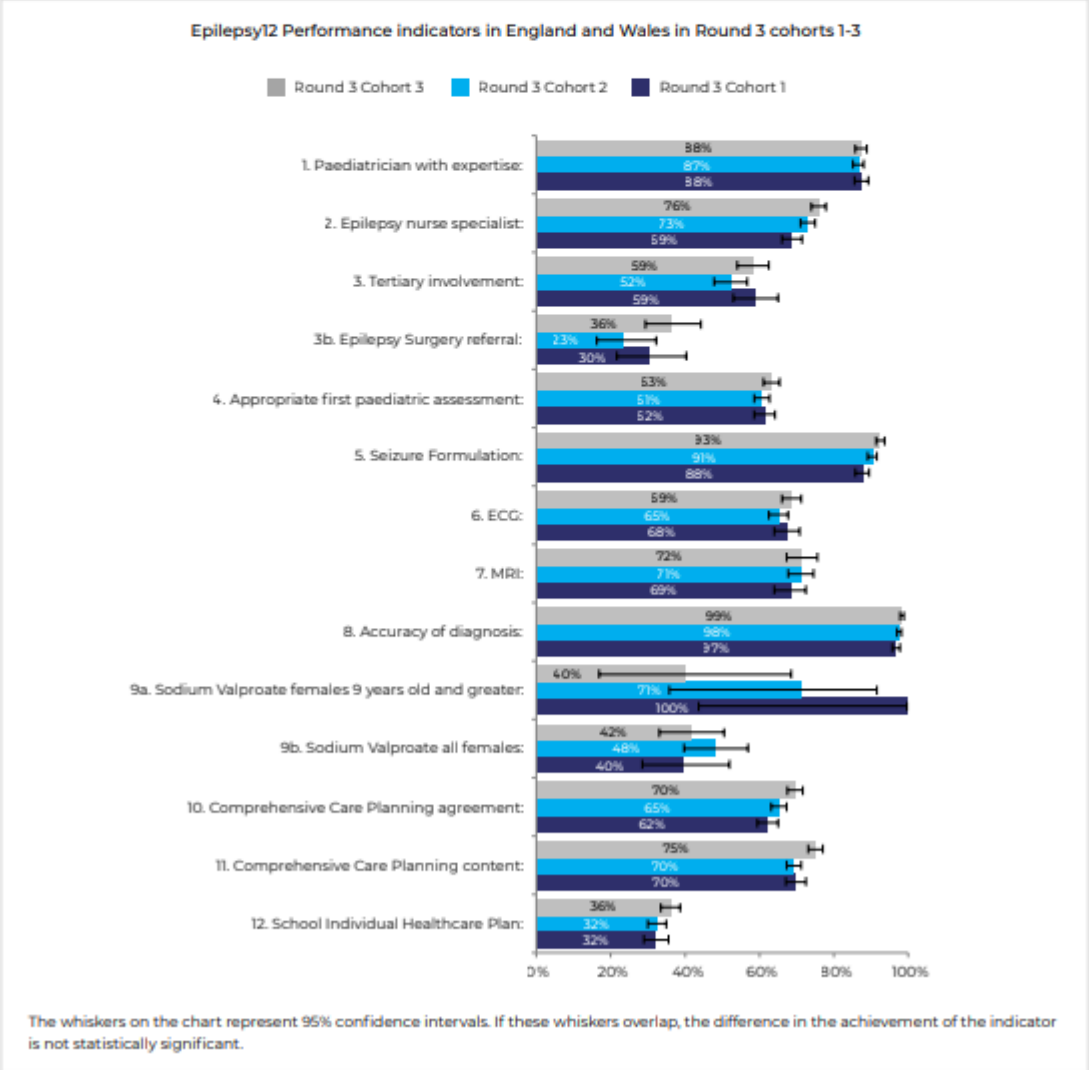


Figure 1: Epilepsy12 Performance indicators in England and Wales in Round 3 cohorts 1-3.

Key messages

Care planning agreement

70% (1379/1974) of children and young people diagnosed with epilepsy, had evidence of an updated and agreed comprehensive care plan.

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.

Transition

There was evidence of increased joint-working to support young people to transition to adult services but the available support for patients varied considerably between services: 65% (75/115) of Health Boards and Trusts reported having an epilepsy outpatient service where there is a presence of both adult and paediatric professionals.

Transition

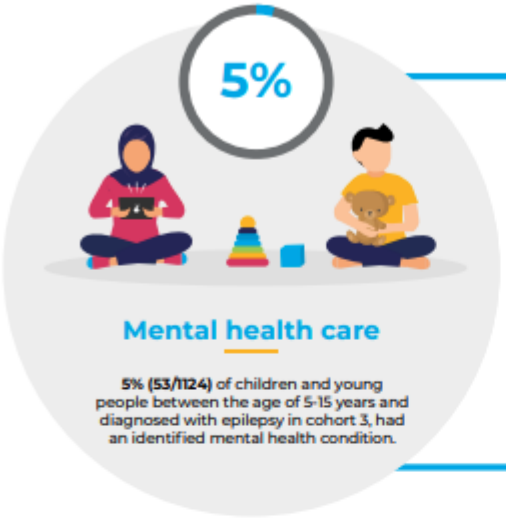
65% (75/115) of Trusts and Health Boards had an adult epilepsy specialist nurse routinely involved in the transition of young people to adult services.

First EEG waiting times

54% (1058/1974) of children and young people diagnosed with epilepsy, obtained their EEG within four weeks of request.

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

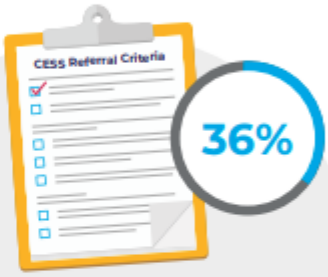
5% (53/1124) of children and young people between the age of 5-15 years and diagnosed with epilepsy in cohort 3, had an identified mental health condition.

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. 36% (49/135) 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.



Children's Epilepsy Surgical Service (CESS)

36% (49/135) of children and young people diagnosed with epilepsy who met surgical referral criteria, had a referral for surgical evaluation.

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.

13 Appendix F DESSCRIBE

14 Appendix G SUDEP Checklist introduction

WHY IS THIS CHECKLIST NEEDED?

Epilepsy is not a benign condition. Fatalities including SUDDEN UNEXPECTED DEATH in EPILEPSY (SUDEP) do happen in some people with epilepsy.

The best protection is being aware of these risks and putting steps in place to improve known risk factors.

There are approximately 1000 sudden epilepsy-related deaths each year, with half of these from SUDEP (1.16 per 1000 people with epilepsy).

SUDEP is considered the most common cause of epilepsy-related death. Other causes are prolonged seizures (status epilepticus), accidents (such as drowning & falls) and suicide.

The causes of SUDEP like SIDS remain under investigation but there is a good and growing body of evidence on risk factors that can be used to support people take simple actions to reduce risk.

RESEARCH SHOWS RISKS FACTORS INCLUDE

- Having either generalised tonic-clonic, nocturnal or status epilepticus seizures.
- Life-style and well-being risk factors such as not taking medications or picking up prescriptions; alcohol and substance abuse and depression.
- Pregnancy is also associated with higher risk for mother and unborn child.

The Checklist covers risk factors associated with both SUDEP & Epilepsy mortality.
The above a just some of the known risk factors.

Evidence has shown that many people who died from epilepsy, especially those of a younger age were not appropriately accessing health services prior to their death.

Reports and judicial inquiries have established many thousands of deaths might be avoided through improved awareness of risk and simple measures such as a care plan which steps-up care when this is needed.

REMEMBER

To learn more about the SUDEP & SEIZURE Safety Checklist,

please visit:
www.sudep.org/checklist

Where you can register your interest in the Checklist and read more about the research underpinning the tool.

For information and research on SUDEP visit **www.sudep.org** and **www.sudepglobalconversation.org**

SUDEP Action
SUDEP.ORG

Royal Cornwall Hospitals NHS
NHS Trust

Cornwall Partnership NHS
NHS Foundation Trust

The SUDEP & SEIZURE Safety Checklist is a collaboration between SUDEP Action, Cornwall Partnership NHS Trust and Cornwall Royal NHS Foundation Trust. The Checklist Project was part sponsored by SUDEP Action helped by Kt's Fund.

SUDEP Action, registered charity 1164250 (England & Wales), SC047223 (Scotland) Epilepsy Bereaved (founded 1995) is part of SUDEP Action

SUDEP & SEIZURE Safety Checklist

FREE ONLINE | REGISTER NOW

QUICK CHECK
www.sudep.org/checklist

Evidenced Epilepsy Management for clinicians
Assess your patients over time
Prioritise clinical activity

5 JULY 2016 MANCHESTER CENTRAL
PATIENT SAFETY AWARDS WINNER

thebmjawards WINNER 2016

QUICK CHECK

ABOUT

The Checklist is designed to support epilepsy risk communication between patient and clinicians, as part of a consultation or annual review.

The SUDEP & SEIZURE Safety Checklist has been developed and used in routine practice in Cornwall. It is supported by a UK Development Group of leading experts in the field.

The Safety Checklist includes 18 risk factors and is underpinned by 47 key scientific references on the topic of epilepsy mortality and SUDEP.

TEN MINUTE RISK ASSESSMENT TOOL

- Helps clinicians to open positive discussions with patients about epilepsy, risk monitoring & actions to minimise them.
- Supports a person-centred discussion of risk, focusing on whether known risk factors apply to a particular patient and how these may change over time.
- Helps clinicians educate people with epilepsy about their personal risks and possible lifestyle changes and actions / treatment that might reduce those risks.
- Provides clinical documentation on repeated risk discussion and management decisions.
- Provides some assurance to families bereaved by epilepsy if a death occurs, that every effort was made to reduce risk.

SUDEP & SEIZURE Safety Checklist

HOW IT WORKS

The Checklist is a Word document listing risk factors flagged a being significant to epilepsy mortality and SUDEP (Sudden Unexpected Death in Epilepsy). Giving clinicians a tool to check flagged risks and note actions available to reduce them.

It works alongside and enhances existing risk assessment practices already in place.

An initial risk assessment is carried out with the patient during their first consultation to provide a base line rating. The Checklist can then be repeated at annual review. However it should also be repeated at more regular intervals when a patient had unstable / changing epilepsy or is undergoing a change in treatment. Those identified previously as high risk may also benefit.

Factors for sudden death include generalised tonic-clonic seizures and nocturnal seizures, non-adherence and absence of supervision.

Epilepsy clinicians have found the tool simple and quick to use (5-10 minutes in clinic)

The Checklist is being used by clinicians working with people with epilepsy across clinical and community settings. They have found the tool simple and quick to use:

"The checklist has supported me to hold difficult discussions, to educate people and to provide reassurance/advice"

"All epilepsy nurses in our team and all consultants use the Checklist"

"I do talk more about SUDEP with patients and carers than I did before. It has made it easier to bring it up as part of the wider risk assessment."

HOW CAN I SUPPORT MY PATIENTS?

- Use the Checklist as part of your standard clinical practice for patients with epilepsy.
- Openly discuss risk with your patients while completing the Checklist.
- Give advice about flagged risks at the same time.
- Ensure your patients attend regular medical reviews.
- Encourage them to become proactive in managing their epilepsy.
- Tell them about **EpSMon**, the mobile App (based on the Checklist) for people with epilepsy to help them self-monitor their health risks in between visits to their doctors.

www.epsmon.com

15 Appendix H Young epilepsy care plan

1

Individual healthcare plan

Date of plan:

Name: Date of birth:

Address:

Postcode:

Name of parent/carer: Telephone:

Diagnosis (Including any other conditions):

Epilepsy syndrome (if known):

Description of child's seizures -

Please give brief a description of each seizure type including possible triggers and any warning signs that a seizure may be about to occur.

Type A:

Typical Duration:

☐ This seizure has emergency protocol, see attached.

Type B:

Typical Duration:

☐ This seizure has emergency protocol, see attached.

Type C:

Typical Duration:

☐ This seizure has emergency protocol, see attached.

Basic seizure management for convulsive seizures

1. Note the time that the seizure starts and ends
2. Move any hazards out of the way
3. Loosen tight clothing and protect the head

Let the seizure run its course. When the convulsions have stopped, place the person in the recovery position and stay with them until they are fully alert. If the seizure shows no signs of stopping after 5 mins (or 2 mins longer than is usual for that person) or the person is injured, call 999.

Please call to inform following a seizure.

* After a seizure, please record the details of the event, including time, date, length and any action taken.

Current Medication

List regular medication with dosages:

1. .....
2. .....
3. .....
4. .....

If the child has an RCPCH epilepsy passport then please check for up to date information surrounding medication.

Impact on learning/behaviour/classroom performance:

(Young Epilepsy's Assessment of Behaviour and Learning in Epilepsy screening tool can be used to help identify areas at risk)

Communication (understanding/speaking skills): .....

.....

Cognition (including memory & processing speed): .....

.....

Emotional/Behaviour (attention/mood, anxiety, social skills, aggression): .....

.....

Motor Skills (fine & gross motor skills, coordination): .....

.....

Adjustments needed to the classroom environment:

Any additional provision requirements (inc additional time for exams):

Activities that require special consideration and risk assessment:

Agreement

Who needs to know about the child's condition and have they been informed:

Teacher ☐ SENCO ☐ TA/LSA ☐

Senior Management Team ☐ Office Staff/First Aiders ☐ Lunchtime Supervisors ☐

This plan has been agreed and consent is given for emergency treatment by:

Child/young person/parents/guardians/epilepsy nurse specialist/prescribing doctor.

Name: ..... (epilepsy nurse specialist or prescribing doctor)

Signature: ..... Date: .....

Name: ..... (child/young person)

Signature: ..... Date: .....

Name: ..... (parent/guardian)

Signature: ..... Date: .....

Name: .....

Signature: ..... Date: .....

Position in relation to child: .....

Date this health care plan should be reviewed: .....

Additional information/instructions: .....

Emergency Protocol - Seizure type .....

Name: ..... D.O.B: ..... Year Group/Class: .....

Emergency medication should be given if seizure type ..... has not stopped after ..... minutes,

or if .....

.....

.....

The emergency medication to be given is: .....

The strength of the medication to be given is: .....

It should be given ☐ orally ☐ rectally ☐ into the buccal cavity (between the cheek and gums)

Circumstances when emergency medication should NOT be given: .....

.....

Circumstances when a SECOND dose of emergency medication may be given: .....

.....

The second emergency medication to be given is: .....

The strength of the medication is: .....

It should be given ☐ orally ☐ rectally ☐ into the buccal cavity (between the cheek and gums)

AN AMBULANCE SHOULD BE CALLED IF: .....

.....

.....

Please call ..... on: ..... to inform.

Named trained individuals who may give emergency medication:

1: .....

2: .....

3: .....

4: .....

16 Appendix I Epilepsy Society seizure diary

seizure diary

epilepsy society seizure diary

This is an A4 version of our seizure diary.
You can print pages as you need them.

how to use this diary

Fill in the sections of the diary that are relevant to you, in as much detail as you want to.
It might be helpful to ask your doctors what information they would like you to note down.

You might like to think about the following to help you look at any changes to your seizures:

- what your seizures are like;
- how often they happen;
- whether you have noticed any situations that trigger (bring on) your seizures;
- whether your medication is working; and
- if you have any side effects.

filling in the diary

Pages 3 to 6 are for details of your seizures. Use one line per day. The dates are written in for you, and you can add the month at the top.

If you have lots of seizures in a day, you could ignore the printed dates and use one line per seizure. Remember to add the date.

Pages 4 and 6 also include a summary chart for the month, called 'My seizures at a glance'. You can fill in one small box for each seizure, against the date you had it. For example, if you had one seizure on the 1st of the month, two on the 3rd and one on the 6th, it would look like this:

Number of seizures (one box per seizure)

Dates of the month

my details

Name _____

Address _____

_____

_____ Postcode _____

Tel/mobile _____

GP _____

Surgery _____

Tel _____

Neurologist _____

Hospital _____

Tel _____

Epilepsy nurse _____

Tel _____

Emergency contact person

Name _____

Tel/mobile _____

Relationship to me _____

my seizures

You can use this section to record all about your seizures. If you have more than one type of seizure you can give each one a code, for example A, B and C. You can use these codes when filling in the diary.

'Awake or asleep' seizures
On the diary pages, the term 'awake seizures' means seizures that start when you are awake, and 'asleep seizures' means seizures that start while you are asleep, as you are falling asleep, or as you are waking up.

Seizure type 1 and what happens to me:

I call this seizure: _____

You can help me by: _____

This is how I feel afterwards:

Seizure type 2 and what happens to me:

I call this seizure: _____

You can help me by: _____

This is how I feel afterwards:

Seizure type 3 and what happens to me:

I call this seizure: _____

You can help me by: _____

This is how I feel afterwards:

Seizure type 4 and what happens to me:

I call this seizure: _____

You can help me by: _____

This is how I feel afterwards:

Month _____	Time of seizure	Seizure code	Awake or asleep	Length of seizure	**Comments.** How many seizures? Any warning? Triggers? Recovery time? Emergency medication taken? Hospital treatment? Medication changes? How did you feel?
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					
15					
16					
17					
18					
19					
20					

Month _____	Time of seizure	Seizure code	Awake or asleep	Length of seizure	**Comments.** How many seizures? Any warning? Triggers? Recovery time? Emergency medication taken? Hospital treatment? Medication changes? How did you feel?
21					
22					
23					
24					
25					
26					
27					
28					
29					
30					
31					
Summary					

my seizures at a glance

Fill in a box for each seizure you have had, against the right day of the month. You could fill in the boxes in different colours for different types of seizure if you like.

Month _____

Number of seizures (one box per seizure)

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31

Dates of the month

Month _____	Time of seizure	Seizure code	Awake or asleep	Length of seizure	**Comments.** How many seizures? Any warning? Triggers? Recovery time? Emergency medication taken? Hospital treatment? Medication changes? How did you feel?
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					
15					
16					
17					
18					
19					
20					

how I feel

Epilepsy is more than 'just having seizures' and managing epilepsy is more than 'just taking the tablets'. How you feel about having epilepsy and taking medication might be different to how other people feel. This might change over time: sometimes you may feel OK about your epilepsy, and other times you may not.

Some people are happy with taking their medication and consider this part of managing their epilepsy. Others may feel uncomfortable or have concerns about taking medication, for many different reasons.

If there are reasons why you don't want to take your medication, or if you have any concerns, you may find it helpful to talk to a friend or to your doctor or pharmacist. Or you can call our confidential Epilepsy Helpline (see below for details).

practical issues

Some people have practical difficulties with taking medication. This might be getting the tablets out of the packet, remembering to take them, or having difficulty swallowing them. Here are some things that might help.

- Having a routine for taking your medication, for example always taking them at breakfast and dinner time, evenly spaced out.
- Using reminders, such as putting a note in a place where you look regularly, or an alarm. For example, you could set an alarm on your phone or watch.
- Tools that help you to remove tablets from blister packs are available from pharmacies.
- If you have problems with swallowing your medication, you could talk to your doctor or pharmacist about whether there are other formulations you can take (such as liquids or granules).

  If it is helpful to talk through these ideas, you can call our confidential Epilepsy Helpline (see below).

See our booklet *medication for epilepsy*.

my questions

You can use the space below to write down any questions that you want to ask your doctor, or things that you want to talk about at your next appointment. You could also use it to write down any answers.

Epilepsy Society, Chesham Lane
Chalfont St Peter, Bucks SL9 0RJ
Registered charity number 206186

epilepsysociety.org.uk

helpline
01494 601 400
Monday and Tuesday 9am to 4pm
Wednesday 9am to 7.30pm
Confidential (national call rate)

Month _____	Time of seizure	Seizure code	Awake or asleep	Length of seizure	**Comments.** How many seizures? Any warning? Triggers? Recovery time? Emergency medication taken? Hospital treatment? Medication changes? How did you feel?
21					
22					
23					
24					
25					
26					
27					
28					
29					
30					
31					
Summary					

my seizures at a glance

Fill in a box for each seizure you have had, against the right day of the month. You could fill in the boxes in different colours for different types of seizure if you like.

Month _____

Number of seizures (one box per seizure)

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31

Dates of the month

my epilepsy medication

I take: _____ _____

_____ _____

_____ _____

You can use the space below to note
any **changes** to your medication type or dose
and any side effects you may have noticed.

Drug name	Dose	Details of dates and any changes	Side effects or comments

my appointments

Date	Time	Who with	Where

17 Appendix J GIRFT patient journeys

Patient journey 1: a patient admitted as an emergency via the general medical take

- Inpatient neurology is only provided for a minority of patients with primarily neurological diagnosis (7%); there is marked variation in the involvement of neurological services in acute neurology, ranging from 0% to 90%.
- 64% of patients with neurological disorders are admitted at sites without neurology inpatient beds.
- At sites with inpatient beds, 41% of patients admitted for longer than one night with conditions that would definitely benefit from neurological care are managed directly under neurology inpatient services.
- Neurology patients are treated where they are admitted; only 0.5% of patients with primarily neurological disorders are transferred to neurology inpatient units.
- The case mix of conditions admitted does not differ between the different types of hospital site (N1–N5).
- Thus, there is marked variation in acute inpatient neurology services, and the likelihood of a patient with a condition that would benefit from neurological management receiving such care will depend on the site where they are admitted rather than their clinical need.

Liaison neurology

- Inpatients with neurological disorders who are not admitted to a neurology bed will depend on the liaison neurology service (where neurologists review inpatients on the ward) for access to neurological advice. Such consultations have a high likelihood of changing diagnosis and management and shortening inpatient stay.
- There is marked variation in access to liaison services, with 96% of N1 sites and 24% of N2 sites having a seven-day service, and 83% of N3 sites and 8% of N4 having a five-day service. Of N4 sites, 22% offer a four-day service, 37% three days and 32% one or two days.
- Only 50% of sites use an electronic system to request referrals, with the remainder using predominantly paper-based, phone or bleeper systems.
- There is marked variation in who delivers the service; services at N1 sites are mainly led by trainees.
- A proactive liaison neurology service, with daily visits to acute medical units, is provided at 37% of N1 sites and 29% of N2 sites.
- Despite being an important part of neurological services, liaison neurology services are not measured in any regularly collected metrics.

Acute neurology clinics

Acute neurology clinics provide the opportunity for prompt assessment of neurological patients, resulting in prompt diagnosis; they can also help to avoid admissions.

There is wide variation in access to acute neurology clinics. About three-quarters of N1–N2 sites and half of N3–5 sites have a dedicated acute clinic or allocated slots in other clinics.

Inpatient neurology services

- There is significant variation in the inpatient neurology services at those sites with inpatient neurology beds.
- At some N1 sites, 40–90% of inpatients with primarily neurological disorders and 60–80% of inpatients with conditions that would definitely or probably benefit from neurological care are treated under neurology; some also cover stroke.
- At some N1 and N2 sites, 15–30% of inpatients with primarily neurological disorders and 37–56% of those with conditions that would definitely or probably benefit from neurological care are treated under neurology.
- Some N1 and N2 sites have less involvement in acute neurology, with fewer than 20% of patients who would definitely or probably benefit from neurological care being under neurology.
- Some N3 sites have developed innovative ways to improve inpatient care without inpatient beds, including inpatient neurology multidisciplinary teams (MDTs).

Patient journey 2: a patient referred to neurology outpatients

- There is marked variation in access to neurology outpatients across different Clinical Commissioning Groups (CCGs), ranging from 400 to 1,600 per 100,000 population for new patients and from 600 to over 3,000 for follow-ups.
- Neurology outpatient departments have limited capacity and demand outstrips supply.

- Advice and guidance and triage of neurology outpatient referrals Advice and guidance services for GPs provide timely advice and potentially avoid the need for outpatient referral. Such services are being introduced and increasingly used at many sites, although activity is currently not collated nationally, limiting analysis.
- Most sites use the NHS e-Referral Service (e-RS) Choose and Book system. However, a number of sites have either developed bespoke systems to allow them to triage outpatients or, since it became available in 2018, adopted the e-RS Referral Assessment System. By triaging outpatient referrals, between 8% and 23% of referrals can be provided with advice directly and promptly.[18]

Outpatients

- Most patients are seen in general neurology outpatient clinics. Specialist clinics for Parkinson's disease, MS, epilepsy, headache and botulinum toxin are available at most N1 and N2 sites. Parkinson's disease, MS, epilepsy and botulinum toxin clinics are available at over a third of all sites.
- Eighteen-week referral to treatment rates vary significantly between neuroscience regions, ranging from 46% to 93% (target 92%).
- Did not attend (DNA) rates vary substantially, from 6% to 31%. If all sites with above-average DNA rates were to achieve the national average of 11.7%, approximately 16,000 additional new appointments and 42,000 additional follow-ups could be undertaken.
- The COVID-19 pandemic has led to the widespread introduction of remote outpatient consultations. This has proved helpful for some patients. The longer-term role for remote consultations will become clearer once the pandemic is under control.

Outpatient investigations

- There is significant variation in access to specialist outpatient investigations, such as lumbar puncture. In some neuroscience regions these are referred to the N1 site, and in others they are done locally. Some sites have trained specialist nurses and physician associates to perform these in outpatients.
- There is marked variation in GP access to investigations including CT (48% can easily access, 16% occasionally) and MRI brain scan (26% easily, 36% occasionally), carpal tunnel studies (41% easily, 15% occasionally), and ulnar nerve studies (11% easily, 20% occasionally).

Coding of outpatient activity

- There is no coding of neurology outpatients by diagnosis, which limits analysis.
- Specialist nurse activity is variably coded, with many consultations being attributed to consultant activity. This distorts comparisons between sites.

Outpatient closures

- We encountered three trusts where outpatient facilities had been closed for new referrals for varying periods. At all three sites the closures were driven by a lack of consultant capacity.

Patient journey 3: a patient with a chronic neurological disorder

Specialist nursing

- Specialist nurses play an important role in the management of many chronic neurological disorders.
- Marked variation in access to neurology nurses between neuroscience regions was reported in the Getting it Right First Time (GIRFT)/Association of British Neurologists (ABN) questionnaire, ranging from 5 to 26 per million.
- Higher numbers of specialist nurses are generally recorded at N1–N2 sites, and a relatively greater proportion of community nurses are based at N3–5 sites.
- Access to specialist nurses also varies notably between condition – for example, there are nearly twice as many Parkinson's disease nurses as epilepsy nurses.

Selected disease-specific services: epilepsy, MS, movement disorders and headache

- Most sites recognise the need for patients to be seen urgently following a seizure or suspected seizure.

[18] ABN Service Committee working group 2019-20. ABN Guidance on Neurology Active Referral Management (aka Advice and Guidance). 2021.

- There is significant variation in the proportion of patients with epilepsy seen within 18 weeks of admission with seizures.
- Sodium valproate carries a significant risk of teratogenicity. There is a significant variation in prescription rates of sodium valproate in women of child-bearing age, from 46 to 290 per 100,000 per CCG.
- There is significant variation in MS disease-modifying therapies. In some neuroscience regions all treatment is delivered at the N1 site. In others it is delivered at most sites within the region. There is significant variation in which drugs are used and the overall expenditure per head.
- There is variation in delivery of botulinum toxin treatments for dystonia, spasticity and headache. In some neuroscience regions these are available only at the N1 site, while in other regions these are delivered at N2 and N3 sites often closer to patients' homes.
- There is significant variation between sites in the acute management of headache. The proportion of patients admitted for one night or less varies from 31% to 95%. Only 3.4% are admitted under neurology.

Neuromuscular conditions and motor neurone disease

- In some neuroscience regions, outpatient provision of intravenous immunoglobulin (used to treat certain neuromuscular disorders) is only available at the neuroscience centre, while others provide it at all local district hospitals and in some the treatment is delivered to patients at home.
- There was marked variation between CCGs in the proportion of patients with motor neurone disease (MND) who died in hospital 2011–16, ranging from 17% to 74%. This suggests that there are opportunities to improve the management of MND patients.

Patient journey 4: a patient requiring highly specialised care

- There is marked variation in the number of patients admitted electively for more than one day at different sites. There is also variation in the services provided by neuroscience centres.
- Highly specialised services are delivered at a limited number of sites, usually owing to a combination of available technology and highly specialised MDT (examples include epilepsy surgery and surgical treatment for movement disorders). There is significant variation in levels of activity at different neuroscience centres.
- The proportion of patients seen within a neuroscience region who come from outside of their usual catchment area varies significantly between neuroscience regions, ranging from 2% to 10% (and 24% for the National Hospital for Neurology and Neurosurgery).
- Supra-regional networks are delivering highly specialised services.

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