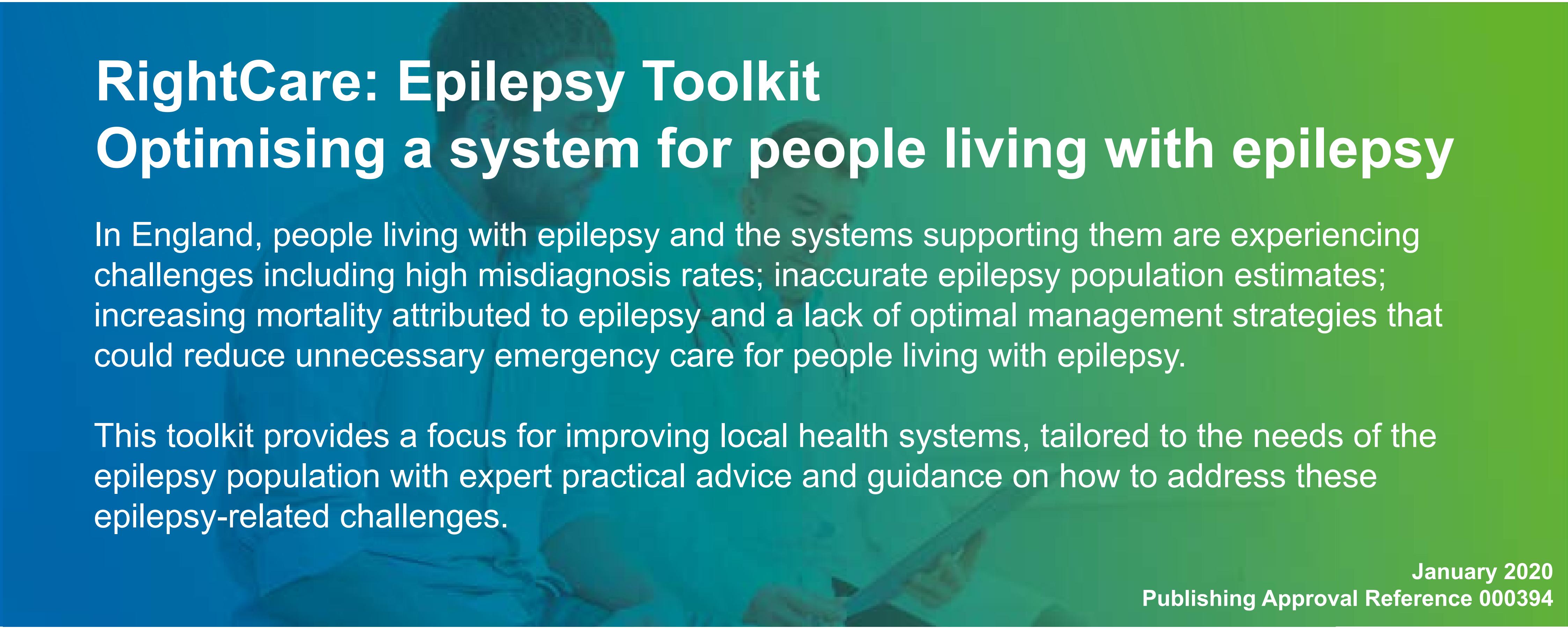
NHS
RightCare



RightCare: Epilepsy Toolkit
Optimising a system for people living with epilepsy

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.

This toolkit provides a focus for improving local health systems, tailored to the needs of the epilepsy population with expert practical advice and guidance on how to address these epilepsy-related challenges.

January 2020
Publishing Approval Reference 000394

epilepsy action

SUDEP Action
Making every epilepsy death count

Young Epilepsy

Informed by relevant NICE recommendations

NICE National Institute for Health and Care Excellence

RightCare Epilepsy Toolkit - Foreword

Peri O'Connor
Healthcare Projects Co-ordinator
Epilepsy Action

'We are delighted to have been part of the creation of this resource supporting service improvement in epilepsy. There are 600,000 people living with epilepsy in the UK. We know from our work as a patient organisation how epilepsy can have a massive impact on all aspects of the lives of these people. In particular the experience a patient has of their local NHS epilepsy service can impact hugely on their wellbeing and quality of life.

We welcome the clear identification of the national priorities in epilepsy care, together with the key actions to take. The toolkit makes it easy to identify individual service priorities through the self-assessment questionnaire and every section provides links to resources and tools to help.

Due to epilepsy for adult services not appearing in the NHS Long Term Plan, it is essential epilepsy is included as a target for change and improvement. We believe this toolkit will help the transformation process'.

'People with epilepsy are at increased risk of dying suddenly and prematurely. Many deaths are in those who are young and otherwise healthy – causing significant grief and trauma throughout communities. Nearly half of these unexpected deaths are potentially avoidable, with improved access to information, services and better risk management. There are pockets of excellent epilepsy service provision across the UK; yet there is also immense variation, putting people with epilepsy further at risk.

As the only UK charity dedicated to raising awareness of epilepsy risks, tackling epilepsy deaths and supporting those bereaved by epilepsy, SUDEP Action recognises first-hand the importance of a core stand in this toolkit - taking a risk management approach to mortality. Reducing epilepsy risks is core to preventing deaths, and much can be done to achieve this. Signposting the bereaved to specialist services who understand this unique bereavement, helping to navigate the aftermath of an epilepsy death, is also crucial. Ensuring lessons are learnt, gaps acknowledged and that every epilepsy death counts.

The best practice examples highlighted in this toolkit, show significant potential for change and many opportunities for local services address the inequalities and variation facing their epilepsy community; helping people with epilepsy to live well, for longer. We hope the publication and use of this toolkit will provide support to make this possible, so that future lives will be saved'.

Sammy Ashby
Deputy Chief Executive
SUDEP Action

Rosemarie Pardington
Director of Integrated Care
Young Epilepsy

'We welcomed the opportunity to be involved in the development of the RightCare: Epilepsy toolkit and are especially pleased that it provides guidance for both paediatric and adult care, as well as covering the challenges at transition.

The epilepsies affect a person globally and often manifest with additional related conditions which, over the course of a person's life, have a greater impact than seizures alone. We welcome the recognition within the toolkit that the different types of epilepsy require a holistic care approach to provide the best possible support and advice to the individual and/or their family. To achieve this holistic approach, it is essential that the precursory steps highlighted in this document to encourage the integration of clinical services, including mental health, with educational and social care for both children and adults, are heard and acted upon'.

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.

Links to other RightCare products:

RightCare Progressive Neurological Conditions Toolkit

RightCare Headache and Migraine Toolkit

RightCare Neurology Data

RightCare Equality and Health Inequality Packs

RightCare Epilepsy Toolkit:
System improvement priorities

Identification and segmentation of epilepsy population

Misdiagnosis

Taking a risk management approach to mortality

Access to epilepsy specific services

Support for specific patient groups

Mental health and emotional wellbeing support

System-wide education and training on epilepsy

Medicines optimisation

Coordination of care

Personalised care

Experience of care

Self-assessment questionnaire

RightCare Epilepsy Toolkit:
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Identification and segmentation of epilepsy population

- Misdiagnosis
- Mortality: taking a risk management approach
- Access to epilepsy specific services
- Mental health and wellbeing support
- Population and whole system approach to education
- Coordination of care

Supporting people in particular groups (children and young people, learning disabilities, pregnancy and older people)

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System improvement priority: **Identification and segmentation of the epilepsy population**

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.

Key areas for focus:

Understand the number of people living with seizures in your area

Understanding where people with epilepsy including children, young people and the elderly live and those who have had a first seizure, will help when planning services.

Have standardised data collection and input approaches

It is important to have a robust data input and collection strategy to ensure that the information to support people living with epilepsy across the system is reliable. This data can support care planning and be used to apply a risk management approach. This is applicable to all data such as epilepsy demography, diagnosis and management and should be shared across professional teams subject to patient consent.

Undertake capacity and demand planning

Once it is known where the population of people living with epilepsy are, matching this demand with workforce and infrastructure capacity is key. A system wide approach should be taken across community, primary and secondary care as well as in specialist and generalist care.

Guidance & best practice

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System improvement priority: **Identification and segmentation of the epilepsy population**

Actions to take:

Understand number of people living with seizures in area

- Work with secondary care services to ensure there is a system in place to refer patients who have attended A&E with a first seizure to either attend a first seizure clinic or their GP is notified for follow-up and that they are added to an epilepsy register if appropriate.
- Ensure people with epilepsy *and* learning disabilities are added to learning disabilities register. This will ensure these patients are captured and therefore instigate health checks and assessments.
- Undertake local analysis such as health needs assessment, Joint Strategic Needs Assessment (JSNA) or health equity audit to understand the number of people with seizures in your area (where they live; demographics; A&E or inpatient admissions).

Have standardised data collection and input approaches

- Put in place data input, collection strategies and guidelines to help improve the quality of data, including coding, and ensure it is consistent across the system.
- Include all appropriate health staff from across the system in the development of data collection strategy and training.
- Ensure numbers known via Quality and Outcomes Framework (QOF) is accessible and shared across the system, including secondary and tertiary care.
- Undertake data cleansing of the QOF register to ensure that it is accurate and includes patients who are currently receiving drug treatment for epilepsy.
- Consider the findings of the Epilepsy12 audit (Royal College of Paediatrics and Child Health) to help improve the quality of care for children and young people with seizures and epilepsy.
- Consider findings of National Audit of Seizure management in Hospitals (NASH) reports as a potential lever for improvement.

Undertake capacity and demand planning

- Undertake a local service review and needs analysis based on the patient population size and service needs
- Utilise simulation modelling tools to improve epilepsy services based on population and local needs analysis.
- Undertake a review of current clinics and services available in the local area, including workforce.
- Undertake an analysis of waiting times to assess patient access to first and follow-up epilepsy services.

Guidance and best practice examples

System improvement priority: **Misdiagnosis**

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.

Key areas for focus:

Supporting accurate epilepsy diagnosis through improved training and resources for clinicians

Clinicians making a diagnosis may not have sufficient training or experience in epilepsy and may not have easy access to the full range of appropriate investigations and tools.

Increasing awareness and education for non-epileptic seizures

Epilepsy has a large differential diagnosis with a lack of understanding about non-epileptic seizures. There is an increased acceptance that misdiagnosis and treatment of non-epileptic seizures as epilepsy is as bad as mistreating epilepsy as non-epileptic seizures.

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System improvement priority: **Misdiagnosis**

Actions to take:

Supporting accurate epilepsy diagnosis through improved training and resources for clinicians	• Ensure the updated NICE guideline (NG127 – 'Suspected neurological conditions: recognition and referral') has been checked and noted in your system for sections relevant to epilepsy. • Support the training of more clinicians for making epilepsy diagnoses. The NICE guideline CG137 – Epilepsies: diagnosis and management (section 1.5: diagnosis and 1.6: investigations) can help support this. • Clinicians should have ease of access to full range of diagnostic tests such as video EEG. • Work towards a greater network of primary care doctors specialising in epilepsy e.g. GPs with Extended Roles (GPwER) and enable access for patients to GPwERs. • Develop better training for improved history taking techniques for neurologists, epilepsy specialist nurses (ESNs), GPwERs, falls clinic doctors and paediatricians. • Develop more epilepsy training/awareness for clinicians working in falls clinics. • Raise awareness for clinicians to use seizure diaries (available for free from Epilepsy Action) and decision making flow charts and toolkits. • Raise awareness for clinicians to use seizure diaries for children and young people too (available for free from Young Epilepsy for children and young people) and decision making flow charts and toolkits. • Support development of better diagnostic tools e.g. patient /witness reportable information (such as questionnaires, video capturing with smartphones) for other peoples input, especially in falls clinics and paediatrics. Utilise Patient Activation Measure (PAM) to identify individuals level of health literacy and therefore gauge who may benefit from self-management support and health coaching. • Better use of data and technology to reduce misdiagnosis and improve outcomes for people with epilepsy. Examples include health focussed applications and digital health management.
Increasing awareness and education for non-epileptic seizures	• Support a better understanding of non-epileptic seizures (main differential together with syncope). • Provide teaching resources about non-epileptic seizures.

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System improvement priority: **Taking a risk management approach to mortality**

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%).

Key areas for focus:

Identifying those most at risk of avoidable or premature mortality and preventing epilepsy related deaths including Sudden Unexpected Death in Epilepsy (SUDEP)

There are known epilepsy mortality risks, some of which are modifiable. It is vital to identify patients that have a higher risk of premature mortality, which may also be related to other comorbidities, in order to provide the support they need. People with learning disabilities are at higher risk of dying from epilepsy and their risk increases as the severity of the learning disabilities increases, therefore providing support and resources on the prevention of epilepsy related deaths, including SUDEP, is important to improving provision of services for patients and families/carers. NICE has guidance on learning disabilities which can support this. However, it should be made clear that all people living with epilepsy should have risk communication, management and review as epilepsy risk factors can change to become fatal in as short a time as three months. The SUDEP Action Epilepsy Deaths Register data often indicate that those not thought to be 'high risk' are dying (and whose deaths could have potentially been avoided). Young people should also be supported as new 'high risks' for premature mortality could develop during transition such as starting university; lack of sleep; alcohol consumption and not taking medication properly or not at all.

Management of urgent care situations and crisis response

Ensuring there is sufficient education, support and resources for patients, families and carers in the identification and management of urgent care and crisis situations. Ensuring emergency services/ urgent care services have the appropriate tools and protocols in place to work with patients at risk.

Guidance & best practice

Actions to take

System improvement priority: **Taking a risk management approach to mortality**

Actions to take:

Identifying those most at risk of dying and preventing epilepsy related deaths including Sudden Unexpected Death in Epilepsy (SUDEP)	• Understand the epilepsy mortality trends in your area and the processes you have in place to act upon them. Understand co-morbidities of high-risk patients and awareness of lifestyle risk factors that may increase the risk of mortality. • Identify those at risk of dying from epilepsy and support them to reduce risks. Flag potential risk factors such as high A&E attendance; not attending clinics and focussing on socially deprived areas. • Education of spotting risk factors enabling people including children and young people to manage with confidence. • Support clinicians to undertake sensitive discussions about lifestyle risk factors with people living with epilepsy so that appropriate referrals can be made to support services or voluntary sector, including mental health support. This requires having established referral systems in place to ensure that patients do not get lost in the gaps. • Implement processes in your system to audit epilepsy related deaths and learn lessons from these to change/improve services for the future. • Signpost bereaved families to specialist support services and encourage family and clinical reporting to the Epilepsy Deaths Register. • Implement and use a standard risk template for people living with epilepsy that crosses organisational boundaries such as the SUDEP and Seizure Safety Checklist tool and patient Epilepsy Self-Monitoring (EpSMon) app. • Use reasonable adjustments to enable people to access services and support. • Identify what is causing premature mortality for people with learning disabilities and utilise other mortality reviews to gain more information and understanding (e.g. LeDeR Annual Reports) and refer the death of a person to these reviews too. • Utilise virtual/teleclinics to promote self-management especially for patients that do not engage with services; miss appointments; do not attend appointments or are at risk. • Use patient activation measure (PAM) and health coaching to improve peoples health literacy, leading to improved self-management. • Support young people in relation to SUDEP through ‘high risk’ periods in their lives such as starting university and other life-style changes. • Refer to relevant NICE Quality Standards on epilepsy for adults (QS26) and children and young people (QS27).

Guidance and best practice examples

System improvement priority: **Taking a risk management approach to mortality (continued)**

Actions to take:

Management of urgent care situations and Crisis Response	- Identify the regular A&E attenders with seizures and ensure the SUDEP conversation has been had about the importance of taking their medication and completing the SUDEP and Seizure Safety Checklist or EpSMon with them. Ensure they are followed-up in primary care. - Ensure ambulance services are aware of those at risk and have rescue protocols in place to ensure a prompt response. Enable paramedics to have access to patient records via mobile technology e.g. tablets to support people initially in crisis and therefore provide appropriate sign-posting or referral at this initial contact point. - Ensure paramedics are trained and equipped to administer buccal midazolam and/or emergency medication for children, young people and adults who have had a previous episode of prolonged or serial convulsive seizures in line with NICE guidance CG137. - Ensure the system has a rescue protocol in place that is accessible and known by all parties including patients and carers. - Shared patient care record/plan so all appropriate parties have access in the event of an emergency. - Signpost services that recommend endorsed literature and resources to help patients/ families and carers to learn what to do in an emergency. - Refer to relevant NICE Quality Standards on epilepsy for adults (QS26) and children and young people (QS27).

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System improvement priority: **Access to epilepsy specific services**

The NICE Quality Standard on epilepsy in adults (QS26) Statement 1 states ‘Adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation’ or if there is suspected epilepsy. The NICE guideline CG137 Epilepsies: diagnosis and management recommendations under 1.4 and specifically 1.4.1; 1.4.2 and 1.4.5 should be referred to following a first seizure.

Patients should be further referred to tertiary services within four weeks for further assessment if there is diagnostic uncertainty; treatment failure or seizures that are uncontrolled as stated in NICE Quality Standard on epilepsy in adults (QS26) Statement 7.

Key areas for focus:

Timely access to specialist services including first seizure clinics

Accessing the appropriate specialist service in a timely manner is important for patients who have experienced a seizure/s.

Accessing alternative epilepsy support in the community

Where there is no provision of Epilepsy Specialist Nurses (ESNs), it is important to have access to alternative means of support in the community. Furthermore, learning from areas where there is best practice in the community is key.

Clear referral and access processes for new and previously discharged patients

Ensuring there are clear and effective referral and access processes for all patients whether they are new or have been discharged is an important area of focus for epilepsy patients. Linking teams across the services to build networks for effective referral and escalation will be a key factor.

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System improvement priority: **Access to epilepsy specific services**

Actions to take:

Timely access to specialist services including first seizure clinics

- Ensure alignment of access with the needs of the patient where appropriate and timely referral to specialist care should be based on clinical need.
- Review with local Primary Care Networks (PCNs) to raise capacity in primary care or link up to other pathways/specialisms to increase capacity where there is a lack in secondary and tertiary specialists.
- Maximise non-traditional methods of specialist contact such as telehealth/virtual consultations. This will free up more capacity and be especially helpful for patients resident in rural areas and patients with no easy access to specialist centres.
- Focus and develop GPs with Extended Roles (GPwER) in epilepsy to further support specialist care. Currently, there are 40,000 GPs in total and therefore potential to develop more specialist capacity.
- Link pharmacy teams and other professionals into training and building effective networks for referral and escalation. Support training of community pharmacists to link into this specialism.
- Ensure NICE guideline CG137 – Epilepsies: diagnosis and management section 1.10.2 is embedded in the case of patients where seizures are not controlled and/or there is diagnostic uncertainty. Referral to tertiary services should be considered if one or more of the seven criteria outlined are met.

Accessing alternative epilepsy support in the community

- Share business cases for community Epilepsy Specialist Nurses (ESNs) for areas where there is good practice for other areas to consider.
- Provide a mechanism to access different support in the community e.g. pharmacy, voluntary sector or a network of services where an ESN is not available.
- Referral to social prescribing for support groups and promote self-management where appropriate. Refer to guidance to help PCNs introduce the new role of social prescribing link worker into their multi-disciplinary teams.
- Refer to Epilepsy12 2018 National Organisational Audit Report where the report aims to help commissioners and epilepsy services measure and improve the quality of care for children and young people with epilepsy and seizures.

Clear referral and access processes for new and previously discharged patients

- Clear referral processes need to be developed that are standardised across the local system which are continually reviewed in response to service changes and technology advances.
- Review which systems are able to adhere to the NICE guidelines referral processes as outlined in CG109, CG137 and NG127.
- Make patients aware of self-referral processes back into system if they were discharged so that they are not starting at the beginning of the referral and access process again.
- Provide accessible information that signposts people to appropriate service.

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System improvement priority: **Support for specific patients groups**

Some patient groups may require additional or more specialised support than others at various points in their life. This could be due to the development of co-morbidities, a temporary change such as pregnancy or a patient that requires additional needs. Having timely and correct information and access to the additional support when needed will mean that their epilepsy can continue to be managed safely, and will minimise the risk of causing harm.

Key areas for focus:

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 (CG137 – Epilepsies: diagnosis and management section 1.17 Young people with epilepsy, Quality Standard 27: Epilepsy in children and young people, statement 4 (Epilepsy Care Plan) and NG127 – Recommendations for children aged under 16). 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 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. NICE Quality Standard 27 statement 9 sets a quality standard for transition period where their epilepsy care is reviewed jointly by paediatric and adult services. Further NICE guidance includes NG43 - Transition from children's to adults' services for young people using health or social care services and Quality Standard 140 including five quality statements.

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System improvement priority: **Support for specific patients groups (continued)**

Some patient groups may require additional or more specialised support than others at various points in their life. This could be due to the development of co-morbidities, a temporary change such as pregnancy or a patient that requires additional needs. Having timely and correct information and access to the additional support when needed will mean that their epilepsy can continue to be managed safely, and will minimise the risk of causing harm.

Key areas for focus:

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. NICE provide guidance on people with learning disabilities .

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.

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System improvement priority: **Support for specific patients groups**

Actions to take:

Support for children and young people

- Refer to the relevant NICE guidance for epilepsy diagnosis and management for children and young people (CYP) CG137 and QS27 .
- Refer to the NICE guideline for Suspected neurological conditions: recognition and referral (NG127) in particular 'Recommendations for children aged under 16' and for young people, 'Recommendations for adults over 16' for epilepsy.
- Refer to CHESS and SEEN reports to gain an understanding of the effect of epilepsy in CYP on cognition and behaviour and how this impacts their education and consequently their life opportunities.
- Ensure all children and young people with epilepsy are screened for cognitive and behavioural difficulties.
- Where capacity and resources allow, ensure paediatric epilepsy clinics have co-located mental health provision.
- Where capacity and resources allow, ensure all children with epilepsy have access to an Epilepsy Specialist Nurse (ESN) who play a key role in supporting continuity of care between settings for people with epilepsy.
- Awareness of mothers of children with epilepsy have higher mental health risks.
- People who work in schools or other educational settings should provide information on supporting young people with epilepsy to ensure they are safe and included in all aspects of school life. Ensure healthcare professionals are supported to give CYP's care at school by working collaboratively with local education providers.
- Support healthcare professionals to give epilepsy awareness and rescue medication training as well as supporting the development of the schools' Individual Healthcare Plans (IHP).
- Refer to the 2019/20 National Tariff Payment System – A consultation notice: Annex DtD Guidance on best practice tariffs where the aim of the best practice tariff (BTP) is to enable access to consistent high-quality care for children with epilepsy.
- Refer to OPEN UK (Organisation of Paediatric Epilepsy Networks) clinical network led by Royal College of Paediatrics and Child Health where the aim is to connect NHS Health Boards and Trusts that provide care for children with epilepsies with regional epilepsy networks to improve integrated care.
- Refer to Epilepsy12 2018 National Organisational Audit Report where the aim of the report was to help commissioners and epilepsy services to measure and improve the quality of care for CYP with epilepsy and seizures.

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System improvement priority: **Support for specific patients groups (continued)**

Actions to take:

Support for people transitioning from child to adult services

- Be clear what the age for transition is and that this is known and followed by all services.
- Implementation and development of a joined up transition process across the system.
- Ensure epilepsy risks are clearly communicated between the paediatric care clinician and the adult care clinician during transition. An epilepsy risks review is performed after transition and that the person with epilepsy is fully aware.
- The transition process is clearly communicated and explained to all patients and their families and carers at an early stage and before transition.
- The transition process needs to be clearly communicated to the GP for people with a learning disability.
- The NICE Quality Standard on epilepsy in children and young people (QS27) statement 9, sets a quality standard for transition period where their epilepsy care is reviewed jointly by paediatric and adult services.
- Further NICE guidance includes Transition from children's to adults' services for young people using health or social care services (NG43) and Transition from children's to adults' services (QS140).

Support for people with learning disabilities

- Ensure people with epilepsy and learning disabilities are placed on the learning disabilities register so they are easily identified as having learning disabilities – this will help services identify them and meet the needs of the individual and will include annual reviews.
- Ensure that specialist epilepsy/neurology services are upskilled and making reasonable adjustments to support the needs of people with a learning disability, including working in partnership with learning disability specialist staff. People with a learning disability should have access to the same range of skills, tests and treatments as everybody else.
- Local learning disability professionals should be upskilled in management of epilepsy, which could include specialist epilepsy nurses or a consultant psychiatrist with a special interest in epilepsy and working in partnership with mainstream services (Royal College of Psychiatrists reports College Report 203 highlights the role of the learning disabilities psychiatrists and College Report 206 which enumerates how people with learning disabilities and epilepsy should be managed from learning disabilities services particularly around prescribing and awareness of poly pharmacy).
- Utilise good practice tools (Purple Light toolkit) in appendices of Royal College of Psychiatrists reports (College Report 203 and College Report 206).
- Upskill healthcare professionals to ensure that they are aware of the adjustments they need to make to meet the needs of the individual – both epilepsy and learning disabilities specialists.
- Ensure that the Learning Disability Standards are known and followed across the system.
- Support around medication – education to ensure medication is taken appropriately. Awareness of stopping over medication of people with a learning disability, autism or both (STOMP). This is a national project involving many different organisations which are helping to stop the over use of these medicines.
- Ensure community specialist nurses in learning disabilities have training and skills in management of epilepsy.
- Reasonable adjustments must be made according to individual patient need and information provided in an accessible and easy read format.
- Refer to NICE learning disabilities topic landing page which includes all NICE products on people with learning disabilities (guidance, advice, NICE Pathways and quality standards).

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System improvement priority: **Support for specific patients groups (continued)**

Actions to take:	
Support in pregnancy	• Important to provide balanced information to girls and women of childbearing age and pregnant women with epilepsy who are taking sodium valproate and other AEDs (e.g. Topiramate) that have been identified as having potential teratogenic effects and that the Pregnancy Prevention Programme is completed where applicable. • Make the 'Maternity Epilepsy Shared Care' Toolkit available and adopted across the system and embed this toolkit into the individual's care plan, where appropriate. • Refer to MHRA sodium valproate toolkit and Pregnancy Prevention Programme • Ensure the workforce that support pregnant women who have epilepsy i.e. midwives and health visitors have had training and education about the condition. • Refer to Royal College of Obstetrics and Gynaecology epilepsy and pregnancy guidelines to support multi-disciplinary team working so that maternity and epilepsy services can be joined up. • Refer to summary of NICE guidance and safety advice for valproate use in children, young people and adults. • Refer to NICE pregnancy products on pregnancy (guidance, advice, NICE Pathways and quality standards) for additional information.
Support for older people	• Ensure there is clarity on the complete comorbidities of patients with epilepsy and who are also frail. • Support poeple with dementia to manage their medication reminders.

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System improvement priority: **Mental health and emotional wellbeing support**

In the U.K., the probability of having depression with epilepsy as a condition is 1 in 3 .Therefore people with epilepsy are at high risk of developing depression, anxiety and other mental health conditions. This is also important for people with a learning disability where common mental health conditions are likely to be missed. Specialist services must include mental health for all patients with epilepsy as there is a proven genetic predisposition to increased mental health issues if you have epilepsy. In addition, mental illness has been linked to greater frequency of seizures in epilepsy. Therefore, there is a need to provide appropriate mental health and well-being support to people living with epilepsy.

Key areas for focus:

All people living with epilepsy know how and where to access mental health and wellbeing support

It is important to identify people living with epilepsy who are subsequently diagnosed with a mental health condition or vice versa quickly so that they are sign-posted/referred to appropriate mental health and wellbeing support. There is a challenge that people with epilepsy and depression and anxiety symptoms are less likely to be referred to Improving Access to Psychological Therapies (IAPT) services because of their pre-existing epilepsy and that the general IAPT services would find these patients complex to treat. Therefore, there is a need to establish an agreed mental health pathway for people with epilepsy requiring access to such services. Appropriate support would also be identified via the Personalised Care and Support Planning stage.

Epilepsy professionals have the training and confidence to provide suitable mental health and wellbeing support

Providing support and training to epilepsy professionals (e.g. epilepsy specialist nurses, neurologists and paediatricians) on mental health conditions that affect epilepsy patients, will benefit the patient's management of both conditions.

Appropriate mental health support from the multi-disciplinary team at time and place of specialist review

By enabling the multi-disciplinary team at the time and place of the epilepsy specialist review with mental health support and training, the team will be able to review and appraise care co-ordination in order to identify and navigate mental health co-morbidities.

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System improvement priority: **Mental health and emotional wellbeing support**

Actions to take:

All people living with epilepsy know how and where to access mental health and wellbeing support	• All people should be signposted for emotional wellbeing support at the point of first seizure. If appropriate, there should be an offer of a mental health referral. Encourage the use of mental health screening tools such as PHQ9 and GAD7. • Families and carers shouldbe signposted to appropriate mental health and emotional wellbeing support services. • Implementing simple screening questionnaires (PHQ9 and GAD7) via GPs or epilepsy specialist could be an easy way to identify patients with a developing or developed mental health condition. Appropriate referral or sign-posting to mental health services can then be triggered. • Implement social prescribing to make the most of the community-based and informal support available. Refer to guidance to help PCNs introduce the new role of social prescribing link worker into their multi-disciplinary teams. • Review guidance on delivering the mental health commitments in the NHS Long Term Plan. • Refer to NICE mental health and well-being products (guidance, advice, NICE Pathways and quality standards).
Epilepsy professionals have the training and confidence to provide suitable mental health and wellbeing support	• Ensure epilepsy professionals have the training to confidently spot signs of mental health conditions, or decline in mental health, and refer or signpost them to appropriate support services. • Have clear referral processes for mental health and emotional wellbeing services within your area that is communicated effectively to epilepsy professionals. • Refer to Epilepsy12 2018 National Organisational Audit Report where the aim of the report was to help commissioners and epilepsy services to measure and improve the quality of care for CYP with epilepsy and seizures. • Ensure pathways are reasonably adjusted to facilitate equality of access for people with a learning disability. • Ensure primary care staff feel knowledgeable and confident to work with people with mental health issues and to avoid 'diagnostic overshadowing'. • Refer to NICE mental health and well-being products (guidance, advice, NICE Pathways and quality standards).
Appropriate mental health support from the multi-disciplinary team at time and place of specialist review	• Multi-disciplinary teams (MDT) having access to specialist mental health support and referral as appropriate.

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System improvement priority: **System-wide education and training around supporting people with epilepsy**

Providing access to robust education and training to healthcare professionals such as GPs, nurses, paramedics and pharmacists who manage people with epilepsy is important in maintaining quality of care. Furthermore, providing education for people with epilepsy, their families/carers, schools and employers is vital especially in emergency situations or when there is an observed change in the patients' symptoms.

Key areas for focus:

Education for people living with epilepsy

Education provided to people living with epilepsy about how to best self-manage; what to do in emergency situations and what to look out for when recognising changes in symptoms.

Education for families and carers, especially in recognising changes in symptoms and emergency situations

Education provided to families, carers and patients about what to do in emergency situations and what to look out for when recognising changes in symptoms related to epilepsy is key in self-management and effectively managing the patients' next course of action.

Education and training for GPs, nurses and pharmacists

There is wide variation in GPs being able to confidently and effectively manage patients with epilepsy, especially those with severe epilepsy. By providing training and education to GPs capacity will be improved elsewhere in the system and will therefore reduce the number of referrals to specialist epilepsy services. Additionally, extending appropriate epilepsy education and training to nurses and pharmacists will further support patients managing their condition.

Education and training and support for paramedics on appropriateness to bypass A&E and also SUDEP risk

Paramedics are commonly called to patients living with epilepsy who are having a seizure. It is important to support paramedics around decision making of when to access the A&E and when not to.

Wider population education and awareness of epilepsy to reduce stigma including employers and schools

There should be training and education for staff in schools/childcare settings as staff have safeguarding responsibilities (keeping children with long term conditions safe at school) and responsibilities for children's educational progress (understand how epilepsy affects learning and behaviour). Efforts need to increase in order to promote education and awareness of epilepsy in all communities, including employers thereby reducing stigma.

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System improvement priority: **System-wide education and training around supporting people with epilepsy**

Actions to take:	
Education for people living with epilepsy	• Signpost people living with epilepsy to e-learning modules on voluntary sector websites e.g. ‘Epilepsy and You’. • Be provided with information by services after first seizure. • Utilise Patient Activation Measure to gauge level of health literacy. Use health coaching to improve the level of self-management.
Education for families and carers, especially in recognising changes in symptoms and emergency situations	• Encourage clinicians to signpost patients’ families and carers to online support from epilepsy specific voluntary sector websites and education such as booklets, online courses and support groups to enable self-education. Furthermore, consider a routine offer for education programmes to include such as: recovery after a seizure; triggers for seizures; medication administration; how to handle a crisis situation etc. • Signpost parents/guardians to online support for children and young people with epilepsy. • Encourage the use of ‘Carer’s Passports’ which identify someone as a carer and therefore enable staff to involve carers in patient care (Commitment to Carers). • Carers will benefit from greater recognition and support through introducing quality markers for primary care that highlight best practice in carer identification and support (Supporting carers in general practice: a framework of quality markers). • Epilepsy Specialist Nurses that are prescribers to support families and carers regarding the management of medication. • Utilise Patient Activation Measure to gauge level of health literacy. Use health coaching to improve the level of self-management.

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System improvement priority: **System-wide education and training around supporting people with epilepsy (continued)**

Actions to take:

Education and training for GPs, nurses and pharmacists	• Providing training for GPs and optimally utilise GPs with Extended Roles (GPwER) in epilepsy to provide more capacity into the system and prevent unnecessary referrals to specialist services. • Embed sodium valproate guidance training for GPs, nurses and pharmacists. Ensure guidance is followed when treating girls/women of childbearing age with epilepsy. • Identify which competencies are needed from GPs to achieve this specialist level and work out a training package to deliver this looking at thresholds and method of delivery (intensive/supervised, light, online, stepped training etc.). • Utilise primary care networks to engage GPs using clinical scenarios. Use GPwERs in epilepsy to diffuse training to other GPs. • Utilise RCGP SUDEP and Seizure Safety e-learning and Health Education England modules on epilepsy for all clinicians and medical trainees. • Extend epilepsy training and education to nurses and pharmacists including those working in the community and GP practices.
Education and training and support for paramedics on appropriateness to bypass A&E and also SUDEP risk	• Provide training to paramedics on epilepsy – knowing when to take patients to A&E and safe non-conveyance to hospital. • Signpost paramedics to use the SUDEP & Seizure Safety Checklist and EpSMon app for people with epilepsy to discuss/explore risks and interventions as needed. Have care plans that are accessible by paramedics. Having use of technology (e.g. tablets) where patient records are accessible. • Care plan available and accessible at home so paramedics can view it when needed. • Paramedics have access to Epilepsy Specialist Nurses where available to support decision making. • Ensure paramedics are trained and equipped to administer buccal midazolam and/or emergency medication for children, young people and adults who have had a previous episode of prolonged or serial convulsive seizures in line with NICE guidance CG137.
Wider population education and awareness of epilepsy to reduce stigma including employers	• Signpost to epilepsy specific voluntary sector websites and initiatives where efforts are being made to increase the public awareness of epilepsy thereby reducing stigma. • Epilepsy may increase short term leave of absence from work, reduce capabilities (e.g. driving) or reduce quality of work in the short term, this however should not discriminate them within the workplace and employers should work with the person in respect of human resources processes surrounding a known medical condition and the impact on work. • Ensure healthcare professionals are supported to give aid CYP's care at school by working collaboratively with local education providers. • Support healthcare professionals to give epilepsy awareness and rescue medication training as well as supporting the development of the schools' Individual Healthcare Plans (IHP).

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System improvement priority: **Medicines optimisation**

The aim of medicines optimisation is to help improve patient outcomes by ensuring that their medicines are taken correctly; avoiding taking unnecessary medicines; reducing wastage of medicines and improving medicines safety. It is about ensuring that the right patients get the right choice of medicine at the right time and encouraging patients to take ownership of their treatment. The NICE guideline on Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes (NG5) and related Quality Standard (QS120) provides guidance on safe and effective use of medicines in health and social care for people taking one or more medicines.

Key areas for focus:

Patient and carer education for medicines - key self-management strategy

Supporting patients, families and carers to play an active role in the management of their medicines by knowing the different types of medication available. This includes how to optimally manage them as well as making personal choices as a result of potential side effects and being aware of these side effects, which is an important part of successful self-management of drug regimes.

Risks of valproate in pregnancy

Sodium valproate should not be prescribed to pregnant women due to the increased risk of serious developmental disorders in unborn babies and these risks should also be discussed with girls/women of childbearing age. Balanced conversations should occur between the pregnant woman and the clinician outlining the mortality risks if the medication was stopped due to fear of harm to the baby and the potential risk to both their lives if this decision was made.

Furthermore, in 2019 NICE strengthened warnings that valproate must not be used in women or girls of childbearing age (including young girls who are likely to need treatment into their childbearing years), unless alternative treatments are not suitable. Women and girls of childbearing age must be fully informed about the risks of taking valproate during pregnancy, and only take valproate if they have a pregnancy prevention programme in place, in line with the MHRA safety advice on valproate.

Individuals have access to medication review when they need it

Patients may need their medication reviewing or changing if they are experiencing side effects or a decrease in seizure control. Where this is the case, patients should be able to access medication reviews by appropriate clinical staff to review their medication and be placed onto a new treatment regime where appropriate.

This medication review could be part of the wider risk review or vice versa as it is known that poor seizure control and medication adherence issues increase epilepsy mortality risks.

System wide specialist support for non-specialist professionals in managing epilepsy medication

Specialists supporting non-specialists in the system about epilepsy medication will provide professionals in primary care to support decisions about epilepsy medication, decreasing the need for specialist review. This can be incorporated in a system wide multidisciplinary team (MDT) approach.

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System improvement priority: **Medicines optimisation**

Actions to take:	
Patient and carer education for medicines – key self-management strategy	• Support patients to understand the benefits of shared decision making by highlighting evidence showing better outcomes for patients who are involved in decisions about their condition and their treatment. • Prescribing pharmacists could provide support regarding management of medications. • Use Patient Activation Measure to identify level of health literacy to further enable self-management. • Signpost patients to resources on epilepsy treatment and medication.
Risks of valproate in pregnancy	• Ensure that local clinical protocols are in place to ensure that pregnant women are not prescribed sodium valproate to treat either epilepsy or a mental health problem. Perform annual review and signpost to MHRA Pregnancy Prevention Programme. • Ensure that the MHRA Pregnancy Prevention Programme is referred to and that relevant Risk Acknowledgement forms are discussed and signed. • Vital that messaging regarding the risks of sodium valproate are shared with patients in the context of full awareness of epilepsy mortality risks, else informed choices about their care cannot be made and may put their and their child's life at risk. • Refer to summary of NICE guidance and safety advice for valproate use in children, young people and adults. • Refer to NICE guideline CG137 – Epilepsies: diagnosis and management section 1.9 pharmacological treatment.

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System improvement priority: **Medicines optimisation (continued)**

Actions to take:

Individuals have access to medication review when they need it – maybe undertaken by pharmacists	• Structured medication reviews to be undertaken by clinical pharmacists located within GP practices in line with the The Community Pharmacy Contractual Framework for 2019/20 to 2023/24: supporting delivery for the NHS Long Term Plan. Ensure that all epilepsy patients are able to access a medication review when they experience side effects or a change in seizure control. • Ensure changes to medication (e.g. shift from brand to generic) are clinically appropriate. • Undertake shared decision making with the patient when it comes to changing medication to ensure that all new dosing regimes, potential side effects and drug-to-drug interactions are discussed and fully understood. • Utilise prescription collection data to further aid the understanding of local people with epilepsy populations – who collects prescriptions or not; who collects repeat prescription but do not attend appointments.
System wide specialist support for non-specialist professionals in managing epilepsy medication	• Have an epilepsy multidisciplinary (MDT) team across the system. • Have routes on clear and timely communication channels to specialists from non-specialists across the system to support decision making on prescribing. • Be aware of patients that repeatedly present in secondary care and may not have had their situation fully relayed to the GP and therefore may not have an opportunity for a medication review, leading to presenting in secondary care again.

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System improvement priority: **Coordination of Care**

It is recommended that people living with epilepsy (children, young people and adults) have an agreed and comprehensive written care plan. Due to a number of lifestyle, health and wellbeing factors being directly related to epilepsy, a care plan is an important tool in ensuring that all aspects of a person's life that could be affected by their epilepsy syndrome and the treatment they are receiving are considered and addressed. Integrating Shared Decision Making and Personalised Care and Support Plans (PCSP) as part of the development of the care plans should be part of the rationale behind coordination of care.

Key areas for focus:

All patients to have a comprehensive care plan (PCSP) in place that is available across all healthcare settings and includes regular review

There is a need for comprehensive care plans (PCSP) to be produced detailing care pathways for epilepsy patients that can be accessed across all services. These care plans should be discussed with the person (or with a family member or carer), then agreed and written and should also include scheduled reviews. A copy of the care plan should be given to the patient to keep as well as a one page profile, such as a patient passport of the person living with epilepsy including interests; hobbies; goals and motivations to self-care.

All patients to have a mechanism of support between appointments

Informing patients on how to access support in between appointments from the epilepsy service, if required, that draws on support from GPs, pharmacists, community services or the voluntary sector.

Embed Making Every Contact Count (MECC) in all settings

Training with epilepsy specialists in Making Every Contact Count will give them the confidence to have brief conversations and shared decision making strategies with patients about how to improve their overall health and wellbeing. It is extremely important for people with epilepsy and clinicians to understand why MECC is important for them in relation to their individual epilepsy. There are still significant gaps in clinical/patient knowledge on epilepsy fatality risks, so decisions about lifestyle aspects mentioned in the MECC such as drinking/smoking/drugs are made from a position of risk ignorance, which can put people with epilepsy even more at risk.

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System improvement priority: **Coordination of Care**

Actions to take:	
All patients to have a comprehensive care plan (PCSP) in place that is available across all healthcare settings and includes regular review	• Care plans should be developed in collaboration with patients with epilepsy thereby creating ownership and facilitating effective implementations outside of clinical settings utilising Shared Decision Making principles (Universal Personalised Care, 2019). • Conduct regular reviews, (e.g. 6 month/annual dependent on patient need) to allow monitoring and adjustment strategies and improve safety and medicines adherence. This should be detailed in the care plan goals. Timings of reviews should be personalised according to patient needs. • Utilise alternative methods for review, for stable patients, including telehealth/ virtual clinics dependent on patient preference. • Link to individual care plan – standardised, being aware of what is in the care plan and having access to it. • Adopt technology solutions to enable timely sharing of care plans across health and social care organisations, in line with the Integrated Care System (ICS) aspirations set out in The NHS Long Term Plan. • Refer to the NICE guideline CG137 – Epilepsies: diagnosis and management section 1.8 management. • Refer to the NICE Quality Standard 26 (Epilepsy in adults) and Quality Standard 27 (Epilepsy in children and young people) : statement 4 epilepsy care plan.
All patients to have a mechanism of support between appointments	• Define the mechanism of support available to patients in between appointments for example what to do should a crisis arise or a simple 'check-in' phone call with patients. • Young people living with epilepsy should know a specific clinician whom they should contact if their epilepsy changing enabling the patient to re-engage with the system if needed.
Embed Making Every Contact Count (MECC) in all settings	• Embed the culture of Make Every Contact Count across the local system.

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System improvement priority: **Personalised Care**

Personalised care means people have choice and control over the way their care is planned and delivered. It is based on what matters to them and their individual strengths and needs.

Key areas for focus:

Effective personalised care and support planning with patients and shared decision making

Personalised care and support planning should address the full needs of the individual, taking steps to address loneliness, isolation, healthy behaviours etc. The process should involve shared decision-making between the individual and the professionals supporting them, putting the patient at the centre of decisions about their own care. Voluntary sector organisations can also play an important role in effective care planning and providing follow up support. The Personalised Care and Support Plan (PCSP) may help to identify a persons need to have a patient activation measure (PAM) i.e. to identify their level of health literacy and subsequent need for health coaching, supported self-management and social prescribing. The PCSP must be shared with all individuals working around the service user.

Advanced care planning

This is the process of people expressing their preferences, values and goals about their future wishes and priorities for their own health and care. It enables better provision and planning of care, helping people to live well and die well in a place and manner of their choosing (Gold standards framework, 2018).

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System improvement priority: **Personalised Care**

Actions to take:	
Ensure effective personalised care and support planning with patients and shared decision making	• Ensure the personalised care and support plan is available across all healthcare settings. • Personalised care and support planning should address the full health and wellbeing needs of the individual as recommended in the NICE guideline CG137 – Epilepsies: diagnosis and management. • Use patient decision aids to help people make informed choices about their healthcare and treatment options. • Use Patient Activation Measure to identify level of health literacy to further enable self-management. • Ensure that staff are aware of local services that they can refer / signpost people with living with epilepsy, to provide support for them outside of primary or secondary care.
Advanced care planning	• Support people living with epilepsy to review their ongoing support needs and personal planning when a change is noted in their care requirements either by themselves, carers or support staff, and clinicians or key workers. • Ensure services actively encourage people they work with to complete an advance care directive in a timely manner and this is known to the family and carers as well as held by all agencies the person engages with. • Ensure services work with people living with epilepsy are confident in recognising changes in symptoms that may require changes in treatment.

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System improvement priority: **Experience of Care**

Experience is important in a number of different, but related ways:

- As a key part of providing high quality care - those providing health and care services view experience as a natural part of providing high quality care, and a good experience is now seen as an important 'outcome' in its own right.
- As a way of improving outcomes - there is strong evidence about the links between experience and the other aspects of high quality care (clinical effectiveness and safety).
- As a way of indicating value for money and whether services are appropriate - only by understanding what people want from their services and continually focusing on their experiences will we truly be sure we are delivering value for money.
- As a way of supporting staff engagement - there is strong evidence to show the links between staff engagement and the experience of service users.

Key areas for focus:

Improving the experience of care for people living with epilepsy and their carers

The poorest care is often received by those least likely to make complaints, exercise choice or have family or carers to speak up for them. Also, there are concerns about unfair discrimination in access to care. Furthermore, they are also the ones most likely to drop out of the system and therefore could be at significant risk. People who use services have vital insights into their care and many are experts in managing their own conditions. Genuine partnerships gives patients' parity of esteem with health professionals and both improve health outcomes and contribute to more cost-effective use of services.

'Good' experience of care will result in people who use services being more engaged with their own healthcare, leading to improved patient/service user outcomes and productivity gains for NHS services.

Ongoing support for family and carers that continues after death

It is important to continue supporting families and carers in the event of an epilepsy related death. Currently, support for families is very localised with large amounts of variation across services.

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System improvement priority: **Experience of Care**

Actions to take:	
Improving the experience of care for people and their carers who live with epilepsy	• Ensure that carers supporting people with epilepsy are identified and are supported to live well. • Have a systematic approach to identifying carers supporting people living with epilepsy who are at risk of not managing their own health conditions. • Services use experience of care feedback from patients and carers to improve services using co-production and co-design. • Localities to review current experience of care and establish plans for improvement. • Do this in a way that is acceptable for people to enable them to work in partnership with their health professionals. • Staff working with people with epilepsy should be confident in recognising that a person may also have other health conditions and feel equipped to engage effectively with patients/carers to discuss referral(s) to wider health professionals. • Review publication of Neurological Alliance Patient Experience Survey (2019). • Refer to the NICE guideline CG138 - Patient experience in adult NHS services: improving the experience of care for people using adult NHS services.
Ongoing support for families and carers after death	• Identify mechanisms for clinical notification of death to ensure all those involved in a patient's care are informed quickly. • Consider reporting the death to the Epilepsy Deaths Register where anyone with knowledge of a death is able to report (families, carers, friends, clinicians). • Ensure families and carers do not go without clinical engagement after death and are signposted to specialist bereavement support. • Utilise the third sector and ensure information about these is shared with all families and carers following death.

Guidance and best practice

This section contains all the relevant guidance, evidence and case studies aligned to each of this toolkit's system improvement priorities and key areas for focus. It supports development of improvement actions when system priorities have been identified.

Key Guidance referenced throughout document (see supporting slides for hyperlinks to each document)

Overarching NICE Guidance:

CG137 - Epilepsies: diagnosis and management

NG127 - Suspected Neurological Conditions

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

NG43 - Transition from children's to adults' services for young people using health or social care services

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

CG138 - Patient experience in adult NHS services: improving the experience of care for people using adult NHS services

NG96 - Care and support of people growing older with learning disabilities

NG93 - Learning disabilities and behaviour that challenges: service design and delivery

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

NG11 - Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

Quality Standard 26: Epilepsy in adults

Quality Standard 27: Epilepsy in children and young peoplev

Quality Standard 140: Transition from children's to adults' services

Quality Standard 120: Medicines optimisation

Quality Standard 142:Learning disability: identifying and managing mental health problems

Quality Standard 101:Learning disability: behaviour that challenges

Quality Standard 187:Learning disability: care and support of people growing older

Key recommendations for research (3&4) in NG144 – Cannabis-based medicinal products

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System improvement priority: Identification and segmentation of the epilepsy population

NICE CG137 – Introduction

NICE NG127 - Suspected neurological conditions: recognition and referral: Please see for recommendations in **adults over 16:**

- 1.1. Blackouts in adults (reference to epilepsy 1.1.1)
- 1.2.10 Dizziness with altered consciousness
- 1.8.5 Dense amnesia
- 1.10.3 Sensory disturbances
- 1.12.2 Smell or taste hallucinations

Please see for recommendations in **children under 16:**

- 1.17 Attention, concentration and memory problems
- 1.20.5 Recurrent dizziness
- 1.27.3 Isolated tingling, altered sensation or paraesthesia
- 1.28.2 Sleep disorders suggesting nocturnal seizures

NICE CG109 - Transient loss of consciousness ('blackouts') in over 16s**:** Please see:

- 1.2.2 Suspected epilepsy
- 1.4.1.1 If the cause of TLoC remains uncertain

NICE indicator NM110

Joint Strategic Needs Assessment and joint health and wellbeing strategies explained. Department of Health and Social Care **(2011)**

NICE CG109 - Transient loss of consciousness ('blackouts') in over 16s**:** Please see:

- 1.2.2 Suspected epilepsy
- 1.4.1.1 If the cause of TLoC remains uncertain

Reliability, validity and responsiveness of a revised scoring system for the Liverpool Seizure Severity Scale Scott-Lennox J, Bryant-Comstock L, Lennox R, Baker GA. *Epilepsy Res.* 1: 53-63 **(2001)**

The Chalfont Seizure Severity Scale. Duncan JS and Sander JW. *J.Neurol Neurosurg. Psychiatry.* 54(10) **(1991)**

The Personal Impact of Epilepsy Scale (PIES) Fisher RS, Nune G, Roberts SE, Cramer JA. *Epilepsy Behav.* 42:140-6 **(2015)**

International League Against Epilepsy (ILAE) is the world's main scientific body devoted to the study of epilepsy, and it has recently revised its classification of seizures

Epilepsy in the United Kingdom: seizure frequency and severity, anti-epileptic drug utilisation and impact on life in 1652 people with epilepsy Moran NF, Poole K, Bell G, Solomon J, Kendall S, McCarthy M, McCormick D, Nashef L, Sander J, Shorvon SD. *Seizure.* 13(6):425-433 **(2004)**

Has the time come to stratify and score SUDEP risk to inform people with epilepsy of their changes in safety? Shankar R, Newman C, Gales A, McLean BN, Hanna J, Ashby S, Walker MC, Sander JW. *Front. Neurol.* **(2018)**

Epilepsy: a public health imperative. *World Health Organisation.* **(2019)**

Epilepsy Commissioning Toolkit (Epilepsy Action and Epilepsy Society)

An example of effective epilepsy service development: Norfolk adult community epilepsy specialist nurse team. Epilepsy Action

Epilepsy12 audit reports aiming to help 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

South Gloucestershire Council Joint Strategic Needs Assessment example

National Audit of Seizure Management in Hospitals

Data Sources

System improvement priority: Identification and segmentation of the epilepsy population

Quality and Outcomes Framework 2017-18 NHS Digital **(2018)**

Quality and Outcomes Framework - Prevalence, Achievements and Exceptions Report England, 2014-15 Health and Social Care Information Centre **(2015)**

Epilepsy data and what it can tell us (Epilepsy Action)

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System improvement priority: Misdiagnosis

Guidance

NICE CG137 - Epilepsies: diagnosis and management

NICE NG127 - Suspected neurological conditions: recognition and referral

Please see for recommendations in **adults over 16:**

- 1.1. Blackouts in adults (reference to epilepsy 1.1.1)
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- 1.8.5 Dense amnesia
- 1.10.3 Sensory disturbances
- 1.12.2 Smell or taste hallucinations

Please see for recommendations in **children under 16:**

- 1.17 Attention, concentration and memory problems
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- 1.27.3 Isolated tingling, altered sensation or paraesthesia
- 1.28.2 Sleep disorders suggesting nocturnal seizures

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

Please see:

- 1.2.2 Suspected epilepsy
- 1.4.1.1 If the cause of TLoC remains uncertain

NICE Quality Standard QS26 - Epilepsy in adults.

Quality Statement 2: Investigations

Quality Statement 3: Magnetic Resonance Imaging

NICE Quality Standard QS27 - Epilepsy in children and young people.

Quality Statement 2: Investigations

Quality Statement 3: Magnetic Resonance Imaging

NICE CG137 Appendix G - The costs of epilepsy misdiagnosis

Implementation and practical examples

E-learning – Health and Social Care modules (Epilepsy Action)

E-learning – modules for practice nurses (Epilepsy Action)

Epilepsy: diagnosis and management in primary care British Medical Journal Learning Module **(2018)**

Preventing misdiagnosis of epilepsy. Ferrie CD. *Arch. Dis. Child*. 91(3):206-209 **(2006)**

Tackling Epilepsy With High-definition Precision Medicine. Kearney H, Byrne S, Cavalleri GL. *JAMA Neurol.* 26(9):1109-1116. **(2019)**

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Free seizure diary Epilepsy Action

Free young person's seizure diary Young Epilepsy

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System improvement priority: Taking a risk management approach to mortality

Identifying those most at risk of dying and preventing epilepsy related deaths including sudden unexpected death (SUDEP)

Guidance

NICE CG137 - Epilepsies: diagnosis and management

NICE NG127 - Suspected neurological conditions: recognition and referral

Please see for recommendations in **adults over 16:**

- 1.1. Blackouts in adults (reference to epilepsy 1.1.1)
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NICE CG109 - Transient loss of consciousness ('blackouts') in over 16s

Please see:

- 1.2.2 Suspected epilepsy
- 1.4.1.1 If the cause of TLoC remains uncertain

Implementation and practical examples

SUDEP Action (free information, leaflets & resources on epilepsy risks for people with epilepsy, their families, carers and clinicians)

SUDEP and Seizure Safety Checklist SUDEP Action risk communication and management tool for clinicians and introductory video

Epilepsy Self-Monitoring (EpSMon) App Risk monitoring and education app for people with epilepsy. Introductory video and supporting NHS 70 video

Specialist epilepsy bereavement support – SUDEP Action, support@sudep.org or 01235 772852

Risk Assessment For People With Epilepsy Epilepsy Society risk assessment forms

Epilepsy Mortality Case Studies SUDEP Action

SUDEP Global Conversation SUDEP Action, Epilepsy Australia & SUDEP Aware (Canada)

System improvement priority: Taking a risk management approach to mortality (continued)

Identifying those most at risk of dying and preventing epilepsy related deaths including sudden unexpected death (SUDEP) continued

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NICE Quality Standard QS26 - Epilepsy in adults.
Quality Statement 1: Referral to a specialist

Quality Statement 6: Prolonged or repeated seizures

Quality Statement 7: Referral to tertiary care

Quality Statement 8: Re-access to specialist care

NICE Quality Standard QS27 - Epilepsy in children and young people.

Quality Statement 1: Referral to a specialist

Quality Statement 6: Prolonged or repeated seizures

Quality Statement 7: Referral to tertiary care

Quality Statement 8: Review

NICE NG96 - Care and support of people growing older with learning disabilities

NICE NG93 – Learning disabilities and behaviour that challenges: service design and delivery

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

NICE NG11 - Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

Patient Activation Measure NHS England

Implementation and practical examples

Learning Disabilities Mortality Review (LeDeR) Annual Report 2018

Epilepsy Deaths Register gathers bereaved family and clinical experiences of epilepsy deaths to help identify themes and learn lessons to inform future epilepsy care & services

Risk of unnatural mortality in people with epilepsy. Gorton HC, Webb RT, Carr MJ. *JAMA Neurol.* 75(8):929-938 **(2018)**

The Adult Profile of SUDEP using the Epilepsy Deaths Register

A community study in Cornwall UK of sudden unexpected death in epilepsy (SUDEP) in a 9-year population sample. Shankar R, Jalihal V, Walker M, Laugharne R, McLean B, Carlyon E, Hanna J, Brown S, Jory C, Tripp M, Pace A, Cox D, Brown Sc. *Seizure.* 23 (5):382-385. **(2014)**

Recommendations to prevent epilepsy deaths SUDEP Action

PHE Neurology mortality report highlighted that people with epilepsy facing deprivation were three times more likely to die

Supporting young people with risk Young Epilepsy

Association of quality of paediatric epilepsy care with mortality and unplanned hospital admissions among children and young people with epilepsy in England: a national longitudinal data linkage study. Hargreaves DS, Arora S, Viveiro C, Hale DR, Ward JL, Sherlaw-Johnson C, Viner RM, Dunkley C, Cross HJ. *The Lancet Child & Adolescent Health*. 3:9 p627-635 (**2019**)

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System improvement priority: Taking a risk management approach to mortality (continued)

Management of urgent care situations and crisis response

NICE CG137 - Epilepsies: diagnosis and management

NICE NG127 - Suspected neurological conditions: recognition and referral

Please see for recommendations in **adults over 16:**

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- 1.28.2 Sleep disorders suggesting nocturnal seizures

NICE Clinical Knowledge Summary – Epilepsy Scenario: Managing an epileptic seizure

NICE Do Not Do Recommendation: CG137 Epilepsies: diagnosis and management - Only prescribe buccal midazolam or rectal diazepam for use in the community for children, young people and adults who have had a previous episode of prolonged or serial convulsive seizures

NICE Quality Standard QS26 - Epilepsy in adults.

Quality Statement 1: Referral to a specialist

Quality Statement 6: Prolonged or repeated seizures

Quality Statement 7: Referral to tertiary care

Quality Statement 8: Re-access to specialist care

NICE Quality Standard QS27 - Epilepsy in children and young people.

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Epilepsy Self-Monitoring (EpSMon) App Risk monitoring and education app for people with epilepsy. Introductory video and supporting NHS 70 video

Impact of the SUDEP & Seizure Safety Checklist & EpSMon app Channel 4 news

Can technology help reduce risk of harm in patients with epilepsy? Shankar R, Newman C, McLean B, Anderson T, Hanna J. *British Journal of General Practice*. 65 (638):448-449. **(2015)**

SUDEP Training package for emergency staff launched by South West Ambulance Service NHS Foundation Trust (SWASFT) and SUDEP Action and adopted by Health Education England.

SWASFT training (outcome from Charlie's story)

Charlie's story and video

Charlie's story: (NHS Resolution)

National sentinel clinical audit of epilepsy-related death: Epilepsy–death in the shadows. Hanna J, Black M, Sander JW, Smithson WH, Appleton R, Brown S, Fish DR. **(2002)** The Stationery Office.

The Adult profile of SUDEP using the Epilepsy Deaths Register

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System improvement priorities:

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System improvement priority: Taking a risk management approach to mortality

Public Health England: Deaths associated with neurological conditions in England 2001 to 2014 Data analysis report p18 **(2018)**

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System improvement priority: Access to epilepsy specific services

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NICE CG137 - Epilepsies: diagnosis and management

In particular:

- 1.4 Following a first seizure
- 1.8 Management
- 1.10 Referral for complex or refractory epilepsy
- 1.20 Review
- Section: Seeing a specialist

NICE pathways - Epilepsy pathway

NICE NG127 - Suspected neurological conditions: recognition and referral

Please see for recommendations in **adults over 16:**

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- 1.28.2 Sleep disorders suggesting nocturnal seizures

NICE CG109 - Transient loss of consciousness (‘blackouts’) in over 16s

Please see:

- 1.2.2 Suspected epilepsy

Implementation and practical examples

Social prescribing link workers NHS England

Experiences of working in a multidisciplinary team NHS England and NHS Improvement **(2019)**

Epilepsy12 National Clinical Audit of Seizures and Epilepsies for Children and Young People National Organisational Report for England Wales **(2018)**

Adult epilepsy nursing team Kent Community Health NHS Foundation Trust

Families of over 300 children avoid driving 30,000 miles for appointments thanks to new hospital alliance NHS England and NHS Improvement **(2018)**

Epilepsy Service University Hospital Southampton NHS Foundation Trust: Wessex Neurological Centre

Adult Epilepsy Nurse Specialist Service Norfolk Community Health and Care NHS Trust

National Neuro Advisory Group Epilepsy (NNAG) event write up The Strategy Unit hosted by Midlands and Lancashire CSU **(2018)**

Epilepsy service provision in the National Health Service in England in 2012. Dickson JM, Scott PA, Reuber M. *Seizure.* 30:26-31 **(2015)**

Epilepsy Commissioning Toolkit (Epilepsy Action and Epilepsy Society)

System improvement priority: Access to epilepsy specific services (continued)

Guidance

NICE Quality Standard QS26 - Epilepsy in adults.
Quality Statement 1: Referral to a specialist

Quality Statement 6: Prolonged or repeated seizures

Quality Statement 7: Referral to tertiary care

Quality Statement 8: Re-access to specialist care

NICE Quality Standard QS27 - Epilepsy in children and young people.

Quality Statement 1: Referral to a specialist

Quality Statement 6: Prolonged or repeated seizures

Quality Statement 7: Referral to tertiary care

Quality Statement 8: Review

RCGP framework to support the governance of General Practitioners with Extended Roles Royal College of General Practitioners **(2018)**

Universal Personalised Care: implementing the comprehensive model NHS England

Implementation and practical examples

Association of Levels of Specialized Care With Risk of Premature Mortality in Patients With Epilepsy. Lowerison MW, Josephson CB, Jette N. *JAMA Neurol.* **(2019)**
SUDEP Action - Access to specialist clinics including first seizure clinics – Patient Stories:

Becky's Story

Charlie's Story

Katie's Story

Annabel's Story

SUDEP Action - Early signposting of bereaved families to a specialist support service – Patient Stories:

Stephen's Story

Richards's Story

Karen's Story

SUDEP Action - Clear referral/access to services for new and existing patients – Patient Story:

Alan's Story

Association of quality of paediatric epilepsy care with mortality and unplanned hospital admissions among children and young people with epilepsy in England: a national longitudinal data linkage study. Hargreaves DS, Arora S, Viveiro C, Hale DR, Ward JL, Sherlaw-Johnson C, Viner RM, Dunkley C, Cross HJ. *The Lancet Child & Adolescent Health*. 3:9 p627-635 (**2019**)

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NICE CG137 - Epilepsies: diagnosis and management

NICE NG127 - Suspected neurological conditions: recognition and referral

Please see for recommendations in **adults over 16:**

- 1.1. Blackouts in adults (reference to epilepsy 1.1.1)
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- 1.28.2 Sleep disorders suggesting nocturnal seizures

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

Please see:

- 1.2.2 Suspected epilepsy
- 1.4.1.1 If the cause of TLoC remains uncertain

NICE NG43 - Transition from children's to adults' services for young people using health or social care services

NICE Quality Standard QS140 - Transition from children's to adults' services

NICE Quality Standard QS27 - Epilepsy in children and young people.

Quality Statement 1: Referral to a specialist

Quality Statement 2: Investigations

Quality Statement 3: Magnetic Resonance Imaging

Quality Statement 4: Epilepsy Care Plan

Quality Statement 5: Epilepsy Specialist Nurse

Quality Statement 6: Prolonged or repeated seizures

Quality Statement 7: Referral to tertiary care

Quality Statement 8: Review

Quality Statement 9: Transition from children's to adult services

Implementation and practical examples

Improving epilepsy care for children and young people: an integrated approach. Young Epilepsy, Institute of Child Health (University College London), Whittington Health NHS Trust and UCL Partners **(2015)**

The identification of educational problems in childhood epilepsy. The Children with Epilepsy in Sussex Schools (CHESS) Study. Young Epilepsy **(2014)**

The psychosocial impact of epilepsy on young children and their families. The Sussex Early Epilepsy and Neurobehaviour (SEEN) Study. Young Epilepsy **(2017)**

Epilepsy12 National Clinical Audit of Seizures and Epilepsies for Children and Young People National Organisational Report for England Wales **(2018)**

Childhood epilepsy: A guide for parents Young Epilepsy

Epilepsy in Infants and Young Children: A guide for parents Young Epilepsy

Seizure diary and handbook for teenagers – for parents and carers Young Epilepsy

Young person's seizure diary Young Epilepsy

Supporting young people with epilepsy: guide for schools Young Epilepsy

Academic achievement in school-aged children with active epilepsy: A population-based study. Reilly C, Atkinson P, Das KB, Chin RFC, Aylett SE, Burch V, Gillberg C, Scott RC, Neville BGR. *Epilepsia*. 55(12):1910-1917. **(2014)**

A population survey of mental health problems in children with epilepsy. Davies S, Heyman I, Goodman R. *Developmental Medicine and Child Neurol.* 45(5):292-295 **(2003)**

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System improvement priority: Support for specific patient groups (continued)

Support for children and young people (continued)

Guidance

Improving the quality of care for children with epilepsy. NICE Shared Learning Database (2012)

Specialist Reporting of Paediatric Neuroimaging. NICE Shared Learning Database (2013)

Supporting pupils with medical conditions at school – Statutory guidance about the support that pupils with medical conditions should receive at school. Department for Education **(2017)**

2019/20 National Tariff Payment System – A consultation notice: Annex DtD. Guidance on best practice tariffs. A joint publication by NHS England and NHS Improvement with relevant tariff guidance in paediatric epilepsy **(2019)**

OPEN UK (Organisation of Paediatric Epilepsy Networks in the UK). Clinical Standards and Quality Improvement team. Royal College of Paediatrics and Child Health

Implementation and practical examples

Guided self-help interventions for mental health disorders in children with neurological conditions: study protocol for a pilot randomised controlled trial. Bennett S, Heyman I, Coughtrey A, Simmonds J, Varadkar S, Stephenson T, DeJong M, Shafran R. *Trials.* 17:532 **(2016)**

Parent's & Carer's Guide SUDEP Action

Parent's & Carer's Guide Leaflet SUDEP Action

Risk management & mortality in young people – Patient stories SUDEP Action:

Erin's Story

Emily's S Story

Kathryn's Story

Colette's Story

Emily's R Story

Association of quality of paediatric epilepsy care with mortality and unplanned hospital admissions among children and young people with epilepsy in England: a national longitudinal data linkage study. Hargreaves DS, Arora S, Viveiro C, Hale DR, Ward JL, Sherlaw-Johnson C, Viner RM, Dunkley C, Cross HJ. *The Lancet Child & Adolescent Health*. 3:9 p627-635 (**2019**)

System improvement priority: Support for specific patient groups (continued)

Support for people transitioning from child to adult services

Guidance

NICE CG137 - Epilepsies: diagnosis and management

See in particular: 1.17 Young people with epilepsy

NICE NG127 - Suspected neurological conditions: recognition and referral

Please see for recommendations in **adults over 16:**

- 1.1. Blackouts in adults (reference to epilepsy 1.1.1)
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- 1.28.2 Sleep disorders suggesting nocturnal seizures

Implementation and practical examples

Epilepsy Specialist Nursing Service - Adults with and without Learning Disabilities Norfolk Community Health & Care NHS Trust

Passport scheme for transition Epilepsy Passport Royal College of Paediatric and Child Health

Transition of children and young people to adult services: best practice pathways guidance. South East Strategic Clinical Networks **(2015)**

Epilepsy12 National Clinical Audit of Seizures and Epilepsies for Children and Young People National Organisational Report for England Wales **(2018)**

Transition from paediatric to adults' services Epilepsy Action

Transition to adult care: Ready Steady Go. University Hospital Southampton NHS Foundation Trust

10 steps to improving transition to adult services. Rogers J, Brook L. *ENT and Audiology News.* 25(6) **(2017)**

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System improvement priority: Support for specific patient groups (continued)

Support for people transitioning from child to adult services (continued)

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NICE Quality Standard QS27 - Epilepsy in children and young people.

Quality Statement 9: Transition from children's to adult services

NICE NG43 - Transition from children's to adults' services for young people using health or social care services

NICE Quality Standard QS140 - Transition from children's to adults' services

NICE shared learning database - Implementing transition care locally and nationally using the 'Ready Steady Go' programme **(2017)**

Implementation and practical examples

Knowledge of epilepsy during transition for young people with epilepsy. The Walton Centre NHS Foundation Trust. NHS Health Research Authority

Transition from paediatric to adults' services. Epilepsy Action

Making a 'JUMP' from paediatric to adult healthcare: A transitional program for young adults with chronic neurological disease. *J. Neurol. Sci.* 15: 395 77-83 **(2018)**

Risk management & mortality in young people – Patient stories SUDEP Action:

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Association of quality of paediatric epilepsy care with mortality and unplanned hospital admissions among children and young people with epilepsy in England: a national longitudinal data linkage study. Hargreaves DS, Arora S, Viveiro C, Hale DR, Ward JL, Sherlaw-Johnson C, Viner RM, Dunkley C, Cross HJ. *The Lancet Child & Adolescent Health*. 3:9 p627-635 (**2019**)

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System improvement priority: Support for specific patient groups (continued)

Support for people with learning disabilities

Guidance

NICE CG137 - Epilepsies: diagnosis and management

See in particular: 1.16 Children, young people and adults with learning disabilities

NICE NG127 - Suspected neurological conditions: recognition and referral

Please see for recommendations in **adults over 16:**

- 1.1. Blackouts in adults (reference to epilepsy 1.1.1)
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NICE NG96 - Care and support of people growing older with learning disabilities

NICE NG93 – Learning disabilities and behaviour that challenges: service design and delivery

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

NICE NG11 - Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

NICE Quality Standard QS142 - Learning disability: identifying and managing mental health problems

NICE Quality Standard QS101 - Learning disability: behaviour that challenges

NICE Quality Standard QS187 - Learning disability: care and support of people growing older

Implementation and practical examples

Learning Disabilities Mortality Review (LeDeR) Annual Report 2018

Epilepsy Care Pathway Pathway for people with learning disabilities. Leicestershire Partnership NHS Trust

Helping people get the right medicines in Bury – case study looking at how people with learning disabilities, autism or both are getting the correct medicines. NHS England

Monitoring nocturnal seizure in vulnerable patients. Shankar R, Jory C, Cox D, Hagenow K. *Learning Disability Practice.* 16(9) **(2013)**

Improving the health and wellbeing of people with learning disabilities: an evidence-based commissioning guide for clinical commissioning groups (CCGs) Improving Health and Lives Learning Disabilities Observatory, Royal College of General Practitioners, Royal College of Psychiatrists **(2013)** – see in particular:

- 7.6.5 People with learning disabilities and epilepsy
- 9.2.3 Young people with a learning disability and epilepsy

Health checks for people with learning disabilities toolkit. and Step-by-step guide to health checks for people with a learning disability. Royal College of General Practitioners.

The Purple Light Toolkit for Epilepsy. How good are your epilepsy services for people with learning disabilities? – A service improvement toolkit. Appendix to Management of epilepsy in adults with intellectual disability Royal College of Psychiatrists College Report 203 **(May 2017)**

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System improvement priority: Support for specific patient groups (continued)

Support for people with learning disabilities (continued)

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The learning disability improvement standards for NHS trusts NHS Improvement

Management of epilepsy in adults with intellectual disability Royal College of Psychiatrists College Report 203 **(May 2017)**

Prescribing anti-epileptic drugs for people with epilepsy and intellectual disability Royal College of Psychiatrists College Report 206 **(Oct 2017)**

The Learning Disability Epilepsy Specialist Nurse Competency Framework Epilepsy Nurses Association (ESNA) Royal College of Nursing **(2014)**

Best practice guidelines for training professional carers in the administration of Buccal (Oromucosal) Midazolam for the treatment of prolonged and / or clusters of epileptic seizures in the community. Epilepsy Nurses Association, Royal College of Psychiatrists, International League Against Epilepsy - British Branch **(2019)**

Implementation and practical examples

Epilepsy Risks Easy Read Leaflet SUDEP Action

Epilepsy Risks Parent/Carer Companion Leaflet SUDEP Action

STopping Over Medication of People with a learning disability, autism or both (STOMP) NHS England

A structured programme to withdraw antipsychotics among adults with intellectual disabilities: The Cornwall experience. Shankar R, Wilcock M, Deb S, Goodey R, Corson E, Pretorius C, Praed G, Pell A, Vujkovic D, Wilkinson E, Laugharne R, Axby S, Sheehan R, Alexander R. *J. Appl. Res. Intellect. Disabil.* **(2019)**

Health and Care of People with Learning Disabilities: 2017-18 NHS Digital

Learning Disability Mortality – Patient Stories SUDEP Action:

Richards's Story

Karen's Story

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System improvement priority: Support for specific patient groups (continued)

Support in pregnancy

Guidance	Implementation and practical examples
NICE CG137 - Epilepsies: diagnosis and management See in particular: 1.15 Women and girls with epilepsy, especially section 1.15.3 Pregnancy NICE valproate summary guide - NICE guidance and safety advice for valproate use in children, young people and adults. Valproate Pregnancy Prevention Programme: actions required now from GPs, specialists and dispensers Medicines and Healthcare products Regulatory Agency **(2018)** Valproate medicines (Epilim▼, Depakote▼): Pregnancy Prevention Programme materials online Medicines and Healthcare products Regulatory Agency **(2018)** Valproate use by women and girls Medicines and Healthcare products Regulatory Agency **(2019)** Annual Risk Acknowledgement Form VALPROATE HAS RISKS IN PREGNANCY Medicines and Healthcare products Regulatory Agency **(2019)** Epilepsy in pregnancy: green-top guideline no. 68 Royal College of Obstetricians & Gynaecologists **(2016)** Additional NICE products on pregnancy NICE indicators NM03 and NM71	Maternity epilepsy shared-care toolkit Pregnancy toolkit for women with epilepsy. **(2018)** Patient leaflet for pregnant women with epilepsy. Royal College of Obstetricians & Gynaecologists **(2016)** Maternal Mortality – Patient Story SUDEP Action: Samantha & Regan's Story

Support for older people

Guidance	Implementation and practical examples
NICE CG137: recommendation 1.18 Older people with epilepsy NICE NG127 - Suspected neurological conditions: recognition and referral Please see for recommendations in **adults over 16:** • 1.1. Blackouts in adults (reference to epilepsy 1.1.1) • 1.2.10 Dizziness with altered consciousness • 1.8.5 Dense amnesia • 1.10.3 Sensory disturbances • 1.12.2 Smell or taste hallucinations	

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System improvement priority: Mental health and emotional wellbeing support

Guidance

NICE CG137 - Epilepsies: diagnosis and management

NICE NG127 - Suspected neurological conditions: recognition and referral

Please see for recommendations in **adults over 16:**

- 1.1. Blackouts in adults (reference to epilepsy 1.1.1)
- 1.2.10 Dizziness with altered consciousness
- 1.8.5 Dense amnesia
- 1.10.3 Sensory disturbances
- 1.12.2 Smell or taste hallucinations

Please see for recommendations in **children under 16:**

- 1.17 Attention, concentration and memory problems
- 1.20.5 Recurrent dizziness
- 1.27.3 Isolated tingling, altered sensation or paraesthesia
- 1.28.2 Sleep disorders suggesting nocturnal seizures

NICE products on mental health and well-being

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

NICE Quality Standard QS142 - Learning disability: identifying and managing mental health problems

Scottish Intercollegiate Guidelines Network (SIGN) - Diagnosis and management of epilepsy in adults. **(2018)**

In particular:

- Chapter 6: 'Psychiatric comorbidity'

Adult Improving Access to Psychological Therapies programme NHS England

Social prescribing link workers NHS England **(2019)**

NHS Mental Health Implementation Plan 2019/20 – 2023/24 NHS England Long Term Plan **(2019)**

Universal Personalised Care: implementing the comprehensive model NHS England

Improving the physical health of people with mental health problems. Department of Health, Public Health England and NHS England **(2016)**

Implementation and practical examples

Epilepsy and you course Epilepsy Action

Parity of esteem for people affected by neurological conditions: meeting the emotional, cognitive and mental health needs of neurology patients. Neurological Alliance. **(2017)**

Low mood, depression and epilepsy Epilepsy Action

Mood and epilepsy Epilepsy Society

The Improving Access to Psychological Therapies manual: appendices and helpful resources. NHS England **(2018)**

Experiences of working in a multidisciplinary team NHS England and NHS Improvement **(2019)**

Epilepsy12 National Clinical Audit of Seizures and Epilepsies for Children and Young People National Organisational Report for England Wales **(2018)**

Juvenile myoclonic epilepsy: Psychiatric comorbidity and impact on outcome. Filho GMdA, Yacubian EMT. *Epilepsy & Behaviour.* 28(1):74-80. **(2013)**

Bringing together physical and mental health: a new frontier for integrated care. The King's Fund **(2016)**

Guidance	Implementation and practical examples
System improvement priority: System-wide education and training around supporting people with epilepsy	
Education for people living with epilepsy	
Universal Personalised Care NHS England Universal Personalised Care: implementing the comprehensive model NHS England **(2019)** Patient Activation Measure NHS England	Epilepsy Action Advice and Information Epilepsy and you course Epilepsy Action SUDEP and Seizure Safety Checklist SUDEP Action risk communication and management tool for clinicians and introductory video Epilepsy Self-Monitoring (EpSMon) App Risk monitoring and education app for people with epilepsy. Introductory video and supporting NHS 70 video SUDEP Action epilepsy risk information Young Epilepsy
Education for families and carers, especially in recognising changes in symptoms and emergency situations	
Universal Personalised Care NHS England Universal Personalised Care: implementing the comprehensive model NHS England **(2019)** Commitment to Carers NHS England Supporting carers in general practice: a framework of quality markers NHS England **(2019)** Patient Activation Measure NHS England	Epilepsy Action Advice and Information SUDEP Action epilepsy risk information SUDEP Action Risk leaflets Epilepsy Self-Monitoring (EpSMon) App Risk monitoring and education app for people with epilepsy. Introductory video and supporting NHS 70 video Childhood epilepsy: A guide for parents Young Epilepsy Epilepsy in Infants and Young Children: A guide for parents Young Epilepsy Carer passport schemes

System improvement priority: System-wide education and training around supporting people with epilepsy (continued)

Education and training for GPs

Guidance

Implementing care closer to home: Convenient quality care for patients Part 3: The accreditation of GPs and Pharmacists with Special Interests. Department of Health **(2007)**

The Adult Epilepsy Specialist Nurse Competency Framework. Royal College of Nursing **(2012)**

The Learning Disability Epilepsy Specialist Nurse Competency Framework. Royal College of Nursing **(2013)**

NICE valproate summary guide - NICE guidance and safety advice for valproate use in children, young people and adults.

Valproate Pregnancy Prevention Programme: actions required now from GPs, specialists and dispensers Medicines and Healthcare products Regulatory Agency **(2018)**

Valproate medicines (Epilim▼, Depakote▼): Pregnancy Prevention Programme materials online Medicines and Healthcare products Regulatory Agency **(2018)**

Valproate use by women and girls Medicines and Healthcare products Regulatory Agency **(2019)**

Annual Risk Acknowledgement Form VALPROATE HAS RISKS IN PREGNANCY Medicines and Healthcare products Regulatory Agency **(2019)**

Epilepsy in pregnancy: green-top guideline no. 68 Royal College of Obstetricians & Gynaecologists **(2016)**

Implementation and practical examples

Resource links for GPs with an interest in epilepsy Royal College of General Practitioners

Specialist nursing of children and young people with epilepsy: RCN guidance for service planning and career development. Royal College of Nursing **(2013)**

Epilepsy Nurse Training and Bursaries Epilepsy Action

SUDEP and Seizure Safety. Essential CPD for primary care. Royal College of General Practitioners and SUDEP Action course.

SUDEP Global Conversation SUDEP Action, Epilepsy Australia & SUDEP Aware (Canada)

E-Learning for Healthcare training resources on Epilepsy and SUDEP Health Education England

Training courses for health professionals Young Epilepsy

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Guidance	Implementation and practical examples
System improvement priority: System-wide education and training around supporting people with epilepsy (continued)	
Education and training and support for paramedics on appropriateness to bypass A&E and also SUDEP risk	
NICE Do Not Do Recommendation: CG137 Epilepsies: diagnosis and management - Only prescribe buccal midazolam or rectal diazepam for use in the community for children, young people and adults who have had a previous episode of prolonged or serial convulsive seizures	SUDEP and Seizure Safety. Essential CPD for primary care. Royal College of General Practitioners and SUDEP Action course South Western Ambulance Service Foundation Trust training (outcome of Charlie's story) Charlie's story SUDEP Action Charlie's story: (NHS Resolution)
Wider population education and awareness of epilepsy to reduce stigma	
Supporting pupils with medical conditions at school Statutory Guidance Department of Education **(2017)**	Epilepsy Society challenging stigma Epilepsy Society SUDEP Action Day (23rd October) SUDEP Action EpSMon NHS 70 Video NHS Guide for schools Young Epilepsy

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System improvement priority: Medicines Optimisation

Guidance

Formulation switching of antiepileptic drugs: A Report on the Recommendations of the Commission on Human Medicines from July 2013. Medicines and Healthcare products Regulatory Agency **(2013)**

Shared decision making on medicines with patients:

- Shared decision making NHS England
- Patient Activation Measure NHS England
- Shared decision making NICE guidelines
- Medicines Optimisation: Helping patients to make the most of medicines. Good practice guidance for healthcare professionals in England. Royal Pharmaceutical Society

NICE Clinical Knowledge Summaries - Epilepsy: prescribing information

NICE Quality Standard QS120 - Medicines Optimisations

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

Clinical Pharmacists in General Practice: A brief guide to getting started for practice teams. Primary Care Commissioning

The Community Pharmacy Contractual Framework for 2019/20 to 2023/24: supporting delivery for the NHS Long Term Plan. Department of Health & Social Care, NHS England and NHS Improvement and Pharmaceutical Services Negotiating Committee **(2019)**

NICE valproate summary guide - NICE guidance and safety advice for valproate use in children, young people and adults.

Valproate Pregnancy Prevention Programme: actions required now from GPs, specialists and dispensers Medicines and Healthcare products Regulatory Agency **(2018)**

Valproate medicines (Epilim▼, Depakote▼): Pregnancy Prevention Programme materials online Medicines and Healthcare products Regulatory Agency **(2018)**

Valproate use by women and girls Medicines and Healthcare products Regulatory Agency **(2019)**

Annual Risk Acknowledgement Form VALPROATE HAS RISKS IN PREGNANCY Medicines and Healthcare products Regulatory Agency **(2019)**

Epilepsy in pregnancy: green-top guideline no. 68 Royal College of Obstetricians & Gynaecologists **(2016)**

Implementation and practical examples

Epilepsy for pharmacists Epilepsy Society **(2018)**

A study of Standard and New Antiepileptic Drugs – SANAD-II NHS Health Research Authority **(2012)**

Cochrane Collaboration Reviews of Antiepileptic Drugs

Importance of balanced maternal risk information SUDEP Action:

- New recommendations on Sodium Valproate **(2018)**
- A closer look at the MBRRACE Maternal Deaths Report **(2017)**
- Overview of Epilepsy Mortality – Valproate Stakeholders Network **(2019)**

Medicines Optimisation briefing for epilepsy. Royal Pharmaceutical Society Centre for Pharmacy Postgraduate Education

How can you encourage medicines optimisation for patients with epilepsy? Royal Pharmaceutical Society Centre for Pharmacy Postgraduate Education

Medicines Optimisation – Patient Stories SUDEP Action:

Emily's Story

Kathryn's Story

Erin's Story

Epilepsy medicines available in the U.K. Epilepsy Action

Experiences of working in a multidisciplinary team NHS England and NHS Improvement **(2019)**

Maternity epilepsy shared-care toolkit Pregnancy toolkit for women with epilepsy. **(2018)**

Levetiracetam is a useful alternative to phenytoin in stopping prolonged epileptic seizures in children. *NIHR Signals.* **(2019)**

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System improvement priority: Coordination of care

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NICE CG137 – Epilepsies: diagnosis and management section 1.8 management

NICE Quality Standard QS26 – Epilepsy in adults Quality Statement 4: Epilepsy care plan

NICE Quality Standard QS27 – Epilepsy in children and young people

Quality Statement 4: Epilepsy care plan

Universal Personalised Care: Implementing the comprehensive model. NHS England **(2019)**

Shared decision making to improve health outcomes NHS England **(2019)**

Make Every Contact Count (MECC) Health Education England

Making Every Contact Count (MECC): practical resources. Public Health England **(2018)**

Making Every Contact Count (MECC):

Consensus statement. Public Health England, NHS England and Health Education England **(2016)**

The NHS Long Term Plan NHS England **(2019)**

Implementation and practical examples

Better Value, Better Care - Your Guide to Commissioning in Epilepsy. Epilepsy Action **(2012)**

Epilepsy Action Care Plan and Review template: The Epilepsy Action 'My epilepsy care plan'. Epilepsy Action

SUDEP and Seizure Safety Checklist SUDEP Action risk communication and management tool for clinicians and introductory video

Epilepsy Self-Monitoring (EpSMon) App Risk monitoring and education app for people with epilepsy. Introductory video and supporting NHS 70 video

Epilepsy Passport for children with epilepsy. Royal College of Paediatrics and Child Health

Dorset Care Record example (linking GP practices; CCG, local authority and Trusts)

Medicines Optimisation briefing for epilepsy. Royal Pharmaceutical Society Centre for Pharmacy Postgraduate Education

How can you encourage medicines optimisation for patients with epilepsy? Royal Pharmaceutical Society Centre for Pharmacy Postgraduate Education

Coordination of Care to reduce mortality– Patient Stories SUDEP Action:

Colette's Story

Becky's Story

Charlie's Story

Emily's Story

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Guidance	Implementation and practical examples
System improvement priority: Coordination of care (continued)	
	Specialist epilepsy nurse role Epilepsy Action An example of effective epilepsy service development: Norfolk adult community epilepsy specialist nurse team. Epilepsy Action Epilepsy good practice compendium. Epilepsy Action and Epilepsy Society. See in particular Vale of York service model. Community based epilepsy service (CICS) referral pathway and service specifications. Camden CCG Long Term Conditions & Cancer Programme. Care planning templates for SystmOne. NHS Yorkshire and the Humber and Epilepsy Action. Community Neurological Service (Pilot). Hillingdon CCG Epilepsy Care Pathway for people with learning disabilities and roles of various professionals including the Care Coordinator. Leicestershire Partnership NHS Trust North Norfolk Community Engagement Panel. Norfolk Community Health and Care NHS Trust **(2017)** Quarriers The Scottish Epilepsy Centre. Charity organisation develops a service to provide specialist support to people with complex epilepsy. Clinical services for adults with an intellectual disability and epilepsy: A comparison of management alternatives. Wagner A, Croudace TJ, Bateman N, Pennington MW, Prince E, Redley M, White SR, Ring H. *Plos One* **(2017)**

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NICE CG137 – Epilepsies: diagnosis and management section 1.8 management

NICE Quality Standard QS26 – Epilepsy in adults Quality Statement 4: Epilepsy care plan

NICE Quality Standard QS27 – Epilepsy in children and young people

Quality Statement 4: Epilepsy care plan

NICE CG138 - Patient experience in adult NHS services: improving the experience of care for people using adult NHS services

Universal Personalised Care: Implementing the comprehensive model. NHS England **(2019)**

Shared decision making to improve health outcomes NHS England **(2019)**

Advance decision (living will) End of life care. NHS England

Patient Activation Measure NHS England

Implementation and practical examples

The Gold Standards Framework

SUDEP and Seizure Safety Checklist SUDEP Action risk communication and management tool for clinicians and introductory video

Epilepsy Self-Monitoring (EpSMon) App Risk monitoring and education app for people with epilepsy. Introductory video and supporting NHS 70 video

Impact of the SUDEP & Seizure Safety Checklist & EpSMon app Channel 4 news

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System improvement priority: Experience of Care

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NICE CG138 - Patient experience in adult NHS services: improving the experience of care for people using adult NHS services

Improving Experiences of Care: Our shared understanding and ambition. National Quality Board **(2015)**

The Government's revised mandate to NHS England for 2018-19 – Objective 2: To help create the safest, highest quality health and care service. Department of Health & Social Care

The NHS Long Term Plan NHS England **(2019)**

Five Year Forward View NHS England **(2014)**

Commitment to Carers NHS England **(2014)**

Improving experience of care through people who use services. NHS England **(2015)**

An integrated approach to identifying and

assessing Carer health and wellbeing. NHS England **(2016)**

Insight Resources. NHS England

Always Events® NHS England

Patient Experience Improvement Framework NHS Improvement **(2018)**

Implementation and practical examples

Patient Experience Resources The Beryl Institute

Case studies Patient Experience Network

Always Events: what have we learned so far? Picker **(2018)**

The National Neurology Patient Experience Survey. The Neurological Alliance. **(2019)**

Epilepsy Deaths Register gathers bereaved family and clinical experiences of epilepsy deaths to help identify themes and learn lessons to inform future epilepsy care & services

Epilepsy Deaths Register – reports and research

Specialist support service for the bereaved SUDEP Action

Providing support:

- during inquest
- with the coronial service
- speaking with health teams
- via counselling sessions and ongoing support calls.

Early signposting of bereaved families to a specialist support service – Patient Stories SUDEP Action:

Stephen's Story

Richards's Story

Karen's Story

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Epilepsy self-assessment questionnaire

These self-assessment questions (SAQ) are designed to help local areas (including STPs, ICSs and PCNs) gain enhanced understanding of their epilepsy system. The RightCare Epilepsy Toolkit provides a benchmark to enable understanding of the key components of an epilepsy system. The questions should be used alongside the Toolkit to facilitate discussion and identify improvement opportunities or exemplars of good practice.

Specifically these questions are designed to:

- Assess the existing system to support people living with epilepsy to provide quality care for them.
- Identify any current gaps in provision and current opportunities to enhance or develop services and systems to support people living with epilepsy, including working with key partners.
- Assess the progress of any system improvements over time.

Rating Key: 1 = Full met, 2 = Partially met, 3, Not met, 4= Not applicable

Section	Self-assessment questions	Rating (1,2,3,4)
Identification and segementation	Are patients attending A&E after a seizure being referred to a first seizure clinic or their GP so that they are placed on the Epilepsy Register asap? Do you have an agreed process in place to ensure that this takes place between secondary and primary care?	
	Are people with epilepsy and learning disabilities added to the learning disabilities register?	
	Have you undertaken an analysis (e.g. JSNA, health equity audit) of your population to understand the number of people that have had seizures in your area? Do you know where they live and what their demographics are?	
	Do you have data input and collection strategies/guidelines in place to help improve the quality of data (including coding) across the system?	

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Section	Self-assessment questions	Rating (1,2,3,4)
Identification and segementation	Will you include all appropriate health staff across the system in the development of the data collection strategy and provide relevant training for staff?	
	Do you know your epilepsy data from the QOF register and are you sharing this information across the system, including secondary and tertiary care?	
	Do you undertake regular data cleansing of the QOF register to ensure it is accurate and includes patients who are currently receiving drug treatment for epilepsy?	
	Are you participating in the Epilepsy12 audit commissioned by the Royal College of Paediatrics and Child Health which aims to improve the quality of care for children and young people with seizures and epilepsy?	
	Have you considered the National Audit of Seizure management in Hospitals (NASH) reports as a potential lever for improvement?	
	Do you utilise simulation modelling tools to improve epilepsy services based on population and local needs analysis?	
	Have you undertaken a review of the current clinics and services available in the local area including workforce associated with supporting and treating patients with epilepsy?	
	Have you analysed waiting times to assess patient access to first and follow-up epilepsy services?	

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Section	Self-assessment questions	Rating (1,2,3,4)
Misdiagnosis	Is the relevant NICE guidance in epilepsy (CG137, NG127, CG109, QS26, QS27) embedded in your system?)	
	Are clinicians signposting people who have had a seizure(s) to keep a seizure diary which is available from the Epilepsy Action website and free to download?	
	Are clinicians being supported to receive training in history taking of patients who have had a seizure(s)? This could be for neurologists, epilepsy nurses, GPs with extended roles (GPwER), falls clinics doctors and paediatricians.	
	Is there an opportunity to develop a wider range of diagnostic tools including patient/witness reports?	
	Is there an opportunity to develop a greater network of primary care doctors specialising in epilepsy (GPwER in epilepsy)?	
	Are family/carers/support networks supported and provided with education on how best to document any events e.g. video capturing using a mobile phone?	
	Do clinicians have access to decision making aids (e.g. decision flow diagrams) and other tools such as witness report questionnaires and smartphone video recordings to aid accurate diagnosis?	
	Do clinicians have ease of access to a full range of diagnostic tests such as video EEG?	
	Are clinicians in the system supported with relevant training, resources and awareness regarding understanding of non-epileptic seizures?	
	Are clinicians aware of the availability of seizure diaries for children and young people (available for free from Young Epilepsy for children and young people) and decision making flow charts and toolkits?	

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Section	Self-assessment questions	Rating (1,2,3,4)
Taking a risk management approach to mortality	Do you know the number of people with epilepsy in your population that have died? Do you understand the mortality trends for your population due to epilepsy and do you have processes in place to act upon them (such as epilepsy related deaths audits and lessons learnt processes)? Do you understand your epilepsy population that are at risk of dying from epilepsy (high A&E attendance, not attending clinics, socially deprived areas)?	
	Are clinicians supported to undertake conversations about lifestyle risk factors with people with epilepsy so that they can be referred to appropriate support services including mental health support e.g. voluntary sector? Are they supported for spotting risk factors for children and young people too?	
	Do you refer to the Learning Disability Mortality Review (LeDeR) Annual Reports and other reviews to identify premature mortality for people with learning disabilities (and epilepsy or just those with learning disabilities?) to gain a better understanding of these deaths?	
	Are paramedics trained and equipped to administer buccal midazolam and/or emergency medication for children, young people and adults who have had a previous episode of prolonged or serial convulsive seizures in line with NICE guidance CG137 ?	
	Is a standard risk template for clinical use regarding epilepsy patients, such as the SUDEP and Seizure & Safety Checklist Tool, known and implemented across the local system?	
	Have you considered the use of virtual/teleclinics to promote self-management especially for patients that do not engage with services/miss appointments/do not attend appointments/are at risk?	
	Do you implement the patient activation measure (PAM) and health coaching to improve people's health literacy, leading to improved self-management?	
	Are you aware of who regularly attends A&E with seizures and are able to ensure the SUDEP conversation has been had with these patients about the importance of taking their medication? Has the SUDEP and Seizure Safety Checklist Tool been completed with them and are they aware of and using the EpSMon app? How will you know that they are flagged/followed up in primary/secondary care?	
	Is there a rescue protocol in place that is known by all parties including patients and carers in case of an emergency?	
	Is there an opportunity to enable paramedics to have access to patient records via mobile technology (e.g. tablets) so that they can appropriately triage and/or refer at this first urgent contact point?	
	Do you have protocols in place so that shared patient care records/plans can be accessed by all parties in the event of an emergency?	
	Do you have resources and literature available that can be signposted to, to help patients /families and carers know what to do in an emergency?	

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Section	Self-assessment questions	Rating (1,2,3,4)
Access to epilepsy specific services	Is access and referral to epilepsy specialist care timely (based on NICE criteria) and based on clinical need of the patient in your systems?	
	Where there is lack of capacity in secondary or tertiary specialists, is there an opportunity to raise capacity in primary care or to link up to other pathways/specialisms to increase capacity?	
	Is there an opportunity to develop non-traditional methods of epilepsy specialist contact such as telehealth or virtual consultations? This may be beneficial to patients living in rural areas or for patients that find access to epilepsy specialist centres difficult.	
	In your system, are there development opportunities for GPs with an extended role (GPwER) in epilepsy to further support epilepsy specialist care?	
	Is there an opportunity to invest and develop pharmacy teams (including community pharmacy teams) and other professionals into training and building networks for referral and escalation in your system?	
	In your system, is NICE guideline CG137 – Epilepsies: diagnosis and management section 1.10.2 embedded in the case of patients where seizures are not controlled and/or there is diagnostic uncertainty? Referral to tertiary services should be considered if one or more of the seven criteria outlined are met.	
	Does your system adhere to the NICE guideline CG109 – Transient loss of Transient loss of consciousness ('blackouts') in over 16s section 1.2.2 for referral processes for suspected epilepsy?	
	In your system, do you have a mechanism for epilepsy patients to access different support in the community (e.g. pharmacy, voluntary sector) where an epilepsy specialist nurse is not available?	
	Do you have access to or can share business cases for community epilepsy specialist nurses?	
	Do you have a process to signpost people with epilepsy to support groups or promote self-management strategies where appropriate in your system?	
	Have you reviewed your system to see which NICE guidelines (CG137 and NG127) are being adhered to for epilepsy? How do you ensure compliance with NICE guidelines (CG137 and NG127) ?	
	In your system, for people with epilepsy, do you have a clear referral process that is standardised and continuously reviewed in response to service changes and technology advances that is known by all?	
	In your system, do you make your patients aware of any self-referral processes so that if they were discharged, they do not need to start at the beginning of the referral process again?	
	For the people with epilepsy in your system, do you provide adequate information that signposts them to appropriate local support services?	
	What are your specific care pathways for people with learning disabilities who have epilepsy?	

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Epilepsy self-assessment questionnaire

Section	Self-assessment questions	Rating (1,2,3,4)
Support for specific patient groups - children and young people	Do you refer to the NICE guidelines for epilepsy diagnosis and management for children and young people (CG137, NG127 and Quality Standard QS27)?	
	Have you referred to the CHESS and SEEN reports to gain an understanding of the effect of epilepsy in children and young people on cognition and behaviour?	
	Are you able to provide children and young people with epilepsy with screening for cognitive and behavioural difficulties?	
	Where capacity and resources allow, is there provision of mental health support in paediatric epilepsy clinics?	
	Where capacity and resources allow, do children and young people with epilepsy have access to an Epilepsy Specialist Nurse?	
	Have you referred to the SEEN report so that you are aware that mothers of children with epilepsies have a higher risk of mental health problems?	
	Are staff working in schools and other educational settings supported to give information and support to children and young people with epilepsy?	
	Are healthcare professionals in your system supported to give help at schools by working collaboratively with local education providers?	
	Are healthcare professionals in your system supported to give epilepsy awareness and rescue medication training as well as supporting development of the schools' Individual HealthCare Plans?	
	Have you referred to the 2019/20 National Tariff Payment System – A consultation notice: Annex DtD Guidance on best practice tariffs where the aim of the best practice tariff (BPT) is to enable access to consistent high-quality care for children with epilepsy?	
	Have you referred to the OPEN UK (Organisation of Paediatric Epilepsy Networks) clinical network led by the Royal College of Paediatrics and Child Health where the aim is to connect NHS Health Boards and Trusts that provide care for children with epilepsies with regional epilepsy networks to improve integrated care for CYP with epilepsies?	
	Have you referred to the Epilepsy12 2018 National Organisational Audit Report where the aim of the report was to help commissioners and epilepsy services to measure and improve the quality of care for CYP with epilepsy and seizures?	

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Section	Self-assessment questions	Rating (1,2,3,4)
Support for specific patient groups - transitioning from child to adult	Is there clarity on your system of what the transitional age should be for a child moving into adult services and is this known and followed by all services?	
	Is the process for transition from child to adult services for people with epilepsy clearly communicated and explained to all patients and their families and carers ahead of the transition?	
Support for specific patient groups - learning disabilities	Are people with learning disabilities and epilepsy placed on the learning disabilities register in your system?	
	Do learning disabilities Consultants in your system have the training and skills in the management of epilepsy and vice versa?	
	Are learning disabilities psychiatrists aware of the Royal College of Psychiatrists reports (College reports 203 and 206) which highlight the role of learning disabilities psychiatrists in the management of people with learning disabilities and epilepsy and also prescribing and poly pharmacy around learning disabilities and epilepsy?	
	In your system, is the good practice tool, Purple Light Toolkit, utilised for people with learning disabilities and epilepsy?	
	Is there evidence of reasonable adjustments being embedded across all epilepsy pathways for people with learning disabilities?	
	Are the learning disabilities standards (Learning Disabilities Improvement Standards for NHS Trusts, 2018) known across your system?	
	In your system, is there support and education for people with learning disabilities and epilepsy around taking medication correctly?	
	Do community specialist nurses in learning disabilities have appropriate training and skills in the management of epilepsy and vice versa?	
Support for specific patient groups - pregnancy	Is balanced information provided to girls and women of childbearing age and pregnant women with epilepsy regarding the potential teratogenic effects of sodium valproate and other anti-epileptic drugs (e.g. Topiramate) in line with NICE guidance?	
	Do you refer to the MHRA sodium valproate toolkit and Pregnancy Prevention Programme for girls and women with epilepsy in your system?	
	Do you refer to the Royal College of Obstetrics and Gynaecology Epilepsy and Pregnancy Guidelines (Green Top) to support MDT working so that maternity and epilepsy services can be joined up?	
	Is the 'Maternity Epilepsy Shared Care' Toolkit available and adopted across the system?	
	Do the workforce in your system that support pregnant women with epilepsy have had training and education about the condition?	
Support for specific patient groups - older people	For people with epilepsy who are frail, what other comorbidities do they have (e.g. CVD, hypertension) and how are they supported to manage all these conditions?	
	For people with dementia and epilepsy in your system, is there support for medication reminders?	

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Mental health support	For people who have experienced their first seizure, are they being signposted for emotional wellbeing support as well as clinical input?	
	If appropriate, is a mental health referral being offered in your system?	
	Is there an opportunity to utilise mental health screening tools such as PHQ9 and GAD7 questionnaires for people with epilepsy in any part of your system via GPs or epilepsy specialists?	
	Are families and carers of people with epilepsy signposted to appropriate mental health and emotional wellbeing support services too?	
	Is there a process to implement social prescribing within your system to support people with epilepsy further?	
	Do epilepsy professionals in your system have sufficient training in mental health conditions and are able to refer or signpost to appropriate support services? Is there training available for epilepsy professionals to recognise mental health problems?	
	Are there clear referral processes for mental health and emotional wellbeing services set up in your system that are communicated clearly with epilepsy professionals?	
	For any MDTs set up for neurology or epilepsy, is there access to specialist mental health support and referrals processes in your system?	

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System-wide education and training around supporting people with epilepsy	Are people living epilepsy in your system being signposted to voluntary sector websites such as Epilepsy Action and SUDEP Action to find a wealth of information on epilepsy including e-learning modules?	
	Are families/carers and support networks signposted to available resources provided by the voluntary sector (e.g. Epilepsy Action and SUDEP Action), in particular education programmes such as post-seizure recovery; triggers for seizures; medication administrations and what to do in a crisis situation?	
	Are you aware of the NHS England 'Commitment to Carers' resource that can further support carers and families of people with epilepsy in your system?	
	Do Epilepsy Specialist Nurses in your system that prescribe (if you have them) are enabled to support families and carers in terms of medication management?	
	Is there an opportunity in your system to develop more training for GPs and utilise GPs with an extended role (GPwER) in epilepsy to provide more capacity in the system and prevent unnecessary referrals to specialist services?	
	Is there an opportunity to develop a training package for GPs and identify which competencies are needed to achieve a more specialist level and to also consider the most appropriate methods of delivery (e.g. intensive/supervised; light; online; stepped training etc.)?	
	Have you considered utilising primary care networks to engage GPs and also to disseminate training to other GPs from epilepsy specialist GPs?	
	Have clinicians and medical trainees in your system utilised e-learning modules on epilepsy provided by Health Education England?	
	Is there an opportunity to provide education and training in epilepsy for pharmacists including those working in the community and GP practices?	
	Are paramedics in your system trained in epilepsy and know when to take patients to A&E and when not to?	
	Do paramedics in your system have access to care plans for people with epilepsy?	
	Do paramedics have access to epilepsy care coordinators (e.g. epilepsy specialist nurses) to support decision making in your system?	
	Are efforts being made in your system and area to increase awareness and education of epilepsy thereby reducing any stigma? For example, by signposting to voluntary sector websites and initiatives?	

Epilepsy self-assessment questionnaire

Section	Self-assessment questions	Rating (1,2,3,4)
Medicines optimisation	Do you know if in your system local clinical protocols are in place to ensure that pregnant women are not prescribed sodium valproate to treat either epilepsy or a mental health problem in line with NICE guidance?	
	Do you refer to the MHRA sodium valproate toolkit and Pregnancy Prevention Programme for girls and women with epilepsy in your system? And perform annual reviews?	
	Is the messaging regarding the risks of sodium valproate to the unborn baby and in the context of mortality risks (if medication was stopped) shared with patients and clinicians in your system clearly and consistently?	
	Are all epilepsy patients in your system able to access a medication review when they experience side effects or a change in seizure control? Are structured medication reviews undertaken by clinical pharmacists located within GP practices in line with the The Community Pharmacy Contractual Framework for 2019/20 to 2023/24: supporting delivery for the NHS Long Term Plan. ?	
	Do you ensure changes to medication (e.g. shift from brand to generic) are clinically appropriate?	
	Do you undertake shared decision making with the patient in your system when it comes to changing medication to ensure that all potential side effects are discussed?	
	In your system is there an opportunity to utilise prescription collection data to further aid the understanding of the epilepsy population within your local geography i.e. who collects prescriptions or not; who collects repeat prescriptions but do not attend appointments?	
	Do you have an epilepsy multidisciplinary team across the system?	
	Do you have routes on communication to specialists from non-specialists across the system to support decision making on prescribing?	
	In your system, are you aware of patients that repeatedly present in secondary care that may not have had their situation fully relayed to the GP and hence have not had an opportunity for a medication review?	
	What consistent, up-to-date, high quality information on medicines do you use right across your epilepsy service so that patients feel empowered yet supported with their medication?	

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Coordination of care	Are you aware of the NHS England Universal Personalised Care: Implementing the comprehensive model document (2019) which sets out the delivery for personalised care?	
	When constructing a care plan for a person with epilepsy do you implement Shared Decision Making principles as set out in the NHS England Universal Personalised Care: Implementing the comprehensive model document (2019)?	
	Do you have a process in place to conduct regular reviews (6 month/annual, dependent on patient need) of epilepsy patients so that effective monitoring and adjustment strategies can be implemented and therefore improve safety and medicines adherence?	
	In the case of stable patients, do you have any facilities to enable alternative methods of review such as telehealth or virtual clinics dependent on patient preference?	
	Do your patients with epilepsy have a copy of their care plan? And, is the care plan available across different healthcare settings and available to all? Is this care plan accessible and in easy read for people with learning disabilities?	
	Is there an opportunity in your system(s) to adopt technology solutions to enable timely sharing of care plans across NHS organisations and possibly across non-NHS organisations?	
	Do you have a defined mechanism or process set out for patients in between appointments, for example, what they should do in a crisis or if there is a facility for a simple ‘check-in’ communication?	
	Do young people with epilepsy and their family and carers in your system know who their epilepsy clinicians are should they need to contact them if their epilepsy is changing?	
	Is the ‘Making Every Contact Count’ approach embedded within your system?	

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Personalised care	Have you ensured that people with epilepsy in your system that have had personalised care and support plans have been completed using shared decision making methods and are supported to undertake self-management for their condition?	
	How do you actively communicate the benefits of shared decision making with patients and utilise the range of tools and resources available to agree care priorities, values and preferences?	
	Have you ensured that personalised care and support planning has addressed the full health and wellbeing needs of the individual?	
	Have you ensured that staff in your system are aware of local services that they can refer/signpost people with living with epilepsy, to provide support for them outside of primary or secondary care?	
	In your system, do you use patient decision aids to help people with epilepsy make informed choices about their healthcare and treatment options?	
	How do you ensure effective communication across specialties and places of care for patients with epilepsy, ensuring full information about changes in care are relayed to everyone from GPs and Epilepsy Specialist Nurses to Paramedics and Specialists in tertiary centres?	
	Are people living with epilepsy encouraged to review their ongoing support needs and personal planning when a change is noted in their support requirements either by themselves, carers or support staff, and clinicians or key workers?	
	Which services actively encourage people they work with to complete an advance care directive in a timely manner and ensure this is known to the family and carers as well as held by all agencies the person engages with?	
	Are staff working with people living with epilepsy confident in recognising changes in symptoms that may require changes in treatment?	

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Experience of care	How many carers supporting people with epilepsy are identified in your local population? Are these carers supported to live well in your system?	
	Do you have a systematic approach to identifying carers supporting people living with epilepsy who are at risk of not managing their own health conditions?	
	Do you use experience of care feedback from patients and carers to improve services in your system using co-production and co-design?	
	Are there plans within your system to improve experience of care? And can you deliver this in way that is acceptable for people to enable them to work in partnership with their health professionals?	
	In your system, are staff working with people with epilepsy confident in recognising that a person may also have other health conditions and feel equipped to engage effectively with patients/carers to discuss referral(s) to wider health professionals?	
	Could you identify mechanisms for clinical notification of death to ensure all those involved in a patient's care are informed quickly in your system?	
	Do you have processes in place to ensure that families and carers do not go without clinical engagement after death and are signposted to bereavement support?	
	Could you for your system, utilise the third sector and ensure information about these services is shared with all families and carers following death?	
	Are you aware of and reviewed the Patient Experience Survey in Summer 2019 performed by the Neurological Alliance?	

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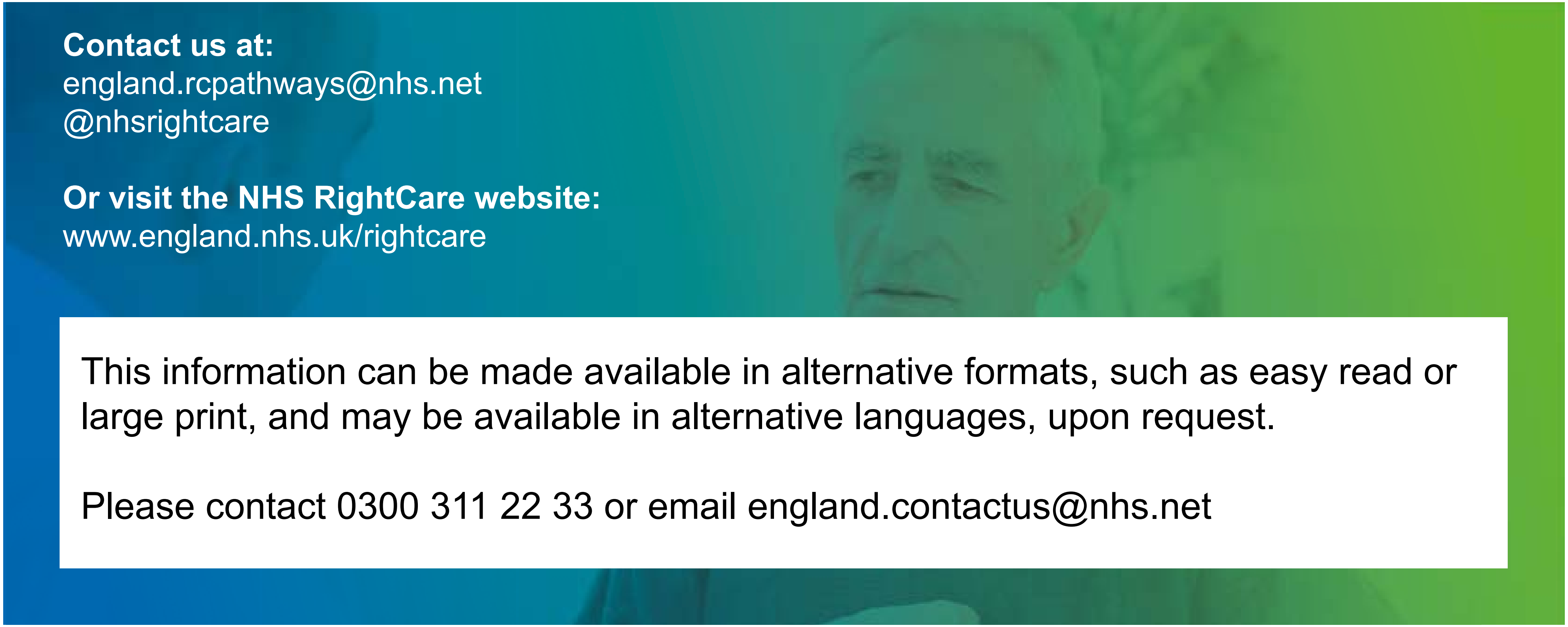
    - Personalised Care
    - Experience of Care
    - RightCare



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