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ALLIANCE



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research uk



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Epilepsy resource navigation tool for commissioners and providers

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How To Use



ABOUT THE TOOL

The Epilepsy resource navigator tool is designed for commissioners, providers and professionals working with the epilepsy population in England. The tool identifies and directs you to the best available resources to commission, design and improve services for people with epilepsy, their families and carers. The information and resources in the tool can help local systems to deliver the **NHS priorities for 2023/24** and the commitments in the **NHS Long Term Plan**, including addressing A&E waiting times and improving performance against the core diagnostic standard.

The tool has been developed by the Neurological Alliance with support from a **steering group of expert health professionals and patient organisations**. Stakeholder interviews were held to inform the content of the tool.



HOW TO USE THE TOOL

Use the **SEARCH PAGE** to be directed to the relevant area or work through each section in order.

Clicking on resource **hyperlinks** will open up a new page in your browser.

The resources and evidence listed in this tool have been selected following an evidence-based literature search and consultation with the expert advisory group. Stakeholder interviews were held to inform the content of the tool. They have been selected to help commissioners and providers to:

- ✓ **Plan a system wide approach to commission and improve services**
- ✓ **Design and implement gold standard pathways and integrated services**
- ✓ **Ensure quality, safety and prevent avoidable harm**
- ✓ **Benchmark good care**
- ✓ **Develop a business case**

Search Page

You can work through each section of the tool in order or use the navigation tool to be directed to your area of interest. You can return to this page using the [SEARCH PAGE](#) on the bottom of each page.

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01 Epilepsy and the system

About Epilepsy

About epilepsy

Epilepsy is one of the most common long-term neurological conditions in the UK. Epileptic seizures are commonly seen in emergency departments and can be life threatening. **1**

For some people, epilepsy can be a life-long condition. For others it can change over the life course. People with epilepsy can have complex needs related to their epilepsy long-term co-morbidities which affect their physical and mental health and influence the biopsychosocial approach to care.

People with epilepsy experience marked variation in care across the country in accessing integrated care pathways and specialist support when needed most, including emergency care. **2**

In England, people living with epilepsy are experiencing health inequalities and challenges including high misdiagnosis rates, inaccurate epilepsy population estimates, increasing mortality attributed to epilepsy especially in pregnant women **3** and people with learning disability and autism **4**. There is a continuing lack of optimal management strategies **5** and disorganised services **6** impacting care, outcomes and efficiency of local systems.

Adopting a systemic, planned approach to the commissioning of coordinated, person-centred services for people with epilepsy, their families and carers (including suddenly bereaved families) could reduce unnecessary emergency care visits, avoidable readmissions, preventable harm and deaths, and enhance productivity, support better health outcomes and tackle health inequalities.



Epilepsy is one of the most common neurological conditions. **7**

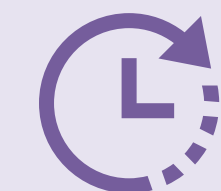
Epilepsy can be caused by genetics, environmental factors and/or be acquired. Research has shown common causes of acquired epilepsies as hippocampal sclerosis, cerebral tumor, traumatic brain injury, stroke and cerebrovascular disease and perinatal causes. **8**



Neurological conditions are the second leading cause of death and the leading cause of disability globally **9**



There are approximately 60 different types of epileptic seizures and people may experience more than one type **10**



Epilepsy affects people of all ages and care needs will vary across the lifespan. The highest risk is in infants and older age groups **11**



Approximately 626,000 people in the UK have a diagnosis of epilepsy and have been prescribed an anti-seizure medication. This equates to an overall population prevalence of 0.97% or 1 in every 100 people who have a diagnosis of epilepsy. **12**

01 Epilepsy and the system

Health outcomes

Mortality

- People with epilepsy live shorter lives compared to the general population **13**
- Epilepsy deaths are in the top 10 of all causes of premature mortality in the UK and represent a significant public health burden, disproportionately impacting the young **14 15**
- Up to 50% of epilepsy-related deaths are SUDEP – sudden and unexpected. 50% of epilepsy-related deaths are SUDEP – sudden and unexpected with exact cause unknown; deaths peaking between age 20-40 **16 17**
- Epilepsy-related deaths increased in UK by 69% pre pandemic with risk including attendance at A&E and lack of seizure freedom **18 19**
- Many epilepsy related deaths are avoidable **20**

Prevention and management

- Many causes of epilepsy, for example head trauma, drug and alcohol abuse, infection, malnutrition and cerebrovascular disease, can be prevented
- After diagnosis, at all ages, the risk of death is substantially reduced by achieving seizure freedom **21**
- In all age groups, seizure freedom is linked to a lower risk of death **22**

Comorbidities

- The prevalence of comorbid physical and mental health conditions is considerably higher in epilepsy than seen in the general population and other chronic conditions **23**

Family members and carers

- Family members and carers of children with epilepsy are under an enormous burden and psychological stress when caring for and coordinating care **24**
- Overall family and carer needs are unmet **25**
- The mental health and well-being needs of people impacted by sudden deaths in epilepsy are not being met and this has been further exacerbated by the pandemic **26**

01 Epilepsy and the system

Health inequalities

Deprivation

- The incidence and prevalence of epilepsy is at least a third higher in the most deprived areas of the UK than the least deprived. **27**
- People living in the most deprived areas are nearly three times as likely to die with epilepsy than those living in the least deprived areas **28**. The deprived are also more likely to die from their epilepsy **29**

Learning disabilities and intellectual disabilities:

- Around 1% of the general population have epilepsy, but this rises to 20% in those with a learning disability
- Around 30% of the people with epilepsy who receive care in any setting will have a learning disability
- Up to 50% of those with severe to profound learning disability have epilepsy **30**
- People with learning disabilities are at higher risk of dying from epilepsy with factors increasing risk including severity of the learning disabilities **31**
- Epilepsy accounts for 40% of all emergency admissions in people with a learning disability **32**
- There have been higher rates of death in people with learning disabilities and epilepsy (5%) compared to the general population who also live with epilepsy (<1%) **33**

Maternal health

- Women with epilepsy presenting to maternal care have a mortality risk that is almost 10 times greater than that of the general maternity population **34** **35**

Older people

- One in every four people newly diagnosed with epilepsy is over the age of 65 **36**
- Epilepsy is increasingly becoming a condition of the elderly, both in terms of a new diagnosis and in terms of prevalence **37**

Prison Population

- Overall prevalence of epilepsy and adult-onset epilepsy has been found to be higher than the general population **38**
- Prisoners with epilepsy have complex demographics which could affect epilepsy care **39**

Disability and economic activity

- Two thirds (66%) of working-age people with epilepsy are unemployed. Disabled workers are paid on average 19.6% less than their non-disabled peers. **40**

Homelessness

- The prevalence of active epilepsy in people who are homeless is estimated to be 12 times higher than the general population **41**

01 Epilepsy and the system

System productivity and efficiency

- People with epilepsy experience marked variation in care across the country in terms of access to services and specialists, quality of care and processes **42**
- The recent NCEPOD review found that epilepsy services are disorganised and not managing risk, with improvement needed across the pathway **43**
- Suspected seizures are the most common neurological cause of admissions **44**
- It is estimated that up to 70% of people living with epilepsy could live seizure-free if properly diagnosed and treated **45**
- 100,000 people present to hospitals each year in England with an epileptic seizure. The National Audit of Seizure Management in Hospitals (NASH) found that most had a prior diagnosis of epilepsy but 18% were not on medication and 48% only on one medication **46**
- NHS RightCare found that around £12.1m would be saved on non-elective spend for epilepsy if Clinical Commissioning Groups (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 **47**
- Reduced resources and available capacity across the system impacted epilepsy care pre-pandemic, with risks increasing since 2020 for patients and clinicians **48**
- Differences in deprivation, age of population, ethnicities, regional coding practice etc. could be potential contributing factors to the significant regional variation in the incidence and prevalence of epilepsy. In 2013-2018 the highest incidence (and prevalence) was seen in the North East, which according to a recent workforce survey by the Association of British Neurologists (ABN), has the lowest concentration of neurologists, whilst the lowest prevalence figures were seen in London, which has the highest concentration of neurologists. **49**

- Patient experience 2021/22 **50**:
 - **43% of adults and 35% of children and young people** with epilepsy reported delays to routine appointments with a specialist nurse
 - **25% of adults and 25% of children and young people** with epilepsy reported delays to a first appointment with a specialist nurse
 - **68% of adults and 37% of children and young people** with epilepsy had not been offered a care and support plan to help manage their epilepsy
 - **65% of young people** with epilepsy had not been offered a named worker to support the transition process between paediatric and adult services, but would find this helpful

02 Commissioning to meet the needs of the epilepsy population

Commissioning epilepsy services locally



The care needs of people with epilepsy will vary depending on the type and severity of their epilepsy and their biopsychosocial needs and co-morbid health conditions



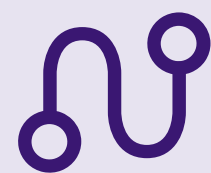
Workforce underpins the implementation of a good model of care. For example, employing sufficient numbers of neurologists **51** and epilepsy specialist nurses **52** **53** will impact quality of care, including equitable and timely access to individualised specialist advice.



Care settings will include a range of primary and secondary care settings including social care, workplace and educational settings. People with epilepsy receive care from a range of providers including NHS, social care, VCSE, local authority and private providers. Care should be delivered as close to home as possible.



Family and carers often have a significant role in providing support or advocating on behalf of a person with epilepsy. This group will have their own support needs that are critical to the overall pathway. Those involved in the commissioning and provision of services are required to give consideration to their needs when designing and delivering services



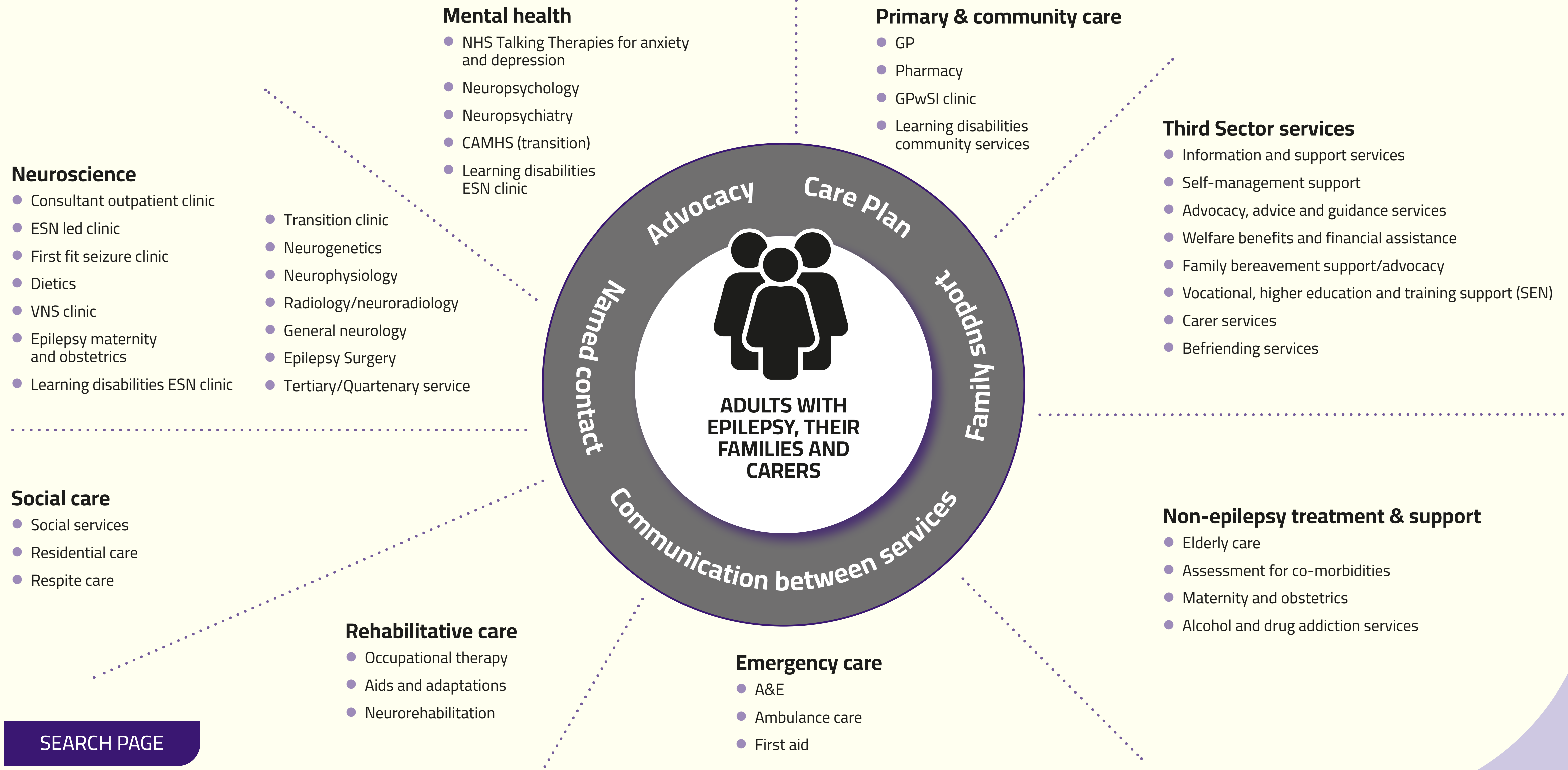
Commissioning should uphold equity of care across the system. An integrated pathway that is resourced to deliver equity amongst the population it is targeting, and one that focuses on removing health inequalities, will improve outcomes, experience and system efficiencies



The service and pathway needs of adults with epilepsy and their families will change (sometimes rapidly). Pathways and services should be able to prepare for and respond to population priorities and rapidly changing needs.

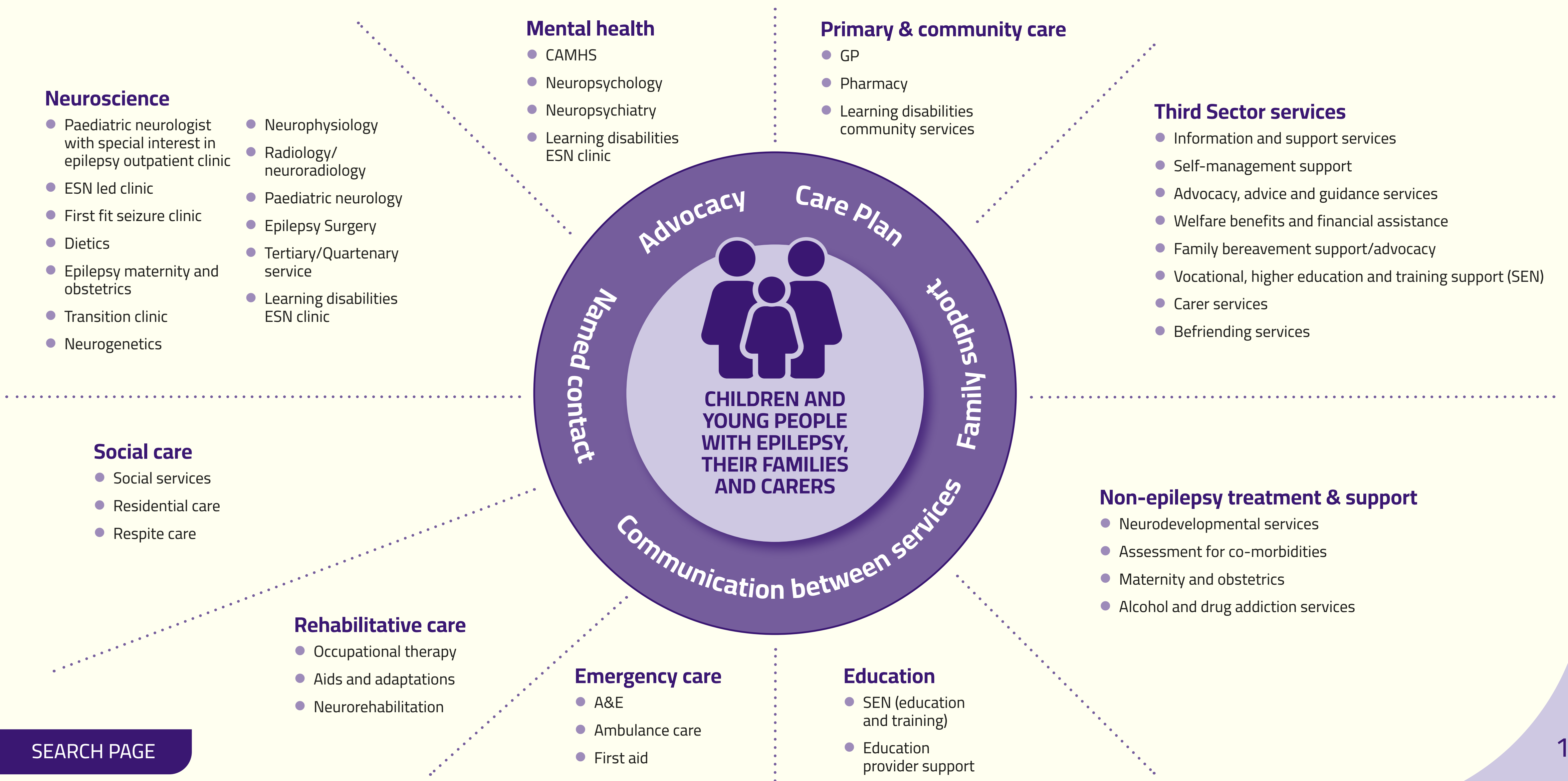
02 Commissioning to meet the needs of the epilepsy population (snapshot)

Adults with epilepsy, their families and carers



02 Commissioning to meet the needs of the epilepsy population (snapshot)

Children and young people with epilepsy, their families and carers



03 Commissioning resources to meet the pathway needs of the epilepsy population

National Guidelines, Quality Standard, Commissioning Toolkits

| Population | Resource | Key features | Supports commissioners and providers to: | | | |
|---|---|--|--|---|--|--|
| | | | Plan a system wide approach to commission and improve services | Design and implement best practice pathways and integrated services | Ensure quality, safety and prevent avoidable harm | Benchmark good care |
| <ul style="list-style-type: none"> Adults Children & young people | Epilepsies in children, young people and adults. NQ217 (NICE, 2022) | <ul style="list-style-type: none"> Guidance for diagnosing and managing epilepsy in primary and secondary care, and referral to tertiary services. Includes a resource impact summary report and baseline assessment tool to support implementation | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Specific pathway groups ✓ Population need ✓ Clinical Research | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Prevent avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Audit tools ✓ Equity of care ✓ Monitoring high spend areas |
| <ul style="list-style-type: none"> Adults | Quality Standards, Epilepsy in adults QS26 (NICE 2013) | <ul style="list-style-type: none"> Quality Standards for diagnosing, treating and managing epilepsy and seizures Describes high-quality care in priority areas for improvement. Includes commissioning implications and potential resource impact of the standards | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Specific pathway groups ✓ Population need | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Prevent avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Audit tools ✓ Equity of care ✓ Monitoring high spend areas |
| <ul style="list-style-type: none"> Children & young people | Quality Standard Epilepsy in children and young people QS27 (NICE, 2013) | <ul style="list-style-type: none"> Quality Standards for diagnosing, treating and managing epilepsy and seizures Describes high quality care in priority areas for improvement Includes commissioning implications and potential resource impact of the standards | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Specific pathway groups ✓ Population need | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Prevent avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Audit tools ✓ Equity of care ✓ Monitoring high spend areas |

03 Commissioning resources to meet the pathway needs of the epilepsy population

National Audits/Audit reports

| Population | Resource | Overview | Supports commissioners and providers to: | | | |
|------------|---|--|--|---|---|--|
| | | | Plan a system wide approach to commission and improve services | Design and implement best practice pathways and integrated services | Ensure quality, safety and prevent avoidable harm | Benchmark good care |
| ● Adults | Epilepsy Commissioning Toolkit (NHS RightCare, 2019) | <ul style="list-style-type: none"> ○ Toolkit for improving local health systems ○ Self-assessment questionnaire to baseline services and assess the extent of improvement activity | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Specific pathway groups ✓ Population need ✓ Clinical research | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Preventing avoidable harm ✓ Safeguarding and vulnerable groups ✓ Safety | <ul style="list-style-type: none"> ✓ Audit tools ✓ Equity of care ✓ Monitoring high spend areas |
| ● Adults | NHS England and NHS Improvement Neuroscience Transformation Programme (NHS email address required) | <ul style="list-style-type: none"> ○ Neurology and Neurosurgery toolkits for commissioners and clinicians ○ Neurology ICS planning tool ○ Neurology dashboard | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Population need | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Preventing avoidable harm ✓ Safeguarding and vulnerable groups ✓ Safety | <ul style="list-style-type: none"> ✓ Audit Tools ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend areas |
| ● Adults | Optimal clinical care pathway for adults: epilepsy (NNAG, 2023) | <ul style="list-style-type: none"> ○ An optimal clinical pathway for adults with epilepsy ○ Sets out optimal care, pathway efficiency savings, alternate workforce model and definition of a specialised service | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Specific pathway groups ✓ Population need | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Preventing avoidable harm ✓ Safeguarding and vulnerable groups ✓ Safety | <ul style="list-style-type: none"> ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend areas |

03 Commissioning resources to meet the pathway needs of the epilepsy population

National Audits/Audit reports

| | | | Supports commissioners and providers to: | | | |
|---|--|---|---|---|---|--|
| Population | Resource | Key features | Plan a system wide approach to commission and improve services | Design and implement best practice pathways and integrated services | Ensure quality, safety and prevent avoidable harm | Benchmark good care |
| <ul style="list-style-type: none"> Adults Children and young people | NASH (National Audit of Seizure Management in Hospitals) | <ul style="list-style-type: none"> National audit report to identify service improvements to reduce the numbers presenting at hospital with epilepsy seizures Includes audit tool and project related reports | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Population need ✓ Clinical research | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Preventing avoidable harm ✓ Safety | <ul style="list-style-type: none"> ✓ Audit Tools ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend areas |
| <ul style="list-style-type: none"> Adults | Epilepsy Care: Disordered Activity? (NCEPOD, 2022) | <ul style="list-style-type: none"> Review of the quality of epilepsy care provided to adult patients presenting to hospital with a seizure and recommendations for local improvement measures Includes 'Commissioners Guide' and an audit toolkit | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Population need ✓ Clinical research | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Preventing avoidable harm ✓ Safety | <ul style="list-style-type: none"> ✓ Audit Tools ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend area |
| <ul style="list-style-type: none"> Children and young people | Epilepsy12 - national organisational audit and clinical audit (RCPCH) | <ul style="list-style-type: none"> Presents data and evidence from the three main domains of Epilepsy12: a clinical audit describing patient care, an organisational audit describing service structures, and related quality improvement activities | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Population need | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Preventing avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Audit Tools ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend areas |
| <ul style="list-style-type: none"> Adults Children and young people | National Sentinel Clinical Audit of Epilepsy-Related Death (Epilepsy bereaved 2002) | <ul style="list-style-type: none"> National audit report. Review and recommendations covering Investigations into deaths (pathology) Care prior to death (general practice and secondary care) Contact with the bereaved family | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Population need | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Preventing avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Audit Tools ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend areas |

03 Commissioning resources to meet the pathway needs of the epilepsy population

National Reports (data analysis)

| Population | Resource | Key features | Supports commissioners and providers to: | | | |
|---|---|--|---|---|--|--|
| | | | Plan a system wide approach to commission and improve services | Design and implement best practice pathways and integrated services | Ensure quality, safety and prevent avoidable harm | Benchmark good care |
| <ul style="list-style-type: none"> Adults | National specialty Report: Neurology (NHS GIRFT, 2021) | <ul style="list-style-type: none"> Recommendations to improve access to care and ensuring services are available close to homes where feasible Recommendations to improve inpatient and outpatient care | <ul style="list-style-type: none"> ✓ Areas for improvement | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Prevent avoidable harm ✓ Safety | <ul style="list-style-type: none"> ✓ Audit Tools ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend areas |
| <ul style="list-style-type: none"> Adults Children and young people | My Neuro Survey (Neurological Alliance, 2022) | <ul style="list-style-type: none"> Biennial survey of the experience of care, treatment and support for people with neurological conditions Epilepsy data is available at national and regional level ICS level data available on request | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Health inequalities ✓ Population need | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Prevent avoidable harm ✓ Safety | <ul style="list-style-type: none"> ✓ Audit tools ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend areas |
| <ul style="list-style-type: none"> Adults Children and young people | Neuro Numbers (Neurological Alliance, 2023) | <ul style="list-style-type: none"> Prevalence and Incidence data for epilepsy and other neurological conditions (England) National and ICS level NHS activity data on admissions, mortality and treatment | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Population need | | | <ul style="list-style-type: none"> ✓ Data and metrics |
| <ul style="list-style-type: none"> Adults | Deaths associated with neurological conditions in England 2001 to 2014 (Public Health England, 2018) | <ul style="list-style-type: none"> Data analysis report about people who have died with epilepsy on their death certificate | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Health inequalities ✓ Population need | | <ul style="list-style-type: none"> ✓ Prevent avoidable harm ✓ Safety | <ul style="list-style-type: none"> ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend areas |

03 Commissioning resources to meet the pathway needs of the epilepsy population

National Reports (Inquiries into deaths)

| Population | Resource | Key features | Supports commissioners and providers to: | | | |
|--|---|---|---|---|---|---|
| | | | Plan a system wide approach to commission and improve services | Design and implement best practice pathways and integrated services | Ensure quality, safety and prevent avoidable harm | Benchmark good care |
| <ul style="list-style-type: none"> Adults Children and young people Learning disabilities | <p>Learning from lives and deaths – people with a learning disability and autistic people (Kings 2021)</p> | <ul style="list-style-type: none"> LeDeR summarises the lives and deaths of people with a learning disability and autistic people who died in England in annual reports | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Specific pathway groups ✓ Population need | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Preventing avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Equity of care ✓ Monitoring high spend area |
| <ul style="list-style-type: none"> Adults | <p>Epilepsy Care: Disordered Activity? (NCEPOD, 2022)</p> | <ul style="list-style-type: none"> Review of the quality of epilepsy care provided to adult patients presenting to hospital with a seizure and recommendations for local improvement measures Includes 'Commissioners Guide' and an audit toolkit | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Population need ✓ Clinical research | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Preventing avoidable harm ✓ Safety | <ul style="list-style-type: none"> ✓ Audit Tools ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend area |

04 Commissioning resources to meet the pathway needs of specific groups of the epilepsy population

| Specific population group | Resource | Key features | Supports commissioners and providers to: | | | |
|---|---|---|---|---|---|--|
| | | | Plan a system wide approach to commission and improve services | Design and implement best practice pathways and integrated services | Ensure quality, safety and prevent avoidable harm | Benchmark good care |
| <ul style="list-style-type: none"> Learning disabilities | <p>Integrating care for people with epilepsy and a learning disability (Step Together, 2020)</p> | <ul style="list-style-type: none"> Describes the elements of a good quality integrated service for people with a learning disability and epilepsy. Enables commissioners and providers to audit what is available for their population and assess the extent to which needs are currently met Offers examples of ways to increase collaboration, improve services and consistency in epilepsy provision, and reduce unwarranted variation | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Health inequalities ✓ Population need | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Preventing avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Audit Tools ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend areas |
| <ul style="list-style-type: none"> Learning disabilities | <p>Step Together Benchmarking Tool (Epilepsy Action)</p> | <ul style="list-style-type: none"> A digital benchmarking tool that enables services to understand the qualities, standards and variation of epilepsy and learning disability services across an area, for example an integrated care system, an NHS Trust, or a devolved nation | <ul style="list-style-type: none"> ✓ Areas for improvement-Health inequalities ✓ Population need | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Preventing avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Audit Tools ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend areas |

Learning disabilities continued on [next page](#)

04 Commissioning resources to meet the pathway needs of specific groups of the epilepsy population

| Specific population group | Resource | Key features | Supports commissioners and providers to: | | | |
|---|---|---|---|---|---|--|
| | | | Plan a system wide approach to commission and improve services | Design and implement best practice pathways and integrated services | Ensure quality, safety and prevent avoidable harm | Benchmark good care |
| <ul style="list-style-type: none"> Learning disabilities | <p>Step Together - Epilepsy Service Evaluation Tool Kit - Learning Disabilities and Autism (Epilepsy Action/ NHSE Midlands 2023)</p> | <ul style="list-style-type: none"> A tool to review and evaluate the provision of integrated epilepsy services across primary and secondary care for people with Learning Disabilities and Autism | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Health inequalities ✓ Population need | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Preventing avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Audit Tools ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend areas |
| <ul style="list-style-type: none"> Learning disabilities | <p>NG217. 9 Psychological, neurobehavioural, cognitive and developmental comorbidities in epilepsy (NICE, 2022)</p> | <ul style="list-style-type: none"> Guidance on providing coordinated care, support and treatment to this population | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Specific pathway groups ✓ Population need ✓ Clinical research | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Prevent avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Audit tools ✓ Equity of care ✓ Monitoring high spend areas |
| <ul style="list-style-type: none"> Learning disabilities | <p>Management of epilepsy in adults with intellectual disability (Royal College of Psychiatrists 2017)</p> | <ul style="list-style-type: none"> This report aims to clarify the role of the psychiatrist in ID in the management of epilepsy It provides a structure from which a competency evaluation can be developed | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Specific pathway groups ✓ Health inequalities ✓ Population need ✓ Clinical research | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Prevent avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Audit Tools ✓ Data and metrics ✓ Equity of care ✓ Monitoring high spend areas |

04 Commissioning resources to meet the pathway needs of specific groups of the epilepsy population

| Specific population group | Resource | Overview | Supports commissioners and providers to: | | | |
|--|--|---|--|---|---|--|
| | | | Plan a system wide approach to commission and improve services | Design and implement best practice pathways and integrated services | Ensure quality, safety and prevent avoidable harm | Benchmark good care |
| <ul style="list-style-type: none"> Maternal health | <p>Saving Lives Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2018-20 (MBRRACE-UK, 2021)</p> | <ul style="list-style-type: none"> Report from the national audit to collect information about all late fetal losses, stillbirths, neonatal deaths and maternal deaths across the UK | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Health inequalities ✓ Population need | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design | <ul style="list-style-type: none"> ✓ Preventing avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Equity of care ✓ Monitoring high spend areas |
| <ul style="list-style-type: none"> Maternal health | <p>NG217 4.6 Support and monitoring for women planning pregnancy or who are pregnant (NICE, 2022)</p> | <ul style="list-style-type: none"> Guidance on providing care for women and girls who are planning pregnancy or are pregnant Includes pathway, referral and workforce recommendations | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Specific pathway groups ✓ Population need | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Prevent avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Audit tools ✓ Equity of care ✓ Monitoring high spend areas |
| <ul style="list-style-type: none"> Young people transitioning to adult care | <p>NG217 11.2 Transition from children's to adults' services (NICE, 2022)</p> | <ul style="list-style-type: none"> Guidance on planning and delivering tailored, person-centred transition to adult services | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Specific pathway groups ✓ Population need ✓ Clinical research | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Prevent avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Audit tools ✓ Equity of care ✓ Monitoring high spend areas |
| <ul style="list-style-type: none"> Older people | <p>NG217 2.1.4 (NICE, 2022) NG217 4.1.2 (NICE, 2022)</p> | <ul style="list-style-type: none"> Guidance on planning and delivering epilepsy support for the older generation | <ul style="list-style-type: none"> ✓ Areas for improvement ✓ Specific pathway groups ✓ Population need ✓ Clinical research | <ul style="list-style-type: none"> ✓ Pathway design ✓ Service design ✓ Workforce | <ul style="list-style-type: none"> ✓ Prevent avoidable harm ✓ Safety ✓ Safeguarding and vulnerable groups | <ul style="list-style-type: none"> ✓ Audit tools ✓ Equity of care ✓ Monitoring high spend areas |

05 Developing a business case Exemplar pathways and service models

| Resource type | Resource name | Resource description |
|----------------------------------|--|---|
| ● Business case guidance | Guide to writing a business case for an epilepsy specialist nurse service (Epilepsy Action) | ○ This guide aims to help NHS managers write a business case to develop an epilepsy specialist nurse (ESN) service |
| ● Optimal clinical care pathways | Optimal clinical pathway for adults with epilepsy (NNAG 2023) | ○ An optimal clinical pathway for adults with epilepsy developed by the NHS England and NHS Improvement Neuroscience Transformation Programme and the National Neurosciences Advisory Group |
| | Optimal Clinical pathways for people with neurological conditions (NNAG 2023) | ○ A suite of optimal clinical pathways for adults developed by the NHS England and NHS Improvement Neuroscience Transformation Programme, and the National Neurosciences Advisory Group. Includes TBI, neurogenetics, transition from children to adult services & mental health |
| ● Good practice service models | Epilepsy Specialist Nurses The Evidence (ESPENTE): a Systematic Mapping Review (Epilepsy Action 2019) | ○ Findings of a systematic mapping review to describe the role of the ESN, to identify evidence that evaluates the effectiveness and impact of that role on services, patients and their families and other healthcare professionals. |
| | SUDEP Action service model of a bereavement service (2020) | ○ Learnings from supporting traumatic grief in the aftermath of sudden epilepsy deaths |
| | Improving epilepsy management with EpSMon: Risk management model (2019) | ○ Improving epilepsy management with EpSMon: A Templar to highlight the multifaceted challenges of incorporating digital technologies into routine clinical practice |
| ● Safeguarding reports | Inspection report: The Meath Epilepsy Charity (2022) | ○ Inspection report and recommendations following review of a residential care home providing personal care to up to 84 people who are living with epilepsy and may have associated learning and/or physical disabilities |
| ● Case studies | 2021 Midlands LeDeR Report – Learning from the lives and deathsof people with a learning disability and autistic people (published November 2022) | ○ The regional report is designed to supplement the national 2021 LeDeR report. NHS Midlands: Independent report on death in hospital in patient setting recommends review of inappropriate residential placements away from families. NHS Midlands has included epilepsy in its' top health inequalities and has developed an action plan including commissioned guidance for commissioners and providers of community and hospital inpatient settings |

05 Developing a business case Workforce learning and development

| Resource type | Resource name | Resource description |
|----------------------------|---|--|
| ● Competency frameworks | Adult Epilepsy Nurse Specialty Competency Framework (RCN) | ○ ESN competency framework |
| | Specialist nursing of children and young people with epilepsy RCN guidance for service planning and career development | ○ Paediatric ESN competency framework |
| | Learning disability epilepsy nurse specialist competency framework (RCN) | ○ LDSEN competency framework |
| | Epilepsy GPwSI competency framework (ILAE) | ○ GPwSI competency framework approved by the Department of Health |
| | Epilepsy Professional portfolio (Epilepsy Action) | ○ Templates for managers and health professionals |
| ● Training and development | Neurology Academy: Epilepsy Academy for professionals | ○ Training resources and events for professionals and providers |
| | Epilepsy Action: Online training for professionals | ○ A range of online learning designed to support people with epilepsy, organisations, education and healthcare professionals |
| | Young Epilepsy: Information and training for education professionals | ○ Support, information resources and training for school staff and students to raise epilepsy awareness and provide guidance on what to do in the event of a seizure |
| | Young Epilepsy: Information and training for health professionals | ○ Training to all professionals as well as conferences and workshops to further your understanding around epilepsy and associated conditions |
| | SUDEP Action: SUDEP training videos for paramedics | ○ A training package for Paramedics and other Health Professionals to help raise awareness of SUDEP and Epilepsy Deaths |
| | SUDEP ACTION & RCGP: Sudden unexpected death (SUDEP) in epilepsy and seizure safety training | ○ This online course, aimed at General Practice, uses video and case studies to illustrate various points in the clinical management of patients with epilepsy |
| | SUDEP Action: Prevention/after a death training | ○ Online training aimed at non-specialists to provide an understanding of SUDEP and epilepsy deaths, reducing risk, practical steps and resources. |
| | Epilepsy Academy | ○ Education for professionals to deliver epilepsy care |

05 Developing a business case

Data and metrics

Data sources and resources to support the development of local metrics

| Routinely collected data within health and social care | Clinical outcome data (national resources) | Patient reported outcome measures and patient reported experience measures (national resources) |
|---|---|---|
| <ul style="list-style-type: none"> • Hospital Episode Statistic (HES) data • Local data collection – referral and diagnosis, care planning, access to specialists, prescribing • NHS England, National Neurosciences Transformation Programme (Neurology Dashboard) | <ul style="list-style-type: none"> • NASH AUDIT • RCPCH Epilepsy 12 audit • NCEPOD, Epilepsy Care: Disordered Activity? • NHS Getting it Right First Time • Public Health England, Deaths associated with neurological conditions in England 2001 to 2014 • Epilepsy Deaths Register • NICE, NG217 baseline assessment tool | <ul style="list-style-type: none"> • Neurological Alliance, My Neuro Survey-Patient Experience • ICHOM, Epilepsy Patient centred outcome measures |

06 Partnering with the epilepsy community throughout the commissioning cycle

Co-production



Co-production means involving individuals with epilepsy as equal partners in designing the support and services they receive. Co-production recognises that people who use health and social care services (and their families) have knowledge and experience that can be used to help make services better, not only for themselves but for other people who need social care.

- **NHS England: Working in partnership with people and communities. Statutory guidance**
Guidance on working with people and communities including legal duties and principles to follow to build effective partnerships with people and communities.
- **Think Local Act Personal**
This resource is for anyone affected by the Care Act including people who use services, families, carers, organisations who provide services and people who commission services.
- **Nesta Co-production catalogue**
Examples of collaborative public services in action are designed to help practitioners learn about co-production practice.

06 Partnering with the epilepsy community

Patient and professional organisation service directory

| Resource type | Resource name | Resource description |
|------------------------------|--|--|
| ● Patient organisations | <input type="radio"/> The Neurological Alliance (England) | www.neural.org.uk |
| | <input type="radio"/> Regional Neurological Alliances | www.neural.org.uk/membership/our-members/ |
| | <input type="radio"/> Epilepsy Action | www.epilepsy.org.uk |
| | <input type="radio"/> SUDEP Action | www.sudep.org |
| | <input type="radio"/> Young Epilepsy | www.youngpilepsy.org.uk |
| | <input type="radio"/> The Daisy Garland | www.thedaisygarland.org.uk |
| | <input type="radio"/> Matthew's Friends | www.matthewsfriends.org |
| | <input type="radio"/> Ring 20 Research and Support | www.ring20researchsupport.co.uk |
| | <input type="radio"/> Epilepsy Research UK | www.epilepsyresearch.org.uk |
| | <input type="radio"/> Dravet Syndrome Foundation | www.dravetfoundation.org |
| | <input type="radio"/> The Brain and Spine Foundation | www.brainandspine.org.uk |
| ● Professional organisations | <input type="radio"/> Epilepsy Nurses Association (ESNA) | www.esna-online.org |
| | <input type="radio"/> Association of British Neurologists (ABN) | www.theabn.org |
| | <input type="radio"/> British Paediatric Neurology Association | www.bpna.org.uk |
| | <input type="radio"/> International League Against Epilepsy (British Branch) | www.ilaebritish.org.uk |

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THE NEUROLOGICAL ALLIANCE

The Neurological Alliance is a coalition working together to improve treatment, care and support for people affected by neurological conditions. Together we campaign to ensure people affected by neurological conditions can access high quality, joined up care and support to meet their individual needs, at every stage of their life.

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www.neural.org.uk Email: info@neural.org.uk

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