

# Bristol JSNA Chapter 2016-17

## Childhood Epilepsy in Bristol, North Somerset and South Gloucestershire

<b>Chapter information</b>	
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<b>Chapter author(s)</b>	Dr Clare Phillpotts, paediatric registrar Dr Laura Guilder, paediatric registrar Dr Joanna Copping Consultant in Public Health Medicine, Bristol City Council
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## Executive summary

### Introduction

Epilepsy is the most common neurological disorder in children, affecting 1 in 220 children nationally. There are over 40 types of epilepsy which are characterised by the tendency to have seizures that start in the brain. Most cases have no identified cause (idiopathic epilepsy) with other cases being as result of brain injury or congenital conditions (secondary or symptomatic epilepsy).

Diagnosis of epilepsy is challenging and misdiagnosis rates are high. Epilepsy is associated with the risk of premature death, poor educational and social outcomes and mental health issues. Optimal management is important as a significant number of people could become seizure free and good control reduces the risk of these adverse consequences. The mainstay of treatment is antiepileptic drugs (AEDs). A small proportion of children benefit from a special diet (ketogenic diet) to control their seizures and some are suitable for epilepsy surgery or the insertion of a Vagal Nerve Stimulator.

There have been a number of national documents over the last 15 years highlighting concern over the standard of care in epilepsy. NICE have developed guidance and standards for childhood epilepsy diagnosis and care<sup>i</sup> and these were used within a national audit, Epilepsy 12 by the Royal College of Paediatrics and Child Health in 2012 and 2014. This audit has highlighted areas where there is room for improvement both nationally and locally<sup>ii</sup>.

Local data collection for childhood epilepsy services is limited. In BNSSG there are thought to be around 1000 children with a diagnosis of epilepsy. NICE estimates that BNSSG would expect around 85 new cases diagnosed per year, however local figures suggests this is an underestimate. There are around 190 attendances at the Children's ED with afebrile seizures each year and 110 emergency admissions for epilepsy in children per year with a small number of children having very hospital stays.

This JSNA chapter relates to children aged under 18. This chapter is a summarised version of the comprehensive health needs assessment for childhood epilepsy in BNSSG.

### Key issues and gaps

1. **Inadequate data:** There are challenges with availability of high quality, timely data both nationally and locally. There is also no local, regional or national database for epilepsy patients. Locally there are difficulties in gathering clear activity data, particularly for tertiary neurology and outcome related data.
2. **Lack of clear pathways:** There is a lack of clear pathways for new and existing patients. In different areas of BNSSG there is a difference in the availability of services for patients.
3. **No standardised assessment:** There are no standardised proformas for the assessment of new patients or for annual reviews. Therefore these processes

are not standardised or equitable.

4. **Insufficient Epilepsy Specialist Nurses (ESN):** There are insufficient epilepsy specialist nurses to provide an equitable and high quality service. There is no ESN cover for secondary care patients in Weston.
5. **Lack of specialist capacity in secondary care.** There is a lack paediatricians with specialist training in epilepsy within the secondary care service in Bristol. Many patients appear to be seen within tertiary care although there is no data to verify this.
6. **No multidisciplinary peer review:** There is no robust multidisciplinary peer review in place locally. This provides an opportunity for review of cases and aims to reduce the misdiagnosis rate and improve the quality of care. Such activity is recommended by national guidance.
7. **No transition pathways.** There are no clear pathways for the transition of patients to adult services.
8. **Limit access to support services.** There is limited access to neurophysiology, neuropsychiatry and neuropsychology support.

### **Recommendations (summary of section 10)**

1. **The development of a single database** to be used by all professionals involved in epilepsy care. This would aid monitoring of prevalence and outcomes, and facilitate communication. This would also improve monitoring or activity within departments to allow for better service planning and development.
2. **The development of clear care pathways** and referral criteria for patients with epilepsy. These should include clear referral criteria to individual services, including affiliated specialities.
3. **The development of proformas for new patient assessment and annual reviews.** The Epilepsy Passport has been produced by the Royal College of Paediatrics and Child Health for this purpose, and its use locally should be considered
4. An **increase in the epilepsy nursing staffing** to meet national recommendations. This is vital to improve patient care and their experience of care. North Somerset should explore the possibility of appointing epilepsy nurses to cover this area for secondary care.
5. **Further training or recruitment within general paediatrics** to ensure adequate specialist expertise is available to meet the needs of the population.
6. There is a need to **establish a robust process for multi-disciplinary peer review** to improve patient care and reduce the misdiagnosis rate.
7. **Appointment of a transition champion** to review the current transition process and make recommendations. This review should be multidisciplinary and involve adult physicians and ESNs.
8. **Improved access to support services:** neurophysiology, neuropsychology and psychiatry support is recommended. These allied services should have clear referral criteria, and be included in the care pathway. Further resources may be required to improve access.

## JSNA chapter report

### A: What do we know?

#### 1) Who is at risk and why?

The commonest cause of epilepsy is epilepsy with no identifiable cause (idiopathic epilepsy)<sup>iii</sup>. Approximately a third of epilepsies are considered symptomatic (secondary epilepsy). These may be associated with brain injury (prenatal / perinatal), congenital abnormalities or genetic conditions or an acquired brain injury (head injury, infection such as meningitis, stroke, tumour)<sup>iii</sup>.

#### Risk Factors for Epilepsy:

<b>Genetic</b>	Approximately 30% of people with epilepsy will have a first degree relative with epilepsy. There is an identified genetic disorder in approximately 2% of epilepsies in all age group <sup>iv</sup>
<b>Socioeconomic Deprivation</b>	The prevalence of treated epilepsy in a study in 1994 – 1998 showed a 25% increase in prevalence in the most deprived groups compared to the least deprived groups <sup>iv</sup> .
<b>Cerebral Palsy and Learning Disabilities</b>	The prevalence of epilepsy in people with mild learning disabilities is 15%. This rises to 30% in people with severe learning disabilities <sup>v iii</sup> . There are varying estimates of the prevalence of epilepsy in children with cerebral palsy, varying between 35% and 75% <sup>vi,vii</sup> .
<b>Post Infectious Acquired Brain Injury (meningitis / encephalitis)</b>	Acquired brain injury following infective meningitis is known to increase the risk of epilepsy, with seizures seen in 12.6% following bacterial meningitis <sup>viii ix</sup> .
<b>Traumatic Brain Injury / Head Injury</b>	Accounts for up to 20% of symptomatic epilepsy <sup>x</sup> . Studies have suggested that following traumatic brain injury there is a 29 fold increased risk of epilepsy compared with the general population <sup>xi</sup> . This risk is proportional to the severity of the head injury.
<b>Gender and ethnicity</b>	Have not been reliably shown to be risk factors for epilepsy <sup>xii</sup> .

#### Adverse Health Outcomes in Epilepsy:

The global burden of disease (GBD) study 2000, estimated that epilepsy accounts for approximately 0.5% of the global burden of disease<sup>xiii</sup>.

#### Mortality

People with epilepsy have a higher risk of premature mortality than the general population. Standardised Mortality Ratios (SMR) have been reported between 2 – 3 times that of the general population<sup>Error! Bookmark not defined., Error! Bookmark not defined.</sup>. Studies of

children with epilepsy have reported higher standardised mortality ratios for children with symptomatic epilepsy between 7 and 13 times higher than the general population. The standardised mortality ratios for children with idiopathic epilepsy, with no associated neurological or learning deficits, are not significantly different to that of the background population<sup>Error! Bookmark not defined.</sup>. Half of these epilepsy deaths are due to sudden unexplained death in epilepsy (SUDEP)<sup>Error! Bookmark not defined.</sup>. The National Sentinel Clinical Audit suggested that 59% of epilepsy related deaths in children were potentially avoidable<sup>Error! Bookmark not defined.</sup>. The reduction in life expectancy for idiopathic epilepsy is minimal, less than a year, when diagnosed before 30 years of age. The reduction in life expectancy in symptomatic epilepsy is greater. The reduction in life expectancy in years, compared with the age at diagnosis and gender is shown in the table below<sup>Error! Bookmark not defined.</sup>.

*Table: Reduction in life expectancy for children diagnosed with symptomatic epilepsy*<sup>Error! Bookmark not defined.</sup>

	Diagnosed by 5 years	Diagnosed by 20 years
Girls	11	10
Boys	13	11

It must be noted however, that epilepsy is such a heterogeneous group of conditions with different aetiologies, comorbidities and response to treatment, that the estimates in this study have significant limitations. The Joint Epilepsy Council has suggested that From 2007 to 2009 in England and Wales, 68,422 years of life were lost due to epilepsy in children and adults with the average number of years of life lost per person being 30 years<sup>xiv</sup>.

### **Morbidity**

The RCPCH review of coordinating care of children and young people with epilepsy published health episode statistics data for 2010-11 showing that there were 10,624 hospital admissions in 0-14 year olds with a primary diagnosis of epilepsy, and 1,257 with a diagnosis of status epilepticus<sup>24</sup>. In 2008-2010 there were 1,053 admissions to intensive care units with status epilepticus. 5% of emergency department and outpatient paediatric attendances are for children with seizure-related problems<sup>24</sup>.

### **Status Epilepticus**

Status epilepticus is defined as a single seizure or group of seizures without full recovery in between lasting for more than 30 minutes<sup>xv</sup>. Studies have estimated incidence of status epilepticus in children to be 17 -23 per 100,000 per year<sup>xvi</sup> with a 16% risk of recurrence within 1 year, and 3% mortality. The highest incidence of status epilepticus was found to be in the first year of life<sup>27</sup>. Status epilepticus has a risk of neurological damage and death.

### **Misdiagnosis**

Misdiagnosis rates in the United Kingdom, where a diagnosis of epilepsy is incorrectly made, have been reported to be 20 – 31%<sup>Error! Bookmark not defined.</sup>. The cost of misdiagnosis of epilepsy in all ages in the UK is estimated at around £46 million for medical costs and £220 million for non-medical costs<sup>23</sup>.

A high level of misdiagnosis means that a significant number of children are being treated with unnecessary antiepileptic medications, possibly suffering side effects, and suffering unnecessary imposed life style restrictions.

### **Behavioural / Psychological Consequences**

The WHO Health Report 2001 acknowledges that epilepsy often results in significant psychosocial consequences<sup>xvii</sup>. Children with epilepsy have approximately double the rate of behavioural disorders compared with the general childhood population<sup>Error! Bookmark not defined.</sup>. A population survey of mental health problems in children with epilepsy in the UK found 56% of children with complicated epilepsy and 26% of children with uncomplicated epilepsy were found to have an associated mental health problem. Approximately 16 % of both groups suffered from an emotional disorder (anxiety or depression). Conduct disorder rates were also high, seen in 24% of complicated epilepsy and 17% of uncomplicated epilepsy<sup>xviii</sup>.

### **Learning Disability**

More than one in five people with epilepsy have learning or intellectual disabilities<sup>23</sup>. Fewer people with learning disabilities and epilepsy will become seizure free compared to those with epilepsy and no learning disabilities<sup>Error! Bookmark not defined.</sup>.

## **Prevention of epilepsy**

### **Primary prevention**

Idiopathic epilepsy is not preventable, but good seizure control can reduce the risk of further morbidity and mortality.

The risk factors for symptomatic (secondary) epilepsy themselves can be reduced by;

- Ensuring optimal antenatal and perinatal care to reduce risk of birth trauma, prematurity, low birth weight, and by smoking reduction measures.
- Injury prevention strategies for reduction of head injury.
- Immunisation schedules and uptake of these to reduce the incidence of meningitis.

### **Secondary/Tertiary prevention**

It is estimated that with optimal treatment, 70% of people living with epilepsy in the UK could become seizure free. However, currently only 52% of people with epilepsy are living seizure free.<sup>23</sup> Reducing ongoing seizures would not only decrease hospital admissions but would potentially improve school performance and attendance in one third of children with ongoing seizures which are likely to affect their concentration, behaviour, and attendance levels at school. Poor seizure control is also a risk factor for anxiety and depression and thus optimizing treatment could reduce the burden of psychiatric comorbidity<sup>10</sup>. The Joint Epilepsy Council 2011 report suggested that just over one quarter of children who needed epilepsy surgery received it. It was reported that over 2000 children with epilepsy were thought to have the potential to benefit from epilepsy surgery<sup>23</sup>.

### **Prevention of Epilepsy Related Deaths**

Ensuring optimal seizure management and control can minimise the risk of SUDEP.

Young adults are most at risk of SUDEP, and most deaths occur at home. Although it is not entirely clear what causes SUDEP, the most important risk factor is the occurrence of seizures – the more frequent the seizures, the higher the risk<sup>xix</sup>. Since most epilepsy deaths are related to seizures, good seizure control is the key to minimising the risk of death. The National Sentinel Clinical Audit (2002) estimated that 59% of children's SUDEP deaths were potentially, or probably, avoidable<sup>Error! Bookmark not defined.,xiv</sup>. Ensuring families and young people with epilepsy are given adequate information on the risk of SUDEP, for example the importance of not suddenly withdrawing treatment, and lifestyle advice such as water safety, can reduce the risk.

## 2) What is the size of the issue nationally and in Bristol?

It is acknowledged that accurate incidence and prevalence estimates for epilepsy are difficult to ascertain due to inadequate and variable reporting, differences in terminology for active epilepsy, coding issues, high rates of misdiagnosis and an unknown number of undiagnosed children with epilepsy<sup>xiv</sup>.

### Estimates of incidence (new cases)

NICE estimates the national incidence of epilepsy in children (requiring AEDs)<sup>Error! Bookmark not defined.</sup> to be around 0.05% per year of children aged 11 years or younger and 0.03% per year in children aged 12-17 years<sup>Error! Bookmark not defined.</sup>. It is estimated that the new referral rate to secondary care for suspected childhood epilepsy is 0.08 of which around 55% would be expected to receive a diagnosis<sup>Error! Bookmark not defined.</sup>.

Using the NICE national incidence rate estimates, and local population data we can estimate that the referral rate for assessment of a possible diagnosis of epilepsy for BNSSG would be expected to be around 154 children per year, of which around 85 would have a diagnosis of epilepsy. Local review of new referrals to secondary care however suggested for BRCH alone that there may be around 200-250 new cases per year, giving a possible incidence of 110-137 new cases per year.

### Prevalence

The joint epilepsy council (JEC) report, estimated the prevalence of children with epilepsy on antiepileptic medications in the UK using a variety of data sources. The prevalence increases with increasing age throughout childhood, because of the chronic nature of such a diagnosis, as shown in the table below<sup>23</sup>:

*Table: National estimates of prevalence of epilepsy by age (JEC 2011)*

Age	Prevalence of epilepsy	Total number with epilepsy in UK
0-4 years	1 in 509	7600
0-16 years	1 in xiv0	51 500
0-18 years	1 in 220	63 400

NICE reports that nationally the prevalence in those aged 17 and under is around 0.3%, around 34,000 children and young people with a diagnosis of epilepsy who are receiving medical treatment in England<sup>Error! Bookmark not defined.</sup>.

There are around 193 000 children under 18 in BNSSG. Using the JEC estimates, there would be expected to be around 880 children with epilepsy aged 0-17. However and

interrogation of the GP database (EMIS) suggested there are nearer 1000 children recorded as having epilepsy.

*Table: Total number of children aged 0-17 with a recorded diagnosis of epilepsy in BNSSG 2016 (91 out of 98 total practices)*

	<b>0-5</b>	<b>6-11</b>	<b>12-17</b>	<b>Total</b>
Bristol	79	179	233	491
North Somerset	31	71	127	229
South Gloucestershire	42	91	104	237
<b>BNSSG Total</b>	<b>152</b>	<b>341</b>	<b>464</b>	<b>957</b>

When broken down by ethnicity, in 384 (40%) of cases the ethnicity was unknown or not stated. When listed the ethnicity of children with epilepsy is shown below:

*Table: Ethnicity of those aged 0-17 with a diagnosis of epilepsy recorded by GP in BNSSG*

	White British	British or mixed British	Other white background	White	Black African	African	Somali
Total	172	266	14	13	12	11	11
%	18%	28%	1.5%	1.4%	1.3%	1.1%	1.1%

### **Mortality**

Nationally, an average of 52 children die each year where epilepsy is recorded as the underlying cause of death Error! Bookmark not defined.

In Bristol, review of the primary care mortality database shows there have been 8 deaths where epilepsy is recorded on the death certificate in those aged 0-17 in the past 9 years (2006-2014). 5 of these deaths were directly related to the epilepsy, and 3 were due to other causes in children with a diagnosis of epilepsy. This is comparable with national data.

### **3) What are the relevant national outcome frameworks indicators and how do we perform?**

The NHS Outcomes framework has one relevant indicator- unplanned admission for asthma, diabetes and epilepsy in children under 19. Whereas Bristol rates are just similar to England, Both North Somerset and South Gloucestershire have a statistically significant lower rate of unplanned admissions.

Table: NHSOF unplanned admissions for asthma, diabetes and epilepsy 2015-16

	Value (per 100,000)	Confidence Intervals
England	311	
North Somerset	236	194-285

South Glos	238	201-281
Bristol	345	310-383

## EPILEPSY

The Royal College of Child Health and Paediatrics (RCPCH.) established the EPILEPSY 12 audit with the first round running in 2012, and the second in 2014. It reviews the care of children presenting with probable epileptic seizures in their first year of care against 12 performance indicators which are based on the NICE and SIGN guidelines. Both rounds have shown gaps between the recommended care and care delivered both nationally and locally<sup>13</sup>.

Below is a summary of the findings locally for the second round of the audit in 2014. Patients were identified using the EEG records. Although 267 were identified initially, 121 did not meet the inclusion criteria. It was not possible to clarify whether or not inclusion criteria were met for another 110. This has resulted in a very small sample size, and the results should be interpreted with caution.

Title	Standard	BRCH Performance (n=33)	Weston Performance (n=12)	National Performance
1. Paediatrician with expertise in epilepsies	Percentage of children diagnosed with epilepsy, with input by a consultant paediatrician with expertise in epilepsies by one year	71% were seen by an expert  75% started on AEDs under supervision of an expert	100% were seen by an expert within a year  100% started on AEDs under the supervision of an expert	87% were seen by an expert  90% were commenced on AEDs under the supervision of an expert
2. Epilepsy Specialist nurse (ESN)	Percentage of children diagnosed with epilepsy referred for input by an epilepsy specialist nurse by one year	57% were referred for input by an ESN within a year  67% who started on AEDS were referred for input by an ENS at one year	0% were referred for input by an ESN within a year  0% who started on AEDS were referred for input by an ESN at one year	63% were referred for input by an ESN at one year
3. Tertiary involvement	Percentage of children with epilepsy meeting defined criteria for paediatric neurology referral, with input of tertiary care by one year	No cases were audited against this standard	0%	57%

4. Appropriate first clinical assessment	Percentage of all children with evidence of appropriate first paediatric clinical history and examination	67%	8%		
5. Seizure Classification	Percentage of children diagnosed with epilepsy with seizure classification by one year.	93%	100%	95%	
6. Epilepsy Classification	Percentage of children diagnosed with an epilepsy syndrome or category	100%	100%	90%	
7. ECG	Percentage of children with convulsive seizures with an ECG by one year.	50%	20%	59%	
8. EEG	Percentage of children who had an EEG in whom there were no defined contraindications.	97%	83%	94%	
9. MRI	Percentage of children diagnosed with epilepsy with defined indications for MRI who had an MRI by one year.	50%	Not audited	72%	
10. Carbamazepine	Percentage of children diagnosed with epilepsy given carbamazepine in whom there were no defined contraindications.	100% (n=1)	Not audited	99%	
11. Accuracy of diagnosis	Percentage of children diagnosed with epilepsy who still have a diagnosis at one year.	93%	100%	93%	
12. Information and advice	Percentage of children diagnosed with epilepsy with evidence of communication regarding pregnancy and contraception and water safety.	0% pregnancy and contraception (n=2)  79% water safety.	100% pregnancy and contraception (n=1)  100% water safety	54% pregnancy and contraception  64% water safety	

There are areas where Bristol is doing well and achieving better than the national average, such as the number of children who have had documented advice on water

safety and the percentage of children having had an EEG within a year of diagnosis. There are however, some areas where Bristol results were poorer than the national average, although it was not a negative outlier in any area. These included:

1. Input from a paediatrician with an expertise in epilepsy
2. Referral to Epilepsy Nurse Specialists was low. The actual percentage referred is likely to be lower, because the 2014 audit did not include many patients cared for by Community Paediatrics. An audit carried out in Community Paediatrics suggested a very low number had ESN involvement. This standard considers referral, as opposed to actually being seen.
3. Having had an MRI by one year if indicated
4. It is unclear whether appropriate referrals are being made to tertiary neurology.

Other concerns highlighted included:

1. There were no designated Epilepsy Clinics including no young people's epilepsy clinic and no transition clinic / unclear transition processes.
2. There was no local database or register of children with epilepsy.

The Weston results show 2 areas where it is a negative outlier:

1. Epilepsy specialist nursing
2. Appropriate first clinical assessment

#### **Local Serious Case Review**

Locally a serious case review investigation in 2006, into the death of a child with epilepsy following falling into a bath of hot water made recommendations which included that the local hospital trusts should "ensure that the support of an Epilepsy Nurse is available to all paediatricians managing children with epilepsy, to emphasise safety precautions and provide further information about epilepsy and its treatment"<sup>xx</sup>

#### 4) What is the evidence of what works (including cost effectiveness)?

##### National Institute for Health and Care Excellence (NICE)

Epilepsies diagnosis and management (CG137)

<https://www.nice.org.uk/guidance/cg137>.

This NICE guidance was originally published in January 2012 and updated in February 2014. In February 2016 a further update was released regarding valproate use during pregnancy.

*Table: Local performance against NICE quality standards*

Standard	How are we doing against these at BRHC	How are we doing against these at WGH
Children and young people presenting with a suspected seizure should be seen by a specialist in the diagnosis and management of epilepsies within 2 weeks of presentation.	Not achieving Unlikely to be achieving in Bristol. Current waiting time is 2-4 weeks to be seen in the rapid access clinic by a consultant with expertise and 2-3 months for an outpatient clinic. Only one general paediatrician with expertise working in BRHC, not all new referrals will be seen by this clinician.	Achieving – WGH In Weston this is largely being achieved, except if the clinician is on prolonged leave.
Children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.	Achieving Most standard EEGs performed within 4 weeks of referral	Performed at BRHC, achieving
Children and young people who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.	Not achieving EPILEPSY 12 data suggests 50% children who should have an MRI have had one in the first year in Bristol.	Performed at BRHC, not achieving
Children and young people with epilepsy have an agreed and comprehensive written epilepsy care plan.	Not achieving This information is not available for secondary or tertiary neurology patients in BRHC.	Not achieving Around 20% of children had a care plan (2016)
Children and young people with epilepsy are seen by an epilepsy specialist nurse who can contact them between scheduled reviews.	Not achieving There are 1.5 WTE Epilepsy Specialist Nurses for paediatric medical patients. There has been long term sick leave and availability of ESN has been extremely limited.	Not achieving There are no ESNs to provide care for secondary level patients in WGH
Children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan.	Not achieving This information is not available for secondary or tertiary neurology patients A small audit in Community	This information is not available.

	Paediatrics showed 9% of children seen by CCHP with a diagnosis of epilepsy had an emergency care plan.	
Children and young people who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.	Not achieving This information is not available from BRHC, but anecdotal information suggests that the wait is between 1-4 months	Would be seen at BRHC under same waiting times
Children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually.	Not consistently achieving timescales Not achieving structure Most patients are seen annually, however some wait longer. The partial booking system can result in some patients slipping through the net. There is no formalised structure for this review,	Achieving timescales  Not achieving structure  Patients are seen at least annually. There is no formalised structure for this review.
Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services	Not achieving There are no transition clinics or formal arrangement or processes for transition across secondary, community and neurology services.	Not achieving There are no transition clinics or formal arrangement or processes for transition across secondary, community and neurology services.

### **NICE guidance on transition to adult services (ng43)**

<https://www.nice.org.uk/guidance/ng43>

NICE have recently published guidance on transition to adult services in February 2016<sup>xxi</sup>. The overarching principles for managing transition are outlined below:

- Transition should address all outcomes including education and employment, community inclusion, health and well-being, independent living and housing options. Agencies should work together within the transition process.
- Transition should be person centred with the young person at the centre of the process and fully involved in decisions.
- Ensuring that transition is developmentally appropriate by taking into account the young person's maturity, cognitive abilities, psychological status, needs in respect of long term conditions, social and personal circumstances, caring responsibilities and communication needs.
- Ensure that transition support is strengths based and focuses on the positives and what is possible for the young person. It should identify the support available to the young person.

The NICE guidance for transition suggests:

- Services should start to think about transition from the age of 13 or 14
- Transition should involve goal setting and at least an annual review.
- It should be ensured that the young person is registered with a GP, and ensuring

they have a named GP should be considered.

- A co-ordinator should be identified for transition who can be anyone involved in their care.
- It should be ensured that practitioners from all required adult services meet the child prior to transfer from children's services. They make suggestions on how this could be done, for example arranging joint appointments, running joint clinics or pairing practitioners from children and adult services.
- Information regarding what to expect from adult services should be given in a timely manner, at least 3 months prior to the final handover.
- It may be appropriate to help the young person to create a personal folder containing relevant information about their health, care, social and educational needs. This should also include their emergency care plan where appropriate.
- If the transfer of care occurs and then the young person does not engage in adult services attempts should be made to contact the young person and other professionals involved within safeguarding protocols.
- It should be ensured that the young person is seen by the same professional for at least the first 2 visits following transition.
- Continuity should also be maintained in social care, the same social worker should do the assessment and planning and support the young person until at least the first review has taken place.

Within this document NICE also offers guidance on setting up a new transition service:

- Data from education and health care plans should be used to inform service planning
- Local integrated youth forums should be set up for transition. These should meet regularly and link with existing structures where possible.
- A gap analysis should be carried out considering what resources are currently available and eligibility criteria for these.
- It is important that particular groups such as those with neurodevelopmental disorders, cerebral palsy, challenging behaviour or those being supported by palliative care are considered.
- The joining up of services for young people with multiple specialists involved should be considered. For example an adult rehabilitative specialist may take the lead.

Locally within BNSSG there is no clear transition pathway for epilepsy patients and no dedicated transition clinics. Patient's experiences of transition to adult services are variable.

### **Clinical outcome review programme**

In 2013 the Royal College of Paediatrics and Child Health (RCPCH) carried out a themed review of morbidity and mortality from epilepsy in children in the whole of the UK. This focused on any child admitted to high dependency or intensive care with a diagnosis of epilepsy for a 10 month period from 1<sup>st</sup> June 2012 to 31<sup>st</sup> March 2013. They collected questionnaire data for 161 children, and then carried out a more detailed notes review for 61 further cases<sup>24</sup>. The recommendations of this report were:

- The NICE and SIGN guidance should be followed
- Peer review should occur regularly as a means of monitoring and improving practice
- Teams should consider the introduction of an epilepsy passport to improve communication and clarity around ongoing management
- If a child with epilepsy is admitted to hospital with a prolonged seizure the named consultant for the child should be notified and review treatment in light of that event.
- Prescriptions for emergency medication and emergency plans should be clear and available to all involved in the patient's care
- Ambulance crews should consider updating protocols so that buccal midazolam is used first line for prolonged seizure
- A&E departments should ensure that they follow APLS guidance for the management of seizures
- Child death overview panels should ensure all children with epilepsy who die have a child death review.
- If a child dies the consultant responsible for the child should ensure that all necessary actions following the death are documented in the child's notes

Following these recommendations an Epilepsy Passport was developed by the RCPCH. This document contains all important information regarding a child's epilepsy diagnosis and management, including an emergency care plan.<sup>xxii</sup>

[http://www.rcpch.ac.uk/system/files/protected/page/RCPCH%20Epilepsy%20Passport\\_0.pdf](http://www.rcpch.ac.uk/system/files/protected/page/RCPCH%20Epilepsy%20Passport_0.pdf)

### **Cost effectiveness of Epilepsy Specialist Nurses**

A study by Liverpool John Moores University, commissioned by Epilepsy Action found that ESNs reduce consultant and GP workloads, optimise and standardise care for individuals with epilepsy and are good value for money. They estimated that by reducing waiting times to see a specialist or general neurological consultant, epilepsy specialist nurses save health trusts £80,000 per year. In Surrey PCT, a new specialist epilepsy nurse reduced attendances at A&E by nearly half in 2005 representing a saving of £17,136 a year. Epilepsy misdiagnosis (which happens in 20-31 per cent of cases, or over 100,000 people) in England costs £23 million and the non-medical cost is £111 million. A specialist epilepsy service could help combat this and a randomised controlled trial (NHS National Workforce Project) found that patients consulting a specialist nurse and a neurologist were less likely to visit their GP, which led to a saving of £184 per patient per year.<sup>xxiii</sup>

## **5) What services / assets do we have to prevent and meet this need?**

### **a) General Practitioners**

GPs may see children with a possible diagnosis of epilepsy (although many will present through the emergency department) and they provide the prescriptions for the majority of anti-epileptic medication, usually with advice from the hospital physicians as most children with epilepsy will be under secondary care. GPs will make onward referral to secondary and tertiary care, and in South Gloucestershire may consult with a GP with a Special Interest (GPSI) for paediatrics for further advice if needed. There are currently

no BNSSG wide guidelines for GPs regarding referral pathway for children with possible epilepsy which results in lack of equality of care with different GPs being aware of /referring to different parts of service. There are 98 GP practices in BNSSG and around 1000 children are recorded as having epilepsy on the EMIS system.

**b) South Western Ambulance Service**

Over 2000 calls reported by the caller as convulsions/fitting were received in 2015.

*Table: Calls to SW Ambulance Service for Convulsions/Fitting 2015. BNSSG Under 18s*

<b>Outcome</b>	<b>Number of calls</b>
Hear & Treat (telephone advice)	43
See & Treat (attend and treat at scene)	664
See & Convey (transfer to healthcare facility)	1574

**c) Children’s Emergency Department (ED)**

Children up to age 16 (or 18 if under specialist care) may be seen in the ED with possible new seizures, an increase in existing seizures or a prolonged seizure .The route to presentation may be self-referral, GP referral or ambulance. The Children’s ED is located in Bristol and provided by University Hospitals NHS Trust. Out of the 9 paediatric emergency medicine consultants, one has expertise in epilepsy. (There is also an ED and ambulatory care unit in Weston General Hospital in North Somerset).

The accuracy and completeness of the data within the ED database is limited. In 2015 there were 37,611 attendances at the Children’s ED of which 185 presented with seizures/epilepsy (excluding febrile convulsions).

A local review August 2014- July 2015 found that 796 children attended with a fit, faint or funny turn, of which 175 were due to seizures/epilepsy / status epilepticus.

**d) Secondary care outpatients**

NICE recommends that in secondary care children with epilepsy should be managed by paediatricians with expertise in epilepsy -a paediatric consultant defined by themselves, their employer and tertiary service/network as having: training and continuing education in epilepsies; AND peer review of practice; AND regular audit (e.g. participation in Epilepsy12)<sup>xxi</sup>.

At Bristol Royal Children’s Hospital (BRCH) there are 7.2 whole time equivalent (WTE) paediatricians and 1 WTE paediatrician with expertise in epilepsy. At Weston General Hospital there are 3 general paediatricians, and 1 with expertise in epilepsy. There are no pathways for referral of children with possible epilepsy at either hospital.

A local survey of new referrals for possible epilepsy was carried out in BRCH which suggested an annual new referral rate of 200-250 children per year. The current clinic

capacity for the general paediatrician with expertise in epilepsy is only around 130 slots. He also has 155 patients under follow up. In Weston, the new patient referral rate is unknown. 98 children with epilepsy are under general paediatric care.

#### e) Emergency admissions for children with epilepsy

National data on emergency admissions 2013-14 shows that 113 children were admitted for epilepsy. The rate in Bristol although now similar to the England average had been increasing over the last few years and the average length of stay is double that of England. Admission rates for North Somerset and S Gloucestershire patients are considerably lower.

*Table: CHIMAT emergency admissions for BNSSG CCGs for epilepsy in 2013-14*

	Admission rate per 100 000 (number)	Bed days per 100 000 (number)	Average Length of Stay
England	77.1	152.5	1.93
Bristol	74.2 (76)	313.4 (321)	4.17
4 most similar CCGs to Bristol	89.6	168.4	1.85
Rank for Bristol (of 221 CCGs) 1 indicates 'best'	101	191	
North Somerset	35.8 (16)	78.2 (35)	2.33
South Gloucestershire	36.0 (21)	70.3 (41)	1.95
BNSSG	55 (113)	193.2 (397)	3.51

More recent local data suggests that for 2015/16 there were 107 emergency admissions, with 20 patients admitted more than once, with some patients having a very long length of stay (the maximum being 52 days).

#### f) Community Paediatrics

Community Paediatrics provides care outside of hospital to children with complex needs and long term disability. This includes children with learning disability and cerebral palsy in whom there is a greater risk of epilepsy. Community paediatricians may manage the care of children with epilepsy alone or in combination with a paediatric neurologist.

There are 3 area bases within Bristol, one in South Gloucestershire and one in North Somerset. All have consultants with expertise in epilepsy. There are no formalised pathways, dedicated epilepsy clinics, standardised care plans, nor clear transition processes. There is no database of current patients with epilepsy under the care of community paediatricians. A local review was carried out for Bristol and S Gloucestershire and found 169 patients with epilepsy. Of these 69 were led by community paediatrics and 46 cases were seen by (or supervised by) a community

paediatrician with epilepsy expertise. The vast majority had no epilepsy specialist nurse involvement.

#### **g) Epilepsy Nurse Specialists**

NICE recommends that all children with a diagnosis of epilepsy should have access to an Epilepsy Nurse Specialist for scheduled reviews, advice between reviews, and for specialist advice on education, health and lifestyle, emergency medication training. There are 1.5 WTE ESNs based at BRCH however capacity has been affected by long term sick leave. There is no electronic database, but based upon paper records, it is thought that the ESN service holds a caseload of around 600-800 cases, with 153 referrals received last year.

#### **h) Tertiary care – Paediatric Neurology**

NICE recommends referral to tertiary care for children with complex epilepsy. This includes those under 2 years old, those whose seizures are not controlled, and those whose diagnosis is not clear.

There are 7.7 WTE paediatric neurologists who cover the South West. Based at BRCH, they do outreach clinics across the region. There is no formalised pathway of referral into tertiary care currently (but this is in development). There is no standardised care plan. For urgent reviews there are ad hoc clinic reviews and review / admission via emergency department. There are no dedicated epilepsy clinics and no multidisciplinary clinics. There are no transition clinics or formalised transition process.

There is no current database of all children with epilepsy under the care of paediatric neurology. There is no database and the number of new patients seen by tertiary neurology with a diagnosis of epilepsy is unknown. The total caseload of epileptic patients is also not known. Based on earlier estimates there are around 1000 children in BNSSG with a diagnosis of epilepsy. Of these around 250 are followed up by secondary care across the two sites, and 70-100 may have their care led by community paediatrics. As suggested by the emergency admission data, it is possible that the majority of those remaining are cared for by tertiary neurology, however data to confirm this is not currently available.

#### **i) Quaternary Care- Children's Epilepsy Surgery Service (CESS)**

Children's Epilepsy Surgery is predominantly carried out in 4 centres in England, one of which is based at Bristol Royal Hospital for Children which serves the whole of the Southwest and beyond. The CESS service has clear referral criteria. It provides multidisciplinary assessment children with epilepsy who may benefit from surgery, undertakes all epilepsy surgery in under 5s and advises whether surgery for children aged 5 or over should be provided locally or by the CESS. This service is commissioned by NHS England.

It is estimated by Epilepsy Action that around 340 children per year could benefit from surgery in England and although rates have increased since the introduction of the CESS,

there are thought to be a number of children who could benefit who do not currently access surgery<sup>xiv</sup>. BNSSG data is not currently available but for the South West, Southampton and Oxford in 2015 there were 76 referrals of which 23 had surgery.

**j) Affiliated specialties:**

There are a number of services that are key to supporting the diagnosis and treatment of epilepsy:

- Neurophysiology (EEGs)- activity data for BNSSG children with epilepsy is not available
- Neuroradiology (MRI scans)- activity data for BNSSG children with epilepsy is not available
- Ketogenic dieticians- 19 BNSSG patients on caseload. Waiting time in 4-5 months
- Neuropsychology- around 30 BNSSG children per year access assessment and advice
- Neuropsychiatry for CESS patients only

**k) Voluntary sector and community assets**

There are several national charities supporting children with epilepsy- Epilepsy Action, The Epilepsy Society and Young Epilepsy. Locally there is a support group Epilepsy Parent Support Group South West which was supported by the ENS service prior to sickness leave.

## 6) What is on the horizon?

The demand for epilepsy services is likely to increase over the next 10 years:

- Increasing child population: BNSSG child population is expected to continue to rise with an anticipated increase of 15000 patients by 2023
- Medical advances include epilepsy surgery advances- stereotactic EEG to pinpoint seizures, convection aided drug delivery, deep brain stimulation, new medications including cannaboids, increasing used of ketogenetci diets and genetic engineering
- Increasing emphasis on good quality transition for young people

## 7) Local views

### Summary of Service Provider Views

A questionnaire to ascertain the views of key general and emergency medicine paediatricians, neurologists, community paediatricians, and nursing staff was undertaken and further augmented by discussions through the Childhood Epilepsy Needs Assessment Working Group.

- Good access to specialist surgery and paediatric neurology

- Lack of capacity in the Epilepsy Specialist Nurse Service (which results in lack of care coordination, care plans, support and advice to outpatients). There is no secondary care ESN provision for patients with epilepsy in North Somerset.
- Lack of capacity and resilience in secondary care (general paediatrics with expertise in epilepsy service) and no cover for annual/sick leave,
- Lack of capacity for supporting services neuropsychiatry, neuropsychology, neurophysiology.
- The emotional, behavioural and psychiatric needs of children with epilepsy are not currently met with in the service.
- There is a lack of adequate resources particularly for elective beds, IT support and investigations
- The lack of clear and standardised pathways of referral and onward care through most aspects of the services for children with epilepsy in BNSSG results in potential inequalities in care and risk of poor patient experience and suboptimal patient care and outcomes.
- Many of the standards expected by NICE are not being achieved, such as written care plans and emergency care plans available to all potential service providers, structured annual reviews, availability of patient information leaflets and education.
- Adolescents who are transitioning to adult services are a particularly vulnerable group and there is great heterogeneity in this process.
- Regular peer review (including for neurophysiology and CCHP) allows for quality assurance but this is currently not available locally.
- The lack of databases results in inability to monitor care, caseloads and outcomes.

### **Summary of Service User and Carer Feedback**

Service user and carer feedback was gathered using 2 methods. A simple questionnaire was distributed to all parents whose child had a diagnosis of epilepsy by nursing staff in out-patients for a 6 week period. A total of 20 questionnaires were returned. A focus group was also held for parents who were involved with a local support group for parents of children with epilepsy. 3 parents attended and contributed to this. There were a number of positive themes- parents felt listened too by clinically expert staff and children were involved in their care. Those with access to the ESN valued the input. Areas for improvement included:

- Lack of initial support following diagnosis, and not knowing who to contact.
- Appointments too short, giving limited time to discuss concerns. They didn't feel that the doctors really understood their child's problems in a holistic manner, rather just focused on the epilepsy.
- There was a long time (typically 6 months) between appointments. During this time there wasn't any contact with the team and a lack of proactive care. If medication doses were changed there was no follow up from this until the next appointment.
- Not enough access to epilepsy nurse specialists.
- Poor communication between staff and departments, particularly with regard to past history and medications.

- Contacting professionals for advice between appointments was described as difficult. There had been particular problems due to sick leave within the ESN service over the past year.
- Practical training in schools for use of emergency medication could be difficult to organise.
- Schools require more training on epilepsy, particularly the potential effects on the whole child, not just the seizures themselves.
- Parents felt that the transition to adult services was unclear and not joined up, which resulted in considerable anxiety
- Parents felt a need for an improvement in the information with which they were provided such as support groups, educational provision, management of seizures etc.
- Some parents described poor communication with parents and children, such as use of medical jargon or being given bad news over the phone.

## B: What does this tell us?

### 8) Key issues and gaps

- 1. Inadequate data:** There are challenges with availability of high quality, timely data both nationally and locally. There is also no local, regional or national database for epilepsy patients. Locally there are difficulties in gathering clear activity data, particularly for tertiary neurology and outcome related data.
- 2. Lack of clear pathways:** There is a lack of clear pathways for new and existing patients. In different areas of BNSSG there is a difference in the availability of services for patients.
- 3. No standardised assessment:** There are no standardised proformas for the assessment of new patients or for annual reviews. Therefore these processes are not standardised or equitable.
- 4. Insufficient Epilepsy Specialist Nurses (ESN):** There are insufficient epilepsy specialist nurses to provide an equitable and high quality service. There is no ESN cover for secondary care patients in Weston.
- 5. Lack of specialist capacity in secondary care.** There is a lack paediatricians with specialist training in epilepsy within the secondary care service in Bristol. Many patients appear to be seen within tertiary care (although there is no robust data to verify this).
- 6. No multidisciplinary peer review:** There is no regular multidisciplinary peer review in place locally. This provides an opportunity for review of cases and aims to reduce the misdiagnosis rate and improve the quality of care. Such activity is recommended by national guidance.
- 7. No transition pathways.** There are no clear pathways for the transition of patients to adult services.
- 8. Limit access to supporting services.** There is limited access to neurophysiology, neuropsychiatry and neuropsychology support.

## 9) Knowledge gaps

### Incidence and prevalence estimates

A diagnosis of epilepsy encompasses many different conditions. Epilepsy often co-exists with other conditions and active and inactive epilepsy pose further challenge. Diagnosis of epilepsy is difficult and there is estimated to be a high rate of misdiagnoses. All of these factors contribute to difficulties in collecting data on incidence and prevalence of epilepsy.

### Local activity data

Lack of electronic databases and variations in coding mean that it is hard to accurately ascertain activity, performance and outcomes. Diagnosis is not coded for outpatient attendances. For areas where data is collected this data is not shared with other services.

### Other information gaps

- CHIMAT data suggests that Bristol is a significant outlier for the length of stay following an emergency admission. Further investigation into this would be recommended.
- The local rate of misdiagnosis is not known
- Because of the current structure of neurology services it is not possible to distinguish epilepsy work from other tertiary neurology work
- There is a lack of information available regarding the long term effects of poorly controlled epilepsy.

## C: What should we do next?

## 10) Recommendations for consideration

3. **he development of a single database** to be used by all professionals involved in epilepsy care. This would aid monitoring of prevalence and outcomes, and facilitate communication. This would also improve monitoring or activity within departments to allow for better service planning and development.
4. **The development of clear care pathways** and referral criteria for patients with epilepsy. These should include clear referral criteria to individual services, including affiliated specialities.
5. **The development of proformas for new patient assessment and annual reviews.** The Epilepsy Passport has been produced by the Royal College of Paediatrics and Child Health for this purpose, and its use locally should be considered
6. An **increase in the epilepsy nursing staffing** to meet national recommendations. This is vital to improve patient care and their experience of care. North Somerset should explore the possibility of appointing epilepsy nurses to cover this area for secondary care.
7. **Further training or recruitment within general paediatrics** to ensure adequate

specialist expertise is available to meet the needs of the population.

8. There is a need to **establish a robust process for multi-disciplinary peer review** to improve patient care and reduce the misdiagnosis rate.
9. **Appointment of a transition champion** to review the current transition process and make recommendations. This review should be multidisciplinary and involve adult physicians and ESNs.
10. **Improved access to support services:** neurophysiology, neuropsychology and psychiatry support is recommended. These allied services should have clear referral criteria, and be included in the care pathway. Further resources may be required to improve access.

## 11) Key contacts

Chapter author - [Clare.phillpotts@cchp.nhs.uk](mailto:Clare.phillpotts@cchp.nhs.uk)

Public Health lead (Bristol) – [Joanna.copping@bristol.gov.uk](mailto:Joanna.copping@bristol.gov.uk)

Bristol JSNA process – website: [www.bristol.gov.uk/jsna](http://www.bristol.gov.uk/jsna) / email: [jsna@bristol.gov.uk](mailto:jsna@bristol.gov.uk)

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