An Economic Assessment of the Roald Dahl Sapphire Paediatric Epilepsy Nurse Specialist Service at Ashford and St Peter's Hospital

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1.0 Introduction

Specialist nursing services can be targeted for financial savings, particularly in the current economic climate of the NHS. However, specialist nurses can find it difficult to demonstrate their cost effectiveness and their clinical value (James 2011, Fletcher 2011) and therefore prevent such cutbacks to their services.

In 2010, Epilepsy Action commissioned Liverpool John Moores University to undertake research on the value of epilepsy specialist nurses. The team recommended that hospital trusts ‘collect meaningful and comparable epilepsy related hospital activity data so that the true extent of the economic value of the ESN can be fully demonstrated’. This economic assessment was undertaken under the auspices of the Royal College of Nursing (RCN) and Roald Dahl’s Marvellous Children’s Charity between June 2017 and January 2018.

1.1 The Purpose

This report sets out the policy context and the current evidence in support for the role of paediatric epilepsy nurse specialist (PENS). It describes the context where this economic assessment was undertaken. It sets out the approach taken to demonstrate the economic value of the role/service, details the true economic costs of the PENS service and presents two case studies to illustrate the potential costs avoided as a result of PENS interventions. The report concludes with a summary and a discussion of next steps.

1.2 The Background

Epilepsy affects 1 in 100 of the population in the United Kingdom (Epilepsy Action 2016). A diagnosis of epilepsy is made following 2 seizures and most people take anti-epileptic medication to reduce the risk of having further seizures. Epilepsy is a chronic illness which affects a person’s emotional, physical, mental and social wellbeing. The National Institute for Health and Care Excellence (NICE) (2012) states that ‘optimal management improves health outcomes and can also help to minimise other, often detrimental, impacts on social, educational and employment activity’.

The RCN competency document (2013) presents the vision of paediatric epilepsy nursing services. Competencies and responsibilities are discussed, including support for the newly diagnosed, liaison between professionals, being a point of contact, undertaking home and school visits, and giving support and information to the family and child.

NICE (2013) states that ‘children and young people with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews’. This is because specialist nurses play a key role in providing continuity of care and ensure that patients and their families have a point of contact. The epilepsy nurse according to NICE (2012) should be an integral part of the network of care of children, young people and adults with epilepsy. Therefore, epilepsy nurses should provide support, information and training for parents, carers and schools.

In 2002 Mills et al undertook a qualitative study looking at what patients wanted from a primary care epilepsy specialist nursing service. Patients were seen in their own homes and interviewed. Although this study (it was part of a larger controlled trial) was small

(12 patients) and focussed on the adult population, key themes of communication, information giving and empathy were identified.

Another study (Hosking et al 2002) focussed on adults with epilepsy seen at a tertiary centre. The team sent questionnaires about the epilepsy nursing service to 193 patients and received 69% back. Themes emerged that the epilepsy nursing service enhanced the management of complex patients, enabled the patient to have better understanding of their chronic illness and empowered them to become confident in managing their illness themselves. A key part of the service was the telephone support available.

An American document published in 2010 (Labiner et al) gives guidance on the type of services and personnel required in specialist epilepsy centres. Specialist nurses are cited as being responsible for providing patient and family education.

The review of mandation for the universal health visiting service (Public Health England 2016) considers the value of this service for safeguarding, health promotion and the prevention of accidents. American research (Council on Child and Adolescent Health 1998, and Supplee and Adirim 2012) have drawn similar conclusions.

In 2016 an American team (Pfafflin et al) undertook a randomised controlled trial with 187 epilepsy patients. The team randomly allocated 92 patients to have contact with the epilepsy nurse and 95 to be controls with routine care only. They concluded with the use of questionnaires (patient satisfaction with information and support, quality of life measures, anxiety and depression scores) that ‘Epilepsy nurses improve the satisfaction of patients with counselling and information about epilepsy and concomitant problems’.

1.3 The Setting

The paediatric epilepsy service is based in a District General Hospital in Surrey. The paediatric epilepsy nurse (PENS) works with two part-time Consultant Paediatricians with an interest in Epilepsy. A visiting Paediatric Neurologist holds multi-disciplinary team (MDT) clinics quarterly. Young people aged 18 are seen with the Adult Neurologist (and the others in the MDT) in the Transition clinic.

The Epilepsy Nurse works 30 hours per week over 4 days and the role is 0.8 whole time equivalent. The post was transferred from a community setting under protected employment terms (TUPE) in April 2017 and the epilepsy nurse has been in post since 2013.

The Pathway to Outcomes model (Appendix 1) highlights the role of the epilepsy nurse and the patient outcomes from her involvement.

2. Approach to Economic Assessment

2.1 Pathways to Outcomes

The Pathway to Outcomes model (PTO) (Appendix 1) highlights the PENS involvement and her role in supporting families and patients. The PTO also details the expected outcomes.

The Paediatric Epilepsy Nurse Specialist offers:

- Home visits for newly diagnosed patients and others on case load as needed
- Nurse-led clinics
- Nurse-led teenage clinics
- Attendance at MDT clinics

- School and nursery training for rescue treatment
- Attendance at social care meetings
- Telephone calls - a mobile telephone number is given to all patients
- Ward visits
- Staff training
- Student nurse placements

Communication, information, education, health promotion, safeguarding, empathy and empowerment are all integral to the role of the paediatric epilepsy nurse (PENS). The PENS endeavours to support families with a telephone service and nurse-led clinic reviews for families. A teenage nurse-led clinic is held three times per month where young people can attend (if they would like) without their parents from age 14-18. In addition, home and school training visits are offered for all children or young people with a new diagnosis of epilepsy.

The home visits are designed for families to feel relaxed and less anxious. The home visit provides the opportunity for people to receive and understand advice and information at their own pace. A pro forma is used, (Table 7, page 21) to ensure that the pertinent issues are discussed. Leaflets and information on epilepsy are given and families are signposted to epilepsy information websites. Children/ young people and family are always given the opportunity to ask questions.

Parents are given the option to meet with the epilepsy nurse briefly without the child. The family can talk about their fears and concerns more openly, and sudden unexpected death in epilepsy (SUDEP) and the risks of seizures are discussed. Many families are anxious about their child’s safety, as well as their behaviour and educational

progress. The epilepsy nurse tries to guide them and refers them to different agencies as needed.
During the contacts with families and young people the epilepsy nurse aims to build rapport and explains that they can ask her anything about epilepsy. Young people and their families can text or email the epilepsy nurse (IT security issues are discussed) which means they have easier access and possibly a quicker response time, particularly if the epilepsy nurse is on visits and not in the office.

Some families may feel uncomfortable calling the consultant 2-3 times per week to ask what they may perceive to be 'silly' questions. Families are advised that contact will be made with the consultants on their behalf and the epilepsy nurse explains that she is a point of contact for their concerns. This means that her involvement can in many cases avoid a consultant telephone call, or GP or consultant appointment.

2.2 The Cost Avoidance Approach

There are a number of approaches to economic assessment (EA) (Chih Hoong and McMahon 2015) and the purpose of the EA coupled with the availability of data and time to undertake the EA determines the approach taken.

For the purpose of demonstrating the value of a PENS, a cost avoidance approach was applied.

To demonstrate the economic impact of the paediatric epilepsy nursing service, scenarios are presented of possible outcomes and a sensitivity analysis is used to offer the reader an estimated range of the economic impact. This approach presents a range of potential costs avoided but not necessarily saved. In this EA, all costs are presented reflecting 2017 prices.

Methods

In order to better understand the PTO, data was collected on the number of patients on the case load.

3.0 Economic Assessment

3.1 **Stratification of case load**

The case load was stratified into red, orange and green dependency levels to identify the needs of the family. Peer review was undertaken with two other paediatric specialist nurses. Criteria for each dependency level was agreed as followed:

1. **High level input – Red dependency**

- Children or young people with newly diagnosed epilepsy (for a (period of 3 months)
- Children or young people with additional needs
- Families with additional needs, like being on a child protection plan or where the parent has mental health needs
- Patients who are having frequent seizures
- Patients who are treated with multiple medications
- Children or young people who have prolonged seizures and need frequent emergency treatment

2. Medium level input – Orange dependency

- Young people who are going through transition
- Patients who usually have well controlled epilepsy who develop breakthrough seizures
- Patients who need medication changes
- Patients who have infrequent seizures

3. Low level input –Green dependency

- Children and young people who are seizure free
- Patients who are seen yearly in clinic
- Patients who need yearly refresher training
- Families who need infrequent epilepsy advice

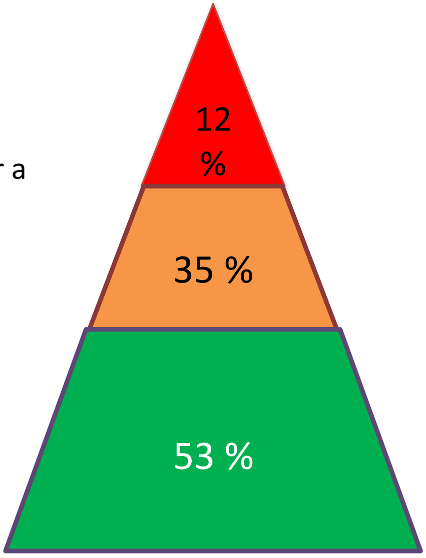
Peer reviewers discussed that children can transition between groups depending on their seizure control and circumstances. Sometimes children may have well controlled epilepsy, but due to family complexities, they need more involvement from the epilepsy nurse.

Peer review additionally confirmed that those patients in the orange group were those who may have ongoing seizures, but do not require frequent interventions, apart from in times of crisis. The orange group may on occasion move to red when they need more involvement for a short time. The families in the green group are those who have yearly follow-up and usually do not contact the service more than 1-2 times per year.

Two typical patients from the high dependency group were identified. The interventions that each family required and the costs that may have been avoided if the epilepsy nurse had not been in post were examined. The families in the case studies were identified to require more interventions and thus be in the red dependency group. The family in the 1st case study had some social concerns and the mother had some medical needs. The child had additional needs and ongoing seizures. In case study 2, the child had frequent seizures and the mother felt very anxious.

Dependency Levels

Diagram 1. Showing percentage of caseload in each level



- Red for the most complex who need many hours of input and support for a prolonged period
- Orange for those who need regular support for a short period
- Green for those who need support initially for a brief period

- Caseload 186 patients on 02/10/17
- 100/186 had a home visit= 54 %
- 26/39 newly diagnosed patients (since January 2017) had a home visit= 67 %

3.2 Cost of service vs Income Received

The PTO (Appendix 1) shows the direct and indirect costs of running the epilepsy nurse service to support families from the three dependency groups. Data was obtained from the Hospital Trust Accountant and are presented with employer costs at 22.5 %. The costs are inclusive of London fringe which is £1345.56 per year (Table 1.).

Table 1 Actual cost data from Trust accountant

		Actual data Including on-costs (22.5%)						
Subjective Code Desc	**Pay at 0.8 wte**	**Apr-17**	**May-17**	**Jun-17**	**Jul-17**	**Aug-17**	**Sep-17**	**Total**
Nurse band 7 Total	**£34775.16 pa (£2897.93 pcm)**	**£3,583.90**	**£3,657.55**	**£3,620.72**	**£3,622.85**	**£3,627.10**	**£3,620.72**	**£21,732.84**
Travel & Subsistence Total					**£78.40**	**£234.44**		**£312.84**
Mobile telephone		**not known**						
Office premises		**no cost identified**						**£0.00**
								£22,044.84

Epilepsy Nurse Band 7 (top point) 30hpw (0.8 wte)

with employer costs for 6 months = £21,732.84

Annually= £43,465.68

(NB. Hourly rate is calculated by dividing total cost to employer / (no. of weeks worked per year x no. of hours contracted to work per week): £43465.68 / (45 x 30) = £32.20 per hour – rounded up to **£32 per hour**).

Plus mileage approximately £120 per month (August is an accumulated total)

Annually=£1440

Total £44,865.68

Mobile phone use is aggregated into a ward level mobile contract. Data reflecting the specific use of the mobile phone by the PENS was not available upon request. The office was already established and the PENS shares with 5 other specialist nurses.

Epilepsy Nurse Income

The income from the CCG is recorded as an organisational benefit on the PTO. This is because the CCG give the hospital the funds to run the service based on the number of children it expects the service to see in a year. Table 2 shows the income data over a six month period during 2017.

Table 2
Actual income data from Trust accountant 2017

Actual Income (data from Trust accountant)								
		Apr-17	May-17	Jun-17	Jul-17	Aug-17	Sep-17	Total
Income from Block contract from CCG (includes nurse-led clinics 10-15 patients per month)	£22,840.00	£3,806.60	£3,806.60	£3,806.60	£3,806.60	£3,806.60	£3,806.60	£22,840.00
Roald Dahl Charity	£500 per year for training							£500.00
								£23,340.00

Epilepsy Nurse **income** from the CCG block contract including home visits and telephone calls, as well as nurse-led clinic income

April to September 2017 =£22,840 for 6 months

£3806.7 x 12 months

= **£45,680.40**

In addition the PENS service has access to + £500 per year Roald Dahl Charity Training fund

= £46,180.4

Yearly totals

Tables 3 and 4 show the Trust Income and Full economic costs of the PENS for the year 2017.

£46,180 – £44,865.68= £1314.32 surplus

Table 3: Trust Income 2017

Income **(data from Trust accountant)**	
	Total per annum
Income from Block contract from CCG (Organisational benefit)	**£45,680**
Roald Dahl Charity Training Fund	**£500**
Total	**£46,180**

Table 4: Annual direct running costs of the service (2017)

Per annum	Pay at 0.8 wte with London fringe	Total with on-cost
Nurse band 7	**£34,775.16 pa**	**£43,465.68**
Travel & Subsistence		**£1,400**
Mobile telephone		**NK**
Total		**£44,865.68**

Direct set-up cost (2017)

Laptop computer **£1492**

Indirect costs

Some indirect costs were identified:

- Printing information leaflets
- Office heating, lighting and equipment
- Manager support
- Consultant
- Secretary
- IT support

These staff members are in post to provide routine care, and supporting the PENS service is not over and above what they would be providing anyway. Therefore as part of this economic assessment they do not need to be quantified or monetised. The printing and office costs are identified, but actual figures are not charged directly to the service, and are not available. The printing of leaflets and booklets is kept to a minimum with generic epilepsy information leaflets and booklets (containing no patient data) sent to families via email as appropriate. Families are also signposted to websites for epilepsy information, reducing the need for large quantities of printing.

The data in Table 3 demonstrates that the income received from the CCG covers the full economic running costs of the PENS (Table 4).

In summary the direct set-up and running costs of the service in 2017 had a small short fall in funding of £85.68. This is due to the one off set up cost of the laptop at £1492. In 2018 the cost will be neutral.

In the next section two cases studies are presented in order to surface the potential costs avoided as a consequence of the PENS service.

3.3 Case Study 1

*Name changed

I was introduced to Victor and his family in the epilepsy clinic and I made contact with mum soon after the clinic appointment. I arranged a home visit a few months later when it became clear that mum needed information repeated regularly and could cope with only one instruction each time. As Victor was initially diagnosed with childhood absence epilepsy we would expect this to have a good prognosis with seizure freedom quite quickly occurring with the first medication. However Victor had many difficulties with medication adherence and mum's parenting capacity.

It soon became apparent that Victor would not take his Sodium Valproate liquid. His diet was quite restrictive and Victor soon discovered that mum was putting the liquid into his yoghurts and refused to eat them. Victor would spit out the liquid if given to him in a syringe. I was able to ask the nursery nurse in the health visiting team to discuss some behavioural strategies to help mum, however, Victor's absence seizures were continuing as mum continued to struggle to get the medication in to him consistently. I also discussed strategies with Victor's dad who appeared to manage better with the medication.

I met with mum at home and I was able to discuss Victor's diagnosis, epilepsy first aid, safety around water and roads and medication adherence. I discussed a different epilepsy medication preparation with the consultant and his medication was changed. This appeared to help with administration and his mother felt that he was having the medication consistently. However his absences continued and he had an incident where he fell in to the road during a seizure. He was not injured and I again explained to mum about ways to keep Victor safe around roads.

On the next planned review with the consultant a new medication (Ethosuximide) was added in. However, mum had difficulty retaining the instruction to continue with both medications and she stopped the Sodium Valproate in error. I made contact with the consultant and GP to re-arrange prescriptions and explained the instructions to mum again. Victor then refused to take the liquid, so capsules were tried. This eventually helped and Victor's seizures do continue but are now less frequent.

Victor recently had a prolonged seizure at school. The school followed my emergency seizure care plan and called an ambulance. This meant he was kept safe and cared for appropriately.

I looked at the number of contacts I had with mum and other multi-disciplinary team members in the 1st year of his diagnosis.

I had 49 contacts with mum (text or telephone calls) = 6 calls of 15 minutes each (approximately) and 43 texts= approximately 2 minutes per text = **176 minutes =**

3 hours @ £32 (inc. on-costs and London weighting) =£96

I had contact with Dad 6 times via telephone or text= 2 calls of 15 minutes each and 4 texts= **40 minutes =£21**

I visited the house once for 1 hour (plus 40 minutes each way travelling time) **= 2 hours 20 =£75**

Mileage 32 miles @ 56p per mile=£18

I attended 2 school meetings (1 hour 30 each time plus 40 minutes each way travelling time) **= £178**

Mileage 32 miles @ 56p per mile=£18

I visited the school to do epilepsy training once (1 hour plus 40 minutes each way travelling time) **=£75**

Mileage 32 miles @ 56p per mile=£18

Victor had 1 visit to Accident and Emergency, but no ward admission

Cost £105

I saw the family in clinic 3 times (1 nurse led and 2 MDT Consultant Led)

Consultant and nurse**-£120 x 2 =£240**

Nurse-led clinic**- (included as part of the PENS funding from the CCG (see PTO), so not possible to break down) 45 minutes @£ 32 per hour (inc. on-costs and London weighting) =£ 24**

I contacted the consultant via email 8 times- approximately 15 minutes to write each email- **2 hours= £64**

I liaised with the GP twice- 20 minutes plus 25 minutes to write and send a fax x2 = 90 minutes @ £32 per hour (**inc. on-costs and London weighting) =£48**

I advised mum to see the GP once- **£37**

I liaised with the health visitor- **3 times x 15 minutes = £24**

The above costings do not include time to write up notes for each contact with family or professional approximately 15 minutes each time.

Approximate cost of interventions (including one referral to GP) over 12 months=£1041

Intervention cost data from the Trust accountant for the clinics, accident and emergency visits and hospital admission. Other data from the Department of Health (2016) and the PSSRU (2017).

My contact with the family appeared to help mum focus on Victor's health needs and enabled her to understand and care for him more effectively. Mum explained recently that Victor takes his medication consistently now. My text and telephone contact with mum may have reduced consultant telephone calls and clinic appointments, as well as unnecessary GP appointments and emergency hospital visits. Mum had a 'port of call' for any epilepsy concerns which arguably enabled her to eventually become more empowered and less dependent upon NHS services. However, Victor and his mum were well supported by other health professionals and it is not possible to attribute mum's change in behaviour to one professional.

My involvement also supported the school in ensuring that he was able to attend regularly and stay safe despite the ongoing frequent absences. The staff explained that they were grateful that a care plan was in place and they had been able to refer to it during Victor's recent prolonged seizure, thus ensuring his safety.

Victor and his family remained on a Red dependency level for longer than I would have expected due to the type of epilepsy that Victor has. However because of mum's health needs and the family situation, my involvement continued. Mum's dependence on contact with me has reduced and Victor has been on Orange for a year now.

Victor continued to see other professionals during the year (health visitor, nursery nurse, social worker, school staff, consultant paediatrician). We were able to use a team approach to support him. However, it is not possible to monetise their involvement. Victor's seizures did improve but unfortunately have not stopped despite 2 medications and monitoring. It has now become apparent that he has a more severe form of epilepsy.

The assumption made here is that in the absence of a PENS, this family would have attempted to use other parts of the health care system more frequently. During my 15 years working with people with epilepsy at a tertiary centre and now a district general hospital, I have supported many families with their concerns about seizures, side effects of medication and schooling issues. I am aware that if families seek help from the consultant's secretary, a message can be left but it may not be possible for the family to speak to the consultant for a few days. The secretary would then advise the family to see the GP or go to Accident and Emergency if they were very concerned. My assumptions are that without my input the family may have needed more interventions identified in Table 5 below.

Table 5 shows the assumed minimum and maximum interventions that Victor required over 12 months. The minimum column shows my assumed interventions prior to peer review with the consultants. The maximum column presents the number of interventions that the consultants (during peer review) believed would be needed in my absence.

Table 5: Cost of assumed interventions required over 12 months in my absence

Case study 1	**Minimum**	**Maximum**
1 GP appointment @£37[3]	5=£185	8=£296
1 Conveyance to hospital via ambulance@ £236[2]	1 =£236	3=£708
1 A and E visit@ £105[1]	1=£105	2=£210
1 consultant calls- 15 minutes @ £64[4] per hour=£ 16	6=£96	8=£128
1 consultant appointment @ £120[1]	4=£420	6=£630
Hospital Admission @ £845 [1]	0	0
Parental call to Consultants' secretary- 5 minutes @ £16[5] per hour=£1.30	10=£13.30	20=£26 *
Total	**£1055**	**£1998**

The Intervention cost data from Trust accountant[1] (2017 data), the Department of Health[2] (2016), PSSRU[3] (2017), the BMA for consultant salary with on-cost and London fringe[4] (2017), and RCN NHS pay scales for band 4 with on-costs and London fringe[5].

*Estimation based on the 6 calls and 43 texts I had received during the 12 months from Victor's mother

In the scenario presented it is suggested that an input with an estimated cost of **£1041**, a minimum of **£1055** and a maximum of **£1998** of costs may have been avoided

Peer review with medical consultant colleagues led to an agreement that the PENS would be unlikely to avoid a hospital admission, but that the role avoided many telephone calls and clinic appointments. The consultants advised that without my service, the secretaries in the paediatric office would receive numerous calls and thus the consultants would need to advise the secretaries to direct patients to their GP or accident and emergency department. In some cases, the consultant would be able to call the family direct or slot them into an extra clinic appointment. However, this would be difficult for the consultants to manage particularly for the families on the red dependency scales. In my absence, many families may struggle to receive the information and support that they need in a timely manner.

Case study 2

*name changed

Lydia is a teenager with frequent seizures occurring at night. Her mum made frequent telephone calls to the Consultant every time Lydia had clusters of seizures. The secretaries found managing mum's expectations and the frequency of calls very difficult. When mum could not speak to the consultant immediately she would contact me and mum could call several times per day until she could speak to someone.

Following a particularly difficult time when mum had called and called until she had been given an appointment to see the consultant, I offered to visit her at home.

I had not been in post at the start of her epilepsy diagnosis. Lydia's epilepsy had been quite settled for one year however as she started to grow during puberty, she started to have frequent seizures. She had a number of admissions to the Accident and Emergency department for injuries associated with her epilepsy and also due to seizure exacerbation.

During my frequent telephone calls from mum it was becoming apparent that she was extremely anxious about Lydia's epilepsy. I believe that my predecessor and the consultant had discussed Lydia's epilepsy diagnosis and how it could impact her life, but was not sure how much mum had retained or been able to process. I made the decision to 'start at the beginning' and discussed the issues which I would usually discuss with a family with a child with a recent diagnosis of epilepsy (see Table 7. below). I visited mum at home (without Lydia being present) after Lydia had had a number of seizures and the new medication did not appear to be helping.

Table 6. Epilepsy information discussed with family and young person with epilepsy on home visits and in follow-up appointments

Issues discussed	
Epilepsy Diagnosis	
Epilepsy First Aid	
Medication and side effects	
Showering/Bathing	
Road Crossing	
Swimming	
Kitchen safety	
SUDEP	
Baby monitor at night	
Medical identity jewellery	
Driving	
Alcohol	
Recreational drugs	
Contraception	
Careers	
Sport and leisure activities	
Education/Exams	
Benefits-DLA	

Mum became tearful during our appointment. It became clear that mum’s frequent telephone calls stemmed from her anxiety about Lydia’s seizures and her safety. Mum knew about SUDEP (sudden unexpected death in epilepsy) and I believed this was the main cause of her anxiety. I was able to spend time discussing the risks but also reassuring mum. I also explained that Lydia has complex epilepsy which has not responded to a number of medications. This means that she will have seizures. I advised mum to call for help when her usual pattern of seizures increase and completed a care plan for her for home and school. I also visited the school twice to undertake epilepsy training.

I reviewed the contacts and interventions over a year

Telephone calls, texts and emails from mum and my replies- 36 (19 before my 1st home visit) 8 telephone calls (15 minutes each approximately) and 24 texts (2 minutes per text) =

3 hours (rounded up) @£32 per hour=£96

Clinic appointments-3 (1 epilepsy clinic, 2 joint neurologist clinics)

=**£120 x 3 (neurology clinic will be higher) = £360**

Mum’s telephone calls to the consultant- **16** from November 2016 to June 2017- not able to be monetised

Mum’s telephone calls to the consultant from June 2017 to November 2017 –none

GP contact- unknown

My contacts (emails/discussion) = with the consultant regarding Victor-12 x 15 minutes= **£96**

Contacts with the neurologist- 2 emails sent (10 minutes x 2) = **£11**

School visits- 2 (1 hour plus 30 mins travelling time each way) = 4 hours= **£128**

Mileage 14 miles @ 56p per mile=£8

Home visits- 2 (1 hour 15 each time plus 30 minutes travelling time each way) =**£144**

Mileage 14 miles @ 56p per mile=£8

Visits to Accident and Emergency via ambulance- 4 due to seizures

= £236 x 4 (conveyance) and £105 x 4 (A and E) = **£1364**

The above costings do not include time to write up notes for each contact with family or professional approximately 15 minutes each time.

Approximate cost of interventions over 12 months= **£2215**

Intervention cost data from the Trust accountant for the clinics, accident and emergency visits and hospital admission. Other data from the Department of Health (2016) and the PSSRU (2017).

Lydia has complex epilepsy. Her visits to hospital for emergency treatment in my opinion were appropriate. Her seizures are unpredictable and require emergency interventions when the rescue treatment given at home does not work. However, I would like to make the assumption that following my intervention, Lydia's mum is now better equipped to manage her epilepsy and seizure exacerbation. She knows when to call for help and no longer calls the consultant frequently about her usual seizures. Mum still maintains contact with me, but this may be because I have made myself accessible.

I was able to note that since my home visit in May 2017, Lydia's mother has called the consultant only twice. I would like to make the assumption that my support and contact with this family has saved the consultant many calls. In the 6 months prior to my home visit mum called the consultant 14 times. I do not believe that Lydia's epilepsy is better controlled, but that mum is better equipped to manage the seizures and her anxiety due to my intervention.

Therefore in my absence there would need to be support from other services as identified in Table 7 below.

Table 7 shows the assumed minimum and maximum interventions that Lydia required over 12 months. The minimum column shows my assumed interventions prior to peer review with the consultants. The maximum column presents the number of interventions that the consultants (during peer review) believed would be needed in my absence.

Table 7. Cost of assumed interventions required in 12 months in my absence

Case study 2	**Minimum**	**Maximum**
1 GP appointment @£37[3]	2=£74	8 =£296
1 Conveyance to hospital via ambulance @ £236[2]	2 = £472	4= £944
1 A and E visit @ £105[1]	6 =£630	8= £840
1 consultant calls- 15 minutes @ £64[4] per hour=£16	4 =£64	8= £128
1 consultant appointment @ £120[1]	2 = £240	6 = £720
Hospital Admission @ £845 [1]	0	0
Parental call to Consultants' secretary 5 minutes @ £16 [5] per hour=£1.30	10 = £13.30	30= £40 *
Total	**£1493**	**£2968**

The Intervention cost data from Trust accountant[1] (2017 data), the Department of Health[2] (2016), PSSRU[3] (2017), the BMA for consultant salary with on-cost and London fringe[4] (2017) and RCN NHS pay scales for Band 4 (mid-point) with on-costs and London fringe[5].

*Estimation based on the 16 calls to the secretaries received in 6 months from Lydia's mother prior to my intervention.

In this scenario presented it is suggested that an input with an estimated cost of **£2215**, a minimum of **£1493** and a maximum of **£2968** of costs may have been avoided.

Peer review

Paediatric epilepsy nurses from other hospitals contributed to peer review regarding the dependency levels for my caseload of patients.

A peer review discussion was held with the consultants in the epilepsy team. This peer review identified that in my absence many more consultant calls, clinic appointments and GP appointments would be necessary. My peers identified that it was unlikely that my role reduces hospital admissions, but we agreed that I may be able to reduce unnecessary visits to Accident and Emergency, or ambulance calls as I encourage families and carers to manage short seizures at home and school according to their care plan, which I complete for them. I was able to undertake a sensitivity analysis using the consultants' suggestions on the number of calls and clinic appointments which they believe would be required in my absence.

Assumptions

Using my clinical judgement and experience I expect Victor's and Lydia's epilepsy to continue to need a high level of support and on occasion due to seizure exacerbation, admissions to hospital. I make the assumption that my involvement does avoid costs, as without my input the cost would be even higher.

With reference to my sensitivity analysis, I make the assumption that for Case Study 1, there was a cost £1055 to £1998 which could be avoided due to my interventions. For Case Study 2, there was a £1493 to £2968 cost which could be avoided. I propose that out of 186 patients, 12 % of the caseload may be comparable to the 2 patients in my case study who require a high level of support and advice. This means that over a year with 22 patients (12% of caseload) requiring £1055- £2968 of interventions, I make the assumption that my service may be able to avoid costs of £23210-£65296 per annum.

4.0 Conclusion

During the economic assessment, an objective approach applying the principles set out in the UK Treasury Green book guidance was used (McMahon and Chih Hoong 2015). This economic assessment has shown that the income received from the CCG offsets the full economic costs of the PENS. As a result of the epilepsy nurse's intervention, the economic assessment has also shown that the PENS service can avoid costs. Peer review has strengthened these assumptions.

The PENS role enhances the epilepsy team. The nurse and consultants work closely together to support families. The nurse's interventions very frequently avoid the need for the consultant to see the patient in clinic, or call them. The assumption can be made that the PENS' input can reduce visits to the General Practitioner (GP), Accident and Emergency, and in some cases calling an ambulance. Peer review reinforced these assumptions and the consultants were in agreement with the perceived costs that could be avoided due to the interventions of the epilepsy nurse.

It is also important to consider the wider benefits of the epilepsy nurse specialist which are more difficult to quantify, such as the impact of reduced seizure burden on the family or less anxiety for the child and family. Improved school attendance and reduced risk of sudden unexpected death are also outcomes which could be examined.

Further work could examine the costs avoided for those in the orange and green dependency groups. Total costs avoided could be identified for the service as a whole. This economic assessment could also be a platform for other specialist nurses who may be under pressure to reduce or cut their services. In addition, consideration could be given for this work to be used to support the adult neurologist in securing agreement and funding for an adult epilepsy nurse specialist at the trust.

This case study was completed by Hannah Chaffe, Roald Dahl Sapphire Paediatric Epilepsy Nurse Specialist, Ashford and St Peter's NHS Foundation Trust in 2017.

Hannah successfully completed an RCN leadership development programme commissioned by Roald Dahl's Marvellous Children's Charity.
The programme was designed to empower Roald Dahl specialist nurses to understand the principles of economic assessment and apply them in their practice in order to demonstrate the value and continuously transform their services.

The programme is endorsed by the Institute of Leadership and Management.

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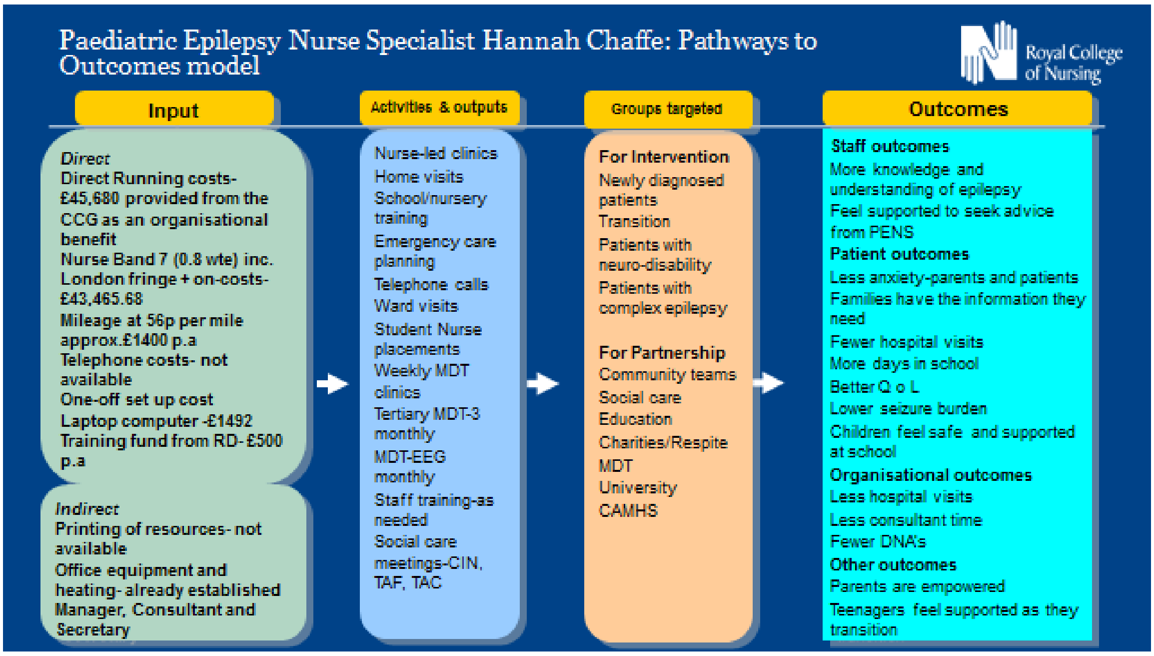
Appendix 1

Pathway to Outcomes model



Paediatric Epilepsy Nurse Specialist Hannah Chaffe: Pathways to Outcomes model

Royal College of Nursing

Input

Direct
Direct Running costs- £45,680 provided from the CCG as an organisational benefit
Nurse Band 7 (0.8 wte) inc. London fringe + on-costs- £43,465.68
Mileage at 56p per mile approx.£1400 p.a
Telephone costs- not available
One-off set up cost
Laptop computer -£1492
Training fund from RD- £500 p.a

Indirect
Printing of resources- not available
Office equipment and heating- already established
Manager, Consultant and Secretary

Activities & outputs

Nurse-led clinics
Home visits
School/nursery training
Emergency care planning
Telephone calls
Ward visits
Student Nurse placements
Weekly MDT clinics
Tertiary MDT-3 monthly
MDT-EEG monthly
Staff training-as needed
Social care meetings-CIN, TAF, TAC

Groups targeted

For Intervention
Newly diagnosed patients
Transition
Patients with neuro-disability
Patients with complex epilepsy

For Partnership
Community teams
Social care
Education
Charities/Respite
MDT
University
CAMHS

Outcomes

Staff outcomes
More knowledge and understanding of epilepsy
Feel supported to seek advice from PENS
Patient outcomes
Less anxiety-parents and patients
Families have the information they need
Fewer hospital visits
More days in school
Better Q o L
Lower seizure burden
Children feel safe and supported at school
Organisational outcomes
Less hospital visits
Less consultant time
Fewer DNA's
Other outcomes
Parents are empowered
Teenagers feel supported as they transition