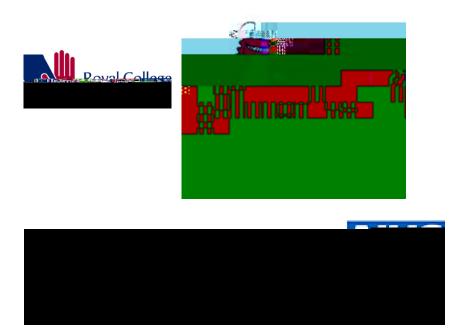
## An Economic Assessment of the Roald Dahl Sapphire Paediatric Epilepsy Nurse Specialist

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Specialist nursing services can be targeted for financial savings, particularly in the current economic dimate 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

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 (RON) and Roald between June 2017 and January 2018.

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.

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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

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

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Children and young people who are seizure free

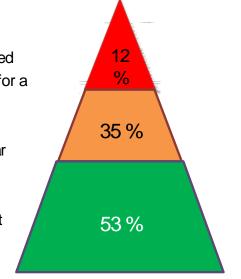
Patients who are seen yearly in dinic

Patients who need yearly refresher training

Families who need infrequent epilepsy advice

# Dependency Levels

- 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 %

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Some	indirect costs were identified	ed:	
1	Printing information leaflets	<b>;</b>	
	_		
	Office heating, lighting and e	equipment	
I	Manager support		
	Consultant		
;	Secretary		
ļ	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

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

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 multidisciplinary 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 =

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

I visited the house once for 1 hour (plus 40 minutes each way travelling time)

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

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

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

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

Consultant and nurse

Nurse-led dinic

I contacted the consultant via email 8 times- approximately 15 minutes to write each email-

I liaised with the GPtwice- 20 minutes plus 25 minutes to write and send a fax x2 = 90 minutes @ £32 per hour (

I advised mum to see the GP once-

I liaised with the health visitor-

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

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).

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 dinic appointments, as well as unnecessary GP appointments and emergency hospital visits.

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 hange 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

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 b 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.

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 h

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.

1 GP appointment @£37 <sup>3</sup>	5=£185	8=£296
1 Conveyance to hospital via ambulance@ £236 <sup>2</sup>	1 =£236	3=£708

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 dinic 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

	present) after Lydia had had a number of medication did not appear to be helping.
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Mum became tearful during our appointment. It became clear that stemmed from her anxiety about 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) =

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

- from November 2016 to

June 2017- not able to be monetised

November 2017 none

GP contact- unknown

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

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

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

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

Visits to Accident and Emergency via ambulance- 4 due to seizures = £236 x 4 (conveyance) and £105 x 4 (A and E) =

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=

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 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 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 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.

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.

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 ad38.91 TmeemBuldor

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### Appendix 1

### Pathway to Outcomes model

