Guide to writing a business case for an epilepsy specialist nurse

Background and context

This guide has been produced by the Joint Epilepsy Council www.jointepilepsycouncil.org.uk and the Long Term Conditions Delivery Support Team www.ltc-community.org.uk It seeks to address the identified challenges of writing a business case or influencing local decision makers to recruit an epilepsy specialist nurse as an integral member of a specialist support team.

The Epilepsy NICE guideline states that 'Epilepsy specialist nurses (ESNs) should be an integral part of the network of care of individuals with epilepsy. The key roles of the ESNs are to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the individual, families, carers and, in the case of children, others involved in the child's education, welfare and well-being. '

Epilepsy Action's report '*Best care: The value of epilepsy specialist nurses*' states that ESNs undertake a wide range of valuable, mainly patient-related activities in various settings. In the absence of ESNs this work would either fall to consultants or simply be overlooked.

This guide complements the '*Commissioning Epilepsy Services Resource Pack for Commissioners*' which is one of the outcomes of '*Best Value, Better Care – Commissioning Epilepsy Services*' conference held on 23rd February 2010 in London.

It is recognised that the potential audiences for this work will range from clinical practitioners with considerable insight into the impact of epilepsy on people's lives and little experience of developing a business case, to those with commissioning experience and little knowledge of the specific condition. This guide draws together the intelligence from all perspectives. It will help to identify the desired outcomes and the costs and benefits accrued in achieving them.

This guide was updated in October 2013.

Purpose and structure

A business case makes a proposal for change. It is desirable that the business case emerges from development work with all stakeholders as part of a process of change rather than a stand alone piece of work.

A business case needs to focus on outcomes that are of priority to key stakeholders involved, especially those who are being asked to fund the proposal. It is therefore beneficial to reflect the link between the business case and the priority in the title.

It is assumed that organisations have a template for a business case. This guide is designed to suggest sources of information to complete that template. It is important that the business case reflects the local perspective.

Support and information
The sources of information are current at the time of writing and are intended to stimulate thinking, however original references should always be sought.

Consultation with stakeholders will increase their engagement in the proposal. Having focused conversations and developing appropriate relationships with colleagues, service users and carers forms a sound basis for the business case and will impact on its eventual success.

Even if the business case is not ultimately successful in achieving funding it may lead to other desirable outcomes through the engagement of stakeholders.

Long Term Conditions Delivery Support Team
We aim to improve the services for people with long term conditions by supporting the implementation of Long Term Conditions policy and strategy. We work with the Department of Health and are funded by NHS.

Become a part of the LTC Community at www.ltc-community.org.uk
Wellington House, 133 – 155, Waterloo Road, London SE1 8UG, Tel 0207 972 3049 Fax 0207 972 4349

Joint Epilepsy Council
The Joint Epilepsy Council of the U.K. and Ireland (JEC) is an umbrella organisation which exists to represent the united voice of the voluntary sector and presents evidence based views on the need to improve services for people with epilepsy, their families, and carers in the UK and Ireland.

The Joint Epilepsy Council of the U.K. and Ireland, PO Box 186, Leeds LS20 8WY, www.jointepilepsycouncil.org.uk sharon.jec@btconnect.com Tel: 01943 871852

Epilepsy Action
Epilepsy Action has been supporting ESNs for over 15 years and has a range of expertise and resources to help a review of epilepsy services. We can provide advice on designing services, care pathways and epilepsy generally. We have a network of local branches and a large database of members to provide local input in to service redesign. To find out more contact the epilepsy services team at services@epilepsy.org.uk or call 0113 210 8800.

Introductory Memo: Key considerations for non-commissioning experts
Commissioning is the process by which local budget holders – such as Clinical Commissioning Groups, identify the health and social care needs of the populations they serve, and plan for and procure the services required to meet those needs. High quality commissioning is based on a strategic and long term view, which delivers better health outcomes for patients, and is cost effective i.e. it secures the greatest possible value for the taxpayer.

Despite the decentralisation of health budgets to the local level, the process of commissioning does not take place in a vacuum – it is shaped by national political imperatives, and residual elements of 'top-down' command and control, as well as the wider economic climate.

The first question NHS commissioners might ask is how to get more for less. 'More' meaning higher quality services which meet increasing demand, increase efficiency and effectiveness and satisfy rising expectations of service users. 'Less' includes net savings, reduction in waste from investments, public sector cash release, and reduced budgets.

Below is a suggestion of some potential issues to be taken into account when developing a business case for the improvement of epilepsy services.

Issue	**Recommended response**
1. Commissioners are measured against their success in tackling local and national health priorities.	• Acknowledge the wider commissioning environment and the principal changes on the horizon. • Identify which national and local health priorities are of main concern for commissioners (refer to the NHS Operating Plan, the NHS Outcomes Framework with national goals, local strategic plans and any other initiatives). Explain how an improvement in epilepsy services, in line with the business case, can help to address other identified major priorities for the NHS (see objectives in section 1).
2. All decisions meet the test of quality, innovation, productivity and prevention (QIPP).	• Highlight the short-term financial gains to be achieved as a result of the service re-design (wherever possible). • Explain which elements of the business case support QIPP, and quantify this wherever possible. Highlight evidence based outcomes and how guidance will be met.

3. Commissioners are responsible for a large range of services.	• Take steps to ensure that decision makers consider your business case (which may take them time and effort to implement) amongst other pressing priorities, and similar proposals. - Build wider support for the business case – secure endorsements from clinicians, professional bodies, local MPs/elected representatives such as Councillors, patients for the case. - Ask others to be advocates for the business case – give other stakeholders (such as local MPs) the information and tools to help them call on NHS bodies to implement the business case. Aim to secure a face to face meeting to talk through the plan and agree next steps (identify allies within the decision makers who can help to make this happen).

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1.	**Objectives**
	Ensure it is clear how each objective will be achieved. Not all of the objectives will be relevant to each business case. Focus on the areas of change important to the specific health economy. Expecting too much from an individual nurse would lead to inadequate service provision.
1.1.	**Objectives of the service** <u>Care related</u> • Effective Personal Care Plans for all patients with epilepsy • Ensure annual patient review (NICE and SIGN guidance) • First seizure support • Support, advice and liaison with other local support for patient and carers • Transition clinics for teenagers entering the adult service • Clinics and advice specifically for women of child bearing age working jointly with maternity services <u>Outcome related</u> • Reduction in inappropriate hospital admissions • Reduction in length of stay • Better concordance with medication and self care • Reduce treatment gap – 70 per cent of the population with epilepsy in the UK could be seizure free with optimal treatment. Currently only 52 per cent of the population of people with epilepsy are seizure free. Source JEC 'Epilepsy prevalence, incidence and other statistics' http://www.jointepilepsycouncil.org.uk/downloads/2011/Joint%20Epilepsy%20Council%20Prevalence%20and%20Incidence%20September%2011.pdf • Ensure equitable access to epilepsy services • Improved and appropriate anti-epileptic medication prescribing <u>Pathway/service related</u> • Facilitation service between primary and secondary care • Effective liaison and joint planning with all agencies in health, social care, education and the third sector • Deliver nurse-led clinics • Improve referral pathway (well timed and appropriate referral) from primary care to neurologists (secondary care) to epilepsy specialists/ epileptologists (tertiary care) • Non medical prescribing (nurse/therapy prescribing) • Building a comprehensive database of the population with epilepsy in the area to include the capture of performance metrics and outcomes as required by commissioning organisations • Ensuring an evidence based and standardised approach to prescribing • Ensuring faster identification of "treatment resistant patients" and

	delivering treatment advice to this patient group • Increase training, education and awareness of epilepsy across the health and social care community. Better integration between social care and clinical services
1.2.	**Measures of success** Outcome measures should be clearly identified together with performance metrics, clinical governance assurances and best practice. It is essential to quantify the benefits to be able to influence an investment or redirection of funds to the business case. This means translating the benefits into measurable, costed targets, including identified costs savings, releasing capacity (in quantifiable terms) or alternative uses of resources. Ensure that the data is available to prove these measures. <u>Care related</u> • Improved patient satisfaction • Improved compliance and appropriate use of anti-epileptic medications • Training of family and carers in the administration of rescue medication, so reducing clinical involvement <u>Outcome related</u> • Reduction in A&E attendances [1] • Reduction in emergency admissions [1] • Reduction in GP consultations [1] • Reduction in out patient episodes [1] • Reduce epilepsy related deaths [2] • Reduce consultant led follow-up care <u>Pathway/service related</u> • Increase access to epilepsy services in the community • More equitable access to epilepsy services • Follow best evidence based practice [1] The potential cost savings can be calculated using Payment by Results (PbR) more information can be found on www.dh.gov.uk/paymentbyresults [2] The Office for National Statistics recorded 9050 epilepsy related deaths in 2010 http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-227638
1.3.	**Target audience, referrals and discharge** Identify the target population of the service (adult, paediatric, learning disabilities or older people). Also define the population by geographic area. Consideration needs to be given to the referral process to the service. Possible options include: • All patients with a diagnosis of epilepsy self refer

	• GP and consultants refer to the service The referral method has implications on the caseload of the service. Discharge from the service needs to be considered to ensure a manageable caseload.
1.4.	**Examples of benefits / outcomes** How people with epilepsy will benefit from the introduction of an epilepsy specialist nurse. How primary care, consultants and other hospital departments will benefit. An attempt has been made to ensure all benefits are tangible. <u>Care related</u> • Healthier pregnancy outcomes for women on anti-epileptic drugs • Better quality of life for people with epilepsy measured with satisfaction surveys • More people with epilepsy in employment • Number of people attending self help groups • Reduction in the number of epilepsy related deaths • Improved health through prompt access to specialist expertise • People with epilepsy experiencing fewer seizures and side effects • Increased awareness of epilepsy amongst other professionals (such as health professional, social services, education, employers and the wider community) • Tailored care and better self management through patient care plans • Empowerment of people with epilepsy and signposting to other services <u>Outcome related</u> • Higher quality of service through improved patient experience scores • Reduction in number of GP appointments – freeing up primary care capacity • Reduction in number A&E attendances reducing costs to the health economy • Reduction in emergency admissions and number non-elective admissions freeing capacity and reducing cost and less disruptive to patients • Reduction in 999 admissions • Higher number of people seizure free • Reduction in misdiagnosis of epilepsy <u>Pathway/service related</u> • Follow best evidence based practice • Reducing costs by using cost effective nurses time rather than consultant or GP time • Improved liaison between primary and secondary care and therefore better patient care pathways • More effective anti-epileptic drug prescribing

	See 5.2 for the baseline cost information that can be used to demonstrate gains against outcomes. For patient focused outcomes, an initial survey of epilepsy patients, their carers or of healthcare professionals, may be beneficial to establish a baseline of patient service satisfactions, employment difficulties and quality of life.
1.5.	**Evidencing outcomes** It is recommended that outcomes are **S**pecific, **M**easurable, **A**greed, **R**ealistic and **T**ime-based (or SMART). Example: Target: 25% reduction in A&E attendances over one year related to baseline activity. Baseline: If there are currently 1,000 attendances there would need to be a reduction of 250. Assumptions: Assuming one in three of the people who see a specialist nurse could be prevented from attending A&E. 750 patients would need to be seen over the year to prevent 250 attendances at A&E. This assumption in not evidence based. Example of lead in time: Induction and competency based skill assessment framework. Non medical prescribing is a 6 month 2 day per week commitment at university with additional supervision from Issues to consider: • Is this realistic (4.1 states that the recommended case load is 250 patients) • The lead in time for the nurse • Whether the data collected provides evidence of the measure • There may be multiple attendances by the same person • Assumed success rate of the nurse's interventions • Number of interventions the nurse would need to make to achieve the measure • The length of time of intervention • The reduction may only be visible in the following year It is recommended that activity projections work on an individual being productive for 42 weeks per year, unless there is a multi disciplinary team that is available for 52 weeks per year. This allows 6.5 weeks annual leave, 2 weeks study leave and 2 weeks potential loss to sickness absence. Based on Agenda For Change – Department for Health.

2.	**Finance of the service**
2.1.	**Evidence of cost effectiveness** The financial model needs to reflect the service description, measures and outcomes. It is advisable to work with the finance team to develop the financial section of the business case. Potential sources of income will vary from organisation to organisation but may include: • Local Operating Plan • Primary Care GP Commissioning • Disinvestment to Reinvest from Acute providers admission tariff – into Primary Care commissioning or PCT Commissioning • Deprivation monies (only available in areas of high deprivation) • Regional Innovation Fund (RIF) & Quality, Innovation, Productivity and Prevention (QIPP) • Epilepsy Action Sapphire Scheme www.epilepsy.org.uk/services/sapphire • Corporate sponsorship, investment and/or partnership See 5.2 for the baseline cost information that can be used to demonstrate gains against outcomes.
2.2.	**Service costs** The following items should be considered, listed as pay with on costs, and non pay. **Pay** costs with 24% on costs and top of scale Agenda for Change pay rates: • Band 7 nurse www.nhscareers.nhs.uk/details/Default.aspx?Id=766 • Band 5 support nurse • Band 2 administration support • Pension contribution (included in above 24%) • Employers National Insurance (included in above 24%) • Administration support (usually calculated on band 2) • Annual leave cover • Sickness leave cover **Non Pay** including: • Travel – realistic for the locality • Uniforms or allowance • Training • Stationery/printing • Leaflets and information for patients • Computer and consumables • Room rental and furniture See appendix A for an example of how to display this information.

	These should be projected over several years of the service to include inflation. These costs will be at least an additional 24% above salary costs and some acute trusts estimate the cost to be an additional 40% above salary costs. The costs may fluctuate over time due to set up costs and increasing the service.
2.3.	**Income** Some business cases increase revenue (through sale of goods or charges for services) that can be offset against the costs of the scheme. Whilst this is not a feature widely experience currently, in some fields it is significant and with the introduction of individual budgets or joint schemes with local authorities this could become an interesting area for inclusion future business cases. The administration costs of collecting the revenue should be included.
2.4.	**Cost data** These data are needed to understand the savings which have been made. Direct costs of current activity include: • Tariffs for hospital admissions • Drug costs and uses • Cost of doctor and nurse led clinics • Banding of current staff costs

2.5.	**Cost comparisons**
	Any cost comparisons must take into account the development and the running costs of the proposal. All data should be used in context and with local interpretation.
	
	The cost basis uses at least two comparisons:
	• Before / current situation (baseline)
	• Future / proposed model of service (target)
	  ○ Direct benefits
	  ○ Indirect, mid to long term impact, with assumptions

2.6.	**Return on investment** This can assist in calculating the reasonableness of a scheme. See 2.7 Benefits = return on investment Service costs For every £1 invested you project 'return on investment' (as calculated above) worth of benefit. Example: If the service costs £360,000 over five years and the benefits are £650,000 over five years £650,000 = 1.8 360,000 For every £1 invested you project £1.80 worth of benefit. Service costs as calculated in 2.2 and Benefits as outlined in 1.4
2.7.	**Test of reasonableness** The cost of the scheme needs to be in proportion to the outcomes achieved. One way this can be assessed is by comparing a unit cost. To calculate a unit cost: Total cost of service = unit cost per patient Number of patients Example: If the service cost £72,000 per year and saw 250 patients per year £72,000 = £288 per patient 250 patients For example if it costs £288 to see each patient considering the assumptions regarding success and depending on the cost of tariff, consider if it is reasonable to pay for that intervention? Total cost as shown in 2.2 and Caseload see 4.1 The reasonableness can also depends on how long it will take to pay back any initial outlay that may be required.

3.	**Demographic information**
3.1.	**Size of population with epilepsy** Epilepsy is a tendency to have recurrent seizures. It can affect anyone, at any age and from any walk of life. It is the most common, serious, neurological condition. Epilepsy is not a single condition; there are about 40 different epileptic syndromes and over 40 and perhaps as many as 50 different seizure types and individuals may have one or several seizure types. Approximately 600,000 people in the UK have epilepsy. This is equivalent to 1 in 103 people. The Age Standardised Prevalence Rate of Epilepsy in the UK: 9.7 per 1,000. Approximately 32,000 new cases are diagnosed per year. The number of people with epilepsy within a health economy can be calculated using document produced by the Joint Epilepsy Council entitled: *Epilepsy prevalence, incidence and other statistics*. The document can be found at http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-227638
3.2.	**Specifics of the population** Prevalence varies by age, gender and social deprivation as well as other factors. It is therefore important to include information on people with learning difficulties, children, transitional (between paediatric and adult), social deprivation, urban, rural, population age or ethnic mix and the impact this will have on the service. www.jointepilepsycouncil.org.uk/Final.pdf
3.3.	**QOF Data (Quality and Outcomes Framework)** This data for everyone with epilepsy over 18 is recorded through QOF and published by the NHS Information Centre from the Quality Management Analysis System (QMAS), a national IT system developed by NHS Connecting for Health. QMAS uses data from general practices to calculate individual practices' QOF achievement Limitations of this data include: • Variation in exception reporting • Uncertainty of the suitability of the review (how it's conducted and by who) The results of the QOF data can be found at www.qof.ic.nhs.uk

4.	**Service Design**

4.1.	**Factors to consider**
	These factors need to be considered to ensure that the service is a success.
	• Nurse's workload – is the case load manageable?
	• Epilepsy Action also recommends that epilepsy specialist nurses have a caseload of no more than 250 patients with active epilepsy, see www.jointepilepsycouncil.org.uk/Wasted-Money-Wasted-Lives.html
	• Urban / rural split and travel
	• Administrative support
	• Working with other agencies
	• Realistic costing
	• Probability of achievability
	• Contingency plans for non delivery
	• Patient consultation
	• Proportion of time spent on:
	  ○ Education of GPs
	  ○ Education of members of the public
	  ○ Education of other professionals
	  ○ Patient consultation

4.2.	**Option appraisal** A business case needs to demonstrate an option appraisal. The option appraisal process shows the range of options there are to delivering the outcomes required. There should be a recommendation for the preferred option. Whilst this is advice on developing a business case for a specialist epilepsy nurse service, it is the clinical outcome for people with epilepsy that is the critical objective. The options discuss the advantages and limitations of each option. All options need to have the advantages, disadvantages and limitations made explicit. No option is perfect. This is where the cost and outcome differences are explicit for comparison. See 2.1 Evidence of cost effectiveness. It must be remembered that an option of 'do nothing' will have associated costs. Some of the limitations might also be probability of recruitment, time to train, lack of interest (for example GPs locally). Advantages might be flexibility of nursing input, community location, and flexible working hours.
4.3.	**What shortfalls there are in the current epilepsy service?** This section should identify the current local service and include how the existing service may not meet national guidelines including the NICE Guidelines 2012, pressures and constraints on the current system. http://www.nice.org.uk/cg137 Shortfalls should be measured against the outcomes that the service is aiming

	to achieve in 1.1. There may also be considerations that fall outside the direct scope of the service but are worth consideration. These may include access to surgery and diagnostic equipment (such as MRI and EEG), diagnosis of epilepsy by non-epilepsy specialists and differences in prescribing protocols between organisations.
4.4.	**Risks** Consider the risks faced by the people with epilepsy if the service is not sufficient and appropriate to the needs of the local population. What risks do these constraints and pressures present? • Sudden Unexpected Death from Epilepsy (SUDEP) • Misdiagnosis • Increased rate of admissions • Uncontrolled seizures • Unacceptable drug side effects • Social issues such as unemployment and isolation • Increased cost of inappropriate access to heath provision by patients with epilepsy • Impact on prescribing budgets Consider the risks that may be faced by the service. These include lack of funding beyond initial period, staff sickness or resignation. The exit strategy at 4.7 should outline how these risks will be handled.
4.5.	**Timescale** Including milestones, such as a nurse being in post, running clinics and the period of time over which there will be return on investment. When considering a new post an induction is required and additional training may be required if the person has not undertaken this role before. This delay in the full service being up and running should be taken into account when setting outcomes. Experience from the community matron and other specialist services models suggests at least a 9 month lead in time to full efficiency in the post; with return on investment clearly achievable within a 2 year period (Derbyshire County PCT – Parkinson's Disease Nurse Specials Report 2010).
4.6.	**Evaluation and impact assessment** Consider: • Metrics and performance monitoring required • Equality impact assessment • Time lines for reporting (often quarterly review) • Appropriate outcome measures across the community including the patient and carer feedback, health and social care impacts. The reporting should reflect the objectives outlined in this business case. Suggested measures of success can be seen in 1.2.
4.7.	**Exit strategy** The exit strategy should consider other options of doing things differently,

	especially where developments might have taken place over a period of time. The impact on other services, including demand, capacity, skills and risks need to be considered. Issues to consider: • Funding is withdrawn • Nurse leaves, or is unable to work – is the patient's care by default returned to Primary and Secondary care colleagues? • Reduction in demand due to patients no longer needing the service because seizures are controlled

5.	**Assumptions and evidence base**
5.1.	**Sources of information** Outline any assumptions made and draw on evidence of the need locally and nationally. Useful documents include: • Best care: the value of the epilepsy specialist nurse www.epilepsy.org.uk/campaigns/save-our-sapphires • Wasted money, Wasted Lives www.jointepilepsycouncil.org.uk/Wasted-Money-Wasted-Lives.htmlTime for Change • Epilepsy in England: time for change www.epilepsy.org.uk/campaigns/timeforchange • Warren E (1998) An evaluation of a nurse specialist/case manager intervention in the management of Epilepsy • Department of Health (2007) Long Term Neurological Conditions. A good practice guide to the development of the multidisciplinary team and the value of the specialist nurse www.healthcareworkforce.nhs.uk/resources/latest_resources/long_term_neurological_conditions.html • Taylor MP (2000) Managing epilepsy: A clinical handbook pg 160 • Latest guidance from NICE http://www.nice.org.uk/cg137 • SIGN – Scottish Intercollegiate Guidelines Network www.sign.ac.uk/guidelines/fulltext/70/index.html • Best Value, Better Care – Commissioning Epilepsy Services February 2010 www.ltc-community.org.uk/articles.asp?action=view&id=5794 • Better Value, Better Care- Your Guide to Commissioning in Epilepsy http://www.epilepsy.org.uk/sites/epilepsy/files/primary-care-resource/epilepsyaction-primary-care-commissioning-book.pdf See appendix B for examples of what these articles include.
5.2.	**Baseline data and costs / benchmarks** Include any current data on the service because this will give a good benchmark when showing the improvements over time. Include information on when the service was established the number of new diagnoses per month or year and national statistics regarding the incidence of epilepsy (www.jointepilepsycouncil.org.uk/Final.pdf). This data acts as a baseline for ongoing monitoring and viability of the service. Baseline data should be collected on all outcomes in 1.5 and demographic data at 3.
5.3.	**Strategic fit** Consider the strategy from Department of Health, Long Terms Condition Team, Strategic Health Authority, Acute Trust, Clinical Commissioning Groups and any other local provider. • NICE (2012) CG137 The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care.

	http://guidance.nice.org.uk/CG137 • Department of Health (2005) National Service Framework for Long Term conditions www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4105361 • World Class Commissioning www.dh.gov.uk • Quality, Innovation, Productivity and Prevention (QIPP) www.dh.gov.uk • National Sentinel Clinical Audit of Epilepsy-related Deaths (2002)

6.	**Additional information to position the business case**
6.1.	**Further information about epilepsy** • Joint Epilepsy Council (JEC) www.jointepilepsycouncil.org.uk • JEC Epilepsy prevalence, incidence and other statistics www.jointepilepsycouncil.org.uk/Final.pdf • National Institute for Health and Clinical Excellence (NICE) www.nice.org.uk • Long Term Conditions Delivery Support www.ltc-community.org.uk • Department of Health www.dh.gov.uk • Brainwave - The Irish Epilepsy Association www.epilepsy.ie • The Daisy Garland www.thedaisygarland.org.uk • David Lewis Centre www.davidlewis.org.uk • Epilepsy Action www.epilepsy.org.uk • Epilepsy Bereaved www.sudep.org • Epilepsy HERE www.epilepsyhere.org.uk • Epilepsy Outlook www.epilepsyoutlook.org.uk • Epilepsy Research UK www.epilepsyresearch.org.uk • EpilepSy Nurses Association www.esna-online.org.uk • Gravesend Epilepsy Network www.gravesendepilepsynetwork.com • International League Against Epilepsy UK chapter www.ilae-uk.org.uk • Matthews Friends www.matthewsfriends.org • Meath Epilepsy Trust www.meath.org.uk • Mersey Region Epilepsy Association www.epilepsymersey.org.uk • National Centre for Young People with Epilepsy www.ncype.org.uk • National Society for Epilepsy www.epilepsysociety.org.uk • St Elizabeths Centre www.stelizabeths.org.uk
6.2.	**Health economy, supporters and others involved** Be clear about who is funding the service and who can access it. The service will impact on other professionals, these may include: Neurologists, paediatricians, learning disability psychiatrists, general practitioners, other specialist nurses in primary and secondary care, practice nurses, occupational therapists, community neurological and rehabilitation teams, community team for people with learning disabilities, community matrons, community hospitals, community nursing teams, ward staff, social workers, pharmacists, psychologists, counsellors, midwives, amongst others. It is advisable to seek their commitment to support the service before setting up the service. Also include if and how other organisations propose to be involved. Local authority, schools, GPs, acute trust, PCT, social care, SHA, carers, mental health professionals, public involvement forum, charities, local neurological forum, epilepsy conference providers, benefits agency, carer support groups. Access to work, local 'condition management teams'.

6.3.	**Change management** Consider how the change will be managed and who needs to be engaged to ensure that the change is a success.

Appendix A – Service Costs

	Year 1	Year 2	Year 3	Year 4	Year 5
Pay costs based on Agenda for Change rates with 24% on costs to account for National Insurance, NHS pensions and other employing organisation overheads such as management.					
Band 7 nurse					
Band 5 support nurse					
Band 2 administration support					
Non Pay Costs - Recurrent					
Travel – realistic for the locality					
Uniform or allowance					
Training					
Printing and ink					
Stationery					
Information for patient (leaflets)					
Land line rental and Mobile phone					
Sickness leave cover					
Non Pay – non recurrent (but needs depreciation costs factored in at year 4)					
Computer & printer					
Specialist equipment for specialist role					
Room rental and furniture					
Total Costs					

It may be useful to work out these costs against the predicted savings to come up with a cost per case saving model.

Appendix B – Extracts from useful documents

Below is a selection of extracts from documents which may be useful. It is always recommended that the reference is read in full to understand the context.

***Long Term Neurological Conditions**: A good practice guide to the development of the multidisciplinary team and the value of the specialist nurse.* (2009)

Misdiagnosis rates in the UK where a diagnosis of epilepsy is incorrectly made are between 20-31 %. Using an assumed rate of 23 %, this equates to 105,000 people with a diagnosis of epilepsy and receiving antiepileptic drugs who do not have the condition. This high misdiagnosis rate has a major impact on people's lives, including the physical implications of the side effects of taking antiepileptic medication. One of the main reasons for the high level of misdiagnosis is the lack of training and the limited access for people with epilepsy to epilepsy specialists (1).

In 2004, the medical cost associated with misdiagnosis in England was £23 million and the non medical cost was £111 million (2). Developing the epilepsy service and having the correct workforce in place should help to improve the rates of accurate diagnosis thus reducing the amount of costs associated with misdiagnosis.

A randomised controlled trial (3) found that patients who consulted an epilepsy nurse specialist as well as their neurologist were significantly less likely to seek additional consultations with their GP or clinic doctors. This led to an annual saving of £184 per patient, as GP and clinician time was freed up by patients being able to access the epilepsy specialist nurse for advice and support.

1 All Party Parliamentary Group on Epilepsy, Wasted Money Wasted Lives: the human and economic cost of epilepsy in England, June 2007
2 Epilepsy prevalence, incidence and other statistics. The Joint Epilepsy Council August 2005. www.jointepilepsycouncil.org.uk
3 Warren E, An evaluation of a nurse specialist / case manager intervention in the management of Epilepsy (RF13, 1998)

www.healthcareworkforce.nhs.uk/option,com_docman/task,doc_download/gid,1635/Itemid,697.html

***Wasted money, wasted lives** (2007)*

All Party Parliamentary Group on Epilepsy inquiry into to the serious shortfalls in service provision for people with epilepsy

- 400 avoidable deaths per year
- 69,000 people living with unnecessary seizures
- 74,000 people taking drugs they do not need
- 189 million needlessly spent each year

www.jointepilepsycouncil.org.uk/Wasted-Money-Wasted-Lives.html

Best Care: The value of epilepsy specialist nurses

Key findings

- ESNs act as a central cog in the care of people with epilepsy.
- Adequate resourcing of the ESN service is crucial to the delivery of high quality care for people with epilepsy – limited resources lead to compromised and fragmented care.
- ESNs undertake a wide range of valuable, mainly patient-related activities in various settings. In the absence of ESNs this work would either fall to consultants or simply be overlooked.
- The ESN service is about improving quality of care. It is an essential service, not a luxury, to ensure patients are 'moved-on' and receive best, not basic, care.
- ESNs are good value for money and the work ESNs do cannot be done by less experienced staff.
- ESNs reduce a consultant's workload. This can lead to cost savings since nurse-led care does not carry the high salary costs associated with consultant-led care.
- Primary care based ESNs can optimise and standardise care for individuals with epilepsy and support and reduce the burden of care for GP colleagues.

www.epilepsy.org.uk/sos

Epilepsy in England: time for change *(2008)*

- Despite NICE guidelines that all people with suspected epilepsy should be seen by an epilepsy specialist, half of Acute Trusts (49 per cent) do not employ one.
- Despite NICE guidelines stating that all people with suspected epilepsy should be seen urgently (within two weeks), most trusts (more than 90 per cent) have waiting lists of longer than this.
- Despite NICE guidelines stating epilepsy specialist nurses (ESNs) should be an integral part of the medical team providing care to people with epilepsy, well over half of Acute Trusts (60 per cent) and PCTs (64 per cent) do not have one.

www.epilepsy.org.uk/campaigns/timeforchange

Specialist nurses Changing lives, saving money *(2010)*

In Surrey PCT, a new specialist epilepsy nurse reduced attendances at A&E by nearly half in 2005. This represents 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 was £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.

www.rcn.org.uk/__data/assets/pdf_file/0008/302489/003581.pdf

NHS could save millions by investing in specialist nurses – RCN *(2010)*

In February 2010 the Royal College of Nursing (RCN) joined forces with almost 40 of the UK's leading health organisations to warn that cutting specialist nurse services for people with long term conditions would be a "false economy", as they began a campaign for guaranteed access to specialist nursing care for all patients with long term conditions.

www.rcn.org.uk/newsevents/press_releases/uk/nhs_could_save_millions_by_investing_in_specialist_nurses_-_rcn

Better Value, Better Care- Your Guide to Commissioning in Epilepsy- What does this mean for me?

- Based on current statistics from the Joint Epilepsy Council, a typical Clinical Commissioning Group with a catchment area of 300,000 population will have an estimated:

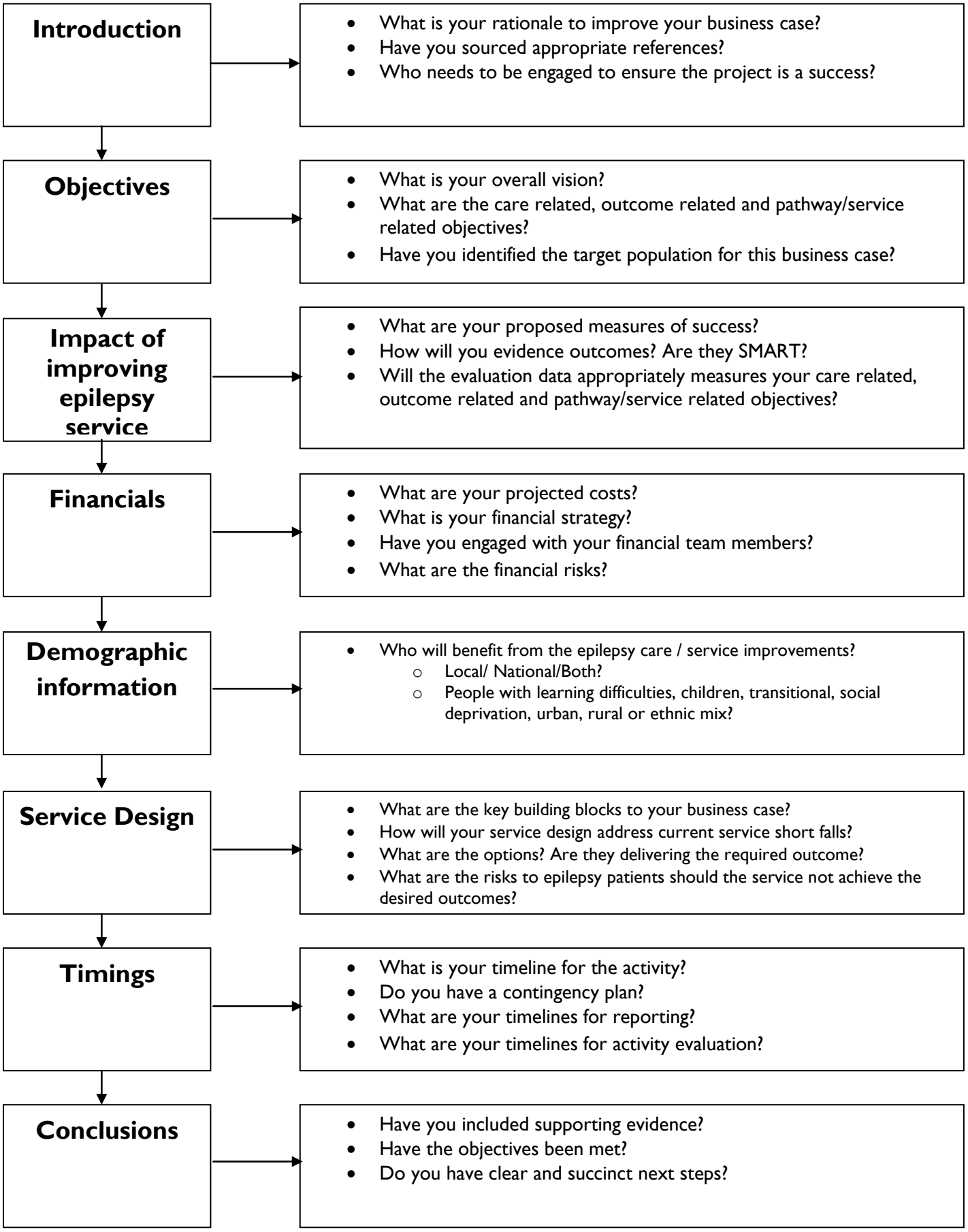
1. 2,910 people living with a diagnosis of epilepsy and being treated with AEDs. Of these, 6 will die from epilepsy-related causes this year
2. 582-902 patients wrongly diagnosed with epilepsy and receiving inappropriate treatment
3. 153 new cases of epilepsy diagnosed this year
4. 524 patients having seizures that would be avoidable with optimal AED treatment
5. 25 adults and 11 children who could benefit from surgery but are not receiving it
6. 57-544 young people (aged 17 years or under) with an epilepsy related emergency admission this year.

Ten questions to consider when commissioning epilepsy care services:

- Will the service be visible and accessible to people with epilepsy within my CCG?
- How many people would use the service?
- Where would the service fit within the referral pathway for people with epilepsy?
- What will the impact be on primary care, and what changes will need to be considered at practice level?
- What are the skill levels of my staff?
- What training could my staff be given to improve their skill levels?
- What information technology and infrastructure would be required to support the service?
- How will patient outcomes be monitored and assessed?
- How might the service develop in response to the assessments?
- How will patients be discharged from the service?
-

- **Appendix C – Structure of your business case**

This flow chart is intended to assist in determining the structure of your business case. The following questions will assist in your team brainstorming and discussion.



Appendix D – Schedule for business case

A clear activity schedule can be helpful in ensuring your business case is completed in a timely manner, and to ensure it contains all the information it needs. The tracker below may assist you in dividing responsibilities and establishing a completion timeline.

Business Case Section	Responsibility	Reviewer	Deadline
Introduction			
Objectives			
Impact of improving epilepsy service			
Financials			
Demographic Information			
Service Design			
Timings			
Conclusion			

Appendix E- Examples of outcome measures taken from business case for Sapphire nurse:

		OUTCOME	Specific Target	How Measure	Action by
£ SAVINGS +	1	QIPP – reduce non elective admissions	£48k savings to be achieved = 24 admissions	Against baseline data – monitor admission rates to show reduction in admissions.	
	2	Reduced consultant consultations		ENS caseload (Not formal £ measure due to block funding of position and none use of PBR/PBR tariff for single f/u Cons or ENS is the same) Impact benefit = increased capacity/consultant time	
	3	Reduced lengths of stay		ENS in-patient screening and support on wards Education/awareness raising on management of condition	

QUALITY IMPROVEMENT

NICE Quality standards - derived either from NICE guidance or NICE accredited sources, and apply across NHS England.

The new quality standards on epilepsy consist of a prioritised set of specific, concise and measurable statements that, when delivered collectively, should contribute to improving the effectiveness, quality, safety and experience of care for people with the condition.

	Statement No. from NICE Quality Standards	Description of Standard		
QUALITY	Statement 4	Adults with epilepsy have an agreed and comprehensive written epilepsy care plan.		
	Statement 5	Adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.		
	Statement 6	Adults with a history of prolonged or repeated seizures have an agreed written emergency care plan.		

	Statement 9	Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services		
	Local	Improve education and awareness for the management of epilepsy for; 1) Patients and carers 2) professionals within the area 3) professionals across the community		
	Local	Development of Care Pathway and clinical Guideline Hospital guideline/pathway		

APPENDIX F- Example of Equality Impact Analysis (annonymised)

Equality Impact Analysis:	
Policy / Project / Function:	Epilepsy Nurse Specialist (ENS)
Date of Analysis:	January 2013
Analysis Rating: (See Completion Notes)	☐ Red ☐ Red Amber ▮ Amber ☐ Green
Type of Analysis Performed: Please Tick ✔	Systematic Policy Analysis ☐ Consultation YES Meeting ☐ Other OK ☐
Please list any other policies that are related to or referred to as part of this analysis	• 2011 report 'Epilepsy prevalence, incidence and other statistics' developed by the Joint Epilepsy Council (JEC): http://www.jointepilepsycouncil.org.uk/downloads/2011/Joint%20Epilepsy%20Council%20Prevalence%20and%20Incidence%20September%2011.pdf • NICE clinical guideline CG137; 'The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care' - which was issued in January 2012. • Strategic Plan 2010-15
Who does the policy, project or function affect ? Please Tick ✔	Employees YES Service Users YES Applicants YES Members of the Public YES Other (List Below) YES YES Primary Care, Secondary Care, Residential/Nursing Care, Voluntary Care

Equality Impact Analysis:

What are the aims and intended effects of this policy, project or function?	The consequence of inadequate management of the condition can result in poor control of symptoms with medication increasing the incidence of seizures, increasing carer burden, all of which lead to increased dependency on health and social care services. With the employment of a local Epilepsy Nurse Specialist, the aim is to improve the availability, access, quality, efficiency and consistency of care which fully supports the 5 key recommendations of the NICE guidelines in ensuring high quality services such as referral for a hospital expert diagnosis, expert review by the appropriate professional, regular access to a Specialist Nurse, timely access to therapies and palliative care whilst providing support in primary care for the management of patients. Some of the outcomes expected by the delivery of the service is to: - 1. Improve access to services, 2. Reduce travelling time to out of area providers and provide care closer to home, 3. Reduce unplanned admissions, 4. Prevent unnecessary extended hospitals stays, 5. Reduce outpatient care by Consultants through Nurse led clinics, telephone contact based in the hospital and community setting, 6. Empower and educate patients to become expert in their condition, 7. Help integrate Health and Social Care – working across all sectors/boundaries from acute setting across the community setting. 8. Co-ordinated care through ENS, 9. Educate health and social care professionals about epilepsy along the patient's care pathway.
Is any Equality Data available relating to the use or implementation of this policy, project or function ? (See Completion notes)	Yes - ☐ No ☐ Where you have answered yes, please incorporate this data when performing the *Equality Impact Assessment Test* (the next section of this document). **See policies listed above. Also… local Public Health deprivation data.**

List any Consultation e.g. with employees, service users, Unions or members of the public that has taken place in the development or implementation of this policy, project or function	• Neurology Patient Focus Group • Neurology Service Review – Neurology Stakeholder Meeting • Epilepsy Action • Epilepsy Nurse Specialist from neighbouring area
Financial Analysis If applicable, state any relevant cost implications (e.g. expenses, returns or savings) as a direct result of the implementation of this policy, project or function	**Costs (£m) *** **PLEASE SEE FINANCIAL SPREADSHEET & FULL SERVICE PROPOSAL** Implementation £ Projected Returns £ Projected Savings £ Please see QIPP Financial Summary Spreadsheet