Health care provision and service re-design for people with epilepsy, with a focus on Primary Care

Dr Gregory Rogers

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University College London

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

Name: Dr Gregory James Rogers

Date: May 10th 2014

Abstract

This thesis reports four studies which have been designed to promote the greater involvement of primary care in the treatment of epilepsy. The primary aim is to study whether programs of high capacity, low interventional care for people with epilepsy are feasible and effective in primary care, within specific programs.

The secondary aims explore the uptake and utility of such programs with preliminary examination on national trends in mortality and hospitalisation for people with epilepsy during the time of the study.

1.) The first study called the Primary Care Clinical Effectiveness program 2 [PRICCE-2] determined the extent to which primary care in East Kent was able to be produce an epilepsy register, ascertain the number of people who were seizure free and identify people at risk from retinal damage from vigabatrin. Also GPs were required to ensure that women were prescribed appropriate contraception and that pregnant women were offered folic acid. The program also studied trends in unplanned visits to hospital which occurred during the program.

The PRICCE-2 project demonstrated GPs are willing to participate [89% of eligible practices in 2001] and could identify people who were seizure free [71.25% by the end of the program.] The identification of people on Vigabatrin was also successful identifying 21 people, [20 were expected,] but the ability to support women with epilepsy was less successful. The number of emergency admissions to the local three hospitals for epilepsy was seen to rise steadily, however diagnostic indexing was fairly poor at this stage.

2.) The second study called the Quality and Outcome Framework, determined the extent to which primary care was able to produce an epilepsy register, record seizure frequency, perform a basic epilepsy medication review and

determine people who were seizure free. Later on in the study, GPs were required to ensure that women were prescribed appropriate contraceptive medication and offered prenatal advice. The program also studied trends in mortality from epilepsy and trends in unplanned visits to hospital for epilepsy.

The study revealed GPs were able to identify people with epilepsy [initially 86.8% rising to 99.8% by 2011], review their medication [95.3% in 2011] and identify people who were seizure free [73.9% in 2011] however they have found it harder to support women with epilepsy with high exception reporting used for this group [36.7% in 2011/12]. The unplanned hospital admissions steadily rose during this time, whilst the mortality for epilepsy began to decline [$R^2 = 0.6118$] however whether this was a casual or causal link could not be determined.

3.) The third study determined if primary care could proactively identify social consequences of active epilepsy including the recording of driving status and social factors affected by epilepsy. It also identified and offered women with epilepsy folic acid, pre conception advice and ensured they were prescribed appropriate contraceptive. In addition it required GPs to identify people with epilepsy under hospital care.

The study revealed that GPs were able to identify social consequences of epilepsy and identify people under hospital care but once again they found it difficult to support women with epilepsy related issues. The restructuring of PCTs at this time resulted in a loss of data.

4.) The final study determined the extent to which pharmacists can be trained to proactively support people with epilepsy in a Medicines Use Review [MUR] format. Pharmacists grasp of epilepsy before and after training and customer’s knowledge and readiness to approach their pharmacist for support were assessed before and after the consultation. In addition pharmacists were taught how to recognise red flag symptoms and directly refer at risk patients to specialist epilepsy services.

The pharmacists readily absorbed the epilepsy training and their customers reported benefit in improved knowledge about epilepsy and also indicated that in future they would seek support for epilepsy from their pharmacist. The direct referral process for epilepsy was not successful however and would need refining in the future.

The overall aim to study whether high capacity, low interventional care for epilepsy is both feasible and effective has I believe, been demonstrated in these studies to be possible. Pro-active care for epilepsy is possible in general practice, with GPs being able to provide high capacity epilepsy care. The influence on admission rates and mortality for epilepsy is less clear and requires further study.

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Author's contribution

The author has been the lead GP for Epilepsy in East Kent for the past 15 years and during this time has been aware of the potential for primary care to contribute further to the delivery of epilepsy care. The concept of proactive support offered to everybody with epilepsy rather than specialist care to a proportion of this group, has been the author's goal throughout this work[1]. This grassroots care is seen as being complementary rather than competing to specialist epilepsy services. It is this overarching objective which unites the four studies and this thesis examines various aspects of the contribution of primary care (see pp 26 for aims).

Study One; Primary Care Clinical Effectiveness program PRICCE-2

The author designed the epilepsy component of the PRICCE-2 study,[see page 74] set the quality standards, offered clinical support to both the practices and the audit team on epilepsy. There was also training to support the program on epilepsy which the author delivered at the local postgraduate centre. The PRICCE-2 program followed on from a pilot simply referred to as PRICCE from which the author was able to take many lessons learnt from this and introduced them into the PRICCE 2. The main one being the replacement of 'idiopathic epilepsy,' with 'all cases of epilepsy,' and hence broaden the scope of the program.

Study Two; Quality and Outcomes Framework

The regional pilot went on become a substantial part of the national Quality and Outcomes Framework[2] [Q.O.F.] The section relating to epilepsy utilised components of PRICCE and the author was credited with having an input into this national program.[see page on page 199]. It received a major redraft in 2007 [see page 207] the author was one of the eleven experts invited to contribute to that also.[3] This group advised on the new standards which were introduced then.

Study Three; Locally Enhanced Service for Epilepsy

The author then designed a Locally Enhanced Service (L.E.S.) for Epilepsy [see page 100] for East Kent Coastal PCG which was designed to explore whether regular GPs could be supported to take on higher levels of care for people with epilepsy. The concept, standards, training and oversight of the analysis were developed by the author. Mrs Sheila Pitt, Eastern and Coastal Kent Lead Commissioner for Long Term Conditions provided commissioning oversight for the project.

Study Four; Targeted Medicines Use Review for epilepsy

The final project the author designed explored whether it was possible to train community pharmacists to deliver support to people with epilepsy and also whether they could effectively identify people at high risk due to their epilepsy and refer them to specialist care. The pilot design and the subsequent project commissioning was discussed and negotiated between the author and local health authorities and pharmacy commissioners. [See page 111] The final training was given by myself with support from Mrs Trudy Thomas from Medway School of Pharmacy (Head of Postgraduate training) and clinical support during the project to the pharmacists was delivered also by the author. The referrals to the community epilepsy clinic were triaged by the author.

Data collection for studies One, Two and Three was organised by the health authority and the data for study Four was collected by the author with advice on the Medicines Use Review format by Medway School of Pharmacy.

The author carried out the analysis of the third and fourth studies, the further analysis of the first two studies and undertook the writing up of these studies.

Glossary of Abbreviations;

East Kent MAAG : East Kent Medical Audit Advisory Group

GMS : General Medical Services

G.P: General Practitioner

GPwSI Epilepsy: GP with a Special Interest in Epilepsy

HES: Hospital Episode Statistics

LES : Locally Enhanced Service

PCT: Primary Care Trust

PDP: Personal Development Plan

P.R.I.C.C.E, 1 and 2: Primary Care Clinical Effectiveness Program 1(pilot) and 2

Q.O.F : Quality and Outcomes Framework

QMAS: Quality Management and Analysis System

I.L.A.E: International League Against Epilepsy

JCPTGP: Joint Committee on Postgraduate Training for General Practice

M.U.R: Medicines Use Review

Overall Aim

The aim of this thesis is to study whether programs of high capacity, low interventional care for people with epilepsy are feasible and effective in primary care, within specific programs.

The secondary aims explore the uptake and utility of such programs with preliminary examination on national trends in mortality and hospitalisation for people with epilepsy during the time of the study. Four separate studies were carried out to assess this and these are listed below.

AIMS

1. **Study One; Primary Care Clinical Effectiveness program 2 [PRICCE-2]**

    1.1. **Determine the extent to which participating primary care practices in East Kent are able to be involved in basic proactive care for epilepsy using a disease register following the PRICCE-2 programme**

    1.2. **Determine the extent to which participating primary care practices in East Kent are able to identify potential problems which can arise as a consequence of suffering from epilepsy. The problems examined were:**

        1.2.1. Identify people who are seizure free
        1.2.2. Ensure the people who are taking vigabatrin have their visual fields measured
        1.2.3. Identify women who are pregnant and also have epilepsy
        1.2.4. Ensure women and children of childbearing age are taking folic acid
        1.2.5. Ensure that women who are taking contraception medication are prescribed appropriate contraceptive medication

    1.3. **A preliminary examination of local trends in hospitalisation.**

        1.3.1. Trends in unplanned visits to hospital for acute problems arising from epilepsy

2. **Study Two; Quality Outcomes framework**

    2.1. **Determine the extent to which primary care practices in England are willing to be involved in basic proactive care for epilepsy using a disease**

register following the QOF programme. The study examined the following aspects of care:

2.1.1. Produce a register for people with epilepsy who are receiving treatment for epilepsy and are over 16 years old

2.1.2. Record the seizure frequency for people over 16 years old

2.1.3. Perform an epilepsy medication review for people over 16 years old

2.1.4. Identifying people on drug treatment for epilepsy who are seizure free over 16 years old

In 2006 the program was reviewed (see p 91] and the minimum age was raised to 18years old as it was proposed that the care for younger patients is generally undertaken outside of primary care.

2.1.5. Produce a register for people with epilepsy who are receiving treatment for epilepsy and over 18 years old

2.1.6. Record the seizure frequency for people over 18 years old

2.1.7. Perform an epilepsy medication review for people over 18 years old

2.1.8. Identifying people on drug treatment for epilepsy who are seizure free over 18years old

2.2. Determine if proactive care in England for epilepsy can successfully become more detailed within the Quality Outcomes Framework.

2.2.1. Ensure that women who are taking contraception medication are prescribed appropriate contraceptive medication

2.2.2. Offer prenatal advice for women with epilepsy

2.3. A preliminary examination of national trends in mortality and hospitalisation during the Quality Outcomes Framework programme.

2.3.1. Preliminary examination of mortality from epilepsy in England

2.3.2. ***Preliminary examination of unplanned visits to hospital for acute problems arising from epilepsy***

3. Study Three; Locally Enhanced Service for Epilepsy for East Kent

The results from the Eastern and Coastal primary Care Trust were obtained as well as detailed results from two large practices in the PCT area. Two data sets were used to assess the following areas:

3.1. To determine if primary care can proactively identify social consequences of active epilepsy

3.1.1. Record driving status

3.1.2. Record social factors affected by epilepsy

3.2. Identify the number of women and children of child bearing age who have epilepsy

3.2.1. Offer women and children of childbearing age folic acid

3.2.2. Offer women and children of child bearing age pre conception advice

3.2.3. Ensure that women who are taking contraception medication are prescribed appropriate contraceptive medication

3.3. Identify people with epilepsy under hospital care

4. Study 4; Targeted medicines use review for epilepsy

4.1. To determine the extent to which community pharmacists can be trained to proactively support people with epilepsy

- ***4.1.1. To be able to answer an anticonvulsant query from a patient with confidence***
- ***4.1.2. To become familiar with epilepsy classification and explain them to customers***
- ***4.1.3. To be able to advise a customer with epilepsy when they could re-apply for their driving licence***
- ***4.1.4. Feel confident in being able to assess how well a patient was taking their anti convulsant medication***

4.2. Determine if the advice given by the community pharmacists during a Medicines Use Review was of benefit to the customers. The MUR is an appointment between the pharmacist and the patient whereby a patient is invited to focus on their medication and is an opportunity to identify any problems associated with their tablets or of the illness for which they are taking them.

- ***4.2.1. improving their understanding of the underlying causes of epilepsy***
- ***4.2.2. Understanding how to lessen the risk of having a seizure***
- ***4.2.3. Determine if the customer was more likely to approach their pharmacist for advice about their epilepsy in the future***

4.3. Determine if community pharmacists can recognise red flag symptoms to allow direct referral to specialist epilepsy services

INTRODUCTION

This thesis describes the evolution of clinical programs which were designed to promote the greater involvement of primary care in the treatment of epilepsy. The hypothesis underlying these studies is that high capacity and low impact programs of care in general practice is possible to achieve within specific programs of care.

Definition of Epilepsy

Epilepsy for this thesis is defined using the ILAE definition 2005

> *"Epilepsy is the name of a brain disorder characterized predominantly by recurrent and unpredictable interruptions of normal brain function, called epileptic seizures. Epilepsy is not a singular disease entity but a variety of disorders reflecting underlying brain dysfunction that may result from many different causes.[4]"*

Over the past few decades the classification of epilepsy has evolved and changes have be made to incorporate the many new discoveries in the aetiology and understanding of epilepsy over that period. Indeed the classification structure can be considered as being in a permanent state of flux[5] of which a full synopsis of the classification of seizures can be found in more detail ILAE website[6]. For the specialist it is important to allow dialogue between colleagues to be accurate and the newer classification also helps to keep the diagnostic and treatment rationale in step with current advances.

For the non-specialist in general practice however this has increased the sense of being "out of date," with epilepsy as even the basic grasp of nomenclature and epilepsy classification can be faltering. This is arguably one of many factors to bring about a diminishing clinical confidence of front line primary care clinicians to treat epilepsy, with the decision to make even simple changes becoming hesitant[7]. The natural progression of this move to specialisation is to see the routine care of people with epilepsy resting solely on the shoulders of epilepsy specialists. As epilepsy is a common neurological condition this may place unnecessary strain on the epilepsy specialist clinics and also see the care of people with epilepsy who also suffer from multi- morbidities such as cerebrovascular disease, becoming fragmented.

History of Epilepsy care in England

There have been several reports conducted to examine the care of people with epilepsy over the past fifty years and it is rather disheartening to see that many of the recommendations have not been adopted. Also the development of services has not improved as much as one would have hoped.

Key amongst these reports are:

- **"***Welfare of Handicapped persons: the special needs of epileptics and spastics*." London: Ministry of Health, 1953[8].
- "*Medical care of epileptics: Report of the sub-committee of the Central Health Services Council*." Central Health Services Council, Ministry of Health, Lord Henry Cohen, London: HMSO, 1956[9]
- ***"****Report of a joint sub-committee of the standing medical advisory committee and the advisory committee on the health and welfare of handicapped persons"* Reid JJA, Department of Health and Social Security,., London 1969[10].
- *"Report of the working group on services for people with epilepsy"*: a report to the Department of Health and Social Security, the Department of Education and Science and the Welsh Office. Winterton PMC, London: HMSO, 1986[11].
- . *"Services for patients with epilepsy: a report of a CSAG Committee"* London: Department of Health, Kitson A, Shorvon S, Clinical Standards Advisory Group, 2000[12]

- *“The National Sentinel Clinical Audit of Epilepsy*-*Related Death: Epilepsy – death in the shadows”*. Hanna N J, et al**.** London 2002[13]

These reports in varying degrees report that care for epilepsy tends to be fragmented and poorly co-ordinated. The need to organise care in a more co-ordinated manner with seamless care between primary and secondary care has been mentioned repeatedly being a key message in the Reid report and highlighted again in 1983 by Goodridge[14] and Shorvon.

The Clinical Standards Advisory Group report nearly 20 years later in 2000 further highlighted this need and offered the suggestion which encouraged the participation of primary care to take a lead role in the community and advised that a lead GP is set up in a practice who has trained in epilepsy to a greater degree than his peer group and oversees the care of people with epilepsy for that practice. It was this suggestion which influenced the author to explore this suggested solution further and developed a system whereby there is a network of General Practitioners with a Special Interest in Epilepsy (GPwSI in Epilepsy.) Also within this report is the suggestion for more structured care for people with epilepsy and this has formed the basis for the main aim of this thesis.

The national sentinel audit into epilepsy related deaths provided powerful evidence for the need for change to improve services for people with epilepsy. The stark facts relating to morbidity from poorly controlled epilepsy produced a persuasive argument to in seeing the commissioning of intermediate care of epilepsy becoming commissioned and the structured primary care program of care financed locally.

Insufficient capacity of clinicians’ actively managing people with epilepsy

The lack of capacity to actively manage epilepsy is a problem which seems likely to increase unfortunately as with an ever aging population, the numbers of people with epilepsy is set to increase. The changing demography of epilepsy has resulted in the greatest prevalence now being seen in later life, with the number of people who develop dementia also increasing, as more people in the UK are reaching older age[15]. Individuals who have been diagnosed with Alzheimer's disease are more at risk of developing epilepsy.[16] The development of epilepsy can be a challenge to detect in this group making a wider awareness of epilepsy an important priority both in Primary Care as well as within specialist services[17].

To help redress this balance the author wishes to explore the extent to which programs of care can safely be introduced for epilepsy and also see if primary care can become increasingly involved in the long term management of people with epilepsy. This does not remove the need for epilepsy specialists; rather it identifies people in need of optimisation of epilepsy care which includes many who will need the input of an epilepsy specialist. The recurrent theme which runs through this thesis is for high capacity care which is seamless and can offer optimisation of treatment to all people with epilepsy and ensuring those with complex needs are the ones seen by specialist clinics.

Primary Care emerging as a specialism

Primary Care entered a new era in the 1990's with General Practice becoming a positive career option for newly qualified doctors[18]. This process has its roots in the formation of the Joint Committee for Postgraduate Training in General Practice [JCPGT] in 1975 with representatives from the General Medical Council and the Royal College of GPs plus representatives from universities. In 1979 it became a requirement to complete a year in general practice as a trainee to achieve certification and in 1982 it was necessary to complete two years of approved hospital posts and a trainee year satisfactorily to be accepted by the committee as a GP . Initially this merely was a certificate that the appropriate time had been completed but by 1990 this was further defined as reaching an acceptable standard. This process was further tightened in 1996 when a process of summative assessment for GP was introduced with a standard of medical competency being introduced and the identification of poorly performing GPs with formative and final summative assessment being undertaken.

These changes were instrumental in lifting the prevailing professional view of general practice from frequently being a final career route for budding physicians and surgeons who had not quite made the grade in a hospital career. General practices was now for doctors who set out with an intent to follow a career path in family medicine[19]. The JCPTGP was a unique body that brought together not only the then divided tribes of general practice (it was a joint committee between the Royal College of General Practitioners [RCGP] and the General Practitioners Committee [GPC]), but also had representation from GP education directors, postgraduate deans, specialists, doctors in training, the Departments of Health and, latterly, the laity.

The role of Primary Care in the management of Long Term Conditions

As the skills increased in primary care in East Kent, so did the desire to treat people with long term conditions proactively rather than merely reacting to acute episodes. There was a realisation amongst family doctors in East Kent in the mid 1990's that opportunities were being missed to preventing illness and that a good deal of primary care was organised to treat and respond to be reactive rather than have resources devoted to the pro-active care of people with long term conditions. To tackle this problem, medical managers had at their disposal several levers to help influence care in general practice;

- **Computerisation**
- **Incentivisation**
- **Education**
- **Support of audit team**
- **Peer pressure**
- **Verification process**

Computerisation of Primary Care

General practice has progressively become computerized and is rapidly heading towards becoming paperless[20]. This has led to the production of computerised disease registers which include registers identifying epilepsy. The registers contain basic diagnosis, medication and demographic data. With these key components present, it has become feasible to conduct targeted review of people with epilepsy, utilising audit to identify people at risk. By the regular review of people with epilepsy a process has also begun to reduce unplanned access to emergency medical services and identify people in need of optimisation of their epilepsy care.

Even though there are multiple software packages for GPs to use, they all retained the capability of performing disease specific searches of their practice database and initially this capability varied a good deal between the software however within time each one developed to allow it to be used for this purpose more readily. PCTs saw the advantages this gave to improved patient care and indeed monitoring of the quality of care in each GP's surgery.

Incentivisation

Financial incentives offered to improve the quality of care can be met with disapproval by many outside of medicine. It would at first glance seem hard to understand why somebody needs to have a financial incentive to perform to a higher level when they are already employed within a professional vocation.[21] The role of financial reward given to achieve targets however is effective in commissioning very specific tasks, such as those described in this thesis. Also the response to them appears to be disproportionate to the value offered. Incentivisation is an integral part of the commissioning of these epilepsy services. With development of the new GP contract in April 2004 for General Medical Services for practices in England, Scotland, Wales and Northern Ireland[22], practices are financially incentivised for delivering measurable levels of quality in patient care, via the evidence-based

Quality and Outcomes Framework (QOF). Between 10–15 per cent of the new money tied to the contract is available to reward practices for providing higher quality services The initial plan was to pay for this program using money taken out of the GPs global sum which they could earn back by taking part in the QOF program.

At that time morale and indeed GP numbers were assessed as being to be too low and the department of health had intended from the outset to increase spending on GP's services[23] and proposed to increase spending from £4.9 billion in 2002-03 to £6.9 billion in 2005-06. The uptake and achievement of the QOF program resulted in a 9.4 per cent higher than expected overall spend on Primary Care. This was as a result of a significant underestimate of how readily practices would take up QOF and indeed how well they would do in achieving the targets which were optional. This supports related work that acknowledges that incentivisation can have a marked effect on behaviour.[24]

The financial incentives appear to be particularly good tool for improving process driven measures and the benefit in some studies has tended to wear off over time[25] however they remain a powerful tool to help direct primary care activity.

Education

In 2003 the year before the launch of the QOF program PCTs were encouraged to develop new approaches to GP education, changes in the training and education strategies.[26] These were advised by the Modernisation Agency as needing to be cost effective and help to deliver the Quality and Outcomes framework. They suggested that education and training should include management skills such as the management of change, audit skills, basic medical skills for all staff members such as basic life support. Also the introduction of critical event discussions was to be introduced and more peer review was encouraged between members of the primary health care teams and secondary care colleagues. The clinical sections of the QOF framework in 2004 contained a clinical introduction offering brief medical update on the areas covered and also revision of the evidence based care recommended at the time.

The new GP contract in 2004 altered the way that GPs organised their post graduate education with the old system of payments from a set of terms and conditions commonly referred to as ‘red book,’ ceased and GP’s post graduate educational allowance payments were abolished. The new GMS contract offered payment which was effectively taken out of their income from the global sum allocated to the practice and were able to earn it back by offering evidence of their successful annual appraisal supported by personal development plans.

Up to this point GPs had to earn points from attending meetings and courses to trigger a PGEA payment to an individual GP however under the new contract following a meeting with a designated appraiser , GP would have their PDP ‘signed off,’ This process on completion would satisfy their annual postgraduate educational requirement. The consequence of self-directed learning can be that GPs tend to spend time studying their interests and omit areas that were of less clinical interest. It would be the role of the appraiser to high-light these areas of need and form a learning plan to include them. The role of ‘GP refresher,’ courses started to shrink from this time on and opportunities to offer education for epilepsy by the traditional tutorial or lecture method reduced. More creative ways have had to be developed such as tutorials on epilepsy via the internet and the author has worked with the British Medical Journal to produce a series of these on epilepsy. There is evidence that epilepsy care guidelines can be taught and delivered at lower cost that other long term conditions and the value of medical education in epilepsy can easily be justified. [27]

Support of the Audit team

One of the benefits of working as part of the larger project was having the support of the East Kent audit team and the author worked with them in PRICCE II to make the standards more clearly defined and measurable. This involved explaining to the group the basic risk factors for epilepsy and also describing areas of epilepsy care such as on-going seizures, contraception, hazards of unmonitored vigabatrin use etc. which were amenable to audit. The audit team also provided basic training to the practices in setting up disease specific searches of their data base and help in data management.

Peer pressure

The phenomenon of peer pressure is a potent factor in directing clinician's choices for medical treatment, in one study it was stated by 29% to be an important factor in the selection of statin for a patient[28]. It can also be used a tool by medical managers to influence clinicians positively and help to improve quality of care for people with epilepsy using healthy competition and indeed can be a useful way to educate colleagues. The pooled knowledge in most large practices would likely be sufficient for most simple routine problems encountered and if one clinician trains in an area they are well placed to share this knowledge with their colleagues.[29] To an even greater extent than PRICCE the practice achievement at QOF become a matter of pride between practices and it was not long before practices would describe themselves where applicable as 'high achievers of QOF.' As time has gone by this has turned somewhat to be something of a stick rather than a carrot and the department of health now freely publish each practice's achievement of QOF as an open indicator to the general public on how well the practice is seen to be delivering these services.

With the introduction of QOF GPs have become more used to peer review and the process of open questioning of their decisions, something previously that they had discomfort with[30], they are now having to become more accustomed to.

Verification Process

For all of these programs of care the health authority collect data at the end of the year using a standardized collection form, with a health authority team visiting all practices at the half-year and year-end. During these visits the QOF team perform random checks on the quality of the data which helps to deter reporter bias and also the team use prevalence and quality data from neighbouring practices to help to assess practice achievement. Having a basis of self-reporting of achievement, incentive driven medical care holds the potential for being influenced by reporter bias. Outcomes reported by the investigator may be influenced as a result of being directly linked to subsequent financial income.

From an audit perspective this method of self-reporting is far from satisfactory however in a pragmatic sense the aim was to drive up the quality of care for epilepsy and not primarily as a program of audit and this still remains a weak point in this project.

The advantages and disadvantages using process measures to assess quality of care.

The measurement of process of care is relatively easy to gather and provides commissioners with useful information to further develop services for patients. There are however both positive and negative aspects to consider before using them as a marker of quality of care. On the positive side they help to provide useful feedback to clinicians on processes they did or did not follow which had the potential to affect patient outcomes. Also following a protocol for patients tends to be safer and has offers less risk of GPs deviating from the standard treatment pathway for that patient. In addition to this, process measures can be collected quickly and easily in contrast to outcome measures which can take a long while to become apparent.

However there must be a strong relationship between the process and the outcome measure. This may be obtained from previously published evidence but can be problematic when used in a practice which treats patients who are generally in poorer health and even though they may receive excellent care they invariably have poorer outcomes. Also there may be complex process to outcome linkages which draw on confounding factors to provide the final outcome. In addition to this while process factors may be meaningful to both clinicians and commissioners they have less direct relevance to patients. The process also usually only captures a specified part of the care provision for the patient and does not include the wider care for that particular disease.

Overall however process measures are a useful tool to monitor the quality of care from providers and are generally accepted by care providers. They can be collected unobtrusively via electronic records and the results provide a useful guide to the quality of care delivered by the service provider. In comparison to this, outcomes have many confounding factors which may be outside the control of the care provider and may unfairly be attributed to a poor level of care.[31]

Defining and classifying clinical indicators for quality improvement.

The assessing of quality of patient care has become increasingly important to both clinicians and commissioners of care and more latterly to the service users who are able to compare these factors via performance lists placed in the public domain. Indicators have been developed in several ways and can include the following

1. As measures that assess a particular health care process or outcome.
2. As quantitative measures that can be used to monitor the quality of important governance, management, clinical, and support functions that affect patient outcomes.

3. As measurement tools, screens, or flags that are used as guides to monitor, evaluate, and improve the quality of patient care, clinical support services, and organizational function that affect patient outcomes[32]

Indicators are based on standards of care which are usually evidence-based and many of which have been put forward by the National Institute for Health and Care Excellence [NICE]. This is a body who are accountable and supported by the department for Health and provides national guidance and advice to improve health and social care. When evidence is lacking, clinical standards can be set either nationally or locally by an expert panel of health professionals in a consensus process based on their experience. The indicators are then used to judge how well clinicians, organizations, and planners have achieved the improvement in care and the processes by which patient care is provided.

Taking evidence gained from clinical trials and systematic reviews to individual patients in primary care can however be challenging. The use of performance indicators by themselves as a method to improve the effectiveness of health care in primary care are unlikely to be a sensitive enough tool to be of use. However, the use of evidence based indicators linked to interventions that improve health outcomes, offers a better instrument to use to assess quality[33].

Examples of measuring process redesign on other disease areas to improvement care.

Diabetes:

In a qualitative review of 41 studies on the management of diabetes in a mix of general practice, community care and outpatient clinics the reviewers sought to examine the role of different interventions including process change on the outcomes of care for people with diabetes. The studies observed changes in outcomes which varied between trials but which included at least one of the following parameters; urinary albumin excretion, attendance of patients, blood pressure , compliance, creatinine, glycaemic control, health maintenance organization, health survey, hospitalizations, macro-vascular complications, micro-vascular complications and quality of life. The aim was to determine the effectiveness of the different interventions targeted at health care professionals and/or the structure of care, in order for the reviewers assess whether the re-organising the structure of care had been shown to have a measurable impact to improve the management of diabetes. The reviewers concluded that interventions which involve a multi system change involving clinicians and support staff to facilitate the structured, regular review of patients in addition to patient education were effective in improving patient outcomes.[34]

The reviewers identified measures to study the impact of process change on diabetic outcomes in 30 of these studies and found that process changes resulted in improved outcomes in 18 studies with a further 7 studies reporting a positive trend. Only 5 studies failed to report any improvement in the outcomes for patients with diabetes as a result of process change.

Inflammatory Bowel Disease;

Another example of the impact of process redesign was undertaken in Sweden where service delivery was re-focused resulting in the delivery of care at the right level, at the right time, by creating a trustful and long-term relationship with the patient. As part of this service redesign a specialist nurse and her assistant staffed the outpatient clinic full time on weekdays. In addition the nurse could offer patients who contacted the clinic an acute visit at the outpatient clinic within two days. For those with no acute symptoms yearly check-ups were offered as either a telephone call or a traditional visit to the clinic.

The findings of the study revealed a reduction in the number of hospital admissions for inflammatory bowel disease and also an increase in the patient supported self-care. The quality of life and haemoglobin levels of these patients were not affected and the system as a whole appeared better for patients as commissioners alike with waiting times reduced considerably. These changes were brought about by service process redesign.

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Primary Care research methodologies

It has been suggested that primary care utilises an eclectic range of research methodologies with a large reliance on qualitative research[35] Statistical methods such as meta-analysis have been developed to summarize and to resolve inconsistencies in study findings—where information is available in an appropriate form however qualitative research requires other methods for interpretation. Consensus methods provide another means of synthesizing information, but are able to use a wider range of information than is common in statistical methods, and where published information is inadequate or non-existent these methods provide a means of harnessing the insights of appropriate experts to enable decisions to be made. Two consensus methods commonly adopted in medical, nursing, and health services research are the Delphi process and the nominal group technique

The Delphi technique consists in a round of relevant individuals who provide their opinions on specific matters. These opinions are then grouped together under a limited number of headings and then re circulated to the members of the group. Following this process the members of the group re rank their agreement with each statement in the questionnaire. These rankings are then summarized once more and re circulated to the group for a final ranking of their agreement with the responses. Finally the re-rankings are summarized and assessed for a degree of consensus- if an acceptable degree of consensus is reached then the process may cease. If not a third round is undertaken. This technique is utilized by NICE to prepare lists of proposed quality statements from their expert topic advisory groups.

The nominal group technique uses a highly structured meeting to gather information from relevant experts usually in two rounds of the group rate, discuss, and then re-rate a series of items or questions. The process starts with participants writing down their views which are then passed on to a facilitator often using a flip chart. Similar suggestions are then grouped together and group discussion is used to clarify the ideas. Each participant then ranks each idea and the results are re-presented. The overall ranking is then discussed and re-ranked and the results tabulated and fed back to the participants.[36]

Consensus development conferences are another qualitative form of group consensus in which, a small selected group people are presented with items from individuals or organisations who are not part of the group and the selected group discusses this evidence and produces a consensus statement. During this process the group use specific methods such as majority voting to obtain aggregate judgements on the information. [37]

A process which utilised the views developed from developed by expert panels using a systematic process to combine evidence with expert opinions has been successfully field tested in terms of reliability, validity, and acceptability of review criteria for angina, asthma and type 2 diabetes.[38]

Another research methodology used in Primary care and is utilised in this thesis is that of Action Research. There are several definitions of Action Research, however the following definition described by Hampshire39 encompasses several of these and is the one I have followed in this project. She describes it as

> *" i) Focusing on change and improvement; ii) involving practitioners in the research process; iii) being educational for those involved; iv) looking at questions that arise from practice; v) being a cyclical process of collecting, feeding back and reflecting on data; and vi) being a process which generates knowledge*. "

It is a step-by-step process, which is monitored by the researcher using a variety of mechanisms such as questionnaires, diaries, interviews, and case studies. The feedback from these methods can then be used to develop modifications and adjustments as necessary with the eventual outcome of improving the ongoing process which is under review.

The practical, problem solving nature of Action Research makes this methodology appears to be well suited to practitioner-researchers who have identified a problem and seek if possible to improve practice.[40] It is utilises a family of research methodologies, which pursue action [or change] and research [or understanding] at the same time using a cyclic process, which alternates between action and critical reflection. It has been used successfully to study and introduce change in General Practice for example it was used in South Wales to develop the teaching of undergraduate students in General Practice [41] It has also been used in the management of long term conditions to develop feasible changes in behaviour such as changing lifestyle behaviour for people with pre diabetes.[42]

The need for higher capacity care to support people living with epilepsy– high volume and low intensity interventions.

Epilepsy – a Public Health Problem?

Epilepsy is a common serious neurological condition affecting nearly 500,000 people in the UK[43] and in America it affects an estimated 2.5 million people and each year accounts for $15.5 billion in direct costs (medical) and indirect costs (lost or reduced earnings and productivity). [44]

There have been many calls to strengthen the input for epilepsy care given by General Practice both in England and America as the numbers involved are relatively large and the primary care workforce is required to contribute to supporting this group.

The need to strengthen epilepsy care by primary care providers has been identified in the States and there is a call to clarify clinical pathways for referrals and for care by specialists. Primary care providers are acknowledged to frequently be the first to see the patient after an initial seizure as evidenced by an American community-based survey of people with epilepsy, where 40 percent of respondents reported that they first saw a family or general practitioner, 32 percent a neurologist, 13 percent a paediatrician, 5 percent an internist, and 5 percent an emergency room physician[45].

In addition to this initial contact, primary care providers may often provide the long-term management of epilepsy care for people whose seizures are well controlled. In a report by the Committee on the Public Health Dimensions of the Epilepsies in America 2012 they concluded that

> *"as there is a significant role for primary care providers in the care of epilepsy patients (often over the lifetime of their patients), it is critical that they are knowledgeable about epilepsy care."*[46]

The Scottish guidelines for epilepsy care [Scottish Intercollegiate Guidelines Network, SIGN] advise that Primary Care should provide a structured annual review and produce an epilepsy register, monitor seizures, assess the side effects of medication and facilitate structured withdrawal from medication where appropriate and agreed. Also to provide information to improve e the quality of life and address women's issues and needs of patients with learning disabilities.[47]

In the UK the NICE guidelines for epilepsy[48] stated that Primary Care played a central role in the provision of medical care to adults with epilepsy. In all of these guidelines the high level care of epilepsy including the diagnosis of epilepsy should rest in the hands of epilepsy specialists however the routine low impact care of this group should be placed in primary care. It is the service organisation and impact of this low impact care which this thesis addresses.

General practice and primary care; the changing landscape

The last decade has witnessed an increasing range of activities which are provided General Practice as GPs play an important role in co-ordinating care provided in other settings. In addition to this there is a trend towards larger practices, with federated models of working which has resulted in general practices being a stronger and better organised.

This development has come in part, as a response to the increasing demand for health services especially from the growing numbers of elderly people who are living with comorbidities. This latter group require general practice to work in partnership with care givers where patients with complex problems receive care from multiple providers and indeed the patients themselves are empowered as much as possible to take an active part in their own health.

The focus has turned away from merely responding to sickness, to one which promotes health not just of the individual but of the local community. This includes care for those who are most in need of care but currently do not receive it with a developing vision to improve the quality of care co-ordination for patients with long-term chronic and mental illnesses. [49]

Introduction to the East Kent Primary Care Clinical Effectiveness programs: PRICCE-1, 1998 – 2000 [see page 200]

This thesis follows the earlier development of the Primary Care Clinical Effectiveness program I (PRICCE 1) which was developed to promote primary care treatment of idiopathic epilepsy. The original hope was that by only selecting only one type of epilepsy it would facilitate the gradual introduction of the epilepsy care program however the term idiopathic was found to be confusing. Practices did not understand clearly what the term meant and the health managers also were not able to offer cohesive advice on what to include. Commissioning leads suggested that it was all epilepsy apart from people with acquired brain injury or else suffering from learning disability. There was a call to re write the program for PRICCE for epilepsy and as a consequence the author was invited to re-design the epilepsy component of the PRICCE 1 and it was launched as PRICCE 2 in 2002 and is studied further in this thesis.

The East Kent model for evidence based and audit driven care for Long term Conditions including epilepsy: Primary Care Clinical Effectiveness program [PRICCE-1]

The Primary Care Clinical Evaluation Project (PRICCE-1) was described as ‘a quality improvement programme[50]’ designed by East Kent Health Authority. Its purpose was to use the tools of audit and incentivisation to improve the care of 13 selected long term conditions , one of which was Idiopathic Epilepsy. The other conditions selected for PRICCE I were Dyspepsia, UTI in children, Leg Ulcers, Angina, Myocardial infarction, Hypertension, Arial Fibrillation, Chronic Heart Failure, High Cholesterol , Asthma, Diabetes and Depression.

It commenced in 1998 and the author was involved with the first pilot program for epilepsy in PRICCE-1 and was the main author of the subsequent program of epilepsy care in PRICCE-2.

The development of a computerised epilepsy disease registers

For the PRICCE 1 pilot there was no comparative data available to assess the quality of care provided before the project started, so no formal comparison was possible however indirect evidence from the medical audit advisory group and anecdotally from individual practices suggested improvement in clinical care. This style of commissioning healthcare now seems fairly unremarkable however at the time it represented a change in mind-set of both clinicians and commissioners both of whom were surprised how many practices participated.

Incentivisation used in the PRICCE program for epilepsy

The metrics were intended to increase over a three year cycle and though ambitious over a third of GP Practices in the area participated in the scheme. By the end of 2 years over 85% of practices were signed up to take part in PRICCE.

The project cost £297,436 in payment to practices in the first year, but also resulted in increased Health Authority management time, increased audit support by the PCT [East Kent MAAG] and cost £20,000 p.a. to run There were also additional prescribing costs, increased hospital referrals, especially to neurology, echocardiography, gastroscopy, and increased pathology tests. Between £70,000 an £100,000 of financial support was provided directly or indirectly by the pharmaceutical industry.

Practices that joined the scheme had a commitment to meet targets in all 13 clinical areas. GP's received on average £3,000 per annum in advance to resource administration needed to be set up in advance of entering the scheme. If the targets were not met this funding had to be returned to the Health Authority

Education program for PRICCE 1

To accompany the support of the specific disease areas was an education program and initially this took the form of a brief educational article at the start of the epilepsy disease area chapter for PRICCE. With time this was adapted to be more helpful to the GPs in understanding how the epilepsy quality standards were drawn up and was followed by a local educational meeting in epilepsy having been requested by the local East Kent GPs. It was at this meeting in the late 1990’s that the author witnessed clearly the changing mind-set towards community based epilepsy care as the local GPs requested the author as a GP specialist in epilepsy to be the main presenter, with the support of the regional epileptologist . At the time I was far from comfortable at this arrangement but very much appreciate the foresight of Dr Lina Nashef in supporting this change in emphasis for a GP meeting. The GP audience required relatively basic general epilepsy knowledge in a style which was more focused on being pragmatic rather than academic and somewhat different in style and content to a similar talk presented to clinicians in Secondary and Tertiary Care.

Audit in PRICCE

Each practice had to satisfy the East Kent medical Audit Advisory Group that they possessed the necessary skills and software available to perform audit of medical records. A partnership formed between the audit team and GPs and the East Kent MAAG team remained a resource that practices accessed frequently during the program.

The criteria required by the practices before being permitted to take part in the program were;

- Past involvement in audit.
- Computers on consulting room desks which were used in the consultation.
- Disease registers established for all areas in the project.
- Written protocols approved by all the relevant Primary Care Team members.
- Completed audits to demonstrate compliance with standards for each condition.
- Ability to provide numbers of patients with each condition (in order to check against their expected prevalence)
- All partners had to agree to be involved in the project and to sign an agreement to that effect.

The author advised the Audit team and the PRICCE steering project to some degree for the PRICCE 1 pilot and was the lead advisor for PRICCE 2 having the major role in re writing the education supplement on epilepsy, re-defining the quality standards, being the first port of call from practices and from the Audit team for epilepsy related problems arising from the program. This work also extended to the commissioners of primary care epilepsy services and the pharmacy support team for East Kent on epilepsy related matters.

Peer Pressure in PRICCE

It was quickly identified that doctors tend to be competitive by nature and have often an inherent tendency to strive to become “top of the class.” There was discussion between practices of their level of PRICCE achievement and practices who had a reputation of being academic practices were drivers in this work. If practices had discovered templates that worked they would share this with other practices and the kudos of being ahead on this had a positive effect of staff morale. There was also accompanying this a sense that what was being done was worthwhile and did indeed make a difference hence effort spent on PRICCE even though financially was relatively minor was seen as time well spent.

Limitations of the original PRICCE 1 pilot

Not only was there a weakness in the original PRICCE 1 pilot in the restricting of the study to only Idiopathic Epilepsy but also the language that accompanied the project tended to be somewhat specialised. Also the clinical metrics were limited and it was soon clear that there was more scope available in the project to improve the care of people with epilepsy in the primary care setting. .

Targets selected for the PRICCE 1 pilot in the treatment of Idiopathic Epilepsy

The markers of epilepsy care selected to demonstrate the active care of epilepsy were

- 70 % of patients should be seizure-free two years from initial diagnosis by 1.4.99 , this means in the previous 6 months and by 1.4.00 in the previous 12 months (If this is not achieved, then the practice must be able to demonstrate why this is so).
- People with epilepsy should be reviewed annually.
- Practices to refer to specialist clinics at the first stage any with neurological signs including impaired learning, those under 16 years old, and those in whom the diagnosis was uncertain. The protocol needed to include the minimum data set and when to refer and factors to be included in a referral letter.

In the original program practices took different views on what to include for epilepsy and whilst some practices selected only those with a firm diagnosis of Idiopathic Generalised Epilepsy and included people with a read code of Primary Generalised Epilepsy other practices who had general epilepsy indexed in their medical records, tended to put all cases into the review. The result was a wide variation in results on the prevalence of idiopathic epilepsy ranging from 0.4% to 0.56% of the practice populations. Also this figure is generally a good deal higher than the expected percentage diagnosed with primary generalized epilepsy. The first wave of the scheme started in April 1998. A second wave of practices joined in April 1999 and a third wave of practices in April 2000.

Uptake of PRICCE-1 by Practices

The pilot demonstrated how rapidly such a scheme would be taken up by eligible practices and by 2001 a total of 89% practices in East Kent were taking part. This uptake is described in the figure 1 below

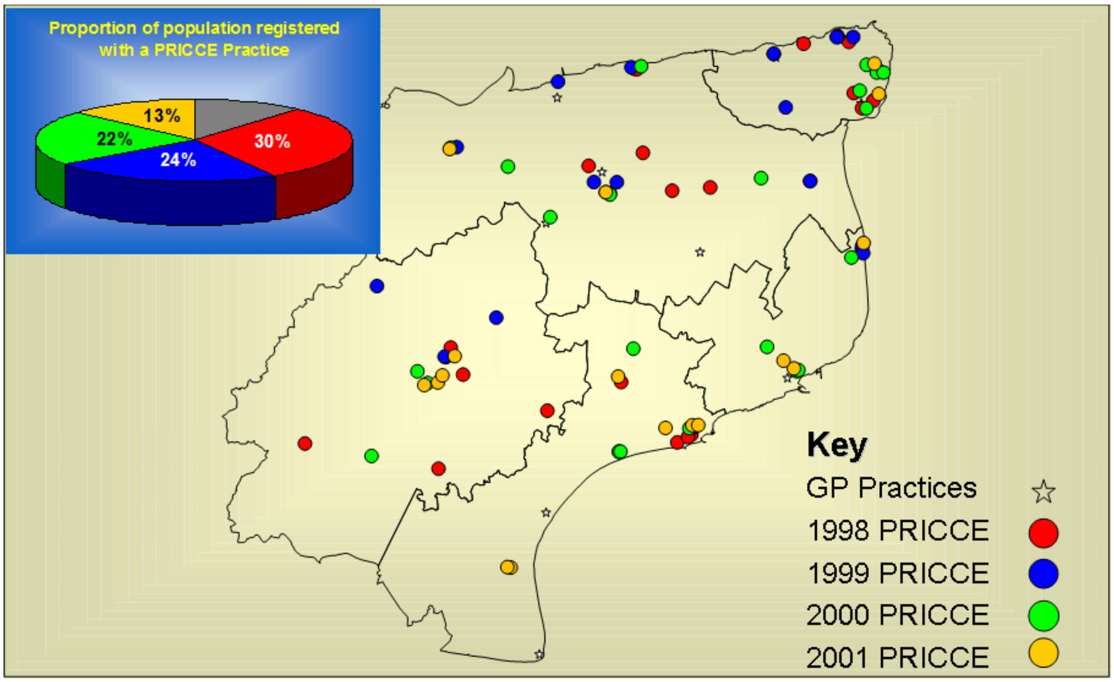

The uptake of PRICCE-1 pilot

Figure 1 Courtesy of East Kent NHS Health Authority 2001

The uptake was greater than originally expected and continues to be very high throughout the PRICCE-2 project and so this thesis studies the ability of the practices taking part to perform simple review of epilepsy and also more complex measures of care for their epilepsy.

From 2002 to 2004 PRICCE-2

From 2002 following the realization that the category of idiopathic epilepsy was problematic for practices to accurately identify the focus was then placed on all people with epilepsy. Also there was a widening of the epilepsy metrics to include recording seizure freedom, matters relating to women and children with epilepsy and a review of people taking vigabatrin for epilepsy. To provide some comparison with previous data the separate category of Idiopathic epilepsy was retained. The term used to describe the population with Primary Generalized as well as Focal Epilepsy was chosen as ‘full,’ epilepsy.

It was at this time that the PCT was re-organized and the previous 5 PCGs were amalgamated to 4 PCTS in the same catchment area.

The Quality and Outcomes Framework (QOF)[51]

From 2004 following the change of the GP contract all practices in England Scotland, Wales and Northern Ireland were eligible to take part in the Quality and Outcomes framework and part of this included the treatment of people with epilepsy. The aim for the department of health was to develop a nationwide scheme whereby incentivised targets for specified diseases would be available. For the treatment of people with epilepsy the aim was to help standardise epilepsy care across the UK and also to rise up clinical standards.

Computerisation for QOF

To take part in the QOF program all practices had to be computerised and have guidance on how to accurately code on their medical systems the disease areas included in QOF and also to use approved coding systems in order for the health authority to extract the data from the GP computer systems and analyse it further. GPs were given financial assistance from the PCTs in order to be able to perform paperless audit of these chronic disease areas.

Incentivisation: Rewarding quality and outcomes [52]

The QOF is divided into 4 categories;

(i) Clinical standards, covering coronary heart disease (CHD), stroke or transient Ischaemic attacks, hypertension, diabetes, chronic obstructive pulmonary disease (COPD), epilepsy, cancer, mental health, hypothyroidism and asthma

(ii) Organisational standards covering records and information about patients, Information for patients, education and training, practice management and medicines management

(iii) Experience of patients covering the services provided, how they are provided and their involvement in service development plans
(iv) Additional services.

Figure 2 - 2004/05 quality scorecard of the potential 'QOF' points which could potentially be achieved

Clinical indicators	**Totals**
CHD including LVD etc.	121
Stroke or transient ischaemic attack	31
Cancer	12
Hypothyroidism	8
Diabetes	99
Hypertension	105
Mental health	41
Asthma	72
COPD	45
Epilepsy	16
Clinical Maximum	**550**

Clinical Care only represented a 550 of the new QOF payments scheme points. There were 1050 points in divided into 4 domains of clinical, organizational, patient experience and additional services. In 2004/05, based on current average list size, each point was worth £75 per practice with an average weighted population. The following year [2005/06,] this figure rose to £120.6 the incentivised scheme allowed for 16 points out of a total of 1050 to be allocated to epilepsy.

Education for QOF

There was no specific education programs developed to support the QOF program however personal development plans became the vehicles by which GPs could identify areas of educational need and tailor-make ways of meeting that need. Some preferred attending lectures; others used e-learning packages whilst others used textbooks on the subject.

Audit for QOF using centralised data collection with verification [53]using the Quality management and Analysis System (QMAS)

The data collection has been improved however compared to PRICCE2 and a system called Quality Management and Analysis System (QMAS) was developed. It is a national system designed specifically to support QOF for use by practices in England.

QMAS can accurately calculate:

- Points achieved against aspiration
- Pounds achieved against aspiration
- Disease prevalence adjustment
- Weighted list size in accordance with practice financial entitlements
- National disease prevalence
- National target population averages

A team of QOF Assessors employed by the PCT visit practices at least annually to check the accuracy of recording of diagnoses and the results of tests to ensure accuracy in QOF data. If following a visit to the practice.[54] Significant areas of concern were identified and where the practice cannot offer a credible explanation, the PCT then begin a process to investigate further and may even involve their Local Counter Fraud Specialist or NHS Counter Fraud and Security Management Service as appropriate.

Peer pressure formally incentivised for QOF

The use of peer pressure has not been introduced for epilepsy care. The emphasis on it however has steadily increased and the health authorities in the latest version of the QOF program have included the following areas which receive a considerable amount of Incentivisation to encourage practices to take part. The areas where finance and potential savings can be made by the practice tend to be the areas where peer group pressure is most heavily utilised by the department of health.

Palliative Care;

- PC2 The practice has regular (at least 3-monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed – 3 points

Medicines Management;

- Medicines 6 The practice meets the PCO prescribing adviser at least annually and agrees up to three actions related to prescribing – 4 points
- Medicines 10 The practice meets the PCO prescribing adviser at least annually, has agreed up to three actions related to prescribing and subsequently provided evidence of change – 4 points

Quality and productivity;

- QP6 The practice meets internally to review the data on secondary care outpatient referrals provided by the PCO – 5 points
- QP7 The practice participates in an external peer review with a group of practices to compare its secondary care outpatient referral data either with practices in the group of practices or with practices in the PCO area and proposes areas for commissioning or service design improvements to the PCO – 5 points

- QP8 The practice engages with the development of and follows three agreed care pathways for improving the management of patients in the primary care setting (unless in individual cases they justify clinical reasons for not doing this) to avoid inappropriate outpatient referrals and produces a report of the action taken to the PCO no later than 31 March 2012 – 11 points
- QP9 The practice meets internally to review the data on emergency admissions provided by the PCO – 5 points
- QP10 The practice participates in an external peer review with a group of practices to compare its data on emergency admissions either with practices in the group of practices or practices in the PCO area and proposes areas for commissioning or service design improvements to the PCO – 15 points
- QP11 The practice engages with the development of and follows three agreed care pathways (unless in individual cases they justify clinical reasons for not doing this) in the management and treatment of patients in aiming to avoid emergency admissions and produces a report of the action taken to the PCO no later than 31 March 2012 - 27.5 points
- QP12 The practice meets internally to review the data on accident and emergency attendances provided by the PCO no later than 31 July 2012. The review will include consideration of whether access to clinicians in the practice is appropriate, in light of the patterns on accident and emergency attendance New indicator- 7 points
- QP13 The practice participates in an external peer review with a group of practices to compare its data on accident and emergency attendances, either with practices in the group of practices or practices in the PCO area and agrees an improvement plan firstly with the group and then with the PCO no later than 30 September 2012. The review should include, if appropriate, proposals for improvement to access arrangements in the practice in order to reduce avoidable A&E attendances and may also include proposals for commissioning or service design improvements to the PCO New indicator- 9 points

- QP14 The practice implements the improvement plan that aims to reduce avoidable accident and emergency attendances and produces a report of the action taken to the PCO no later than 31 March 2013 New indicator – 15 points

National realisation that change was needed in the management of epilepsy
The deficiencies on the provision of care for people with epilepsy are still being reported unfortunately and for the time being ensure that epilepsy continues to be included in the QOF program.

In 2007 the All Party Parliamentary Group on epilepsy [APPG] published a document that set out sobering statistics about the state of epilepsy care in the UK.[55] The report highlighted that there were 400 avoidable deaths per year in the UK and that approximately 69,000 people were living with unnecessary seizures. On top of this £189 million pounds was needlessly spent each year as a consequence of gaps in provision. It describes how social stigma, secrecy and medical ignorance has led to a poor service where patients cannot confidently expect good treatment at primary or secondary care.

The problem identifying people with epilepsy is a recurrent theme in reports assessing the provision of care for epilepsy.[56] The American Epilepsy Society and in addition reported that without a structured program of care that the management of epilepsy tended to become confusing and needed clear guidelines. In America also there was a degree of confusion as to which group of clinicians should be actively involved in treating people with epilepsy. The program of care for epilepsy in QOF is certainly not perfect however it does facilitate everybody with epilepsy being offered an annual review.

Development of a Locally Enhanced Service (LES) for epilepsy

Historical perspective

When the Quality and Outcomes framework was launched nationally the standards set within it for epilepsy were less demanding and fewer in number than the PRICCE-2 project it replaced. The care of epilepsy in East Kent therefore ran the real risk of taking a step backward. To ensure that the high standards which were previously set were not lost a Locally Enhanced Service for Epilepsy was developed in 2006 and made provision for these higher standards to continue to be commissioned. This was available for Eastern and Coastal Kent PCT only.

Computerisation for the Locally Enhanced Service for Epilepsy

This was by now fully established in East Kent and practice staff were proficient and accurate when indexing the requirement needed to be audited on computer.

Incentivisation

A Locally Enhanced Service offers GPs is defined as;

"Enhanced services are:

> *(i) Essential or additional services delivered to a higher specified standard, for example, extended minor surgery*
>
> *(ii) Services not provided through essential or additional services. These might include more specialised services undertaken by GPs or nurses with special interests and allied health professionals and other services at the primary-secondary care interface. They may also include services addressing specific local health needs or requirements, and innovative services that are being piloted and evaluated[57]."*

The enhanced service was awarded 12 points which were set to have an equal value as 12 extra QOF points per practice on full attainment of the program for epilepsy.

Education arrangement for the epilepsy locally enhanced service

The enhanced service required a lead GP to undergo extra training in epilepsy which was relatively informal and merely required a certificate of attendance at the education event.

Audit for the epilepsy locally enhanced service

The remit of the LES was to provide an incentivised level of service above the current standards required in QOF. These metrics include ensuring that more in depth questioning on epilepsy control and also wider issues such as social and emotional well-being. They also included female related issues. The discussion between the doctor and patient on these areas was then subject to end of year audit. The areas to audit were somewhat difficult to record for audit purposes as they included targets set to improve the wider health and social care needs with the GP's taking part helping to provide the support where possible and if not sign posting the patients to suitable agencies The clinicians taking part had to record the fact that they had offered people who required information on driving, safety, employment and female issues where appropriate.

Peer Pressure

This tool was not specifically used in the enhanced service but as in PRICCE practices who were known to take a lead in primary care services tend to be the ones who took part in the scheme. Unfortunately with the loss of the central record within the changing PCT computer records more formal analysis on the impact of peer pressure is not possible

The potential role for the Community Pharmacist

The department of health in recent years has promoted commissioning the location of care to be close to home [58]and arguably the closest clinician to the patient with epilepsy is the community pharmacist. Community pharmacists are arguably the closest people to deliver care to people with epilepsy when judged by the pharmacist being the clinician who is at the end of the delivery of care pathway for everyone taking anticonvulsants. To receive their medication people with epilepsy will need to see their pharmacist to anti-epileptic drugs. The potential role which a community pharmacist can offer in supporting a person with epilepsy has yet to be fully realised[59]. They are ideally situated to provide literature, educate about disease therapy, encourage adherence, explain side effects and provide information of potential drug interactions.

One American study, reported that most people with epilepsy used their pharmacists to answer queries on drug interaction and adverse effect information[60]. Patients also responded that they would welcome greater input from their pharmacists and indeed would value collaboration between their epilepsy specialists and their pharmacists. Areas of potential increased help included improved quality of life, help with medication compliance and help keeping a seizure diary. The question of who would pay for this service whilst being an issue in America is not so for the UK as the National Health Service includes currently for the provision for a medicines use review.

Poor compliance with medication is a key factor in mortality and morbidity in epilepsy and the pharmacist as well as the family doctor are ideally placed to detect this[61]. The importance and prevalence of poor medicines adherence for people with epilepsy is well known and there are strategies and indeed practical ways for a non-epilepsy specialist to help[62]. Amongst recommended actions clinicians can take is checking

- *For an agreement between doctor and patient before prescribing AEDs*

- *If prescription ordering shows a low medicine possession ratio [ordering prescriptions late]*
- *Whether the patient conserves AEDs by missing or reducing a dose*
- *Whether the patient has to skip doses to reduce side effects*
- *If the patient misses doses unintentionally due to poor memory*
- *If the patient sometimes skips doses*
- *If the patient has missed at least a dose in the previous week*

Developing the role of the community pharmacist in England

The Department of Health have recognised the opportunity for pharmacists to take a more prominent role in the care of patients. The provision of community pharmacist services in the UK ensures that community pharmacists are directly accessible by the public and are available in longer hours than most other primary care clinicians. They are in addition also situated usually in prominent and easy to access positions and can be seen as being as accessible as a local supermarket.

In 2005 the department for Health introduced the Medicines Use Review (MUR)[63] whereby accredited pharmacists can undertake structured reviews with patients on multiple medicines, particularly those receiving medicines for long term conditions. The purpose of the MUR service is to maximise the benefits of the medication and also to reduce wastage. This was updated 2011 and received further minor amendments in 2012. In this scheme pharmacies can perform up to 400 MURs per year. National target groups have been set to guide the selection of patients who will be offered the review and helps patients understand their therapy and looks to identify any problems they are experiencing along with offering possible solutions.

In a typical MUR the patient's actual use and experience of taking their medicines is assessed and then the pharmacist offers assistance in cases of poor or ineffective use. By identifying problems such as side effects the pharmacist works to minimise problems uncovered hence aiding their effective use. In an MUR, the pharmacist will consider all the medicines the patient is taking, including those which aren't prescribed

From 1 October 2011, contractors were expected to perform at least 50% of MURs on patients in one (or more) national target groups. The three target groups are:

- patients taking high risk medicines (on a national list)
- patients recently discharged from hospital who had changes made to their medicines while they were in hospital
- patients with respiratory disease.

In addition to the above, MURs can still carried out on patients who are not within the target groups. Pharmacists are expected to select patients most likely to benefit from the MUR service.

From 1 July 2012 the method for data capture was implemented which included changes to the data that need to be collected during the consultation and revised information being sent to the PCT on request.[64] This information includes;

- Patient demographic details,

- Target group
    - *respiratory*
    - *high risk medicine*
    - *post-discharge*
    - *not in a target group*

- Total number of medicines being used by patient:
    - *prescribed*
    - *over the counter and complementary therapies*

- Healthy living advice provided at MUR (using the following options):
    - *diet and nutrition*
    - *smoking*
    - *physical activity*
    - *alcohol*
    - *sexual health*
    - *weight management*
    - *healthy living advice not applicable at this consultation*

- Matters identified during the MUR (using the following options*):*
    - *patient not using a medicine as prescribed (non-adherence)*
    - *problem with pharmaceutical form of a medicine or use of a device*
    - *patient reports need for more information about a medicine or condition*
    - *patient reports side effects or other concern about a medicine*
    - *other (free text information can be entered in the clinical record)*
    - *no matters identified during MUR*
- Action taken / to be taken (using the following options):
    - *information/advice provided*
    - *yellow card report submitted to MHRA*
    - *referral – patient's issues raised with the medicine need to be considered by the GP practice or another primary health care provider*
    - *other (free text option in clinical record)*

- As a result of the MUR the pharmacist believes there will be an improvement in the patient's adherence to the medicines as a result of the following (more than one may apply):
    - *better understanding/reinforcement of why they are using the medicine/what is it for better understanding/reinforcement of when/ how to take the medicines*

    - *better understanding/reinforcement of side effects and how to manage them*
    - *better understanding/reinforcement of the condition being treated*

From 1 September 2012 community pharmacists are only required to inform a patient's GP that an MUR has taken place if an issue has been raised that the pharmacist believes the GP should be aware of.

The Target group introduced in 2012 MURs included patients taking any of the following high risk medicines: non-steroidal anti-inflammatory medication, anticoagulants (including low molecular weight heparin) anti-platelets and diuretics.

Also it includes patients who had recently been discharged from hospital and who have had a change in medicines during their hospital stay. In addition patients with respiratory disease were singled out for special care being focused on those taking the following medicines for asthma or COPD. The medicines included are adrenoreceptor agonists, antimuscarinic bronchodilators, theophylline compound bronchodilator preparations, corticosteroids, cromoglicate and related therapy, leukotriene receptor antagonists and phosphodiesterase type-4 inhibitors.

Epilepsy was not included however it would seem an ideal long term disease to benefit from being made one of the target groups. It was not known if pharmacists could be trained to deliver such a service. The purpose of this pilot is to see if it would be possible to train and equip community pharmacists to offer support for people with epilepsy. The pilot went one stage further in that it offered the pharmacists the authorisation to refer people with epilepsy to the community epilepsy clinics run by the GPwSI for epilepsy.

For the duration of the pilot, the community pharmacists using the medicines use review specifically looked for people who were exposed to an increased risk from their epilepsy AND were not currently accessing specialist health care. They were given referral rights to specialist epilepsy care. One of the areas which a community pharmacist was to focus on was the monitoring of medication compliance and systems such as NexPhase pharmacy dispensing software can be used as it has the capability to note when prescriptions appear to be requested too infrequently.

The need for additional support for people with epilepsy

Also the study with community pharmacists included assessing whether it was feasible for a specially trained pharmacist to offer support and appropriate literature to people with epilepsy hence providing an extra source of support. Clinical confidence in the management of epilepsy was enhanced by a day's educational update in epilepsy for Pharmacists delivered through the Medway School of Pharmacy. Information leaflets on living in epilepsy provided by Epilepsy Action were available for Pharmacists to use.

The value of targeting Medicines Use Reviews

Previously medicines use reviews were currently not targeted as they tended to be ad hoc and local informal comment suggested that they tended to be taken up by already well informed and well managed patients. The Pharmacist sends the GPs a notification list periodically and would offer recommendations which ran the risk of being lost in the practice's paperwork. By allowing Pharmacists to refer directly within agreed parameters to Intermediate care the MUR becomes a dynamic and more effective tool in the hands of a very skilled and arguably currently underutilised pharmacist.

Strengthening the place of community pharmacists in the Primary Care Team

GPs will need to feel confident in their pharmacist colleagues in order to welcome them as partners in patient care. In addition to this they will be required to trust their ability to refer patients who appear to have red flag symptoms to Intermediate Care. The study included training of pharmacists in the process of referral and utilised a referral template to help ensure the correct people were seen and that standards across the group were maintained by all. The possession of referral rights to pharmacists is a significant move into bringing pharmacists under the Primary Care Team and paves the way, if successful, to closer working and collaboration between the two groups

The role of Epilepsy Specialist Nurses

The development of epilepsy nurse specialists has taken place over the last few decades and has developed into a very skilled workforce to a standard where 18% of the U.K's epilepsy specialist nurses are medication prescribers[65]. Most of this group prescribe a new drug weekly and most nurses titrate medication daily. This skill needs to be kept active as after gaining qualification there is evidence that nurses do not prescribe or prescribe infrequently. The value of nurse prescribing can be summarised as

- *Enabling a holistic approach*
- *Overcoming delayed access to medicines*
- *Response in a timely fashion*
- *Increased the nurses autonomy*[66]

Investment in epilepsy specialist nurses to bridge the gap and increase capacity will help but more diversity is needed. The support nurses offer is different to that which a doctor offers. There is evidence to suggest that Epilepsy Specialist nurse history taking was reported to be similar with the neurologists however the diagnostic process can produce a different result with a 25 % disagreement in diagnosis [67] It may be also that nurses are less certain of diagnosis and tend to order more investigations. It is certain that there will be some overlap of skills and that capacity and flexibility to a network of care can be increased but it would not surely be wise to see the role doctors and nurses offer as being identical.

Commissioning services for epilepsy requires a clear target of the outcomes to be expected from the clinical workforce and it would be a mistake to expect improvement in the wrong outcomes. Epilepsy Specialist Nurses have been found to achieve improved levels of communication with patients compared to other health professionals and also higher levels of patient satisfaction.[68] It is not clear if there is improvement in health status and use of other health care services and may produce an adverse effect on patient’s perception of epilepsy affecting on patient’s everyday life. This has been postulated to be due to heightening awareness of the restricting effects of this illness. The role of the nurse as a support to people with epilepsy is undoubted but they cannot with the evidence to date, be expected to improve health outcomes but they play a valuable role in improving patient quality of life.

Intermediate Care – the role of GPs with a Special Interest in Epilepsy (GPwSIs)

The introduction of GPs with a special interest in epilepsy has been steadily increasing over the last decade[69] and it was envisaged in 2002 that there was potential for this group of GPs with special training to contribute to the care of people with epilepsy in the UK Over time, certain areas have seen this take place and it has been suggested that they can be a focal point of epilepsy care in the community.[70] With an aging population there is a pressing need to increase capacity and develop a better shared care model with the development of GPwSIs to act as focus at primary level. Within this structure the movement of the patient to the appropriate health care provider should be seamless and so the patient sees the ‘right person and the right place and at the right time,’ with mind given to the DH policy of a desire to see the patient receive ‘care closer to home[71]

The Association of British Neurologists in their report looking at how they foresee neurology services developing over the next decade suggest that for the long term care of people with neurological conditions that whilst the initial diagnosis and treatment be the domain of neurologists, care should be followed up in the community. This community team led by professionals with specialist expertise including nurse specialists, GPwSIs and professionals allied to health. These community teams should have close links and easy access to the appropriate DGH based neurologist.[72].

The scope of this thesis

This thesis addresses the role of the primary care team which includes practice nurses but does not explore the role of the epilepsy nurse specialist who in East Kent hold their clinics within hospital out-patient clinics.

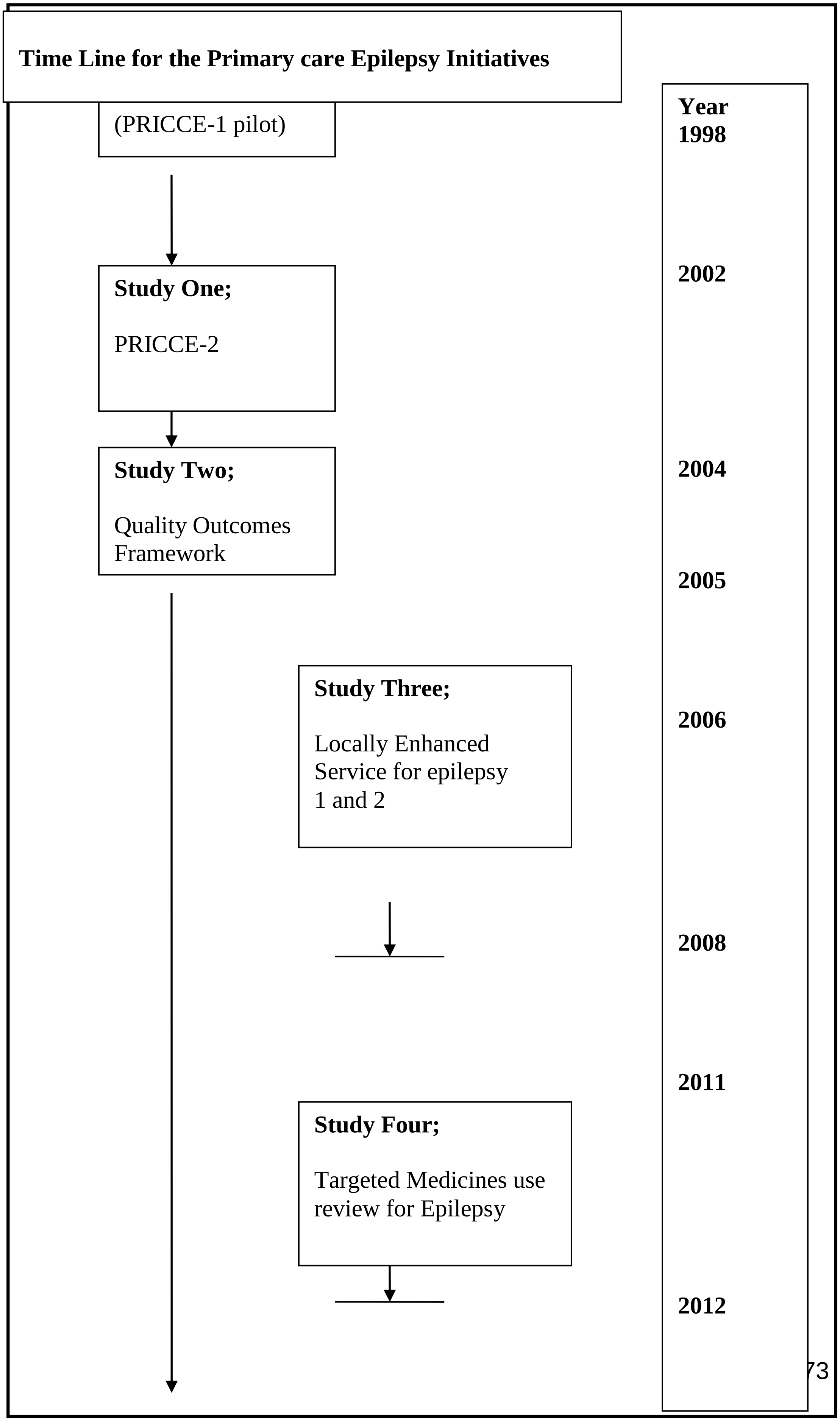
The follow chapters describe this progression of epilepsy care development which took place in primary care and sets out to find answers to the aims set out in the thesis.

The Link between the Studies

The aim underpinning this work is to see primary care proactively supporting everybody with epilepsy rather than care being reactive being offered to only a sub group of the cohort. The need for specialist services is not diminished as inevitably more complex problems associated with the management of epilepsy are discovered and dealt with electively by epilepsy specialists.

The author seeks to examine whether primary care is willing to become involved and goes on to explore the level of expertise that it is possible to deliver. The work regionally in study One; PRICCE-2 was used to develop the national program for epilepsy in QOF. Following this the Locally Enhanced Service for Epilepsy examined the extent to which GPs care for epilepsy can be more complex. The lessons learnt on the training and assurance of quality of advice given by the practice staff were utilised in the community pharmacists Medicines Use Review pilot for epilepsy.

If these schemes are successful it should be possible to see a change in the support offered by primary care when comparing the situation at the beginning of Study One to the end of Study Four.



Time Line for the Primary care Epilepsy Initiatives

METHODS

1 Study One; PRICCE-2 2000 - 2004

The study started in 2002 and followed on from the successful PRICCE-1 pilot. The overall aim of the study was to improve the care of people with epilepsy and to start a process of care for epilepsy which was pro-active rather than being simply reactive to problems and indeed crisis. As mentioned in the introduction one of the major differences was the expansion of the target group for epilepsy which was originally only those with idiopathic epilepsy and was widened to all people with epilepsy in PRICCE-2. The previous definition of idiopathic epilepsy [see page 17] was helpful initially but caused confusion in practices both in understanding which patients were to be included and also in lack of information in the medical notes defining the epilepsy classification. This led to non-conformity between practices and indeed it was unclear why the majority of people with epilepsy would not be included in this program. The term ‘full epilepsy,’ was used by the PRICCE team to highlight that all cases of epilepsy were to be included. All patients with epilepsy should be included in the audit as all epileptic fits regardless of aetiology have inherent dangers.

Also in PRICCE-2 there was a widening of the epilepsy metrics which in PRICCE-1 was to review people with idiopathic epilepsy annually, to undertake to refer people to specialist clinics at the first stage if they had any underlying neurological signs such as learning disability and if they were under 16 years old and to aim for seizure freedom in 70% of people with idiopathic epilepsy and if this was not achieved to be able to explain why it was not achieved.

The PRICCE-2 study kept these standards for PRICCE-1 and added to them more complex tasks for the GPs to aim for all people with epilepsy. This expansion included proactively managing epilepsy related matters relating to women and children with epilepsy and also asked for a review of people taking vigabatrin for epilepsy. This was a unique opportunity for the author to become involved and investigate whether practices would be able to attempt more complex requirements for the epilepsy component of PRICCE-2. To provide some comparison with previous data the separate category of Idiopathic epilepsy was retained.

It was at this time that the PCT was re-organized and the previous 5 PCGs were amalgamated to 4 PCTS in the same catchment area.

The project team set in place the following pre requisite factors which were utilised to bring about change in proactive care for epilepsy and indeed other long term conditions. The factors selected to commence the change in the pattern of care for PRICCE were;

- Computerisation
- Incentivisation
- Education
- Support of audit team
- Peer pressure

Computerisation

All practices ran computerised data bases and were well versed in indexing accurately the medical records to facilitate accurate audit.

Incentivisation

Following the successful practice visit by the PRICCE team the practice was invited onto the PRICCE scheme and an upfront payment of £3,000 was made to the practice to allow for the restructuring of systems required to be in place to run the project. A contract was then put in place with the practice to achieve the PRICCE targets

Education

Background given to Practices informing them why improving control of epilepsy is necessary

I. Epilepsy is one of the most common neurological disorders and affects 1.5 million people at some time in their lives, especially during childhood and old age. With 1-2 new cases per 2-4,000 people a year

II. In 1996 over 1,000 people died from epilepsy in the UK

III. More people die from epilepsy a year than the combined mortality figures of cot deaths and HIV

IV. A survey of patients attending The National Hospital for Nervous disorders Queens Square revealed that 1:200 patients of this clinic died due to their epilepsy each year

V. Optimising the care of patients with epilepsy minimises this risk hence the need to promote the best possible care of all patients with epilepsy

VI. A recent CSAG survey revealed that only 51.5% of the 1,652 patients surveyed had remained seizure free in the preceding year. Epilepsy clinics aim at 70% seizure free over the previous 2 years.

Support of the Audit team

The audit team worked closely with practices and to some degree became extended members of the practice and were usually warmly welcomed by the practices and become a useful source of information and advice

Peer pressure

This was informal and not incentivised however there was a strong professional rivalry between practices and practices that previously had little to do with each other and indeed started to form helpful relationships. The early achievers in

PRICCE were certainly seen as being ‘ahead’ of the others who were still waiting to reach the standard necessary to embark on PRICCE

Setting the standards

The standards were initially developed for all of the thirteen disease areas included below:

Idiopathic Epilepsy
Dyspepsia
UTI in children
Leg Ulcers
Angina
Myocardial infarction
Hypertension
Atrial Fibrillation
Chronic Heart Failure
High Cholesterol
Asthma
Diabetes
Depression

Validation Process

The criteria for PRICCE with the standards for most areas being the product of a regional discussion group however the section on Idiopathic epilepsy was written by Dr Lina Nashef and was offered for comment to the author and Dr Henry Smithson. For PRICCE-2 however the standards were set by the author and ratified by Dr Tony Snell the East Kent medical director as well as the East Kent Medical Audit Advisory Group [East Kent MAAG.] The clinical literature was used to help set these standards[73],[74] and also a pragmatic approach to set baseline standards such as developing an epilepsy register

For each subsequent section in this chapter the rationale for selecting the standard is given

Verification and Storage of Data

As the programme was incentivised and money was paid for the achievement of PRICCE standards the health authority oversaw the collection of data at the end of each year of the scheme. As part of the scheme, participating practices conducted an audit of their achievement against the standards used for epilepsy. These were produced on standardised forms issued by the health authority an Excel spreadsheets and deviations from the standards had to be listed.

The end of year reports were sent to the health authority and manual paper copies of these were saved in the health authority offices. Health authority staff intended to visit all practices at the half-year and year-end. The medical director of the Health Authority and members of the East Kent MAAG team carried out these visits in the first year of the project. This offered an opportunity for practices to raise issues and describe progress. At the year-end they report apparent failures to health authority for consideration. It was the eventual achievement or otherwise of the standards that was measured and payment given if the standards had been achieved.

This data was available to author at year end and to facilitate access to such a large volume of information the data was later summarised and tabulated electronically using a uniquely designed Microsoft Access programme by the East Kent MAAG team.

1.1 Determine the extent to which participating primary care practices in East Kent are able to be involved in basic proactive care for epilepsy using a disease register following the PRICCE-2 programme

To be welcomed to take part in the program the practice4 was required to present evidence that it was willing to engage fully with the PRICCE program. This included being able to demonstrate the following criteria;

- The practice should have a protocol for the evaluation of all new cases
- The practice must be able to identify all patients with epilepsy
- All new patients should be appropriately assessed and investigated so their seizure type and aetiology can be established wherever possible
- There must be evidence of discussion amongst the primary health care team [and if applicable secondary care] around any critical events - including unexpected death in epilepsy, significant injuries, burns or drowning, status cases and near-miss cases.
- A target of 70% seizure free during the previous year should be achieved. If this is not achieved despite good compliance the patient should be referred to a specialist clinic.

This list of proactive care was developed largely on a pragmatic basis and the acquisition of a disease register for epilepsy is seen as the basis from which this study could advance.

1.2 Determine the extent to which participating primary care practices in East Kent are able to identify potential problems which can arise as a consequence of suffering from epilepsy

1.2.1 Identify people who are seizure free

Using the practices structures described in 2.1.1 the practice was able to determine home many of their patients with epilepsy were seizure free. This standard of seizure freedom was chosen by Dr Lina Nashef and retained by the author for PRICCE-2 as it remains one of the key factors in reducing mortality and morbidity for epilepsy.

It was hard to verify the data offered by practices however practices who recorded higher than average rates of seizure freedom were questioned on this. Providing they could satisfy their health authority visit however the declared values were taken as being correct.

The selection of seizure freedom as a quality standard was not formally validated as it was taken for granted at that stage by the author to be a key marker of quality of care.

1.2.2 Ensure the people who are taking vigabatrin have their visual fields measured

Vigabatrin is now known to cause peripheral field loss in the vision in 30% of patients [some studies have reported rate of up to 50%] .The onset can be gradual and unnoticed as central vision is not affected. Its occurrence can be picked up early by formal visual field testing All patients on vigabatrin were identified and their visual fields checked twice a year. If visual field loss is noted they should be referred to an epilepsy clinic urgently. The effects appear to be irreversible or incompletely reversible. Consideration should be given to referring all patients on vigabatrin to specialist clinics for further evaluation if not already under secondary or tertiary care.[75]

The evidence from the available scientific literature was taken as the basis for justifying and indeed validating this standard.

1.2.3 Identify women who are pregnant and also have epilepsy

Pre natal advice to female patients with epilepsy must be offered and those on higher risk regimes for causing foetal abnormalities referred to specialist clinics. Also all patients who become pregnant and have a diagnosis of epilepsy should be referred to specialist care - control often becoming more difficult during pregnancy.

This standard was chosen as it was hoped to make the local GPs more aware of the teratogenic risks associated with anti convulsant medication. The GPs were encouraged to consult the British National Formulary and at the training given prior to the programme they were reminded that Phenobarbitone, Phenytoin and Sodium Valproate were all particularly know to be potentially teratogenic.

1.2.4 Ensure women and children of childbearing age are taking folic acid

Folic acid 5 mg to be offered to all women and girls who are sexually active in the reproductive years should be offered folic acid 5 mg and this should be continued to the 16th week if they become pregnant[76].

This evidence from the scientific press was used by the author to validate this standard and as it was not widely known about by GPs and it was hoped that this standard would help to rectify this gap in knowledge.

1.2.5 Ensure that women who are taking contraception medication are prescribed appropriate contraceptive medication

All patients on enzyme inducing anti convulsants and oral contraceptive should have the dose of their contraceptive checked to ensure adequate contraception is provided.

The validation of this standard was taken on pragmatic grounds at this time by the author. GPs arguably should always consider whether the oral contraception prescribed interacts with their anti convulsant medication however many medications were prescribed on hand written scripts without the advantage of computer software to warn of interaction. This standard was chosen to try and remedy this risk.

1.3 A preliminary examination of local trends in hospitalisation.

1.3.1 Trends in unplanned visits to hospital for acute problems arising from epilepsy

This standard was chosen to assess whether there was any discernable impact on unplanned admission to hospital from the PRICCE-2 project. Even though this was uncontrolled and exposed to confounding factors, the link between improved elective care and unplanned admissions was made

Analysis Plan

The overall aim of the PRICCE-2 programme was to assess the utility and uptake of a low impact audit driven process of health care delivery at Primary Care level. It was the uptake and implementation by individual practices in East Kent which was being measured and so simple descriptive statistical analysis was chosen to evaluate the data.

Descriptive statistics defined as;

> *"... measures of different aspects of a population (or a distribution of population values). The population may be finite, as is the case for example when it consists of a set of data, or it may be infinite."*[77]

The descriptive statistics were used to describe the main features of the practices both as they joined the scheme and as they performed in the programme. Inferential statistical methods were not utilised as it was only the sample which was studied and there was at this stage no plan to extrapolate to the wider population of all GP practices in East Kent or indeed England. It was for this reason that probability theory was not utilised. The data sets were presented by the author in graphical format. There was no provision to explore non responding practices in this project.

2 Study Two; Quality and Outcomes Framework

Following the success of the PRICCE-2 project the department of health commissioned the Quality and Outcomes Framework [QOF] which was developed as a national scheme which drew heavily from the lessons learnt in PRICCE. This heralded a new era whereby primary care provided a key role in the management of long term conditions. Included in this group was epilepsy and a good deal of the development put into place by the author in PRICCE-2 was then carried on in [see page 199] QOF Following the introduction of QOF the care of people with epilepsy would benefit from being part of a pro-active and structured care program. The ability of primary care on a national scale to take part in proactive epilepsy care was examined in this study and included incentivised targets for people with epilepsy. It was not certain however how GPs across the country would receive this scheme and also how quickly they would reach the targets.

The pre requisite factors which were needed for PRICCE also needed to be in place nationally and required the same ingredients of

- Computerisation
- Incentivisation
- Education
- Support of audit team
- Peer pressure

Standards for Epilepsy

The targets set for epilepsy were standardised throughout the country and initially were set at a relatively basic level which required practices to develop an epilepsy disease register which could be accessed easily to help facilitate the proactive care of people with epilepsy. For the first time in the UK everybody with epilepsy would be invited to an appointment with their GP and asked how they felt their epilepsy care and control was doing. Also they received an epilepsy medication review and were specifically asked if they were experiencing side effects. The target for seizure freedom was also introduced with the aim of achieving 70% seizure freedom. The standards used are set out in table 1 and each one carried a specified reward of QOF points.

Setting the Standards

The standards drew heavily from the East Kent work on PRICCE-2 and included the section including epilepsy. The level of care for epilepsy provided by general practice was limited at this time and the standards set were pragmatic and indeed basic such as developing a disease register however this formed the necessary pre requisite to develop the programme.

Where national guidance was available the central QOF team built on this and the author was a member of the expert panel who developed these standards [see page 207.]

Reporting and Verification of results

It was intended from the beginning that all reporting of performance by the GP practices would be electronically gathered via the clinical software systems and a report would be run annually which can be submitted to the local health authority.

The standards chosen had an identifiable source in the clinical record and required GPs to accurately index their medical records to be able to extract this data accurately. In general the primary care organisations were expected to conduct detailed or intrusive verification procedures, unless there was a suspicion that incorrect figures may have been returned, or indeed if they suspected fraud. However on the annual visits by the health authority it was expected that the visiting team select cases for more detailed investigation from time to time on a random basis.

Quality Management and Analysis System [QMAS]

The Quality Management and Analysis System (QMAS) was a national IT system developed by the Department for Health which was solely used by the primary care organisation and not the GPs themselves. It is used to produce an accurate evidence on the quality of care that practices deliver to patients. It could not be manipulated by the practices and it produced an electronic record of the practice achievement.

The GP system suppliers of the various GP clinical software programs designed and integrated data communication which will send the information required overnight at the end of each month. The information sent is anonymized information, with the guarantee that the QMAS software did not interrogate GP computers so could not breach confidentiality.

The data was then saved onto a national department of health central server and amalgamated to provide a large range of statistics on clinical activity both on a practice level as well as a local health authority level. This data was analysed primarily by the Public Health Observatories.

The information is made public and can be accessed by the local primary care organizations to allow comparison with local and national averages. Information and results for this thesis regarding QOF were made possible by the very large infrastructure provided by the Department for Health electronic records generated and published using QMAS.

Analysis Plan.

The overall aim of the Quality and Outcomes Framework for epilepsy was to assess the utility and uptake of a low impact audit driven process of health care delivery at Primary Care level. It was the uptake and implementation by individual practices in England which was being measured and so simple descriptive statistical analysis was chosen to evaluate the data.

The assumption was made that the sample size was approaching the population size [i.e. approaching complete uptake from all the practices in England] and so inferences gained from the study could be reasonable assumed to near that of the general population. It was for this reason that probability theory was not utilised.

The descriptive statistics were used to describe the main features of the practices both as they joined the scheme and as they performed in the programme. There was no provision made in this study to explore non responding practices. The data sets were presented by the author in graphical format.

The data on mortality was gathered as described below [please see page 94] the available data on line was collected from the however it was not in an age standardised format. It was for this reason that the author contacted the local Public Health Observatory to enlist their help in converting it to a directly standardised rate from 2001 to 2010. They also recalculated my initial trend analysis [R^2] which offered an insight into the trend in mortality for people with epilepsy in England.

Table 1 Standards for Epilepsy 2004

Indicator	**Points**	**Payment Stages**
Records		
EPILEPSY 1. The practice can produce a register of patients receiving drug treatment for epilepsy	2	
Ongoing Management		
EPILEPSY 2. The percentage of patients age 16 and over on drug treatment for epilepsy who have a record of seizure	4	25 - 90%

frequency in the previous 15 months		
EPILEPSY 3.The percentage of patients age 16 and over on drug treatment for epilepsy who have a record of medication review in the previous 15 months	4	25 - 90%
EPILEPSY 4. The percentage of patients age 16 and over on drug treatment for epilepsy who have been convulsion-free for last 12 months recorded in last 15 months	6	25 - 70%

2.1 Determine the extent to which primary care practices in England are willing to be involved in basic proactive care for epilepsy using a disease register following the QOF programme

2.1.1 Produce a register for people with epilepsy who are receiving treatment for epilepsy and are over 16 years old

Epilepsy Indicator 1: The practice is asked to produce a list of people who are receiving treatment for epilepsy; the fact that they are receiving treatment is taken to mean that they have a current rather than a previous history of epilepsy. The register is used to record patient over 16 yrs. old and this is on the assumption that patients under 16 yrs. are generally being treated by specialists. The epilepsy disease register of people with epilepsy over the age of 16 yrs. allows for Primary Care Organisations to compare the expected and the reported incidence of epilepsy.

The justification for this indicator is straightforward as a disease register forms the pre-requisite tool for subsequent indicators of epilepsy care. The register is only for people with active epilepsy and are ‘receiving treatment’. Practices had to refine their previous disease register for epilepsy to exclude people who had epilepsy in the past but who were now off treatment and seizure free.

2.1.2 Record the seizure frequency for people over 16 years old

Epilepsy Indicator 2: The percentage of patients aged 16 and over on drug treatment for epilepsy who have a record of seizure frequency in the previous 15 months. Following the recommendation offered by the SIGN guideline [78]it was expected that GP’s recorded the following details

- Seizure type and frequency, including date of last seizure
- Antiepileptic drug therapy and dosage
- Any adverse drug reactions arising from antiepileptic drug therapy
- Key indicators of the quality of care i.e. topics discussed and plans for future review

The definition for seizures and in particular whether this referred to only convulsive seizures or any form of seizure was not very clear in earlier documents but in 2008 redraft of the QOF protocol it was clarified and made clear that this referred to all seizures independent of whether the person with epilepsy had lost awareness or not.

The rationale for selecting this indicator was because it was recognised that epilepsy is often poorly managed in general practice, and there are insufficient specialist resources to provide specialist supervision for most patients. It is for this reason than the details in the preceding paragraph identified in the SIGN guidelines were chosen to begin a process whereby Primary Care can start to form a unified resource to support people with epilepsy and used to validate this standard.

No recommendation was made in the SIGN guidelines on the frequency of the review hence a pragmatic decision was made for this to be an annual one.

2.1.3 Perform an epilepsy medication review for people over 16 years old

Epilepsy Indicator 3: The percentage of patients aged 16 and over on drug treatment for epilepsy who have a record of medication review in the previous 15 months. It was the first time in the UK that people with epilepsy were proactively asked annually if their anticonvulsant medication was satisfactory and if it was suiting them.

It is established good practice for any prescriber of medication to review the medication and assess it both in terms of efficacy and tolerability but also to review the dosing instructions to ensure that no inadvertent slip up has occurred in the repeat prescription process. It seems natural to include this specifically for epilepsy.

2.1.4 Identifying people on drug treatment for epilepsy who are seizure free over 16years old

Epilepsy Indicator 4: The percentage of patients aged 16 and over on drug treatment for epilepsy who have been seizure free for the last 12 months recorded in the last 15 months

Seizure freedom was recognized as being a sensitive marker of good epilepsy care however it was recognized than due to multiple factors outside of the GP’s control e.g. refractory epilepsy or repeated patient non-compliance or not presenting themselves to appointments they GPs were allowed to ‘exception report,’ these people

2.1.5 Produce a register for people with epilepsy who are receiving treatment for epilepsy and over 18 years old

Epilepsy 5: The practice can produce a register of patients receiving drug treatment for epilepsy aged from 16 to 18 years old and over in the 2006 review. The decision to only include patients 18 yrs. and older was based on the assumption that people under this age are under Paediatric Specialist care. The introduction of the phrase 'receiving treatment' is included to exclude people who previously were diagnosed as having epilepsy but who are now seizure free and off medication. This helps to provide a clearer picture of seizure freedom as it reports only people with active epilepsy. The practice also provides prevalence data comparing those on the active epilepsy list with the total practice population which allows PCT's to verify that those with previous history of epilepsy have been excluded.

2.1.6 Record the seizure frequency for people over 18 years old

Epilepsy 6: The percentage of patients age 18 and over on drug treatment for epilepsy who have a record of seizure frequency in the previous 15 months [4 Points Payment stages 40-90%] Epilepsy 6 and 7 follow recommendations that practices record in the notes the seizure type and frequency including the date of the last seizure and details about medication such as current anti-epileptic medication and a record of previous adverse reactions to anti epilepsy medication. This recommendation is based on NICE clinical guideline [79] (2004)

'all individuals with epilepsy should have a regular structured review …in adults this review should be carried out at least yearly by either a generalist or a specialist.' This guidance therefore supports the current epilepsy indicators which are in essence the component parts of an annual structured review, where clinically appropriate.'

2.1.7 Perform an epilepsy medication review for people over 18 years old

Epilepsy 7: The percentage of patients age 18 and over on drug treatment for epilepsy who have a record of medication review involving the patient and/or carer in the previous 15 months [4 Points Payment stages 40-90%]

2.1.8 Identifying people on drug treatment for epilepsy who are seizure free over 18years old

Epilepsy 8. The percentage of patients age 18 and over on drug treatment for epilepsy who have been seizure free for the last 12 months recorded in the previous 15 months [6 points Payment stages 40-70%] Epilepsy 8 now applies to people over 18 yrs. old and has been maintained as the importance of seizure freedom is still stressed in the guidelines. The assumption that exception reporting will be fairly high in this group is reflected by the lower seizure freedom being set at 70% which in reality is relatively high. The aim is for GP's to record seizure freedom as accurately as possible.

2.2 Determine if proactive care in England for epilepsy can successfully become more complex within the Quality Outcomes Framework.

2.2.1 Ensure that women who are taking contraception medication are prescribed appropriate contraceptive medication

In 2011 the QOF epilepsy standards started to become more challenging and the request was given for GPs to assess carefully a women with epilepsy's anticonvulsant and oral contraception to ensure they did not interact thereby exposing the women to increase risk of seizures or of pregnancy.

Rationale for including a section of women and epilepsy

In the UK is estimated that there are 131,000 women with epilepsy who are of child bearing age (12 or over and under the age of 50) and one in 200 women attending antenatal clinics are receiving antiepileptic drugs[80]. Around 2500 women with epilepsy will have a baby each year in the UK. AEDs taken during pregnancy are associated with an increased risk of major congenital malformation. Women with epilepsy taking one AED have a chance of having a baby with a major congenital malformation of slightly over 3.5 per cent, which is higher than the background chance of 1-2% while those taking two or more anticonvulsants the level rises to 6%. [81]

In a survey of women with epilepsy, only 28 per cent of participants aged 19 between 19 and 34 years old had received information about oral contraception and epilepsy medication.[82] NICE clinical guideline on epilepsy recommendations as a key priority for implementation: "Women and girls with epilepsy and their partners, as appropriate, must be given accurate information and counselling about contraception, conception, pregnancy, caring for children, breastfeeding and menopause”.[83]

The Scottish guidelines for epilepsy states: "Advice on contraception should be given before young women are sexually active. Women with epilepsy should be advised to plan their pregnancies."[84] Primary care is well positioned to offer this advice and the addition of this standard is important if somewhat ambitious.

Epilepsy 9: The percentage of women under the age of 55 years who are taking antiepileptic drugs who have a record of information and counselling about contraception, conception and pregnancy in the preceding 15 months *[*3 points payment stages 40-90%.]

2.2.2 Offer prenatal advice for women with epilepsy

Also in Epilepsy 9 is the requirement for GPs to discuss issues relating to conception and an opportunity to review a woman's anticonvulsant medication if she is planning to conceive. The GP is directed to identify women who are taking an unacceptably teratogenic anti-epileptic medication and also gives the opportunity to talk about pregnancy.

2.3 A preliminary examination of national treads in mortality and hospitalisation during the Quality Outcomes Framework programme

2.3.1 Preliminary examination of mortality from epilepsy in England

The Office for National Statistics [ONS] publish data on avoidable mortality in England and Wales, and this includes deaths for epilepsy in age bands of 5 years for males and females. The author collected this data from the ONS web site[85] and collated it to provide direct mortality statistics .The Public Health Information Specialist at the Kent and Medway Public Health Observatory was contacted and kindly supplied under my guidance, the directly standardised mortality rates for epilepsy for 2001 to 2010 using the pooled data which I had collected. [See page 193] They supplied data which included using trend analysis (R^2) statistical analysis.

2.3.2 Preliminary examination of unplanned visits to hospital for acute problems arising from epilepsy

At the request of the author [see page 211] data on unplanned hospital attendance was collected from the Kent and Medway Primary Care Trust. The data was extracted from the Hospital Episode Statistics [HES] website which is described on the website as being

> *'a data warehouse containing details of all admissions, outpatient appointments and A&E attendances at NHS hospitals in England.'*[86]

To gain selective access of the very large volume of data a further computer software program was used called using a service provided by a program called 'Dr Foster Intelligence,' which their website describes as

> *'Dr Foster exists to make healthcare data better and help healthcare organizations improve the quality of care. We are the leading provider of healthcare information and benchmarking solutions in England – and increasingly, worldwide analyses HES data.'*[87].

The PCT have a subscription to use the website and kindly recovered the data used in the thesis under my direction. [Please see page 234.]

Evolution of the Standards set for Epilepsy in the QOF Framework

Updates made to QOF in 2006

In the same way that PRICCE was updated periodically the same has occurred with QOF and in 2008 the program was reviewed and the minimum age was raised from 16 years old to 18 years old. The reason for this was as a generalised a GP could treat long term conditions of adults however the view was taken that paediatricians should be in charge of epilepsy up to the age of 18 years old. Also as mentioned previously patients were now assessed against whether they were suffering from any form of seizure e.g. including absence attack, auras etc. rather than just being reported as being free from generalised convulsive seizures.

Update made for QOF in 2011[88]

The working group [including the author] recommended an additional standard in 2009 which was added in 2011[89] and was the percentage of women with epilepsy under the age of 55 who are taking antiepileptic drugs who have been given information and counselling about contraception, conception and pregnancy

Epilepsy Standard 9: The percentage of women under the age of 55 years who are taking antiepileptic drugs who have a record of information and counselling about contraception, conception and pregnancy in the preceding 15 months. (3 points)

Update introduced in 2012

In 2012 GPs were permitted to included telephone consultations as a method of reviewing people with epilepsy. This introduction follows a trend in Primary Care towards managing people's illnesses by telephone consultations rather than purely face to face consultations. The advantages and disadvantages of doing so are outside the scope of this thesis but it can be envisaged that it will be necessary to tailor make the review for people who find it hard to communicate effectively via the telephone[90].

Exception reporting for QOF

As income for practices was dependant on achieved in the QOF program exception reporting was introduced to QOF so that practices should not be penalised for having a practice population who were more difficult to manage than their neighbouring practices. The assumption was that to exception report the patient for not attending they would have not attended three appointments that year or had asked not to be included in the project. This facility to exception report patients by GP's was controversial but it was set in place so that a doctor was not penalised for having more difficult to control patients. Seizure control gives some indication of how effective the management of epilepsy is however and exception reporting was analysed closely by the health authority and if there were some practices who had exceptionally higher rates they were closely questioned to explain the reason for this.

Indicators to permit a person to be awarded an exception report.

There are occasions where people were exception reported for problems such as not attending appointments or frailty and this resulted in a lower denominator. In 2006 a clearer detail was provided on who could be exception reported and be excluded from QOF. This is provided to help remove GP's receiving financial penalties from underachieving targets for reasons outside of their control.

A. Patients who have been recorded as refusing to attend a review who have been invited on at least three occasions during the preceding twelve months.

B. Patients for whom it is not appropriate to review the specific chronic disease parameters due to particular circumstances e.g. terminal illness, extreme frailty

C. Patients newly diagnosed within the practice or who have recently registered with the practice, who should have measurements made within three months and delivery of clinical standards within nine months e.g. blood pressure or cholesterol measurements within target levels

D. Patients who are on maximum tolerated doses of medication whose level of outcome remain sub-optimal

E. Patients for whom prescribing a medication is not clinically appropriate e.g. those who have an allergy, another contraindication or have experienced an adverse reaction

F. Where a patient has not tolerated medication

G. Where a patient does not agree to investigation or treatment (and after a reasonable discussion or written advice they have given their informed dissent), and this dissent has been recorded in their medical records

H. Where the patient has a supervening condition which makes treatment of their condition inappropriate e.g. cholesterol reduction where the patient has liver disease

I. Where an investigative service or secondary care service is unavailable.

Achieved points as a percent of the points available for QOF.

As the administration of the QOF project was linked to the payment for performance by the practices there was concern that some practices may be penalised financially f they did not have any patients for certain clinical areas and so would not be able to claim the points as they had no patients pertinent to an indicator.

The end of year figures may therefore be at risk of misrepresenting the practices medical achievement. To allow for this the maximum number of points available for each practice were adjusted, effectively removing points from the calculation denominator where both of the following conditions apply:

- the practice does not have any patients in the indicator denominator.
- the practice has reported no exceptions for the indicator denominator

Hence using this calculation the indicator denominator plus indicator exceptions must equal zero. [91]

3 Study Three. Locally Enhanced Service for Epilepsy 1 (2005 – 2006)

First version of the Epilepsy Enhanced Service 2005-2006

[see page 243]

In Eastern and Coastal Kent Primary Care Trust GP's commented that the standards which were set by the Quality and Outcomes Framework were less exacting and indeed more basic than the standards set for the Primary Care Clinical effectiveness project. This would have led to the standards of proactive care for people with epilepsy to have gone down and so the author proposed a further study whereby GP practices were invited to raise the standards even higher for epilepsy. This would allow the author to assess how much more regular GPs were able to provide in support of people with epilepsy. This was provided in a Locally Enhanced Service. The pre requisite factors which were needed for QOF were also needed to be in place by the practices taking part in the enhanced program locally and like QOF contained the same components of

- Computerisation
- Incentivisation
- Education
- Support of audit team
- Peer pressure

All practices ran computerised data bases and were well versed in indexing accurately the medical records to facilitate accurate audit.

Incentivisation

In 2005/06 each practice contracted to provide this service would receive the following 'QOF' points in table2

Questionnaire to all patients with epilepsy	3
Women with Epilepsy	4
Driving	1
Social	3
Links to secondary care	4
Total:	15

Table 2 Points allocated to Epilepsy Locally Enhanced Service 2005/2006

Education

The education model was based on the suggestion made by the CSAG report on Epilepsy that a GP was nominated by the practice to take a lead for epilepsy. They had to attend basic training provided by the PCT [delivered by the researcher] that is provided as a prerequisite to providing this enhanced service. This is brief detail only, and only 1.5 hours. It was process driven with certificate of attendance rather than examination focused. The training was open to all of the practice clinicians and in practice was delivered to several of their team

The Introductory seminar contained the following topics;

- Introductory video session: seizures,
- Epidemiology of Epilepsy
- Basic functional anatomy of the central nervous system
- Overview of Epileptic Syndromes
- Medical Treatment of Epilepsy
- Some imaging techniques used to investigate epilepsy
- Female Issues relating to epilepsy
- Social Aspects of Epilepsy – Quality of life in epilepsy
- Marriage Epilepsy and the family

- Sudden unexpected death in epilepsy
- Employment
- Drivers' licenses

Audit support

The development of templates to both gather and to record information were developed by the PCT and offered to the practices to use. The audit leads in the practices taking part were by now expert in the skills required to run searches on their computer systems and they helped in the development of the audit tools which were shared by all participating practices.

Patient Questionnaire

The practices were asked to offer a questionnaire to patients regarding their epilepsy which was then handed in to the surgery to aid the identification of areas of need for the patient. If the patients required help to complete this form it was made available on request. Questions included in the questionnaire;

- Basic demographic details
- Question asking when they last saw their GP regarding
- Seizure frequency
- Details of any attendance to Accident & Emergency (A&E) as a result of their epilepsy
- For those who had been to A&E whether their GP had seen them as a result of this to review their epilepsy
- Details of their epilepsy medication
- Whether they drive
- If they are currently in paid employment with a supplementary question to those not in a job if they would wish so to be
- Whether they live alone

- If they have someone you consider a carer for that person’s details
- Asked if they had been made aware of the safety issues with regards to epilepsy?
- If no, would you like to receive more information regarding safety issues?
- The offer was given if they would you like to speak with someone with regard to your epilepsy? If they did who they would like to be placed in contact with e.g. GP, a GP who specialises in epilepsy or a specialist nurse,
- Whether they would like to receive emotional advice regarding epilepsy
- If they were under a hospital consultant for their epilepsy and if so who that was and when they were last seen

For children under 16

- If they were happy with the provision of help from their school with regard to their epilepsy.

For women aged 14 – 55

- Details of any contraception used
- If becoming pregnant is a real possibility whether they had talked about issues relating to pregnancy and epilepsy with their GP including advice of high dose folic acid

Data Collection and Verification

The achievements in reaching the set standards were self-reported by the participating practices. There was no formal process in place to validate the results and they were received in trust by the health authority. The results collected on an annual basis and submitted as pooled results to the PCT using an Epilepsy Local Enhanced Service Monitoring Sheet. Advice was also given on how to code the medical notes to allow for simpler auditing of the outcome of the consultations and of the services delivered to the patients. The service added the opportunity to gain extra 15 QOF points for the epilepsy component of QOF.

Peer Pressure

This was seen as being purely supportive and practices tended to pool useful tips together and would share templates between each other on an informal basis. It was not incentivised.

3.1 To determine if primary care can proactively identify social consequences of active epilepsy

Development of Templates

The practices were directed to provide more detailed datasets of their patients with epilepsy and care was extended to social care in addition to medical care alone. The practice should develop (or maintain if they already exist) templates for annual review of all patients [both paediatric and adult] with epilepsy to include the following factors.

This can be seen as an extension to the process used in PRICCE-2 and QOF to set a register in place at the start of the programme

Social factors [target 80% in year 1 and 90% in year 2]

3.1.1 Record driving status

There was no formal validation of this standard which was developed by the author. The rationale for choosing it was as a surrogate marker of well controlled epilepsy as it required people with epilepsy to be seizure free for a year. Also it was seen as a way of raising the profile of personal independence for people with epilepsy and the introduction of a wider holistic approach to epilepsy care by GPs.

3.1.2 Record social factors affected by epilepsy

This was an opportunity to identify areas where epilepsy is known to negatively affect social well-being and practices were given information leaflets and resources to help sign-post additional services if they identified areas of need. Included within this were education issues for paediatric patients and the encouragement to ensure that schools made adaption’s to the needs of children with epilepsy.

Employment status was also explored and again if someone with epilepsy felt they were be discriminated against they were given information of epilepsy and employment. Also the Royal British Legion employment service was recommended for those who required support to enter the workplace once more.

The social circumstance of the person with epilepsy was also explored and factors such as whether they lived alone or with family was noted in the patient health record. The isolation that can occur as a result of epilepsy was explained to the participating GPs at the preliminary educational session and GPs were encouraged to find clubs and societies for people who were lonely or socially isolated to join.

GP’s were also encouraged to discuss basic safety issues e.g. bathing, cooking, etc. and supply the patients with information which they could take away and referrer to later. The main leaflet used for this was the Epilepsy Action’s leaflet on safety.

For some of the people with epilepsy they may be still having problems with the stigma associated with the illness and this group of patients were offered counselling or an appointment with an epilepsy specialist to discuss further.

This area was selected by the author for use and did not follow any formal validation. As was true for driving status and epilepsy this standard was to facilitate a holistic approach to care rather than a simple medical one.

3.2 Women with Epilepsy: rationale and validation

One of the purposes of the Locally Enhanced Service for epilepsy was to allow local practices to continue with the higher standard of care they provided for women with epilepsy than was required for QOF. The justification and the validation of this section mirrors that which was used in the QOF section of women of childbearing age. [See page 92.]

3.2.1 Identify the number of women and children of child bearing age who have epilepsy

To take part in the locally enhanced service the practices were required to be conversant with the list of Anti-Epileptic Drugs (AEDs) that interact with the Oral Contraceptive Pill (OCP) – as tabulated in the NICE guideline for epilepsy. [Target 100%]. They also had to ensure that women of child bearing age were placed on an appropriate contraception if required [i.e. not on anti-convulsant medication that interacts with ICP, etc.]

The rationale for this is that this standard is the pre –requirement for more targeted support for women with epilepsy

3.2.2 Offer women and children of childbearing age folic acid

It was explained in the educational event that that folic acid at a dose of 5mg was useful in preventing neural tube defects for women of childbearing age and all women who could possibly conceive were offered it. The prescribing of folic acid was therefore a natural standard to include in this programme

3.2.3 Offer women and children of child bearing age pre conception advice

Women of child bearing age were asked if they intended to become pregnant in the near future and if so their anticonvulsants were reviewed to ensure that they were on the least teratogenic medication. If the GP discovered that they were taking a high risk anticonvulsant they were then referred to specialist epilepsy services to review their care and to see if less teratogenic therapy was possible. Also the need for a target of seizure freedom was highlighted and women were encouraged to aim for seizure freedom and referred when appropriate to specialist services.

Once again, the rationale for this was taken by the author directly from the PRICCE-2 programme and this was what the standard was validated from.

3.2.4 Ensure that women who are taking contraception medication are prescribed appropriate contraceptive medication

The participating practices were also asked to review the women of child bearing age who were using contraception to ensure that the method used was effective and did not interact with their anti convulsant medication.

Once again, this standard draws its origins from the PRICCE-2 project and rather than take a step backward in care following the less onerous requirements of QOF in the early years it was taken by the author as the basis to validate this standard.

3.3 Identify people with epilepsy under hospital care

At the time when the enhanced service was running, data from hospitals was still occasionally incomplete and GPs were required to ask the people with epilepsy if they were being seen in a specialist epilepsy clinic and indeed if so who they were under. This also gave the PCT information about the number of people who were receiving specialist care in each practice.

Also if the specialist clinic had recommended changes in anticonvulsant medication, the GPs were required to check that the medication titration and doses were correct. Also to ensure they had offered patients the therapeutic manoeuvres suggested by the clinics and had been seen to follow the suggestions outlined in the clinic letters. This was developed following the experience of running epilepsy clinics and witnessing patients returning who had not had these changes acted upon from one clinic to the next.

The validation for this was not from the literature but rather from observation by neurology colleagues and by the author. It was based on the experience of seeing that many people with epilepsy returned to out patient’s clinic with none of the recommended changes in their anti convulsant medication having been put into place from the last visit. This is not an ideal situation and is both inefficient use of specialist services but also potentially detrimental to the patient. This standard was aimed to identify people who were under hospital care and ensure that there was good shared care in place between the hospital and the GP.

Study Design: The outcomes of two practices compared

The original aim was for this study to take the form of a study which served as an extension of PRICCE-2 and shared with this first study its aim to explore the utility and uptake of an audit driven process of health care delivery at Primary Care level. The difference in this study was however that it took the level of care higher and involved the addition of social and psychological aspects of care for people with epilepsy. The results of the study were gathered electronically by the participating practices and collated in a pooled data set design by the PCT. This was then stored electronically onto the Eastern and Coastal Kent computer. The author was then allowed access to this pooled data after the health authority had calculated the payment due to the practice.

In addition results from two practices were compared in detail, both of whom had retained their complete data sets on their computer server. The data from these practices was delivered electronically to the author which allowed analysis to take place. They were both large practices and one held a GPwSI clinic for epilepsy whilst the other one did not. The data from these two practices had been collected by the practice staff but no verification process was utilised.

Analysis Plan and Loss of Local Data

As the original aim was to study effectively an extension of PRICCE-2 it shared with this first study its aim to explore the utility and uptake of an audit driven process of health care delivery at Primary Care level. The difference in this study was however that it took the level of care higher and involved the addition of social and psychological aspects of care for people with epilepsy. It was the uptake and implementation by individual practices in Eastern and Coastal which was being measured and so simple descriptive statistical analysis was chosen to evaluate the data.

Inferential statistical methods were not utilised as it was only the sample which was studied and there was at this stage no plan to extrapolate to the wider population of all GP practices in East Kent. The data collected by the health authority were stored on the Primary Care Trust [PCT] central offices and were to be downloaded by the author for further analysis. No analysis of the data was undertaken by the PCT. Unfortunately the data was deleted from the PCT server without the knowledge of the author or indeed the PCT commissioner Mrs Sheila Pitt who oversaw the programme from the PCT perspective. This occurred at a time of substantial upheaval with the merging of the East Kent PCTs and then the devolution of commissioning to the Clinical Commissioning Groups.

However the author managed to obtain achieved results from the two practices who still had their complete data sets stored on their practice computers.

The information sets were presented by the author in graphical format and the performance of the two practices was compared.

4 Study Four. Targeted Medicines Use Review for Epilepsy; Feasibility Study

This final study continues the lessons learnt in the first three studies and explores whether community pharmacists are able and willing to support people with epilepsy in the community. If builds on the work of PRICCE-2 and QOF in offering low input care to all people with epilepsy but also adopts the more advanced features of the Locally Enhanced Service for Epilepsy. The community pharmacists underwent training which was centred around the Medicines Use Review (MUR) for epilepsy and offered general community pharmacists the opportunity to deliver more advanced care for epilepsy. In addition to education the author also provided them with a source of literature which was linked specifically to the various components of the MUR and was supplied by Epilepsy Action. This ensured that the information given by the pharmacists to the patients was of a reliable and accredited standard.

In addition to this the community pharmacists were awarded referral rites to the GP with Specialist Interest clinics in the community for epilepsy. The referral could take place for defined parameters and was a step to include pharmacists into the primary care team. In contrast to the work with GPs the community pharmacists were working with little in the way of incentivisation with the payment for the completed MUR being part of their basic income.

There is arguably nobody better placed than the pharmacist to support people with epilepsy as they are easily accessible and are usually conveniently located in the community with pharmacies often being situated in the high street. It was not known if pharmacists could perform this task and the study took the form of a pilot to establish if this were possible and to gain an early insight into its effectiveness.

Overview of the method used to develop, run and analyse the medicines use review pilot.

As with the previous studies the components put in place were developed and the majority was developed by the author with support from the Medway School of pharmacy to help with providing a teaching environment that was familiar to the pharmacists.[see page 260] They also provided the information packs describing the project to the pharmacists who took part.[see page 272] The pre requisite factors which were needed to take part in the targeted MUR for epilepsy pilot were put into place and contained the same components of

- Computerisation
- Incentivisation
- Education
- Support of audit team
- Peer pressure

Computerisation

The community pharmacists utilise a database which is different to that of general practice and which in future work could possibly have been explored more. The patients were selected largely by the prior knowledge of the pharmacists, some were opportunistic and others were targeted from the pharmacy database. The MURs were completed using computerised template on the pharmacy computerised system.

Incentivisation

Unlike the primary care projects the community pharmacists did not receive any financial incentives above that which they could already receive but performing a routine non targeted MUR. The incentive for many was the prospect of using their skills to a greater degree than currently offered in the pharmacy. Also the opportunity to be involved in a pilot was an incentive for other.

Even though the project had very little cost involved permission was required from the local community pharmacy service commissioners who were consulted to explore whether this project was practicable and to gain their consent to its trial. Following this a wider series of meetings with the primary Care Trust and GP commissioners was made to gain their approval to go ahead with the project. A small amount of money was received to pay for the hire and refreshments needed on the educational event and also some back fill costs for locum pharmacy cover.

Education

Following their approval an invite to all community pharmacists practicing in Thanet, East Kent was sent out inviting them to take part. In order for them to be involved in the pilot they were asked to attend a training day for epilepsy run by the author at the Medway School of Pharmacy. The Training on Epilepsy was both developed and delivered by the author and the areas covered were;

- Classification of Epilepsy
- Basic neuroanatomy revision to assist the understanding for focal epilepsy
- Examples of different types of seizures – videos
- Revision of anti-epileptic medication
- Basic Epidemiology of epilepsy
- Mortality and epilepsy
- Women and epilepsy
- Sexual dysfunction and epilepsy
- Psychological consequences of epilepsy
- Epilepsy and the family
- Social aspects of epilepsy
- Employment and epilepsy
- Driving
- Referral Criteria to the Epilepsy Specialist services

During this training appropriate patient information leaflets were suggested to support the pharmacists when talking with the patients as supplied by epilepsy action and they were freely available on the day for the pharmacists to familiarise themselves with. Following the training the pharmacists split into groups and had a series of role plays where they practiced their skills with imaginary patients [role playing based on a series of scenarios that individuals were given to act from] and then their colleagues offered directed feedback on their performance. [See page 285]

Studying adherence of medication

A standardised method of assessing medication adherence was discussed and comprised the percentage of anti convulsant medication taken on the best week and on the worst week. The method added the number of times a week the medication was successfully taken at the appropriate time divided by the ideal number of times it should have been taken and then expressed as a percentage.

For example if a medication is taken twice a day the first line to check is how many of the morning tablets were taken in a good week and how many in a bad week. Then the same process for the evening dose. By adding the best morning and evening doses and dividing by 14 this can be turned to a best percentage adherence and the same then repeated for the worse week. This produces a range of adherence than can be shared with the patient and used to communicate in a numeric form between health care professionals Following this an agreed start and finish date for the project was set by the group of willing pharmacists and the project ran its course in October 2011.

Validation of the importance and inclusion of medicines adherence

The NICE Guidelines advising on medicines adherence[92] offers a case for including this area in medicines review and hence is a good candidate for the pharmacists targeted MUR for epilepsy. It states that between a third and a half of medicines that are prescribed for long-term conditions are not used correctly which represent both sub-optimal benefit for patients and also represents an economic waste of resource. Pharmacists are directly involved in the provision of medication to patients and it seemed appropriate for the author to include this area. The guidelines advise that non-adherence should not be considered the patient's problem as it often results from a failure to gain the patients intent to take the medication or from practical considerations which hinder the patient taking the tablets.

The pharmacists are trained to follow a patient-centred approach which encourages informed adherence with the identification of barriers to adherence.

Support by Audit team

To provide specialist advice above that supplied on the training day the author was available to offer support and advice to the community pharmacists in order to maintain a seamless link between the pharmacists and epilepsy services.

Steps were taken to avoid the key risks

1. Lack of expertise in epilepsy amongst the pharmacy team was acknowledged and addressed. There was an assessment questionnaire to assess the level of knowledge before the training and the subsequent questionnaire to assess the effectiveness of the epilepsy training. The standardisation of advice given by the community pharmacists was ensured by ensuring they shared information from the relevant Epilepsy Action patient support leaflets. This was seen as accredited information which was being imparted to the patient. The patients were able to take the leaflets home with them to ensure that information was not mistaken and could be referenced by the patient at a later date.
2. Overload the Intermediate Care Team – Space was cleared in the appointment to allow room for potential increase in the number of referrals and additional clinics earmarked if required.

3. Complaints of equality of care from people with epilepsy in other localities in East Kent. This is an inevitable problem with running a pilot of a new service however ensuring that the pilot is evaluated quickly to estimate feasibility for a wider roll out of the service will help to minimise this.
4. Daily and weekly pharmacy workload- There was a need to ensure that there is protected time for doing the epilepsy MURs and that the funding for the work done be guaranteed

Referrals to the epilepsy specialist services were received during this time and triaged by the author. Following the month's trial in October 2011 the outcomes were collated and a plenary meeting was help with those involved and with input from the Primary Care Trust and Clinical Commissioning Group to draw conclusions from the exercise.

Peer pressure

This was not incentivised and indeed the whole pilot rested on the laudable professionalism of the community pharmacists to take part. For many the opportunity to move out from the general work of community pharmacy dispensing was the only necessary trigger but contained in that was some degree of peer pressure to take part.

4.1 To determine the extent to which community pharmacists can be trained to proactively support people with epilepsy

The effectiveness of the training session was performed in a very simple manner with a series of questions which are outline below set to the community pharmacists both before and then after the training day. These questions were not validated and the numbers of pharmacists involved were small but it did help to gain a picture of whether the project could be feasible to develop on a larger scale.

The questionnaire used to assess the pharmacist's grasp of knowledge was developed pragmatically by the author and was not formally validated. The justification for this was that there was little time spare for a formal clinical knowledge examination and the results were used to help inform the pilot. If the study is extended, then it would be worth considering a more formalised assessment of pre and post training clinical acquisition of knowledge and also of skills in the clinical simulations.

4.1.1 To be able to answer an anticonvulsant query from a patient with confidence

The scenarios used were relatively simple ones, which the author developed to test the pharmacist's ability to answer a patient who was asking about issues relating to their medication. This process is currently one of the core features of the standard medicines use review. The clinical scenarios used which could reasonably be faced by any pharmacist supporting a person with epilepsy.

4.1.2 To become familiar with epilepsy classification and explain them to customers

This was assessed by a simple question presented at the start of the educational event and repeated at the end of the day and aimed to form a basic assessment of how well the pharmacists had grasped the basic classification of seizures. It was included to promote the uptake of information later on in the training session of basic seizure classification and the use of the leaflet by Epilepsy Action 'Seizures Explained.'[93]

4.1.3 To be able to advise a customer with epilepsy when they could re-apply for their driving licence

This question regarding eligibility to drive for a person with epilepsy and was specifically covered on the education program. It was used to promote the awareness of the need to have this information correctly at hand and later was a useful way to promote the booklet by Epilepsy Action 'Driving and Epilepsy.'[94]

4.1.4 Feel confident in being able to assess how well a patient was taking their anti convulsant medication

Community pharmacists are trained to assess patient medication adherence and this question was included to establish if this skill was already present at the start of the day and if it were possible to improve it further. Later on in the training event techniques for assessing this were discussed.

4.2 Determine if the advice given by the community pharmacists during a MUR was of benefit to the customers

This again was a simple assessment which was completed by the customers to the pharmacy before and after they had received a targeted MUR in epilepsy. The format was that of a simple questionnaire which although not a validated one, was very specific to the situation in which people with epilepsy could expect help from their community pharmacist. There were four questions to this questionnaire and its use on patients was approved by the Kent and Medway PCT research and audit team who considered that the questionnaire was being run on a basis of service evaluation. The fuller documentation for this is included in the appendix.

4.2.1 Improving their understanding of the underlying causes of epilepsy

The first question was to gain insight into the person with epilepsy’s knowledge of their condition. It offered some insight into how much understanding the patient had of their illness and if they knew how their epilepsy had been classified either in general terms or more specifically.

4.2.2 Understanding how to lessen the risk of having a seizure

It was not known if it would be possible to reduce the risk of a person with epilepsy suffering a seizure and this was asked before and after the MUR. This question was designed to see if the community pharmacists were able to empower the people with epilepsy and help them to better manage their own risks of having a seizure.

4.2.3 Determine if the customer was more likely to approach their pharmacist for advice about their epilepsy in the future

Having undertaken a targeted MUR for epilepsy it was interesting to see if the person with epilepsy in any way altered their prior view of the role of a community pharmacist. The questionnaires were anonymous and allowed the patients opportunity to be frank in their answers.

4.3 Determine if community pharmacists can recognise red flag symptoms to allow direct referral to specialist epilepsy services

The community pharmacists were taught in the education session about red flags for epilepsy and if they identified anybody who had one of these they were then asked to refer the patient to the community GPwSI epilepsy service. The referral form went to the GPwSI administrative centre and included a copy of the completed MUR plus the brief single sided referral form which explained the reason for the referral.

The referrals on reaching the GPwSI administrative centre were triaged by the author who communicated with them on a case by case basis about whether their referral fell into the criteria to be seen. The author is the clinical lead of the primary care epilepsy service and this would be true for all referrals to the service however temporary provision was put in place during the study by which both the community pharmacist and the patients GP were keep fully aware of the referral and the action s leading from the referral. It was also agreed that the first clinic letter would be sent to the community pharmacists [as well as to the GP and patient,] by way of feedback following the referral.

Referral to Specialist epilepsy services

In order to try and ensure that the number of referrals was to some degree controlled the author liaised with the PCT and agreed upon a set of criteria or ‘red flag symptoms,’ which were eligible to be refereed [see page 269]. The eligibility to meet the criteria for people who were over 16yrs and not under specialist epilepsy care already had to be met and the indications for referral were;

- Emergency admission to A&E or treatment by Paramedic Ambulance Service within the past 12months
- On-going seizures / worsening seizures.
- Pre-natal hazard identified in women receiving medication which is potentially teratogenic.
- Hazardous poor concordance of medication [taken as being estimated as less than 80%]

These red flags were pragmatically chosen by the author as being reasons where a referral to be seen in an epilepsy specialist clinic would be straightforward to establish and also on some degree of urgency. The referral criteria were then discussed by the local Thanet Clinical Commissioning Group and approved for the duration of the pilot.

Analysis Plan and Data Storage

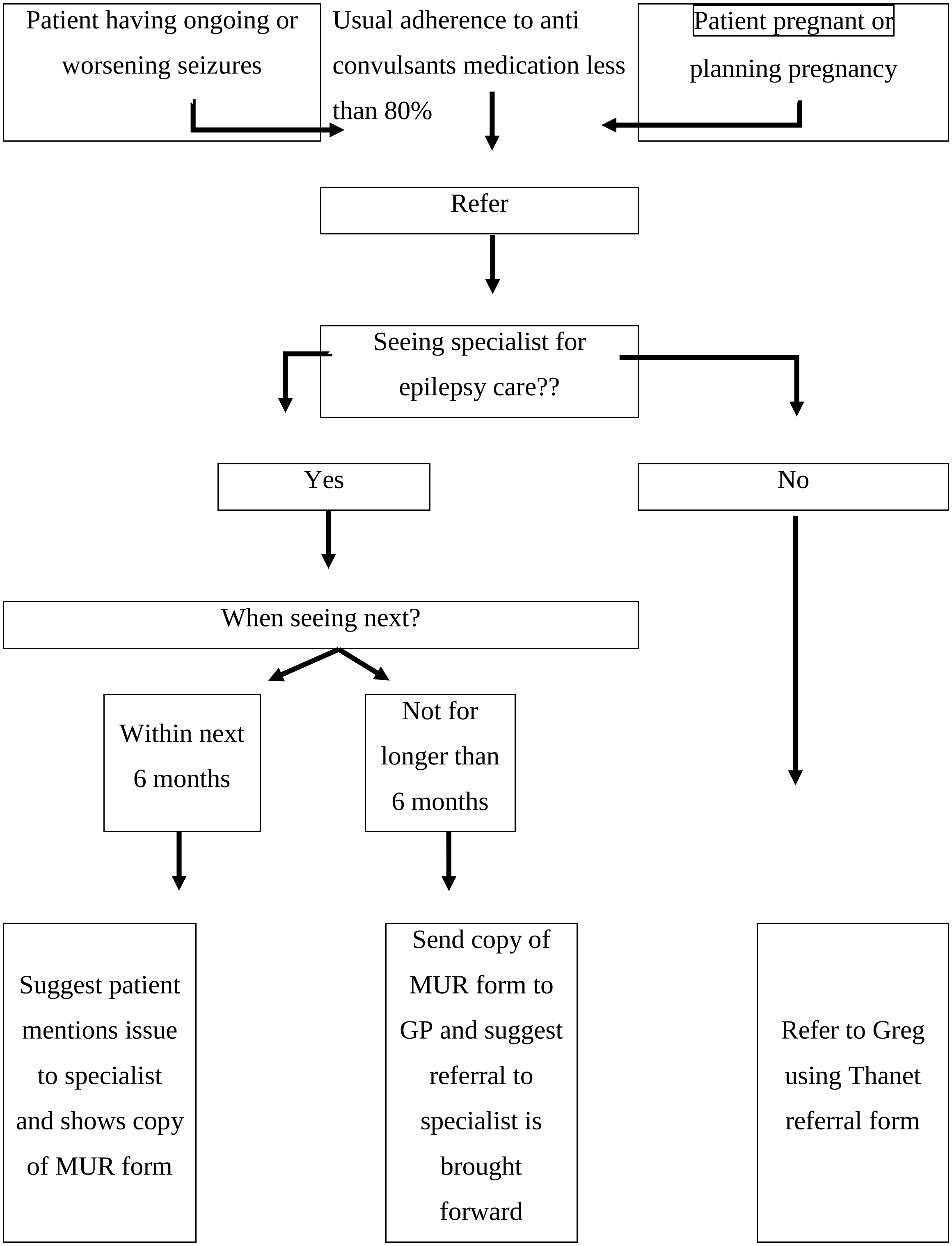
The overall aim of the targeted Medicines Use Review for epilepsy was to assess the utility and observe the novel method of health care delivery to support people with epilepsy delivered by community pharmacists. It was primarily a feasibility study of the assimilation and application of epilepsy knowledge by the community pharmacists which was measured and also the response to the input from patients. For this small pilot study simple descriptive statistical analysis was chosen to evaluate the data. As it was small pilot study aimed at probability theory was not utilised.

The pre and post education questionnaires were recorded on paper and the results held by the author. The MURs were conducted by the pharmacists and a copy of each of the reports was held by the health authority and by the author in paper format. The analysis was decided upon by Mrs Trudy Thomas Head of Post Graduate Education at Medway School of Pharmacy and the author. None of the questionnaires were validated however as this was primarily a feasibility study and the numbers were small. Inferential statistics would need too high a power to be feasible in this small locally funded study. The data sets were presented by the author in graphical format.

Support from the Under Secretary of state for Health – Paul Burstow

The author discussed the original idea of this study with Mrs Laura Sandys MP for Thanet South who is both his MP and also the Chair of the All Party Parliamentary Group on Epilepsy. She was keen to see the project put into action and discussed it with Mr Paul Burstow the under-secretary of state for health and he gave a written confirmation of his support to the local health authority managers. This helped to secure the funding necessary [£3,000] to undertake the study and a copy of this correspondence is enclosed in the appendix. [See page 283.]

The algorithm used for the referral process



RESULTS

1 Study One; Primary Care Clinical Effectiveness program, PRICCE-2

Non responders

For all of the aims in this section there was no information obtained to offer an insight as to what made a practice take part in the project. The management team [Medical Director and the East Kent MAAG] considered this to be due to practices who were not fully computerised and also due to the lack of expertise within the practices to accurately code their electronic records. This was not however formally assessed**.**

Aims,

1.1 Determine the extent to which participating primary care practices in East Kent are willing to be involved in basic proactive care for epilepsy using a disease register following the PRICCE-2 programme

In table 3 we see that the number of people identified as having epilepsy by the participating practices started off fairly low with practices initially in 2002 only identifying epilepsy as occurring in 0.27% of their practices populations however by the end of the program this number had been extended to 0.51% of the population who were identified as having epilepsy. In Figure 2 this figure can be seen to rise significantly as the practices become more adept at identifying patients reflecting that their disease registers where becoming more accurate. [For raw data please see Appendix page 219]

Year	Number of people included in the study	Percentage of the participating group with epilepsy
2002	986	0.27
2003	2605	0.48
2004	2969	0.51

Table 3 Percentage of People with all Epilepsy included by Participating practices for PRICCE-2

Year	The number of people with epilepsy reviewed	Percentage of people with epilepsy reviewed
2002	955	96.43
2003	2491	96.06
2004	2821	95

Table 4 Percentage of people with epilepsy reviewed with time for PRICCE-2

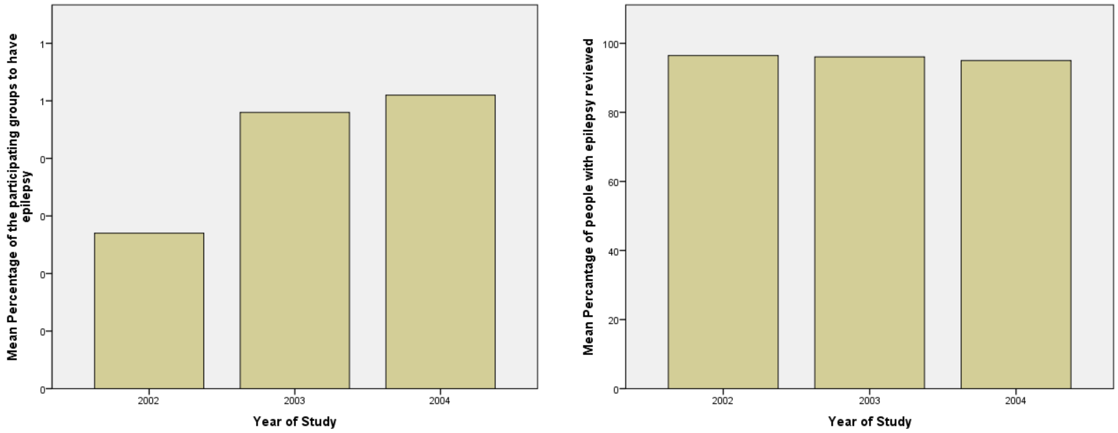


Figure 2 Graphs showing the percentage of people with epilepsy in the participating groups between 2002-2004 and the percentage of these who were reviewed.

1.2 Determine the extent to which participating primary care practices in East Kent are able to identify potential problems which can arise as a consequence of suffering from epilepsy

1.2.1 Identify people who are seizure free

Table 5 demonstrates how practices became more proficient at identifying people who were seizure free and as the numbers increased during the course of the study the percentage of people who found to be seizure free decreased slightly as demonstrated in figure 3. [For raw data please see appendix page 219.]

Year	Number of people Seizure Free	Percentage of People seizure free
2002	731	73.46
2003	1882	73.61
2004	2074	71.25

Table 5 Patients identified as being seizure free 2002 - 2004

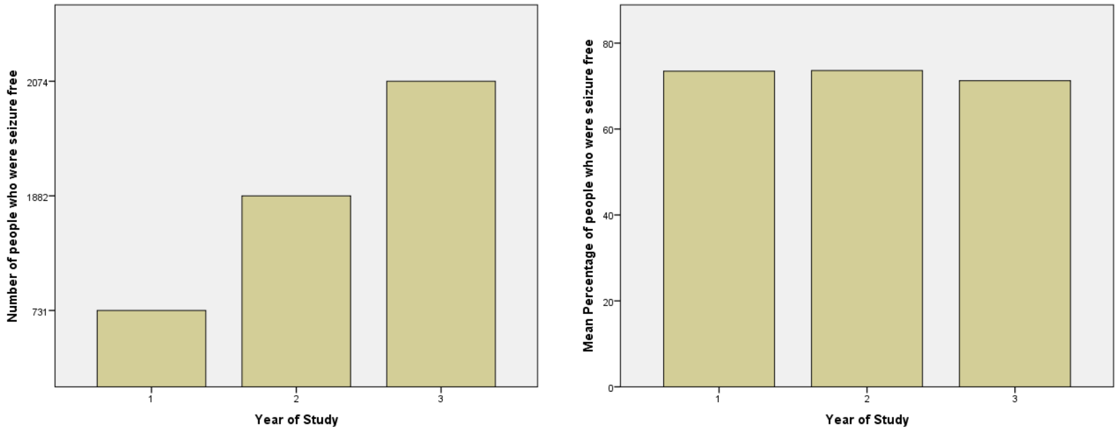


Figure 3 Graphs showing the number and percentage of people seizure free 2002 - 2004

1.2.2 Ensure the people who are taking vigabatrin have their visual fields measured

Vigabatrin

Table 6 demonstrate that GPs can proactively become able to identify people with epilepsy who are at risk of peripheral field visual loss as a result of the use of vigabatrin and is further represented in figure 4. This would arguably have been outside of the normal scope of the GPs. The trend over the 3 years of the study was for the number of people identified and to have completed visual field testing is to increase year on year. This supports the theory that if directed, GPs can perform more selective audit of their patients and oversee the necessary steps to minimise untoward risk from treatment with Vigabatrin. [For raw data please see appendix page 219.]

Year	Number of people with Epilepsy in Vigabatrin	Number of people on vigabatrin who had visual field tests in previous 6 months	Percentage of people on vigabatrin who had visual field tests in previous 6 months
2002	5	3	66.7
2003	18	10	54.16
2004	21	12	55.95

Table 6 Review of people with Epilepsy on Vigabatrin for PRICCE-2 2002-2004

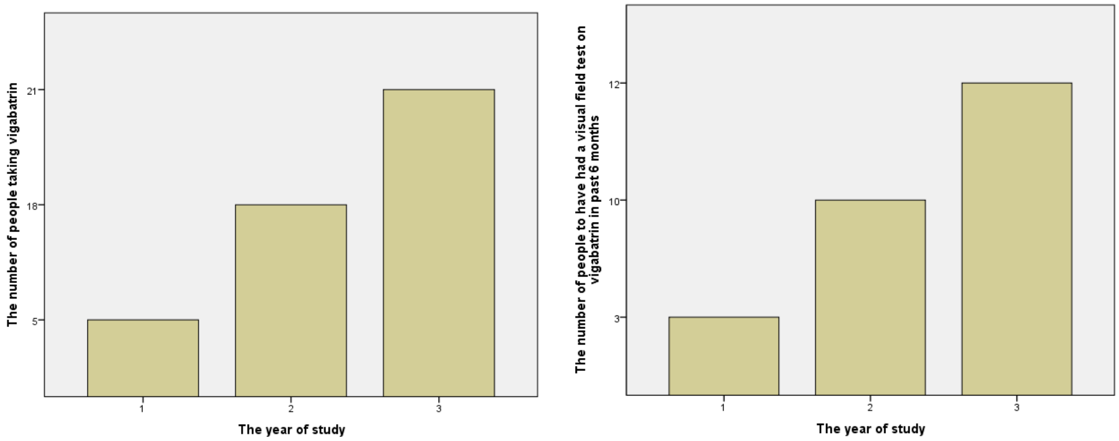


Figure 4 Graphs showing the number of people identified as being on vigabatrin and the percentage to have received a visual field examination in the previous 6 months

1.2.3 Identify women who are pregnant and also have epilepsy

Pregnancy

Women with epilepsy were proactively identified by the project and as a result received a program of care as prescribed by the PRICCE protocol. [For raw data please see appendix page 219.]

Year	Number of women with epilepsy who were pregnant
2002	11
2003	21
2004	16

Table 7 Women identified during the PRICCE project as being pregnant

The results in table 7 above demonstrate only limited success in that the numbers reported are low and the practices ability to identify and proactively manage women with epilepsy and who were pregnant did not improve during the course of the project. The denominator for the quality standard was not known however can be extrapolated from work conducted at this time on the pregnancy rates for people with epilepsy.

1.2.4 Ensure women and children of childbearing age are taking folic acid

Number of Women on folic acid

With doubt cast onto the accuracy of GPs to record and monitor pregnancies in women with epilepsy the study of whether they can reliable offer folic acid supplementation to this group is called into doubt. Table 8 below presents the number of women who finally received folic acid supplementation in pregnancy and the results are a good deal lower than were to be expected. [|For raw data please see appendix page 219.]

Year	Number of women receiving folic acid	Percentage of pregnant women on folic acid
2002	8	71%
2003	13	67%
2004	12	81%

Table 8 Number of pregnant women with epilepsy receiving folic acid

No specific cause was identified at the time which helped to understand why the adoption of this standard was so low by the participating GP practices.

1.2.5 Ensure that women who are taking contraception medication are prescribed appropriate contraceptive medication

Women with Epilepsy who have had their contraceptive checked

The results for this standard are recorded in table 9 below.

Year	Number of women on enzyme inducing AED and oral contraceptive	Number of women in whom no change was required	Percentage of women who required no change in contraception
2002	19	9	57
2003	25	24	100
2004	53	24	19

Table 9 **Women on oral contraception who have had their contraception checked**

These results appear to reveal that the number of women to have their anticonvulsant checked increases during the project however the outcome of this check seems to vary widely. In 2004 only around half of the women appeared to be taking adequate contraception however the year before none of the women appeared to require a change. Also the number of women included for this standard in the PRICCE-2, project appear to be very low in number. In table 14 it would seem that there were over 150 women with epilepsy and in the peak of fertility [aged 25-34yrs] and many more who were of child bearing age as presented in table 10 below. [For raw data please see appendix page 219.]

Year	**Total female population included in PRICCE-2**	**Total number of women aged 15-44yrs included in PRICCE-2**	**Total number of women aged 25 - 34yrs**	***Expected number of women with epilepsy aged 25-34 ****	**Total number of women included in PRICCE-2 aged 15-44**	***Expected number of women aged 15-44 in PRICCE-2 to have epilepsy****
2002	238591	85843	27327	139	85843	438
2003	303135	103707	32939	168	103707	529
2004	292251	104822	31828	162	104822	535

* using the prevalence recorded in 2004 of 0.51% of the population with epilepsy

Table 10 Number of women included in PRICCE-2 who were of child bearing age

1.3 A preliminary examination of local trends in hospitalisation.

1.3.1 A preliminary examination of trends in unplanned visits to hospital for acute problems arising from epilepsy

The national trend over the previous decade for unplanned epilepsy admissions was fairly stable [95] but at the time of the PRICCE project the numbers admitted appears to be increasing as demonstrated in figure 5 below. The numbers admitted does seem somewhat erratic and may reflect poor quality data however with epilepsy featuring in the admission data regardless of whether an admission was primarily due to the epilepsy. [For raw data from Eastern and Coastal Kent PCT please see appendix page 232.]

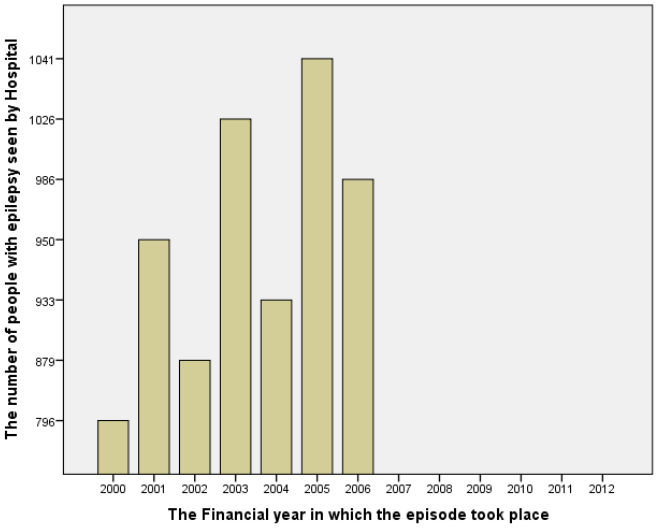


Figure 5 **The number unplanned visits to hospital for acute problems arising from epilepsy**

2 Study Two; The results from the Quality and Outcomes Framework

The results for QOF are collected and published by the department of health. [See page 235] The results obtained in this manner have supplied the results for the aims listed for QOF below.

Non-participating Practices

There was no formal study on practices who did not take part in the Quality and Outcomes Framework project however the participation in the UK of practices has remained very high with very few practices not being involved[96]. Although the participation by practices in QOF is voluntary, a large proportion of income for the practices rests upon joining in with the framework of care and largely ensures participation. In addition league tables are available to the general public which quote the practices performance in QOF as a marker of quality of care. This too is a strong incentive for practices to take part.

2.1 Determine the extent to which primary care practices in England are willing to be involved in basic proactive care for epilepsy using a disease register following the QOF programme

2.1.1 Produce a register for people with epilepsy who are receiving treatment for epilepsy and are over 16 years old.

Just as was seen in PRICCE-2 the uptake of QOF by practices in England was swift and widespread. The amount of information obtainable varied a little in the earlier years of QOF with detailed information available England in 2004/05 [97] and 2005/06.

The results taken from these QOF statistical publications revealed that

- The number of practices involved was 8576 with 119,168.3 epilepsy points achieved representing 86.8% of the total achievable for Epilepsy 1-4
- This uptake was improved further in 2005/2006 with an average of 93.7% of the available points being achieved for Epilepsy 1-4

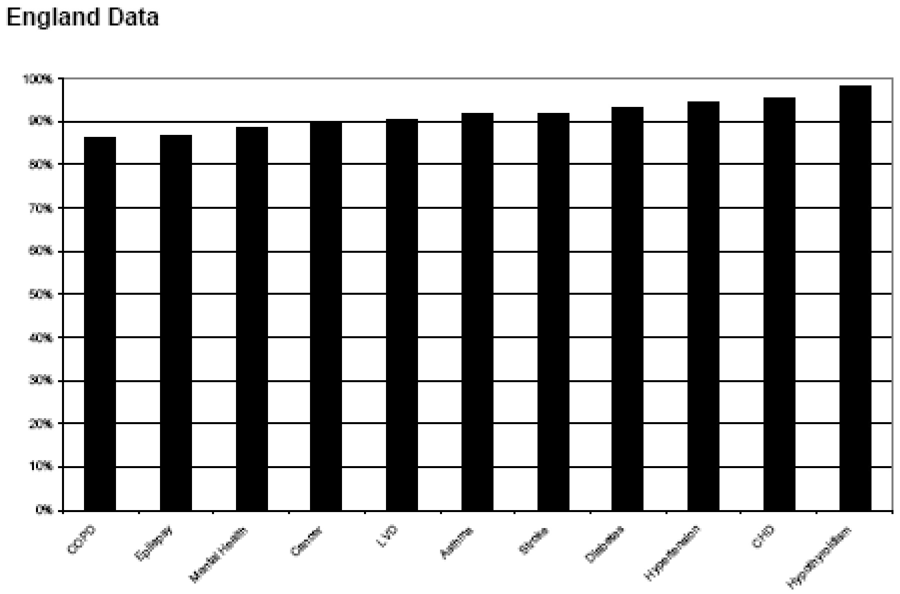


Figure 6 The uptake of QOF areas by practices in England 2004/05

Whilst the uptake was remarkably good the results from the English practices revealed that the least successful clinical areas were chronic obstructive pulmonary disease (COPD) and epilepsy (figure 6.) From April 2006 onwards more information was available and allows greater analysis as is tabulated below

QOF Achievement for Epilepsy 1 (alongside data for seizure frequency for people over 18 years old from 2008) [For raw data please see appendix page 235.]

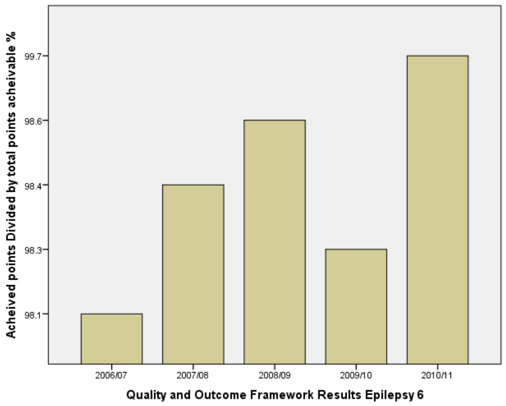
Year	**Achievement**
2004/05	86.8 total average
2005/06	93.7 total average

2006/07	99.9
2007/08	99.9
2008/09	99.9
2009/10	99.6
2010/11	99.8

These results reveal that not only is Primary care willing to be involved in basic proactive care it is able to engage and identify problems arising from epilepsy as measure by the Standards involved with seizure frequency, and medication review [Epilepsy Standards 6, 7 and 8 from 2006 onwards.] [For raw achievement figures please see page 235.]

2.1.2 Record the seizure frequency for people over 16 years old (alongside data for seizure frequency for people over 18 years old from 2008)

The ability for practices to become organised and able to record the seizure frequency for people with epilepsy steadily increased from 2006 to 2011 as illustrated in figure 7 below and laid out in table 11.



Quality and Outcome Framework Results Epilepsy 6		
	Achieved/Available%	Sum of indicators/Sum of denominators%
2006/07	98.1	95.6
2007/08	98.4	95.6
2008/09	98.6	95.6
2009/10	98.3	95.3
2010/11	99.7	95.6

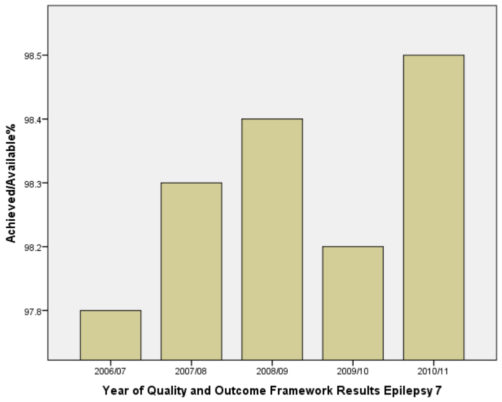
Figure 7 Ep 6 Achievement 2006-2011

Table 11 Ep 6 Achievement tabulated

These results demonstrate very clearly that practices are highly successful in identifying the frequency of seizures for people with epilepsy in their practice. [For raw data please see appendix page 235

2.1.3 Perform an epilepsy medication review for people over 16 years old (alongside data for seizure frequency for people over 18 years old from 2008)

In addition to being able to determine a patient's seizure frequent the GP practices were also able to invite patients in on an annual basis and ask them if they had any side effects of indeed other issues relating to their anti-convulsant medication. Although this standard is process driven it does begin a process whereby a person with epilepsy can express their satisfaction or otherwise of their epilepsy treatment in a proactive fashion. [Figure 8, Table 12.]



Quality and Outcome Framework Results Epilepsy 7		
	Achieved/Available%	Sum of indicators/Sum of denominators%
2006/07	97.8	95.2
2007/08	98.3	95.2
2008/09	98.4	95.2
2009/10	98.2	95
2010/11	98.5	95.2

Figure 8 Ep 7 achievement 2006- 2011

Table 12 Ep 7 achievement tabulated

Practices are highly successful reviewing the anti-convulsant medication for people with epilepsy in their practice.

2.1.4 Identifying people on drug treatment for epilepsy who are seizure free over 16years old (alongside data for seizure frequency for people over 18 years old from 2008)

Identifying people who were seizure free was somewhat harder and practices were only just able to achieve the 70 % target for this as demonstrated below in figure 9 and table 13.

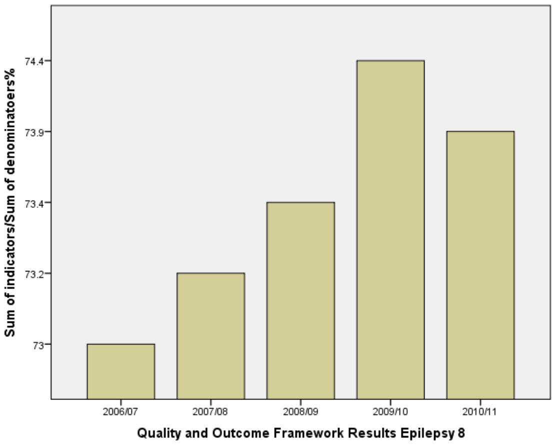


Figure 9 Ep 8 achievement 2006 - 2011

Quality and Outcome Framework Results Epilepsy 8		
	Achieved/Available%	Sum of indicators/Sum of denominators%
2006/07	87.3	73
2007/08	88	73.2
2008/09	88.8	73.4
2009/10	89.1	74.4
2010/11	89.5	73.9

Table 13 Ep 8 achievement tabulated

The level of seizure freedom has risen modestly over the 5 years of the program rising from 73% in 2006 to 73.9% in 2011

In 2006 the program was reviewed and the minimum age was raised to 18years old

The results from 2006 onward only included people who were 18 years old and older rather than the previous figure of 16 years. This had little effect on the data overall and have been grouped together in the figures and tables seen above. The areas affected by this age change are as follows;

1.1.1. Produce a register for people with epilepsy who are receiving treatment for epilepsy and over 18 years old
   - *Data included in 3.2.1.*

1.1.2. Record the seizure frequency for people over 18 years old
   - *Data included in 3.2.1.1*

1.1.3. Perform an epilepsy medication review for people over 18 years old
   - *Data included in 3.2.1.2*

1.1.4. Identifying people on drug treatment for epilepsy who are seizure free over 18years old
   - *Data included in 3.2.1.3*

[For raw data please see appendix page 235.]

2.2 Determine if proactive care in England for epilepsy can successfully become more complex within the Quality Outcomes Framework.

2.2.1 Ensure that women who are taking contraception medication are prescribed appropriate contraceptive medication –Epilepsy 9

2.2.2 Offer prenatal advice for women with epilepsy – Epilepsy 9

> *“Epilepsy 9. The percentage of women under the age of 55 years who are taking antiepileptic drugs who have a record of information and counselling about contraception, conception and pregnancy in the preceding 15 months”*

The introduction of Epilepsy 9 as a marker is still relatively early on it it’s development but the first year of use has now been reported and like PRICCE-2 reveals that this has been quite a challenge for practices to achieve. It has the second highest exception report rate of 36.7% [For raw data please see appendix page 235.]

A detailed breakdown of Epilepsy QOF 2011/12 is not available at the time of writing this thesis

Exception Reporting

Exception reporting was introduced to offer a legitimate way forward for GPs to maintain their income when faced with a population who have epilepsy which is difficult to control. It is a way of allowing doctors not to be penalised for having hard to treat patients on their practice register however it can also have the potential of being used where targets need to be met and the practice are slightly short of the target. It is a clinical judgement invariably on who is on the maximum tolerated treatment or who is deemed as ‘not suitable,’ to include in the QOF analysis. To help counter this the exception reporting percentages between neighbouring practices are compared and a practice who is using this route more than their peers explored in greater depth.

There are visits paid by the PCT twice a year and now for yearly to assess the data quality and check that correct protocol is being used.

Exception reporting has been going down however it has risen again of late and this figure is difficult to interpret. [Figure 10]

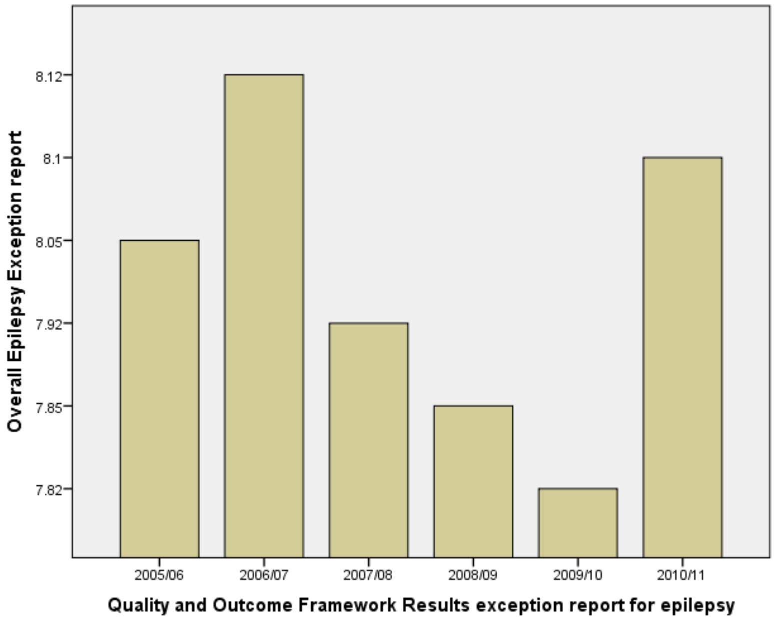


Figure 10 Overall exception reporting rate for epilepsy 2005 - 2011

Exception reporting for Epilepsy 8 [percentage of patients reported as being seizure free] The exception reporting rate the more challenging standard of achieving seizure freedom in 70% of the included practice patients with epilepsy is higher than the overall exception reporting rates as indicated in figure 11.

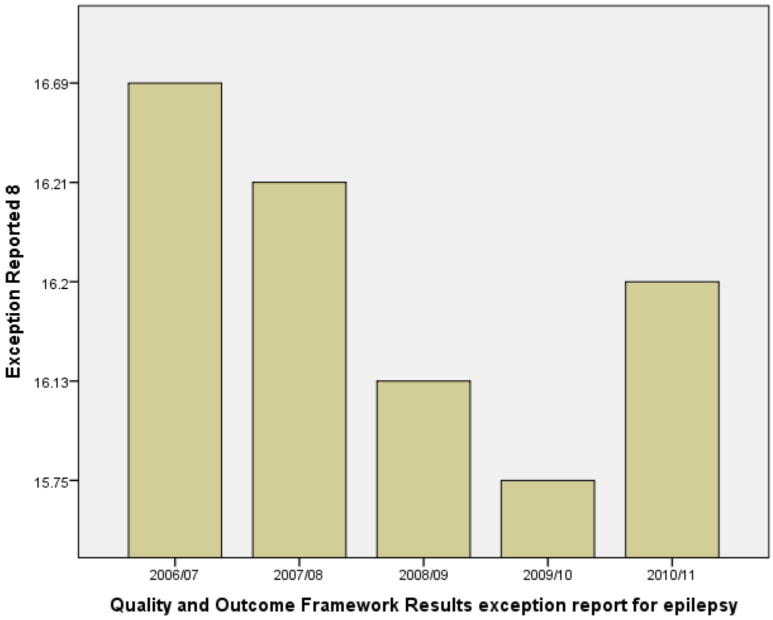


Figure 11 Exception reporting for Epilepsy 8 2006 - 2011

Tabulated results of seizure overall exception reporting and in particular the challenging Epilepsy 8 (70% seizure freedom) as demonstrated below in table 14.

	Overall Epilepsy Exception report	Exception Reported 8
2005/06	8.05	
2006/07	8.12	16.69
2007/08	7.92	16.21
2008/09	7.85	16.13
2009/10	7.82	15.75
2010/11	8.1	16.2

1.2. Table 14 Quality and Outcome Framework Results exception report overall compared to epilepsy 8

[For raw data on exception reporting please see page 225.]

2.3 A preliminary examination of national trends in mortality and hospitalisation during the Quality and Outcomes Framework programme.

2.3.1 A preliminary examination of trends in mortality from epilepsy in England

The mortality rates for England and Wales have been static for many decades but over the past 3 years they appear to be reducing. It is hard to estimate how much of this is due to the Primary Care increasing involvement in the long term management of epilepsy but it may reasonably be considered as a factor. The figures obtained in figure 12 were obtained from public health data for England and are not age standardised. The R^2
un-standardised regression coefficient is 0.531 as demonstrated in table 19 where p=0.01

[For information on the raw data please see the appendix 214.]

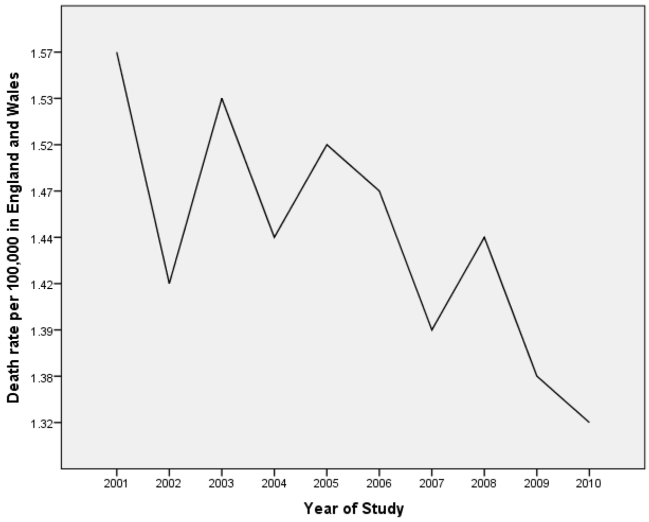


Figure 12 Death rate for both sexes per 100,000 in England and Wales

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.764[a]	.583	.531	.05234

a. Predictors: (Constant), Year of Study

ANOVAa

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	.031	1	.031	11.186	.010[b]
	Residual	.022	8	.003		
	Total	.053	9			

a. Dependent Variable: Death rate per 100,000 in England and Wales

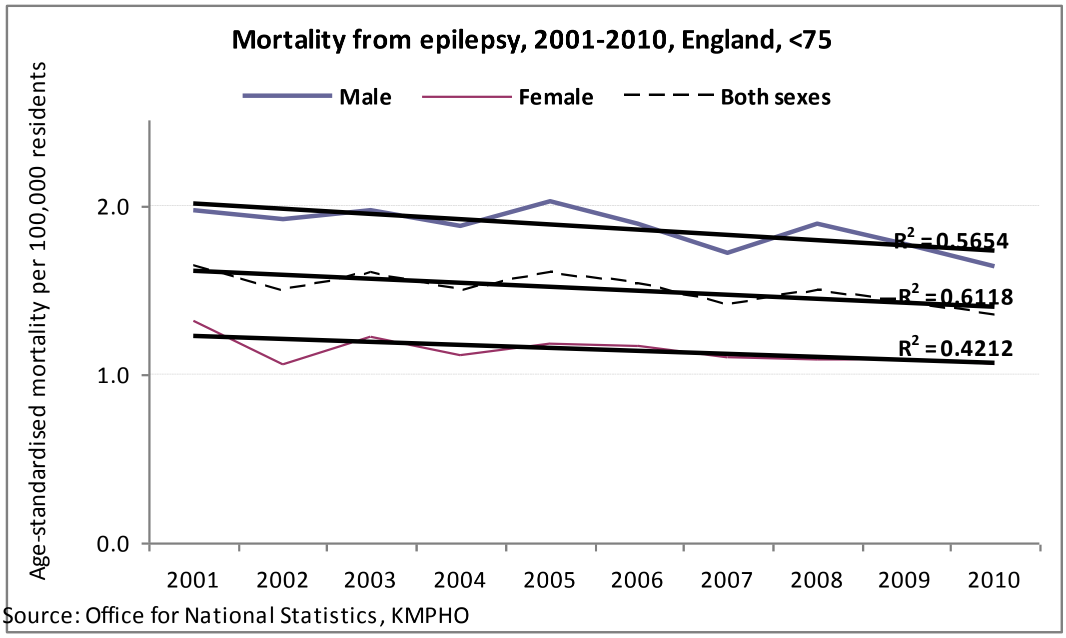
b. Predictors: (Constant), Year of Study

Table 15 Tabulated regression analysis of mortality rates 2001-2010

To obtain age standardised mortality rates the author approached the public health observatory to assist in producing age standardised data which is presented in figures 13 to 19 below and this confirms the trend for deaths from epilepsy to be decreasing over the past 10 years. This represents the first time since accurate records have begun that the mortality for epilepsy in the UK is decreasing. The mortality rates appear to be a downwards trend, more noticeable among males than females, with gender rates converging over the period. [For the correspondence with this group please see appendix page 211.]

The Public Health Observatory for Kent and Medway confirmed these findings as follows;

Figure 13 Mortality from epilepsy 2001 – 2010 [age-standardised]



Source: Office for National Statistics, KMPHO

	Year / directly age-standardised mortality per 100,000 residents aged under 75										
Population	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**	
Male	**1.96**	**1.91**	**1.97**	**1.88**	**2.02**	**1.89**	**1.72**	**1.89**	**1.76**	**1.63**	
Female	**1.32**	**1.07**	**1.22**	**1.12**	**1.18**	**1.17**	**1.11**	**1.09**	**1.09**	**1.06**	
Both sexes	**1.64**	**1.48**	**1.59**	**1.50**	**1.60**	**1.52**	**1.41**	**1.49**	**1.42**	**1.34**	
Source: Office for National Statistics, KMPHO											

	Year / numbers of deaths aged under 75									
Population	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**
Male	**459**	**449**	**469**	**449**	**489**	**461**	**424**	**468**	**440**	**411**
Female	**317**	**253**	**296**	**274**	**288**	**287**	**275**	**268**	**280**	**269**
Both sexes	**776**	**702**	**765**	**723**	**777**	**748**	**699**	**736**	**720**	**680**
Source: Office for National Statistics, KMPHO										

Table 16 Mortality from epilepsy – age standardised for 2001 - 2010

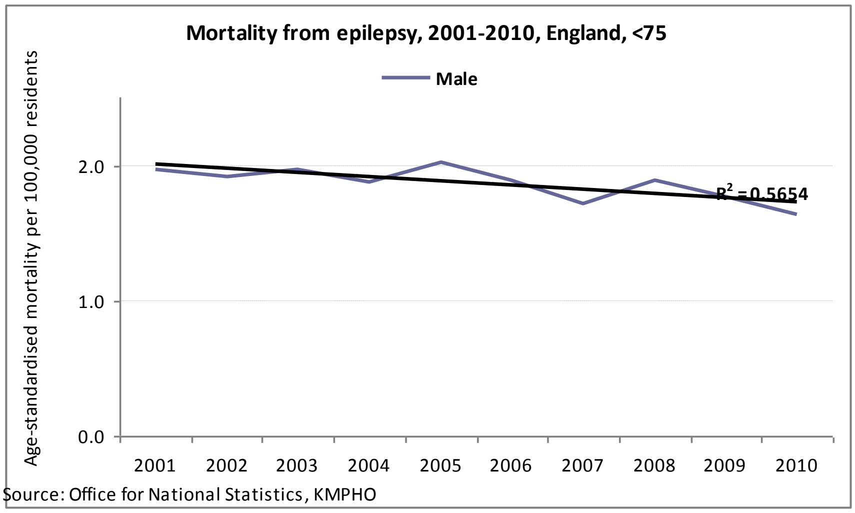


Figure 14 Mortality from epilepsy – age standardised for males

[For data as sent to author by the Kent and Medway PHO please see appendix page 216.]

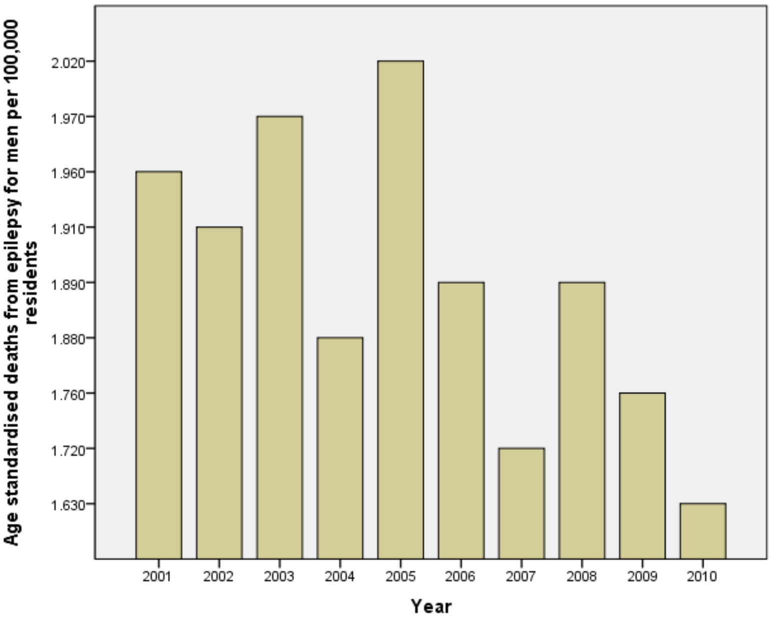
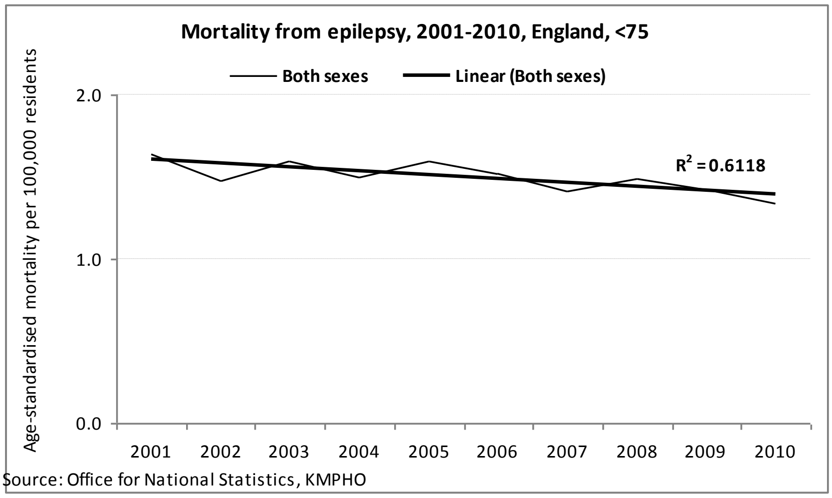


Figure 15 Graph representing mortality from epilepsy – age standardised for males

The reduction in mortality rates for men appears to have taken place towards the second half of the decade.



Source: Office for National Statistics, KMPHO

Figure 16 Trend analysis for mortality from epilepsy – both sexes

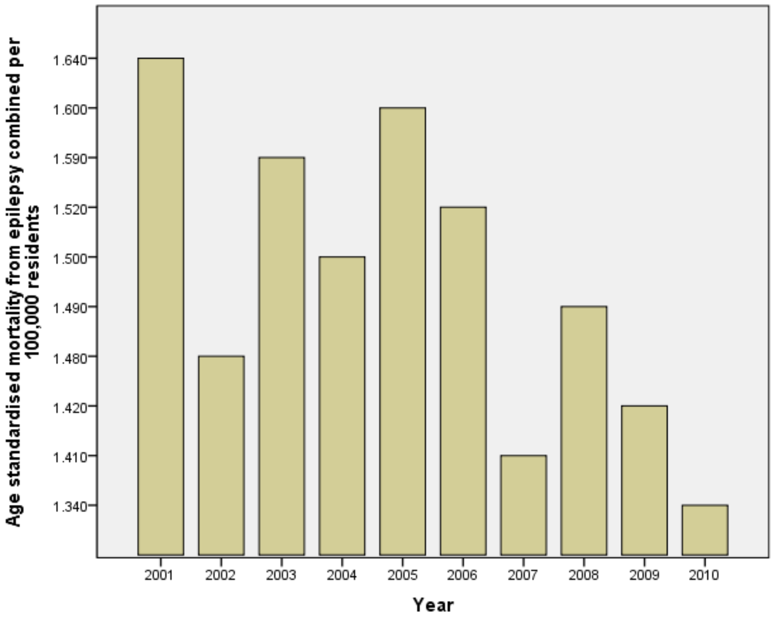


Figure 17 Graph represent the age standardised mortality for epilepsy for both sexes

The early part of the decade had a somewhat erratic mortality rate however the second part of the decade shows a trend for the combined mortality rate to have reduced over this period starting around 2005 and continuing to the end of the decade.

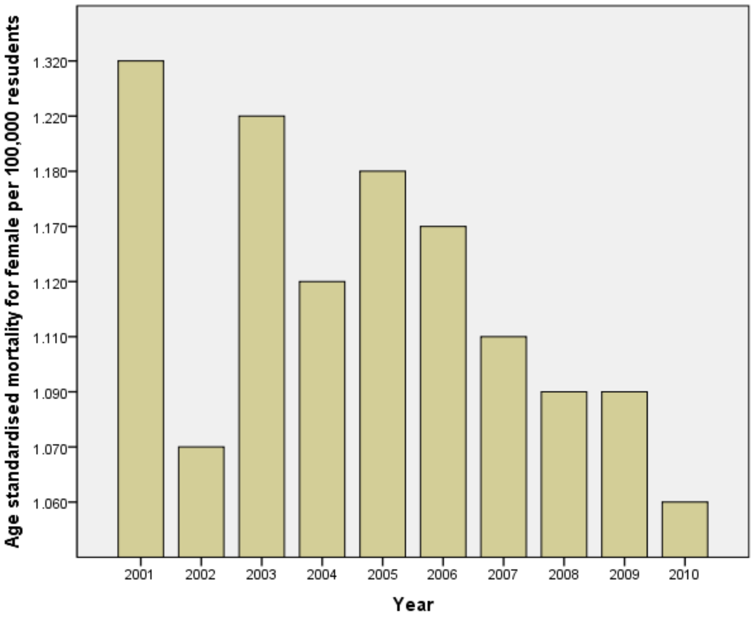


Figure 18 Mortality from epilepsy – age standardised for females

The reduction in mortality rates for women appears to have taken place towards the second half of the decade and the low rate in 2002 has weakened the trend analysis.

Source: Office for National Statistics, KMPHO

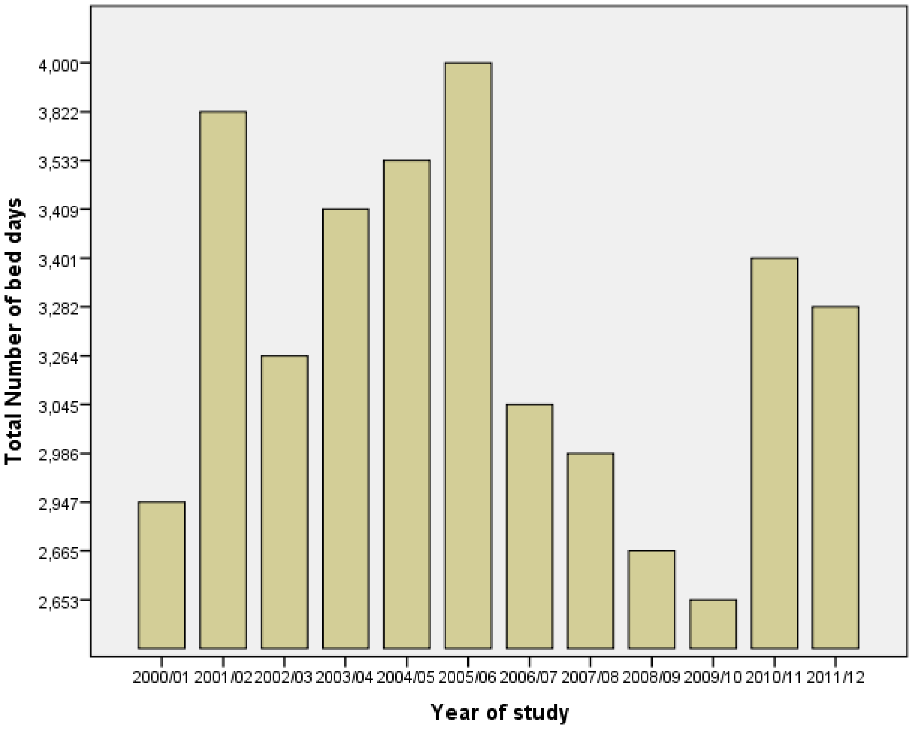
Figure 19 **Graph demonstrating trend analysis for mortality from epilepsy – age standardised for females**

2.3.2 A preliminary examination of trends in unplanned visits to hospital for acute problems arising from epilepsy

To obtain this data required support from the Primary Care Trust [see page 241] information team and using Dr Foster hospital analysis data they supplied the information in figures 20 and 21 which is also tabulated in tables 17 and 18. The data first describes the number of actual admissions for epilepsy as displayed in figure 20 and also reports the number of people seen in hospital for epilepsy but not necessarily admitted in figure 21.

Hospital Admission rate for East Kent

Table 17 Bed Days



Total bed days for epilepsy from 2000 to 2012

Year	Total Bed days
2000/01	2947
2001/02	3822
2002/03	3264
2003/04	3409
2004/05	3533
2005/06	4000
2006/07	3045
2007/08	2986
2008/09	2665
2009/10	2653
2010/11	3401
2011/12	3282

Figure20 **Epilepsy Admissions for East Kent PCT from Epilepsy [all bed days]**

The number of bed days has been steadily reducing until 2010 and from here the number has risen sharply. This rise in admissions coincides with the opening of the neurology unit at Kent and Canterbury hospital with the addition of a video telemetry service. By looking at the number of 'epilepsy spells,' the figures are steadily rising with time for East Kent which represents the number of unplanned attendances to A&E.

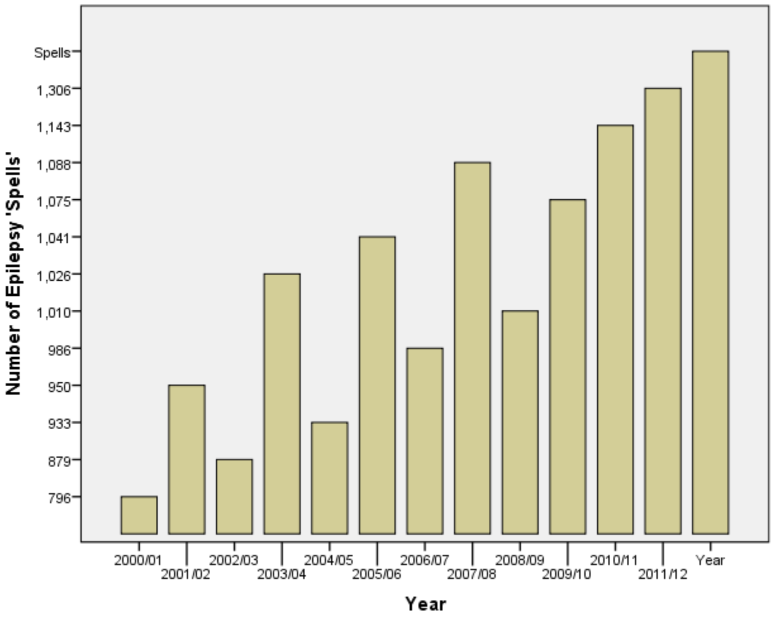


Figure 21 Graph of epilepsy spells per year

Total bed days and 'epilepsy spells' for epilepsy from 2000 to 2012

Year	Total Bed days	Spells
2000/01	2947	796
2001/02	3822	950
2002/03	3264	879
2003/04	3409	1026
2004/05	3533	933
2005/06	4000	1041
2006/07	3045	986
2007/08	2986	1088
2008/09	2665	1010
2009/10	2653	1075
2010/11	3401	1143
2011/12	3282	1306

Table 18 Bed days + Spells

This represents a general increase in the number of people being seen for epilepsy by the East Kent Hospitals.

[For raw data please see appendix page 232.]

3 Locally Enhanced Service for Epilepsy

Loss of data

The data which was collected by surgeries and organised onto an Excel spreadsheet designed by the PCT was submitted at the end of the financial year and placed onto the Canterbury and Coastal PCT computer system. The data was then pooled by the technical team there and processed to identify payment due to the practices following their achievements in the epilepsy care according to the standards set in the LES. Following this the data was to be made available to the author for analysis following the study design as laid out in the aims of this thesis.

Unfortunately this coincided with the merging of the local Primary care trusts into one single one call East Kent PCT ad in the merger the data was deleted from the health authority’s computer before the author had opportunity to analyse it. A search was conducted for several months to try and track down this data by myself and the PCT information technology team and the Long Term Conditions commissioning team but unfortunately none of the data could be rescued.

The pro-forma of the spread sheets is included in the appendix please see page 250 .

Data compared from two practices

Two large practices retained the information they had submitted for the Locally Enhanced Service for Epilepsy [LES] and this was made available to the author for further analysis. Practice A had prior expertise in epilepsy [the author being based there] and Practice B had no special grounding in epilepsy but received basic training in epilepsy by the author as a pre requisite to take part in the LES.

Practice B is noted to be very well organised and the majority of its partners have gained Fellowship status on the Royal College of GPs. Practice A started before Practice B but found the work involved too onerous and stopped completing the LES after their second year in 2007. Practice B had less difficulty and continued on until the withdrawal of the service in 2009

3.1 To determine if primary care can proactively identify social consequences of active epilepsy

3.1.1 Record driving status

The results from Practice A and Practice B are displayed in table 19 below and show that practice B were able to identify nearly twice as many drivers with epilepsy than practice A. [For full set of data please see appendix page 251 for practice A and page 253 for practice B.]

Approval from the Research and Development lead to use the pooled data is recorded in the appendix page 255

year	Practice A List size	Practice B list size	Practice A people with epilepsy	Practice B People with epilepsy	Practice A prevelance	Practice B Prevelance	Practice A med, age and sex recorded	Practice B Med,agd and sex recorded	Practice A driving status	Practice B Driving status
2005 to 2006	12891		107		0.83		107		57	
2006 to 2007	13442	13786	100	126	0.74	0.91	100	126	44	76
2007 to 2008		13985		124		0.89		124		88
2008 to 2009		14172		114		0.8		114		90

Table 19 Results from Practice A and Practice B

3.1.2 Record social factors affected by epilepsy

These results were collected by the practice and any points raised in it were discussed at the epilepsy review and are displayed below in table 20. Practice B were able to identify nearly twice as many social factors included in the LES compared to Practice A

Year	Practice A social factors	Practice B Social factors
2005 to 2006	57	
2006 to 2007	54	101
2007 to 2008		96
2008 to 2009		106

Table 20 The number of records of social factors affected by epilepsy

3.2 Identify the number of women and children of child bearing age who have epilepsy

3.2.1 Offer women and children of childbearing age folic acid

These results displayed in table 21 reveal that both practices were able to identify women of childbearing age with epilepsy and were able to perform fairly uniformly in their ability to offer folic acid.

3.2.2 Offer women and children of child bearing age pre conception advice

It is interesting to note that the practice with no prior epilepsy training but good practice organisation were able to offer a slightly higher level of pre conceptual advice when compared to the practice who had previous experience of epilepsy.

3.2.3 Ensure that women who are taking contraception medication are prescribed appropriate contraceptive medication

These results were collected by the practice if there was a conflict to resolve with the interaction between their anti-epileptic drug and oral contraceptive this was dealt with or advice was sought.

Year	Practice A women with epilepsy	Practice B Women with epilepsy	Practice A women of childbearing age	Practice B Women of child bearing age	Practice A CBA offered folic acid	Practice B CBA offered folic acid	Practice A CBA offered preconception advice	Practice B CBA offered preconception advice	Practice A CBS and aed vs cointraception Check	Practice B CBS and aed vs contraception check
2005 to 2006	52		29		2		0		1	
2006 to 2007	48	61	23	25	7	3	1	4	6	4
2007 to 2008		58		26		3		6		11
2008 to 2009		50		24		2		7		15

Table 21 The number of women taking contraception who are taking contraception medication are prescribed appropriate contraceptive medication

3.3 Identify people with epilepsy under hospital care

Both practices were able to create a clear record of who was receiving specialist care for their epilepsy and who was solely under the care of their GP. There seems to be little difference overall in the number under specialist care [table 22]. Practice B reported that they were able to carry out advice suggested in hospital letters completely

Year	Practice A under hospital care	Practice B Under hospital care	Practice A AED actively managed	Practice B AED actively managed
2005 to 2006	34		107	
2006 to 2007	20	37	?	37
2007 to 2008		11		11
2008 to 2009		19		19

Table 22 The number of people with epilepsy under hospital care

4 Study Four: Targeted Medicines Use Review for Epilepsy

Educational Event for Community Pharmacists on Epilepsy

Thirteen community pharmacists spent a day preparing for the targeted medicines use review for epilepsy. Of these thirteen, ten pharmacists went on to conduct the MURs in Thanet, the other three pharmacists worked outside of the study geographical boundary unfortunately and could not take part in the project at this stage but wished to be included if the project was spread to a wider area.

The event consisted of a full morning lectures and videos updating their epilepsy knowledge and in the afternoon was devoted to role playing the targeted MURs with their peers. The month's pilot was undertaken following this and the community pharmacists demonstrated their ability to pro-actively support people with epilepsy by assessing medication concordance, counselling on relevant areas of epilepsy care as dictated by the consultations and offering appropriate literature.

4.1 To determine the extent to which community pharmacists can be trained to proactively support people with epilepsy

4.1.1 To be able to answer and anticonvulsant query from a patient with confidence

The training day started with a questionnaire to measure self-perceived knowledge of epilepsy and was followed up with a questionnaire following the training. At the start of the day the pharmacists reported that they felt confident to help a customer with a query regarding their epilepsy medication before the training day the pharmacists were relatively unsure however by the end of the day they were certainly more confident as demonstrated by figure 22

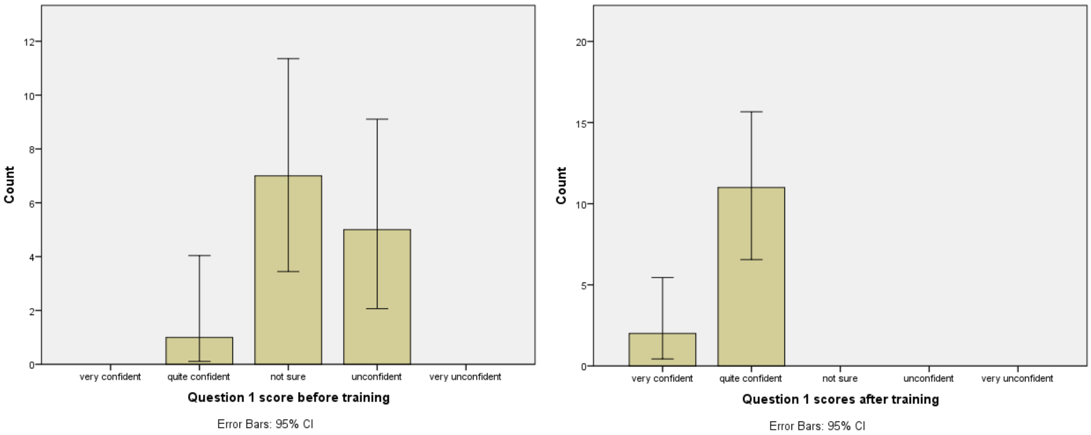


Figure 22 Graphs demonstrating the pre and post training confidence at answering AED queries

4.1.2 To become familiar with epilepsy classification and explain them to customers

When the pharmacists were asked if they were confident to help a customer who wanted information about complex partial seizures initially they were not very confident but after the training they were significantly more confident as demonstrated in figure 23

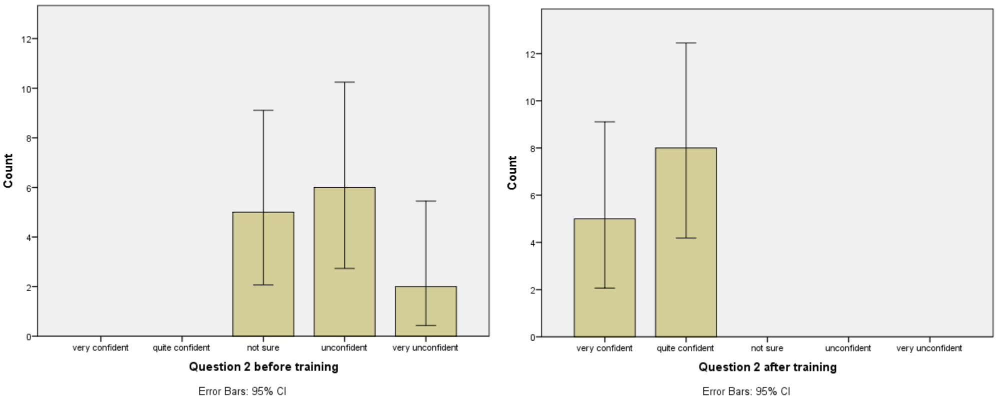


Figure 23 Graphs demonstrating the pre and post training confidence at answering classification queries

4.1.3 To be able to advise a customer with epilepsy when they could re-apply for their driving licence

The third question reported in figure 24 had the biggest improvement when comparing the before and after responses and that was relating to their ability to advise a customer when they could re-apply for their driving licence. The confident intervals for this question did not cross over suggesting that the response was certainly significant.

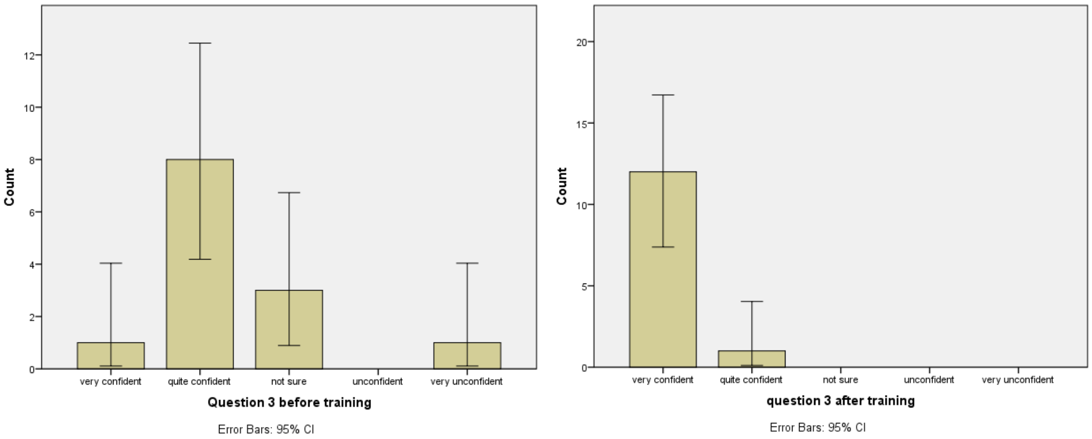


Figure 24 Graphs demonstrating the pre and post training confidence at answering driving queries

4.1.4 Feel confident in being able to assess how well a patient was taking their anti convulsant medication

Finally the pharmacists were asked to rate their knowledge of being able to assess how well a patient was taking their epilepsy medication reported in figure 25. This is the most generic question of the four and the principles could hold true for all long term conditions however there was still an improvement in their self-rating by the end of the day.

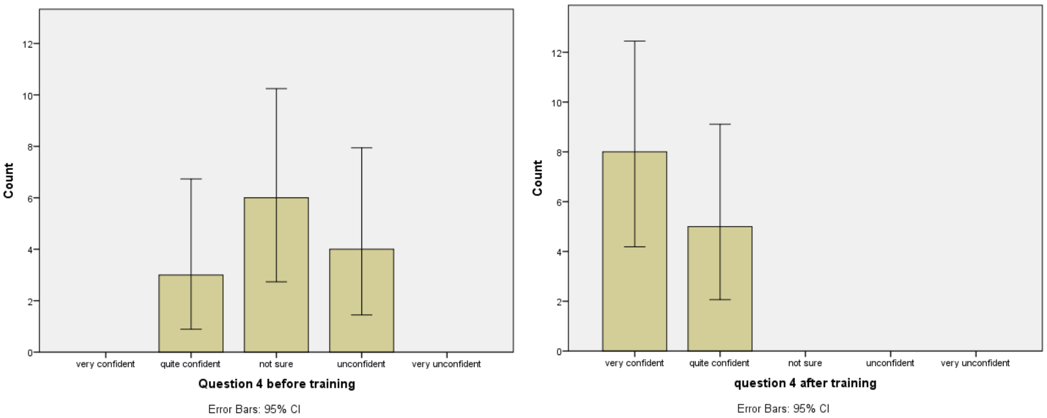


Figure 25 Graphs demonstrating the pre and post training confidence at assessing concordance

4.2 Determine if the advice given by the community pharmacists during a MUR was of benefit to the customers

4.2.1 Improving their understanding of the underlying causes of epilepsy

There were 17 patients interviewed for their MUR and of these 13 completed questionnaires and four did not complete one. Three of these patients were not given one by the pharmacist at all and one only answered one or two of the questions. Despite the low numbers the questionnaires which were obtained, revealed that the patients with epilepsy had quite a wide variation of knowledge about their epilepsy however by the end of the MUR this was more unified and either stayed the same or was improved as displayed in figure 26.

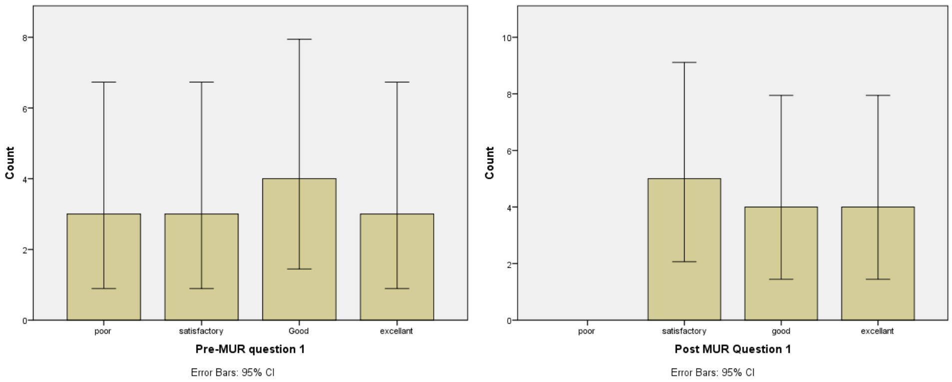


Figure 26 Customers pre and post MUR understanding of the underlying causes of epilepsy

4.2.2 Understanding how to lessen the risk of having a seizure

When the people with epilepsy were questioned on their knowledge of how to lessen the risk of having a seizure this was initially fairly evenly spread however after the MUR as demonstrated in figure 27 it polarised to being more confident about minimising the risk.

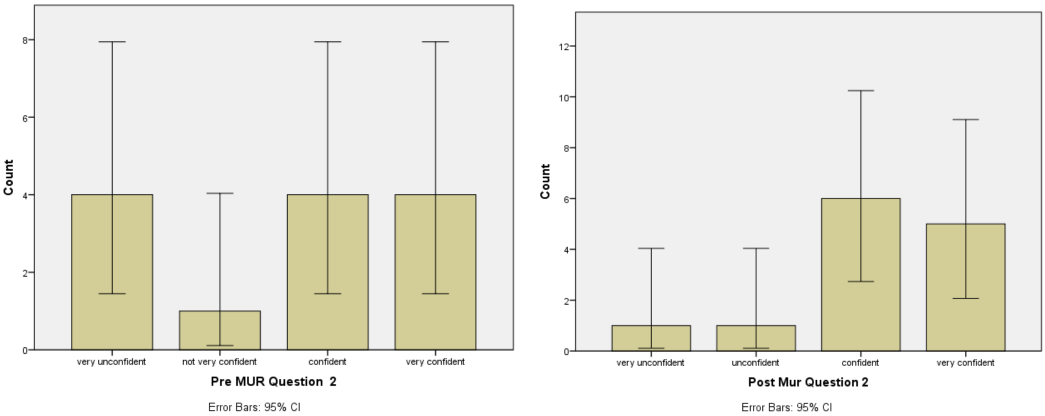


Figure 27 Customers pre and post MUR understanding of reducing the risk of having a seizure

4.2.3 Determine if the customer was more likely to approach their pharmacist for advice about their epilepsy in the future

The final question revealed the most impact with people with epilepsy reporting that they were unlikely to consult their pharmacist if they required advice about their epilepsy however after the MURs this had increased. It was good to see that the pharmacists had gained the trust of the patients very effectively and as displayed in figure 28 it improved following the MUR.

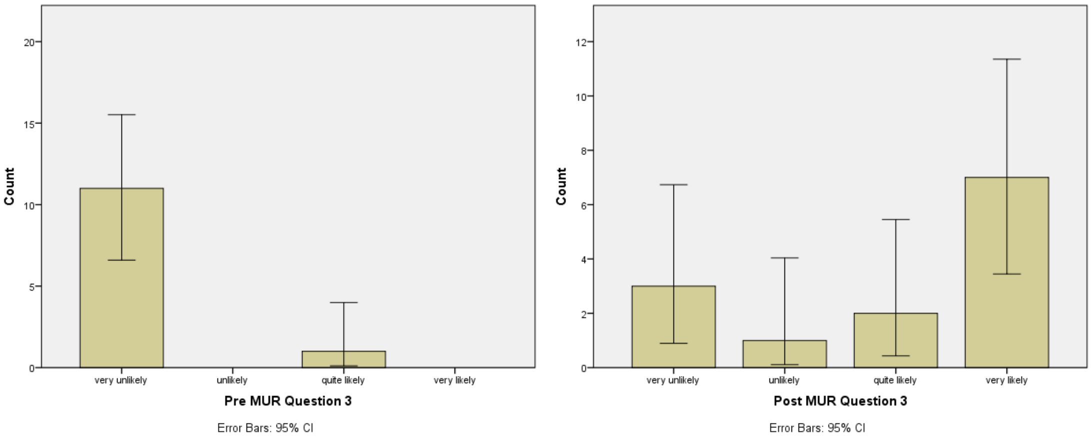


Figure 28 Customers pre and post MUR likelihood of using their pharmacist for epilepsy advice in the future

4.2.4 Determine if community pharmacists can recognise red flag symptoms to allow direct referral to specialist epilepsy services

During the month's pilot there were five referrals made to specialist services from two of the ten pharmacists involved in the pilot which were all rejected by the author who triaged all the referrals to the GPwSI community epilepsy service. These referrals were outside of the parameters of the referral guidelines.

- 36 year old male – rejected as already under specialist care
- 32 year old male – rejected as not diagnosed as having epilepsy
- 17 year old male – rejected as already under specialist care
- 75 year old female – rejected as did not fit referral criteria
- 65 year old male – rejected as does not fit criteria

The information gained at the MUR was of high quality and the pharmacists demonstrated that they could record their discussions well and also list the information given to the patients successfully as below in table 23.

5 Results from Targeted Medicines Use Review pilot for epilepsy

Patient	Action Plan	Recommendation	AED	Adherence %
1	Not Sure of Seizure Type	Seizures Explained	CB	95
	VNS Makes her cough	See ESN	LTG	
	Memory problems	Memory and Epilepsy booklet given	RTG	
	Occasionally uses alcohol	Alcohol and epilepsy discussed	VPA	
2	Unsure of epilepsy knowledge	Seizures Explained	LVT	98-100
	Seizure triggers unknown		PGB	
3	Unsure about her epilepsy	Seizures Explained	LVT	90
	Seizures worsening	Safety and Epilepsy - remain under specialist		
	Has two seizures a year that require hospitalisation discussion about weight and alcohol			
4	Unsure of seizure type	seizures explained	CBZ	85
	Ongoing seizures	see specialist every 6 months	VPA	
	Driving [non driver		TPM	
5	Ongoing seizures	Sees GPwSI	PHT	90
	Unsure of triggers	Seizures Explained	CBZ	
		Epilepsy and safety		
	Memory problems	Memory and epilepsy		
6	Ongoing seizures	Declined leaflets	CBZ	100
		Adv to bring appt forward for specialist	ZNS	
7	Ongoing seizures	DNAs QEQM specialist - adv see GP to re arrange	GBP	100
		Safety and epilepsy		
8	On going seizures NEAD			
	Referred to the Marsden- has not heard back yet	Chase referral via Dr Rogers GPwSI	VPA	
	If NEAD consider on going usage of VPA			

9	Last seizure 2010 - no longer under specialist care	Safety and epilepsy	VPA	100
		See GP if has any further seizures	CBZ	
10	Discussion about the course of epilepsy Last sz 3 yrs ago	Under specialist care	PHT	100
	Tiredness	possible side effects of DZ and PHT	DZP	
11	Did not understand epilepsy	Seizures explained	PHT	
	Problem with bright lights	Photosensitivity and epilepsy	PGB	
12	On-going seizures - under Prof Shorvon	Seizures explained		
	Not sure about seizure type? Focal? NEAD			
	Strips lights a problem	Photosensitivity and epilepsy	CBZ	
	Hormonal triggers and epilepsy	Women and epilepsy		
		Memory and epilepsy		
13	Unsure about her epilepsy type	Seizures explained	CBZ	
	Avoids flashing lights	Photosensitivity and epilepsy		
	Driving and stopping medication discussed and driving Very unkeen to loose licence	Driving and Epilepsy		
14	Does not know type of epilepsy	Seizures Explained	VPA	
	Does not like flashing lights	Photosensitivity		
15	Unsure what type of epilepsy she has	Seizures explained	LTG	
	On-going seizures x4 last week and admitted	Under neurologist, safety leaflet	LVT	
	Driving discussed - keen to regain licence	Driving and epilepsy	VPA	
	Female issues	Women and epilepsy	CB	

16	On-going seizures and has VNS. Mixed sz type	Seizures Explained	LCS	100
	Can have daily seizures	Safety and epilepsy, under 2' and 3' care	LTG	
			LVT	
			CBZ	
17	Unsure about which type of epilepsy	Seizures Explained	VPA	
	Feels unsafe going out doors	Safety and epilepsy	LVT	
	On-going seizures	Wants a second opinion about their epilepsy->GP	TPM	

Table 23 Tabulated outcomes of the Medicine’s Use Reviews

DISCUSSION

Study One: Primary Care Clinical Effectiveness program 2 [PRICCE-2]

Summary of the main results of PRICCE-2

The PRICCE-2 project successfully demonstrated that doctors in primary care are generally willing to become more involved in the management of epilepsy. The impact of PRICCE-2 could possibly be called a milestone in the management of long term conditions in the UK as it marked the beginning of pro-active evidence based care for the whole population. It is hard to recall how patchy and generally inadequate the provision of care was in the late 1990's. Then, care tended to be reactive to crisis and was delivered to those who presented for treatment, rather than to pro-actively offer care to people identified as having epilepsy.

Strengths of PRICCE-2

The major positive impact however was that it marked the start of the mind-set in primary care where the person with epilepsy was firmly placed in the centre of care. The simple fact of asking somebody how they perceive their illnesses to currently be and if there are any hitherto unknown problems with their treatment started a snowball effect. It gave people with epilepsy a voice that previously was rarely heard and started to raise expectations in healthcare for epilepsy. The take up rate for PRICCE-2 was far higher than was initially predicted and this high take up rate was echoed in the national roll out of the program in QOF.

I. **Practice Register.**

The development of a disease register was certainly possible and it became clear that the primary care team were able to engage with computerised systems to identify and invite people with epilepsy to attend for an annual review. This process revealed that the disease indexing on medical systems had to be accurate and that GPs and practice staff could only operate a pro-active care program for long term diseases if they used computerised rather than written notes. In parallel to this it was seen to be important also for GPs and practice staff to be accurate in their computer usage and for the need to use diagnostic terms and labels accurately on their computer systems.

II. Seizure Freedom.

GPs found it fairly hard to identify people who were seizure free initially and required training to fully comprehend the different forms that a seizure could take. This study however demonstrates that within the structure of primary care it is possible to record seizure freedom proactively and in doing so identify people who are at risk from ongoing seizures. The practices reached the target however of over 70% of patients being seizure free from the start.

III. Vigabatrin.

The identification of people on vigabatrin was successful and the number of people identified is similar to what one would have expected. The training for the program included information about the hazards of peripheral field loss with vigabatrin and GPs understood the need to identify people taking this drug who were not being followed up by optometrists who would perform 6 monthly visual field tests in this group. When a person with epilepsy moves they can lose contact with the epilepsy clinician who commenced vigabatrin and as for many it worked very effectively there were occasions when a new referral to a neurologist did not seem necessary hence the drug was unmonitored. Also if a patient chose not attend a follow up clinic and was removed from the epilepsy follow up they too took vigabatrin without monitoring and it was these two groups in particular who benefited by this program in PRICCE-2 as they were referred to specialist clinics once more.

IV. National prescribing of Vigabatrin

In order to assess whether the number of people identified in PRICCE-2 correlated to the numbers one would expect to be taking it a review of the prescribing habits of clinicians was undertaken and the numbers of people with epilepsy who one would expect to be taking vigabatrin were extrapolated. In England 2002 the

Prescription Costs Analysis data reported that 30,200 prescriptions of Vigabatrin issued[98]. England had a population of 49,649,100 according to ONS Population statistics for 2002, which equates to approximately one script of vigabatrin for every 19,773 person in the population. This is based on the assumption than scripts are issued monthly and then the medication is contained in one script per person and not in smaller composites. There assumptions would lead this figure to likely represent the highest figure likely to be calculated for and average person in the English population and the real answer is likely to be less prevalent. On this basis with a population of 427,232 which is the denominator used for the PRICCE Project in 2002 [see table 24 below] one would expect around 22 scripts for Vigabatrin in 2002. By 2004 the knowledge of the side effects of using vigabatrin were more widespread and its use had stated to decline resulting in 23,500 scripts being issued in England.

The number of participants for PRICCE at this time was illustrated in Table 25 below. With a recorded population of England being 50,109,700 and using the same assumptions as above the top estimate of vigabatrin usage would be one script for every 25,587 person in the population hence in East Kent in 2004 one could assume a maximum of 20 people to have been taking vigabatrin on a monthly basis.

2002	Ashford PCG	103,440.00
2002	Canterbury PCG	162,199.00
2002	East Kent Coastal PCG	89,907.00
2002	Shepway PCG	81,686.00
	Total Population	437,232.00

Table 24 Population details of the number of participants in PRICCE as recorded by the Health Authority in 2002 and 2004

Col1	PCG/PCT	RegPop
2004	Ashford PCT	105,345.00
2004	Canterbury and Coastal PCT	140,712.00
2004	East Kent Coastal PCT	191,247.00
2004	Shepway PCT	99,118.00
		536,422.00

Table 25 The individual populations of the four PCTs in 2004.

The figure reported in 2002 is lower than this predicted figure[99] however by 2004 it is 21 people who were reported which is surprisingly close to this predicted figure and would suggest that the data reflects expected population norms by the end of the study.

V. Profile of Epilepsy.

Another area of success for the PRICCE-2 project was the raising of the profile of people with epilepsy. Previously GPs had a vague notion of how many people they had on their lists with epilepsy and who they were whereas now the GPs knew with greater confidence who required epilepsy medication. At medical educational events epilepsy was mention more frequently and in a sense epilepsy was re-discovered by the GPs in East Kent. As a direct result of this the failings of the current epilepsy service were identified and the medical commissioners started to look at the unmet needs of people with epilepsy in East Kent and started to commission a more robust epilepsy service.

VI. Programmes of care

Developing a program for epilepsy and indeed other long term diseases also offered medical managers a useful tool to improve patient services as the combination of computerisation, incentivisation, education, support and peer group pressure is relatively easy to manage. The new era whereby general practice could be shaped to deliver co-ordinated and evidence based care for people, which was targeted by means of audit to identify entire populations with specific diseases had begun.

VII. Education

General practitioners and their ancillary staff demonstrated that with sufficient training and support from administrative staff they are able to identify people who are seizure free and also be commissioned to perform specific tasks such as ensuring that everybody in the practice taking an anticonvulsant such as vigabatrin have the necessary care and follow up.

Weaknesses of PRICCE-2

There were certainly weaknesses apparent in the PRICCE-2 programme. Epilepsy has long been considered to be a Cinderella subject and this has been compounded by GPs feeling and indeed being perceived as being, unskilled in that area [11]. When a patient reveals that they have a specific problem related to epilepsy the GP is then placed in a position to help the patient either using their own skills or by referring the patient for specialist help.

I. Process driven project

One of the prime weaknesses of PRICCE-2 was the principle of the programme being focussed on process rather than outcome. The practices were tasked to complete the processes which had been requested rather than be measured against a change in the outcome. The advantages of this have been discussed already [please see page 40,] however the counter argument would be that patients' improved health outcome was assumed to occur rather than be accurately evaluated.

II. Reporter bias

A recurrent problem that was first high – lighted in the PRICCE project and has been seen in the subsequent incentivised programs of care is the influence of reporter bias. It would seem to be an inevitable consequence of any system whereby the providers of care report their outcomes and are then paid accordingly. The overarching aim was to provide a vehicle to improve care rather than to produce a scientific audit and from a commissioning viewpoint this is tolerated. This does not reflect fraudulent activity as data extracted by computer searches however was directly from the medical records and deviation from the truth would amount to a serious breach of professional conduct and there were no reports during the project of this having occurred. It is more likely to influence clinical judgement as to whether someone can be exempted on medical grounds from reaching a target.

III. Exception reporting

The concept of exception reporting whereby people with epilepsy would not be included in the denominator if their epilepsy control proved refractory to treatment. This was decided in many cases by the GP involved and the presence of reporter bias had not been controlled against. This was all the more likely as high achievement in PRICCE-2 was linked to higher reward for the reporter. Where payment is linked to performance as it does in all of the schemes studied this continues to be an important factor to take into consideration.

IV. Management of clinical issues for women with epilepsy

It is unclear why GPs found that this was difficult and the reported number of women reviewed was lower than expected. It is hard to speculate why this could have been and was reflected in the other areas relating to health related areas for women with epilepsy.

Low reported numbers of women with epilepsy

To estimate what the predicted number of women with epilepsy in this population the author drew from literature written at around the same time as the study to offer an indication of the number of women likely to have been present with epilepsy. The pregnancy rate for women with epilepsy in a study of women with epilepsy in 2000 revealed a pregnancy rate of 6.1/1000 [100]. Using this pregnancy rate the number of women expected to be pregnant in East Kent in 2002, 2003 and 2004 are calculated below in table 26. The report by Fairgrieve et al reports that the proportion of all pregnancies to women with epilepsy to be 6.1/1000.) Of the 359/400 known pregnancy outcomes in the study there were 330 live births (three sets of twins); two medical terminations, two stillbirths, 22 miscarriages, and five terminations. To calculate a figure for the women of East Kent the figures below use the same 6.1/1000 figure and then reduce it by 330/359 = 0.836 to allow for pregnancies that would not go on to require ante natal care.

Table 26. Predicted number of pregnant women who also have epilepsy in East Kent 2002 - 2004

	Code	Population		Live Births	(Thousands)
2002					
Kent		**1,331.2**		**14.5**	
Ashford	29UB	103.0		1.3	
Canterbury	29UC	135.4		1.3	
Dover	29UE	104.6		1.0	
Shepway	29UL	96.3		1.0	
Thanet	29UN	126.8		1.3	
			East Kent	**5.9**	
	Expected number of pregnancies for women with epilepsy = 35				
	Expected number of live births = 32				
2003					
Kent		**1,337.8**		**14.8**	
Ashford	29UB	104.3		1.3	
Canterbury	29UC	137.1		1.4	
Dover	29UE	104.7		1.0	
Shepway	29UL	96.4		1.0	
Thanet	29UN	127.6		1.3	
			East Kent	**6.0**	
	Expected number of pregnancies for women with epilepsy = 37				
	Expected number of live births = 34				
2004					
Kent		**1,346.5**		**15.3**	
Ashford	29UB	105.4		1.3	
Canterbury	29UC	139.5		1.4	
Dover	29UE	105.3		1.0	
Shepway	29UL	97.1		1.1	
Thanet	29UN	128.0		1.4	
			East Kent	**6.2**	
	Expected number of pregnancies for women with epilepsy = 38				
	Expected number of live births = 35				

Expected birth rates for women with epilepsy calculated at a rate of 6.1 births per 1000 births in the population

Expected number of live births approximated at 92% of the total number of pregnancies

When the expected figures are tabulated with the reported figures there is clearly quite a large discrepancy as described in table 27 below. From these figures it would seem that only approximately a third of the expected number of women with epilepsy were included in the study.

Year	Number of Women in PRICCE-2 who were pregnant	Total number of women aged 25 - 34yrs	Expected number of live births
2002	11	27327	32
2003	21	32939	34
2004	12	31828	35

Table 27 Expected verses the recorded number of women 2002-2004 with epilepsy who are pregnant

Folic Acid. It follows that the number of women offered folic acid was also reduced as it did not seem that GPs had fully understood the need for folic acid supplements in women with epilepsy and the numbers of women treated and to have only 10 women a year in East Kent receiving this is somewhat disappointing.

Contraception. The potential interaction between anticonvulsant medication and the oral contraceptive pills was likely already known by GP and hopefully would have been addressed prior to the PRICCE-2 project however the figures of women who have had this checked are surprisingly low. It may be because it was hard to record accurately in the notes and the coding used to identify it not used and so it was not picked up by the end of year computer audit.

V. Reduced access to GPs

As practices needed to set aside more appointments for proactive care, the numbers of appointments, the number of acute appointments was effectively reduced. Up until this point it was usually relatively easy to obtain a GP appointment however from here onwards it was more difficult to gain access to a GP

In an attempt to provide more appointments this number of practice nurses grew to provide extra resource to perform the disease specific clinics and blood testing specified in the long term disease management plan. When the author started as a GP in his current practice there was only one practice employed nurse however currently with a practice only around 15% in size there are now 4 staff nurses and 3 health care assistants. The request to identify women who were pregnant with epilepsy and who were in need of pre natal advice however was not as successful and many practices did not take this up fully. It is not clear why this occurred and would require further study to find out why it occurred.

VI. Unplanned hospital visits.

The impact on the number of emergency admissions to the local three hospitals for epilepsy steadily increased with a background that the epilepsy admissions to remain stable over the previous decade [101] . The data collected on hospital admissions however in the first decade of this century was known to be fairly poor with inaccurate computer indexing being used. It was not always clear if epilepsy was included in a patient’s admission computer entry whether this was the cause of the admission or if this was a co-incidental illness. Also blackouts and seizures could be mislabelled as being epilepsy. The data available to the eye appears inconsistent with numbers appearing to alternate high then low on alternate years. The GP computer systems were being improved during PRICCE-2 as was the data quality but this had not quite started in hospital data for acute admissions.

In addition the data in 2002 was of relatively poor quality because the indexing of the cause for admission was given a low priority and was entered into the hospital activity reports by non-medical staff who gathered the diagnosis from hospital discharge letters. If the patient’s discharge letter was not always clear it was difficult to determine if they had been diagnosed with epilepsy or else suffered an isolated non epileptic seizure. Also if the epilepsy code was used it was not always possible to tell whether epilepsy was the cause of the admission or a secondary and non-contributory long term condition. These mitigating factors however where constant throughout the two years of the study and so the data was requested from the East Kent MAAG team to see if there was any visible trend in activity.

The results of PRICCE-2 in Context

The introduction of PRICCE-2 was at perhaps ahead of its time and it is hard to recall back when GPs did not run electronic disease registers and tended to practice reactionary medicine. The advent of computerisation and pro-active audit to identify people who could benefit from being offered evidence based treatments of care was in its infancy. From this basis the primary care contribution of care for people with epilepsy developed and though many parts of the process as indicated above were flawed, the overall impact for an increased awareness and responsibility by GPs to look after people with epilepsy is undoubted.

The scope of what GPs could offer was not tested in PRICCE-2 nor was the impact of the primary care led provision at grass roots level to any successful degree but a process certainly had started whereby people with epilepsy were being brought directly to the attention and care of GPs.

Ideas for future study following PRICCE-2

The GPs in East Kent were led in this project by an enthusiastic team and it was welcomed with remarkable acceptance by the local GPs. It was not clear if this was in part due to the charisma of the medical director or the support from the clinicians [including the author for epilepsy] and audit team. It had gained the Department of Health’s attention and it seemed logical to roll this programme out nationally to see if the same enthusiasm for pro-active care could be generated nationally as well as locally. To do so would require standards to be set lower so that all GPs were able to feel part of the programme and perhaps the standards set at a lower common denominator albeit with the very best evidence base to guide them.

PRICCE-2: support for the hypothesis

Consideration of the results for PRICCE-2 in supporting the hypothesis that high volume and low impact care for epilepsy is possible to achieve by use of a programme of care has offered support to the hypothesis. The only caveat to this was that women and epilepsy required more attention and perhaps exploration of why practices failed to achieve as well in this area compared to how they fared in the other sections of PRICCE-2

Study Two - Quality Outcomes framework

Summary of the main results of the Quality Outcomes Framework

The lessons gained in PRICCE were now extended to form a national program for pro-active, audit driven evidence based care and epilepsy had the benefit of being included in this program. It was not clear how practices would respond to evidence based care being imposed on them and indeed how they would respond to incentivised targets to reach the disease standards. The lesson learnt from PRICCE was that GPs welcome it and joined in rapidly and achieve high standards quickly and this was the case with QOF. The uptake by practices took the government by surprise and resulted in the new General Medical Services Contract of 2004 resulting in a higher than planned pay rise to GPs who hit the targets which were thought to be aspiration. The achievement of 87% of the epilepsy target in 2004/05 was very good indeed but more was possible and by 2010/11 99.8% of the epilepsy achievement had been reached.

The strengths of the Quality and Outcomes Framework

I. ***Seizure frequency***.

It was clear from the start of the program in 2004 that GPs were able to organise their practices to pro-actively manage epilepsy and more detailed information was available in 2006 to analyse this further. The ration of sum of indicators by the sum of denominators stayed high throughout with almost 96% of the practices achieving full achievement. The process of inviting people with epilepsy into a GP surgery and asking them on an annual basis sounds initially very simple and unlikely to achieve anything of significance however it marks a definite change in mind-set for epilepsy care in the UK. Prior to this time people with epilepsy would largely only see their GP if there were problems with their epilepsy which they wanted to remedy. People who did not realise that their seizures were poorly controlled, those who generally avoided seeking medical help and those who were in some way impeded from seeking help either by frailty or by reduced mental ability would generally not seek help. Most GPs would re-authorise the patients prescriptions periodically and if they had not seen the person recently invite them in however this was not formalised on a national level.

By obtaining the knowledge on seizure frequency GPs would then be made aware of people hitherto unknown to them who had poor control of their seizures. The method of resolving this was left up to the GP and not included in the guidelines for QOF

II. Epilepsy medication review.

This was also a step forward in the management of people with epilepsy because through it GPs became aware of some of their patients who were taking their medication but suffering considerably from side effects of their medication. With around 95% of the total score being achieved by the practice it ensured that most people with epilepsy were able to inform their GPs if they had side effects from their medication. If they did it was possible for GPs not to take action but again the opportunity was made available for the patient to be heard. The QOF study did not give prescriptive guidance on what to do when side effects were reported but it was possible for GPs either to answer some of the queries themselves or else to seek expert help on alternatives. There was no formal suggestion to assess concordance with medication however during the review of medication people with very poor concordance would be quickly apparent.

III. Seizure freedom reported in QOF.

This is arguably the most important standard used in QOF for the management of epilepsy in primary care as if offers a surrogate marker of good care. The results from QOF revealed that 73% of people with epilepsy were seizure free in 2006/7 rising to 74% by 2010/11. Community based surveys report a lower seizure freedom rate would have been expected [11] however this figures only relates to the number of people in the epilepsy denominator for the practice and not the total number of people in with epilepsy in the surgery. The use of exception reports, for example to exclude people who have declined being offered an epilepsy review, means that the QOF figures reporting seizure freedom cannot be used to determine the true seizure freedom rate in the community. Nonetheless it is still a very useful tool to help reduce the number of people with on-going seizures and neighbouring practices can be compared to see who has excluded an excessive number of patients to achieve the target.

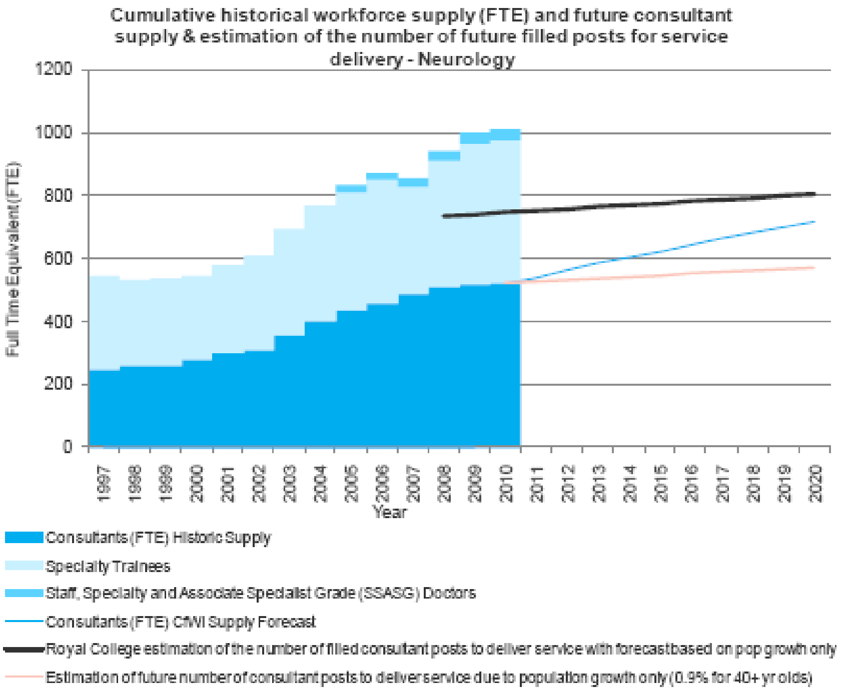
IV. Mortality trends for epilepsy

In the second half of the decade the mortality rates for epilepsy appear to be falling. This is truly very encouraging and represents the first time in recent history whereby the mortality of epilepsy in England has been seen to fall.

The reasons for this reduction are surely diverse but it is of interest that they coincide with the introduction of study two with the commencement of a national program to pro-actively manage epilepsy available to the entire population with epilepsy. This may have played a part in the reduction of epilepsy related deaths however it is impossible to firmly link the two.

Other factors which could have been involved include the increase in neurologists as depicted in figure 29 which is taken from the centre for workforce intelligence report in August 2011[102]

Figure 1: Cumulative historical workforce supply (FTE) and future consultant supply & estimation of the number of future filled posts for service delivery - Neurology



Source: Historical supply data (NHS IC, 2011a), Supply forecast (ESR, 2010), (NHS IC, 2009) and workforce assumptions. Estimates of number of posts to achieve full service delivery use population projections (ONS, 2010) and, RCP estimates (2007).

Figure 29 Cumulative historical workforce supply for service delivery in neurology

Another factor which may be implicated is the increased number of anticonvulsant medications with the introduction of 7 anticonvulsants during this time [eslicarbazepine, lacosamide, levetiracetam, oxcarbazepine, pregabalin, stiripentol, and zonisamide.]

There have also been several influential report published over this decade starting with The Clinical Standards Advisory group report of the working group on services for people with epilepsy in 2000 [11] Then in 2002 there was a report following the publication of the 'National Audit into epilepsy related deaths :epilepsy death in the shadows' [12] . In 2004 NICE produced its guidelines 'The epilepsies. The diagnosis and management of the epilepsies in adults and children in primary and secondary care,' [51]. Then in 2008 the report 'Wasted money, wasted lives: the human and economic cost of epilepsy in England,' by the all-party parliamentary group on epilepsy [30].

It would be highly presumptive and indeed misleading to suggest that this study supports the notion that the Quality and Outcomes Framework was instrumental in this trend of a slight fall in mortality for epilepsy however it is more reassuring than an increase in deaths would have been since its inception. Further work is required to explore this observation more fully.

The weaknesses of the Quality and Outcomes Framework

I. Process driven rather than outcomes based

Much of the QOF like PRICCE-2 is simply 'process driven,' and it was unclear if measuring process rather than outcome would achieve positive results for patients. This thesis assesses the impact of a largely process driven system of care. Others have also studied the impact of QOF and report that comparing figures between 2004 and 2008 it seems likely that QOF has led to improvements in patient outcomes[103]. One cautionary note is that such programs of care could create incentives for practices to avoid caring for more chronically unwell and medically fragile patients. This aspect of process verses outcomes as a tool to improve care is explored above in the section for PRICCE-2 and the principles remain the same. [Please see page 166.]

II. Exception reporting.

An area of contention for QOF is the use of exclusion criteria for 'unsuitable,' patients. The results from the quality outcomes framework in 2005 were analysed and the mean pay-performance gap for 65 indicators was studied and this included the targets for epilepsy[104]. It revealed the existence of a treatment gap and part of this gap whereby eligible patients are potentially excluded and this was seen to be due to targets being set at less than 100%. Another cause of this treatment gap was suggested as being due to patients being exception reported.

With time however the number of people who had been exception reported slowly reduced but would never likely become zero for example those with terminal illness and extreme frailty. This number is likely to be a constant background figure in the community as are those excepted because they have only recently been diagnosed with epilepsy. The group of people however who had refused to attend a review despite three invites where steadily encouraged with time and were drawn into the system and so the levels of exception reports steadily fell. Also people who were reported to be on the maximum tolerated drugs were offered opportunity to be considered for alternative medication.

As a result of these measures the overall exception report for epilepsy fell from 8.05% to 7.82% in 2009/10 and a drop in the exception reporting for Standard 8 – seizure freedom falling from 16.7% in 2006/07 to 15.75% in 2009/10. In 2010/11 however there was a rise in exception reporting and it is unclear why this could be however practices by this stage were somewhat selective in which areas they put their resources into.

III. Gamesmanship in QOF

Some areas of QOF offer points that are easy to achieve and there are others such as epilepsy where some components are more difficult. Also some areas such as the quality improvement section in QOF offer high numbers of points to perform processes such as peer review that are on relatively easy to perform (although powerful in influencing clinicians care) and other such as epilepsy where there are fewer points on offer to practices. This can lead to practices choosing to place less effort and indeed resource in certain areas to allow them to divert attention to areas where the rewards are higher or easier to achieve. This phenomenon is not universal however and reassurance can be gained by reports of areas around the UK who strive to achieve the best for people with epilepsy. In a study of a resource poor area of Wales it was revealed that GPs are motivated to prioritise epilepsy care despite its challenges with a steady rise in quality of care[105]. This contrasts to some areas of England where the attainment in some practices appears to have dropped since the introduction of newer and more lucrative QOF targets.

IV. Female issues relating to the management of epilepsy

The introduction of the QOF medical standard ‘epilepsy 9’, whereby women were offered prenatal advice which included counselling about contraception, conception and pregnancy was a difficult task for GPs. This echoes the low levels of attainment for the corresponding section of PRICCE-2. The detailed breakdown of achievement figures are not yet available and have still to be processed by the department of health however we do know that the exception reporting is very high at 36.7% which is the second highest exception report percentage in the entire QOF long term disease portfolio.

It would be helpful to study this further and determine why this group is not being looked after as well as the other areas. Factors involved may be due to lack of education for GPs on female issues relating to epilepsy. It may also be due to poor provision of specialist services for women with epilepsy to meet any need that potentially could be uncovered.

V. Admission rates for epilepsy

The admission data for people with epilepsy is still tending to increase despite these interventions however many other factors are involved here such as changing demographics, different patterns of behaviour by people with epilepsy, changing patterns of behaviours by community and front line services who are involved when someone suffers from a seizure. The change of out of hours health care also changed during the past decade, since the introduction of the new GP contract in 2004, GPs did not work through the night on call as they had done so previously and it became common practice for out of hours clinicians to suggest that an ambulance is called when somebody had a seizure. Another factor may be the reluctance to administer rectal diazepam to abort a seizure from carers involved in the paediatric and learning disability community for fear of incrimination of abuse[106]. As the use of buccal midazolam increases over rectal diazepam the previous reluctance to intervene by using rectal diazepam for acute seizure control will be overcome in favour of the buccal route. Time will tell if this becomes a factor in reducing unscheduled hospital admissions.

Putting the results from the Quality and Outcomes study in context

The lessons learnt in PRICCE-2 were mirrored almost exactly by the Quality and Outcomes Framework. The response to the challenge to deliver pro-active care by GPs exceeded expectations and the uptake was higher than expected. The ability to identify people with epilepsy and treat them pro-actively was successfully undertaken across the country. The recent introduction of standards of care for women with epilepsy also lower than expected and the number of exception reports for this group was the second highest of any area examined in QOF.

It supports the theory that GPs are both a willing and able workforce to deliver evidence based care for people with long term conditions and pertinent to this thesis this includes people with epilepsy

Ideas for future study

There are clearly several areas which require further study which include:

I. Repeat the study with the support of robust statistical analysis, in an attempt to determine of outcomes of unplanned admission to hospital as a result of epilepsy and indeed if mortality from epilepsy is influenced by high volume and low impact care.
II. Explore why female aspects of epilepsy care appear to be difficult for GPs to undertake. This research may start with a study of why women have been excluded from QOF. In addition the impact of this style of programme of care has with regard to contraception failure due to accidental interaction with anti-convulsant medication and also the effect on subsequent pregnancies.
III. For the future extending this study to involve wider aspects of care such as the psychosocial aspects of care for people with epilepsy which can be undertaken in primary care would also be of value.

QOF – Support for the hypothesis

Consideration of the results for QOF in supporting the hypothesis that high volume and low impact care for epilepsy is possible to achieve by use of a programme of care has offered support to the hypothesis. Once again, the only caveat to this would be that women and epilepsy required more attention and perhaps exploration of why practices failed to achieve as well in this area compared to how they fared in the other sections of QOF.

Study Three - Locally Enhanced Service for Epilepsy for East Kent

Summary of the main results from the Locally Enhanced Service for Epilepsy

Although the results from the LES for epilepsy were limited it did support the idea that GPs were able to offer a wider support for epilepsy than had already been offered in the Quality and Outcomes framework. This study required the GPs to ask people with epilepsy about psychosocial aspects of their epilepsy care and in addition facilitated the delivery of accredited information where needed. The variation between practice A&B however illustrates that this more in depth support requires organisation and commitment by the whole primary care team rather than having one or two enthusiast supported of epilepsy care [as was the case in Practice A,] to make it a success

The Strengths of the Locally Enhanced Service for Epilepsy

I. Ability to identify social factors affected by epilepsy

It was relatively straightforward to enquire about driving status and both practices managed to answer this part with ease. Practice B however were able to provide almost double the number of reports on social factors including enquiring about the adequacy of education provision for children and whether the patients were currently employed.

They were also better able to enquire about family support and provide information about safety to people with epilepsy on their register. The prior experience regarding epilepsy for Practice A did not seem to be of great benefit here and this gives some indication that the personnel rather than the knowledge of the practice plays a very important role.

II. Ability to identify problems relating to women and girls with epilepsy in the epilepsy Locally Enhanced Service

Both practices were able to supply support and information on an equal basis and reported that they had consulted with their female patients on contraception, prenatal and natal advice. This was continued from the work in PRICCE-2 and later was taken up nationally in QOF where the exception reporting was very high. Whilst PRICCE-2 and QOF reveal that GPs find it challenging to discuss epilepsy related matters to this group the LES did not seem to find it so. It is unclear why this was but it may be due to the GPs taking part having exposure to training which specifically dealt with the problems involved.

III. Links with Hospital Care

Both practices could identify people with epilepsy who were under hospital care and there was little difference between the two practices

III. Education about epilepsy prior to enlisting into the programme

The education event for GPs in the area to a higher level in epilepsy from what was required for QOF was received enthusiastically and opportunity was provided to speak to the GPs in the area in preparation for the LES at educational events locally. Since the time many of the LES the lead GPs in each practice have remained interested in epilepsy and referrals to the community epilepsy service frequently come from these former lead GPs.

IV. Use of accredited literature to support people with epilepsy

The method of using accredited literature from epilepsy action was useful and leaflets on specific topics were signposted for GPs and practice nurses to use with people with epilepsy successfully. This process ensured that the information given was correct in its content and also by offering a leaflet could be accurately referenced at a later date by the patients.

Weaknesses of the Locally Enhanced Service for people with epilepsy

I. Low Uptake

One of the areas of the LES which was not successful was the low uptake amongst GPs following the initial launch. The reason for this was not studied in this thesis however it did come at a time when the finance invested into general practice was high following the new GMS contract. As a consequence GPs had less incentive to earn extra income particularly the relatively low level of income from the epilepsy LES.

In addition there was a large amount of change already taking place in primary care and practices tended to focus their effects and indeed staff training on QOF rather than focusing on the LES.

II. Fragmented support from the Primary care Trust

The introduction of the Locally Enhanced Service for epilepsy coincided with a major structural re-organisation within the PCTs and this had the consequence that only part of the new PCT area were able to offer the LES and it was denied to other areas. This had the effect of not being promoted by the PCT and the management of it was weaker than it had been before. It became clear that the administrative support was vital to support such a programme which although it was available for practices in the East Kent area it was not actively promoted and as a result have a very low profile. This would likely not have enhanced the uptake of the study by GP practices.

The contrasts between Practice A and Practice B

Two practices were reported on in detail for this thesis. Practice A has had prior expertise in epilepsy [the author being based here] and Practice B with no special grounding in epilepsy but received basic training in epilepsy and were noted to be very well organised with the majority of its partners have gained fellowship status on the Royal College of GPs. Practice A started before practice B but found the work involved too onerous and stopped completing the LES after their second year in 2007. Practice B had less difficulty and continued on until the withdrawal of the service in 2009.

This highlights the need for appropriate incentives [financial or otherwise] to be necessary to ensure engagement in programs of care for epilepsy. Practice A had elected to focus their resources on other projects. This despite the active lobbying of the author and was largely due to a change in practice manager and lead practise nurse necessitating rationalisation of resources. Practice B however where highly organised and were able to absorb the extra work required to complete the LES for epilepsy with greater ease.

Putting the results of the Locally Enhanced Service into context

I. National merging of PCTs in 2006

The launch of the Locally Enhanced Service was initially successful but the duration of the enhanced service was limited to only one Primary Care Trust and when the groups were merged in 2006 to form larger Primary Care Trusts it was one of many enhanced services which was not actively promoted and eventually withdrawn in 2009. It was difficult for the PCT to hold different enhanced services for practices who were in the same jurisdiction and as a result the study had only limited success.

Also the support needed to run the service was limited with priorities including realignment of commissioning of services by the previous PCTs. Practices ran the enhanced service somewhat in isolation and PCT monitoring of it was limited.

II. Future roles for primary care in the treatment and support of people with epilepsy

The locally enhanced service demonstrated that primary care can be trained to proactively identify social consequences of active epilepsy and then be able to offer information and advice to help meet these needs. If can also signpost people to appropriate services for problems that are outside of its scope. Until the introduction of the LES primary care was focused more in dealing with people who reported relatively mild symptoms relating to epilepsy and the rest it tended to refer and not to actively manage. In this new program it demonstrated that it could also offer support to people with refractory epilepsy and could help to improve their quality of life. This group were still almost invariably under the care of secondary or tertiary epilepsy centres however there was addition care that could be offered by general practice between appointments.

III. Holistic care for Epilepsy

It provided an opportunity for GPs to realise that their general skills in epilepsy were relevant and useful when treating people with epilepsy included questioning on the need for counselling and social issues. It proved helpful to view people with epilepsy as not only having mediation and disease control related problems but also emotional and social consequences of their illness.

Ideas for Future Study

This study was weakened by the loss of local data and it would be helpful to repeat the study on a wider number of practices and with good statistical support to help evaluate the impact of holistic care for people with epilepsy including studying any impact it may have on their quality of life.

The reasons for Practice A dropping out of the scheme early were not formally studied and if the study was repeated any non-responding practices and indeed practices who abandoned the study mid-way could be questioned more fully.

The ability for these practices to successfully manage to address issues relating to women and their epilepsy was noted. It would be of interest to explore the factors in more detail to compare how these practices managed to do so and if it were the training which features of the training were useful so that it could be replicated.

Support of the Locally Enhanced Service for Epilepsy of the Hypothesis

This study supports the hypothesis that practices are able to provide a low impact care for people with epilepsy and indeed that the care may be developed to include psychosocial aspects of epilepsy care. It does not confirm that they have the necessary capacity however as demonstrated by Practice A left the study early. The exact reason for it doing so was not fully answerable by this study nor is the actual impact on the people with epilepsy who were seen during the study.

Study Four. Targeted medicines use review for epilepsy

Summary of the main results from the targeted Medicines Use Review for epilepsy by community pharmacists

The Pharmacists in this pilot study have demonstrated that they are able to be trained to pro-actively support people with epilepsy and the response from the pharmacy customers indicates that their input into the care of this group is well received and they will look to utilise the skills of their pharmacists more in the future. The training on referral protocol will need to be reviewed and clarified in future targeted MUR programs.

The strengths of the targeted Medicines Use Review for Epilepsy

I. Education event used to train community pharmacists

The community pharmacists presented themselves voluntarily to be trained in epilepsy and in doing so likely self-selected a group who were enthusiastic to learn more about epilepsy. The group however were not particularly confident about their knowledge of epilepsy and when they entered the training day many politely expressed that they felt they needed to be taught a good deal about epilepsy before commencing the study. The questionnaires before and after he training express this low starting point clearly however by the end of the day they were more confident in their knowledge.

II. Epilepsy related questions from customers

The pharmacists answered that they were initially unconfident about answering epilepsy related queries from customers but by the end of the simple training they were either quite confident or very confident to be able to do so. There had been some doubt expressed by commissioners whether it was possible to train community pharmacists to become confident in advising people with epilepsy and this pilot demonstrated this concern appears unfounded. Pharmacists receive a good deal of neurological training in their undergraduate studies and their knowledge of the pharmaceutical properties of anticonvulsants is certainly of a high standard. What did not appear to happen was the linking of this knowledge to their day to day dealing with customers. The training built on the lessons learnt in the LES for epilepsy in using patient support leaflets as a reference library for the pharmacists to use. In doing so they did not have to retain every detail about epilepsy in their minds and also it ensured that the information given to patients was reliable and accredited. Their former training in neurology was certainly robust enough to place these tools and they were generally confident by the end and wanting use these new skills and tools with their customers.

III. Concordance with medication

The pharmacists were not sure if they would be able to accurately assess their patents to see if they were taking their medication regularly. The initial answer was replaced by the end by being very confident on being able to assess their patients. This role of community pharmacists is one which I gather is taught in some depth at the Medway School of Pharmacy and needed simple practical advice to develop a uniform way of assessing and recording concordance amongst their customers. Poor concordance was a red flag reason for referral in the study however during the four weeks of the targeted MR project none of the referrals were for poor compliance.

IV. Patient perspective – education about their epilepsy

The targeted MUR for epilepsy was a new experience for the customers and the first question was a challenging on whereby they answered of the MUR had helped them to understand the underlying causes of their epilepsy more. Despite the complexity of this the post MUR results generally revealed that they had learned more about their epilepsy and the leaflet by epilepsy action ‘Seizures Explained,’ was found to be very useful [107] being taken by 12 people seen during the study. They also received advice on a regular lifestyle and good concordance and again the majority of people improved their scoring when asked if they felt confident that they could minimise their risk of a seizure.

V. Future intentions for people with epilepsy to seek support from their pharmacist

This question had the greatest change in response with the majority reporting that prior to the MUR they would be very unlikely to seek advice or support from their pharmacist. By the end of the MUR however the majority answered that they would be very likely to seek help or advice when they required t from their pharmacist. This reveals that based on this feasibility study patients are willing to see their community pharmacist as a legitimate clinician who is well placed to offer them help with their epilepsy. Currently this provision has been very limited in the UK and is likely to be sporadic however it may be possible to develop this further and further studies may be helpful in determining the potential scope which is available from the community pharmacist.

VI. The content of the MURs for Epilepsy

In the documentation from the MURs it was clear that a good deal of counselling on epilepsy had taken place. Many people had expressed their interest in understanding their epilepsy more and 12 leaflets on seizures explained were taken. Also safety and epilepsy was a frequent topic and 4 people took a copy of the leaflet ‘safety and epilepsy,’ by Epilepsy Action[108]. Other areas covered were memory and a leaflet ‘memory and epilepsy,’ by Epilepsy Action[109] was given and so to was a leaflet on ‘alcohol and epilepsy,’ again by Epilepsy Action[110] to one patient. Photosensitivity was mentioned by several and the Epilepsy Action leaflet on ‘Photosensitivity,’[111] was given to four patients. Issues relating to driving were discussed and two patients were given the leaflet ‘Driving and Epilepsy,’[112] by Epilepsy Action and finally two women has questions relating to epilepsy and were given a copy of the epilepsy action leaflet ‘Women and Epilepsy.’ [113]

Weaknesses of the targeted Medicines Use Review for epilepsy

I. Referral rights for community pharmacists

Initially there was understandable concern raised by the medical commissioners over the possibility that there would be a large increase in the number of people being referred to specialist care and the resultant increase in costs incurred to the health authority. This feasibility study however did not demonstrate any such link. There was however several inappropriate referrals to the GPwSI epilepsy clinic and for future MUR programs for epilepsy will require more careful explanation to help minimise this problem. Community pharmacists currently do not make referral as a rule to specialist services and it is not something they have encountered to any degree previously.

The problem was averted by the author offering simple triage and reviewing all of the referrals before the appointments were sent out and was able to easily re-direct these to the appropriate care. Each pharmacist was contacted and had the reason for the redirection of referral explained and the patient's GP was informed as well. The referral form in all of these cases was not followed and the referrals were clearly not in the remit of the study however it would be made even clearer in any potential future studies.

I would recommend persevering the with referral pathways from the community pharmacists as they are undoubtedly the people closest to the patient on the clinical care pathway. This places them in an ideal position to identify people who are not currently accessing specialist care for epilepsy and are in need of having their epilepsy treatment optimised.

Putting the results of the Medicines Use Review in context

The locally enhanced service provided useful lessons in how to provide high quality advice from non-specialists using accredited information and led to the development of targeted epilepsy medicines use reviews being piloted. The pilot was successful and plans are underway to offer epilepsy targeted MURs in Wales later this year. This will offer a new method of outreach to identify people who are in need of treatment but who are currently not accessing specialist epilepsy services... It will also produce a widespread network of support for people with epilepsy and help to engage community pharmacists into the proactive care of people with epilepsy.

Ideas for future study

I. Hospital admission rates

If there were to be further study into the use of community pharmacists in supporting people with epilepsy if would be interesting to compare the admission rates to hospital for people before and after the intervention by the pharmacist to see if there were any significance difference. The group particularly to focus on would be the group who are currently at risk of morbidity and mortality from their epilepsy as they do not access conventional care via their GP or their neurology services

II. Medicines Adherence

Also it of interest to see if the intervention by the community pharmacists had any impact on the medicines adherence by the people with epilepsy. The pharmacists training includes study on medicines adherence and this skill could be brought to bear on the population with epilepsy. An additional arm to this study could explore in the group who were non adherent to their anticonvulsant medication if the encounter with the community pharmacist altered either their unscheduled care or indeed their psychosocial consequences of their epilepsy. This recommendation comes as a consequence of this short study identifying two people who were noted to be suffering from uncontrolled seizures and one was advised to contact their epilepsy specialist nurse and the other to see if their consultant appointment could be brought forward.

III. The impact of a Pharmacist with a Special Interest in Epilepsy [PhwSI epilepsy]

The study of having the support of a Pharmacist with a Special Interest in Epilepsy would add an extra dimension to any future studies as they would hold in depth knowledge both of the role and skills of a community pharmacist in addition to the epilepsy skills of a PhwSI.

Support of the targeted Medicines Use Review of the Hypothesis

The targeted Medicines Use Reviews for epilepsy support the hypothesis that low interventions with a system that potentially has a high capacity is feasible. This small pilot study took a group of pharmacists whose pre training knowledge of epilepsy was limited and by the end increased their confidence and knowledge in epilepsy. This was assessed using a simple and unverified assessment of their knowledge however in all cases their responses improved. In addition the impact of their intervention on people with epilepsy was both well received and helpful with a swing in response by the patients to suggest that they would use their pharmacists again in the future to support them with their epilepsy.

In addition the use of accredited information given by the pharmacists to the patients appeared to have been used appropriately and was seen as being successful. These features all support the hypothesis that it is feasible for primary care to offer low impact and high capacity care to people with epilepsy. It also suggests that the patients find benefit from this intervention. No statistical analysis was possible due to the small sample size and if the study was extended would be necessary to extrapolate with confidence the benefit or otherwise of their role in supporting people with epilepsy. In addition an economic model could be developed to assess the impact on the health economy following such an intervention.

CONCLUSION

Re-organisation of the model of care for epilepsy

These four studies explore the scope for primary care to play an augmented role in the management of people with epilepsy. The criticisms by many national reports over the last 50 years is that the care for people with epilepsy has been disjointed and poorly organised and if at the very least primary care is the common ground to help co-ordinate these resources then the outlook for people with epilepsy will surely be improved. As everybody in the UK currently has a GP who holds their medical records and also oversees their medication , it should be possible to ensure that everybody with epilepsy is offered access to the appropriate level of epilepsy service to keep the impact of their epilepsy on daily living to the minimum possible.

PRICCE was highly significant in that it started a process whereby the person with epilepsy had a say in their care. They were asked if they were still having seizures and also if their medication suited them thereby starting a chain of events to see the provision and care of epilepsy in the U.K. increase steadily with time. It is only the GP who holds the disease register that makes this possible and the QOF program shows how relatively simple it is to organise an evidence based program of care to monitor a long term condition such as epilepsy

It would seem reasonable however to adopt a degree of optimism for the future of epilepsy care. It is not difficult to imagine that this is set to improve over the next decade. The current trend is for the focus of developing services offering personalised care for people which is close to home. In this model the patient is at the centre of the care making process and is able to make informed choices on their treatment and have an input into what services they would prefer. This is likely to require greater capacity in epilepsy care provision than is present at the moment and at a cost that is sustainable by the health service. This thesis identifies ways in which this may be promoted and how the capacity for care in the community be increased.

Pro-active Care

The early work with the PRICCE-2 study paved the way for evidence based medicine for epilepsy to be offered to everyone with the illness using the tools of an accurate disease register and computer driven audit. At that stage only basic functions appeared possible in Primary care but it still generated the impetus for people with epilepsy to be taken notice of and the process of patient centred care began. The more complicated aspects of living with epilepsy especially for women was not initially successful however with time this has now become within the grasp of most GPs.

National Programs of Care for Epilepsy

For the population as a whole to benefit, the regional study needed to be adopted nationally and whilst the study was directly linked in with the author’s work the magnitude of scale necessitated the program to be run and managed by the department of health. This has been a great success and steadily the level of care managed regionally has been adopted on a national level. This may have in part contributed to the rise in the profile of epilepsy which is arguably higher now than it was a decade ago.

Patient education

If one accepts that the capacity of care for people with epilepsy needs to be increased then focus should be placed on the epilepsy care pathway. Support needs to be increased not only at the acute presentation of epilepsy but also consideration given for improving sources of support for people living with epilepsy. There is a need to mobilise as wide an ongoing support network as possible for the long term management of people with epilepsy[114] which includes the patient themselves being given greater responsibility for their welfare. This can be achieved by encouraging the patient to actively participate in looking after their own epilepsy, developing shared care for epilepsy, implement management guidelines and facilitate the use of clinical information systems. Education is a key role in this process and a lack of education for people with epilepsy has been identified for many years. It is surprising to see that some of the concerns about the lack of patient information 17 yrs. ago are unfortunately much the same as they are now.[115] Some of the aims of patient education is to improve their understanding of their illness, thereby promoting improved compliance with medication and being more aware of triggers[116]. The providers of this information could be quite varied ranging from epilepsy charities, community pharmacists, practice nurses, GPs, GPwSIs in epilepsy and epilepsy specialist nurses who traditionally offer a major lead in this area. A specialist nurse is epilepsy already has a very established role in providing advice and information and performs the role of educator to the patient thereby encouraging self-management.[117] Nurses also play a role in helping to co-ordinate patient care and improve a patient's quality of life[118].

Community Pharmacists support for people with epilepsy

This thesis also looks at the feasibility of establishing community pharmacists as a support for people with epilepsy. The community pharmacists involved in the pilot were highly motivated and professional in their approach to studying epilepsy and offered a service which was appreciated by people with epilepsy. They were receptive to training and could apply the information they learned well with their patients and tailored the advice and information required by the patients effectively. The post MUR scores given by the patients indeed confirmed that they were successful in doing so and they were seen as being a useful point of contact which the majority said they would turn to in the future. With a health care system now geared to place the patient in the centre of their care and that the care should be a close to the patient's home, the input of community pharmacists would seem ideally placed.

The role of the General Practitioner in the care for people with epilepsy

This thesis has demonstrated that the regular general practitioner also has a role to play in the on-going care for people with epilepsy. After initial assessment by secondary care the majority of people with epilepsy are referred back to their GP however in the past epilepsy reviews were somewhat haphazard until the new GP contract 2004 was introduced, which included the quality and outcomes framework for epilepsy[119].

The introduction of the National Institute for Clinical Effectiveness [NICE] in 1999 led to the development of developing standardised care in England, based on evidence based research. In 2005 joined the Health Development Agency and though still referred to as NICE changed its title to The National Institute for Health and Clinical Excellence. In addition to raising standards of health care general practitioners have steadily become paperless and the use of electronic databases has led the way for targeted patient care using audit tools and for improved sharing of information[120].

Recommendation has been made that the routine ongoing management of epilepsy should take place in primary care however it would seem that without incentivisation, general practitioners readiness to take on this role is lacking[121]. With the right factors in place however this thesis supports the move to provide high capacity, low impact care for people in epilepsy in general practice...

Impact of QOF on Epilepsy reviews in general practice

It appears clear that QOF has improved aspects of epilepsy care in the UK. In an audit of epilepsy care at the introduction of QOF and followed up 4 yrs. later, it revealed that the introduction of QOF for 13 practices in the Chester area had significantly increased the annual review rate of people with epilepsy and was sustained. The number of people under shared care fell over this time which may be due to tighter influence by hospital managers to reduce the number of follow up episodes in out patient's clinics. Within the report is caution that the care pathways for epilepsy are by no means perfect with a surprisingly high figure of 48% of people were who had poorly controlled epilepsy were found not to be under specialist care.

The next decade of care for epilepsy in the community

The next decade of clinical care for epilepsy is likely to change considerably and some insight into these changes may be possible by taking a review of the processes described in this thesis exploring how services for people with epilepsy have developed over the past decade. It seems likely that the move towards community based care will continue and that the incentivisation for primary care involvement in epilepsy will continue. The standards will steadily become more challenging to achieve and social aspects of epilepsy care could be added to the current framework. The delivery of care for people with epilepsy will likely take on a more complex form with devolved health planning to the different regions in the UK resulting in a range of solutions to local population challenges and preferences.

The epilepsy team of the future will hopefully include more clinicians as the numbers with epilepsy appears set to rise and in the future a team may include a psychogeriatrican who can offer advice to their colleagues on epilepsy which associated with dementia. The role of community pharmacists may also increase further and specially trained Pharmacists with a special interest in epilepsy may well soon be available to help support the work of the general community pharmacists.

The involvement of the voluntary sector may also develop further with greater involvement being given to the service users in designing services. It may be that services such as GPwSIs in epilepsy and community based epilepsy specialist nurses will be employed by the epilepsy charities as providers of care and commissioned by the clinical commissioning groups [87]. This will help to focus the care on people with epilepsy and help to avoid the competing interest of profits over service.

If the current trend to improve epilepsy services continues and its profile continues to rise the Cinderella status of epilepsy care as it was 10 years ago hopefully should be relegated permanently to history. Alongside these changes the next decade will undoubtedly bring new advances in the understanding and treatment of people with epilepsy. Those involved with the care and support of people with epilepsy will surely need to keep reviewing their care for this group of people and hopefully go on to witness a significant change in the outlook for people with epilepsy.

The primary aim of this thesis has I believe been demonstrated, with the four studies successfully promoting greater involvement of primary care in the treatment of epilepsy. Clearly defined programs of high capacity, low interventional care for people with epilepsy appear to be both feasible and effective in primary care..

The influence on admission rates and mortality for epilepsy is less clear. There are many influences on the admission rates for epilepsy which would need to be taken into account before the impact of primary care programs could be clearly demonstrated. In addition, it would be highly presumptive and indeed misleading to suggest that this study supports the notion that the Quality and Outcomes Framework was instrumental in this trend of a slight fall in mortality for epilepsy. Further work is required to explore this observation more fully.

APPENDIX

1 Correspondence between PRICCE and QOF

Email from Dr Tony Snell – former Medical Director of East Kent PCT to confirm the researcher's link with the Primary Care Clinical Effectiveness Project and thereby with the Quality and Outcomes Framework

From: Tony Snell [mailto:Tony.Snell@harmonicpo.com]
Sent: 23 July 2008 16:57
To: G ROGERS
Subject: RE: Hello

You are correct – PRICCE turned into QOF. Therefore all you say is correct, so go for it. In fact you can say you wrote chapter in PRICCE and whatever turned up in QOF that is same is all down to you

Kind Regards,

Dr Tony Snell

Medical Director,
Harmoni,
Regus Building, Cardinal Point, Park Road,
Rickmansworth, Herts WD3 1RE
T: +44 (0) 1923 715 043
F: +44 (0) 1923 715 001
M: 0752 5986308
E: tony.snell@harmonicpo.com
W: www.harmonicpo.com

2 Document describing PRICCE-1 Protocol

SUMMARY OF PRICCE 1 STANDARDS 1998 [26]

The following criteria must apply to all disease areas :

Disease registers must be set up for all disease areas covered by the project.

There will be a written protocol approved by all the relevant Primary Care team members.

Complete audits to demonstrate compliance with standards for each disease

If a practice can demonstrate clearly any particular reason why they are so disadvantaged as to be unable to meet a particular standard, then a discussion can take place between practice/EKHA/MAAG/LMC.

***Idiopathic* Epilepsy**

Definition - Fit in last 2 years or on medication.

Examples of patients to be referred to suitable specialist at the first stage:

Those with neurological signs, including impaired learning.

Those under 16 years old.

Those whose diagnosis is uncertain.

The protocol must include documenting the minimum data set and when to refer and factors to be included in a referral letter.

70 % of patients should be seizure-free two years from initial diagnosis by 1.4.99 , this means in the previous 6 months and by 1.4.00 in the previous 12 months (If this is not achieved, then the practice must be able to demonstrate why this is so).

The review of patients must be audited annually.

3 Document describing the PRICCE-2 Protocol

PRICCE 2 Chapter 3 Epilepsy Standards

STANDARDS FOR TREATMENT OF EPILEPSY

Information on Epilepsy

Epilepsy is one of the most common neurological disorders and is defined as a tendency to recurrent seizures; thus patients who have a single epileptic seizure do not have epilepsy. (Patients with a single epileptic seizure should be advised not to drive).

3.2 The patient's epilepsy needs to be assessed in terms of:
Seizure type
Epilepsy syndrome
Relevant aetiology

International League Against Epilepsy : Classification of Epileptic Seizures

Partial Seizures (seizures beginning locally)
Simple partial seizures (consciousness not impaired)
With somatosensory or special sensory symptoms
With automatic symptoms
With psychic symptoms
Complex partial seizures (with impairment of consciousness)
Beginning as simple partial seizures and progressing to impairment of consciousness (with or without automatism)
With impairment of consciousness at onset (with or without automatism)
Partial seizures secondarily generalized
Secondary to simple partial seizures
Secondary to complex partial seizures

Generalised Seizures (bilaterally symmetric and without local onset)

Absence
Myoclonic
Clonic
Tonic
Tonic-clonic
Atonic

Unclassified Epileptic Seizures (due to inadequate or incomplete data)

Adapted from Commission on Classification and Terminology of the International League Against Epilepsy

The establishment of a patient's seizure type should occur within the framework of the seizure classification of the International League Against Epilepsy

3.3 Patients may experience more than one type of seizure, as shown in table 2.

The Three most Common Syndromes of Idiopathic Generalized epilepsy

	Absence	JME	GTCS
Age at onset (y)	5 to 15	9 to 18	Any Age
Seizure Type(s)*	Absence	Myoclonic Generalized Tonic-clonic	Generalized Tonic-clonic
EEG	3 Hz S & W	>3 Hz S&W Polyspikes	Generalized S&W Normal
Photosensitivity	Childhood 15% Juvenile 7.5%	30%	10% GTCS on awakening 13%
Likelihood of remission	Excellent	Poor	Good

* Most common seizures at presentation JME = juvenile myoclonic epilepsy; GTCS = generalisec tonic-clonic seizures S & W = Spike and wave

The cause of epilepsy varies from genetically determined, space-occupying lesions (such as tumours), to damage caused by vascular events such as thromboses and clots.

Epidemiology of epilepsy:

Incidence 50-70/100,000/year
1-1.5/2,000/year

Prevalence 20-30/1,000/life time

Point prevalence 5-7/1,000
10-14/2,000 of these 6 will be fully controlled
3 will have less than one fit per month
4 will have more than one fit per month

3.5 There is a raised mortality in the disease due to accident and drowning and to the etiological factors behind the disease such as progressive tumour; but that apart there is an incidence of Sudden Unexpected Death in epilepsy (SUDEP), all factors leading to a mortality ratio of 2.8. However, epilepsy has a good prognosis with those going into remission doing so early in the illness. Figures from Goodridge (Tonbridge) 1984 show that 19 years after the initial diagnosis 19% of patients still had no fits, 65% going into remission within 5 years of onset.

3.6 Each GP will have approximately 1-2 new cases per year, or 4 cases in a practice of 4 GPs.

There should be an awareness of differential diagnosis (at least 10% of cases are wrongly positively diagnosed). Table 4 lists the differential diagnosis for epilepsy.

Differential diagnosis for epilepsy:

Transient ischaemic attacks
Syncopal attacks, NB. Cardiac causes
Anoxic seizures
Acute vertigo
Hyperventilation
Drop attacks
Breath holding attacks
Non epileptic attack disorder (Pseudo-seizures)

Table 5 lists the minimum data set for epilepsy.

Minimum data set for epilepsy:

Clear history – diagnosis is based on the description, all efforts should be made to interview witnesses. Record the events before, during and after the attack, the circumstances in which the attack occurred, the speed of onset and the speed of recovery.
History of drugs and alcohol
Family history
Neurological examination
Electroencephalogram (EEG) for all children, and adolescents and young adults and/or computed tomograph (CT) scan (CT scan in children is not routine), or MRI depending on clinical circumstances.

3.9 The practice must have policies for referral of individuals at the first stage. Table 6 lists examples. Ideally all new patients should be referred to a specialist clinic. If resources do not allow this, then as a minimum the following referral policies should be considered

Examples of patients to be referred to neurologist or paediatrician as appropriate at the first stage:

Those whose diagnosis is uncertain
Children and young adults
Those with neurological signs, including impaired learning
Those who wish it
Those requiring identification of underlying cause

3.10 There should also be consideration of referral to a psychologist.

3.11 There should be an agreed policy with the neurologist (or evidence of discussions between the practice and the secondary health care provider) to include the following (see Table 7).

Factors to be considered in shared policy for patients suspected of having epilepsy:

Which patients to be referred to the neurologist at first diagnosis
Reasonable waiting times before the patient is seen in outpatients is agreed by the Primary Care Organisation. All patients must be seen within a certain number of weeks (which must not be greater than the number set out in the Patient's Charter).
Driving regulations must be discussed at referral.
Drug therapy is not usually started at this stage.
Offering information about local and national self help groups.
Offering advice on safety issues.

3.12 The practice should have a template for a referral letter where a diagnosis of epilepsy is suspected. Table 8 lists factors, which could be included in the template.

Factors to be included in a referral letter to a neurologist:

Fit timing and frequency
Aura
Witness description of ictus and post-ictal period
Medical History

3.13 There should be an annual review of patients with epilepsy. Table 9 lists the checks, which should be carried out.

Checks which should be carried out at review of epileptic patients:

Compliance with driving regulations
Fit frequency from chart
Manipulate drug regime on basis of frequency and side effect
Drug levels measured where appropriate
i. For compliance
ii. Toxicity
iii. Possibility of increasing dose of poor control.
Pre conceptual counselling, (OCP and enzyme induces)
Referral for specialist opinion during pregnancy
Discuss safety issues, e.g., lifestyle in relation to bathing, working and leisure at heights, waterfronts, and dealing with heat and fire.
Folic acid supplementation to females of reproductive age.
Side effects of medications counselling.
Seizure triggers such as alcohol or binges, sleep deprivation, and photosensitivity.

Standards for the Diagnosis and Management of Epilepsy

3.14 The practice should have a protocol for the evaluation of all new cases.

3.15 The practice must be able to identify all patients diagnosed with epilepsy.

3.16 All patients diagnosed as suffering from epilepsy and/or their carers should be provided with factual information in the form of leaflets, booklets, etc., with further contact details where appropriate (eg, British Epilepsy Association, the National Society for Epilepsy or the Epilepsy Task Force). The information should be sufficient to enable the patient and/or carer to participate in discussion about their care.

3.17 All advice to patients and/or carers must be documented in the patient's notes. All patients must have an EEG and/or a CT scan, as agreed with the secondary provider(s).

3.18 No diagnosis of epilepsy should be made without a witness and after only one fit.

3.19 There must be annual audit carried out by the practice on the assessment and diagnosis and management of patients with epilepsy. (The time to first appointment should be compared with the hospital agreement).

3.20 The practice must have written protocol for managing patients diagnosed as having epilepsy. The protocol must include the management of patients retained within the practice. Where patients are not controlled there should be consideration of referral for specialist advice.

3.21 The protocol should include documenting the minimum data set (Table 5) and when to refer (Table 6) and factors to include in a referral letter (Table 9).

3.22 The protocol should include time scales for reviewing those patients (at least annually), and updating the disease register. A named individual should be responsible for these reviews.

3.23 The protocol should include managing of emergencies - those patients with status epilepticus - and there should be evidence that emergency first aid had been discussed with the patient and/or relative/carer.

3.24 This protocol should be agreed with the neurologist or appropriate specialist.

3.25 The practice must have a policy for re-referral to a neurologist in the case of new symptoms/signs, poor control or end of disease. (Drugs may be withdrawn after 2 years fit free in absences and 4 years in other types so long as there are no neurological signs, there is no mental retardation and less than 30 fits have occurred. An estimation of the individual risk should be calculated and discussed, (Liverpool data)).

3.26 The doctor's emergency bag should contain in-date diazepam in its various forms.
3.27 Where the doctor suspects that a patient is experiencing pseudofits, then this patient should be referred to a psychiatrist if a neuropsychiatrist is not available.

Outcome or Proxy Outcome Standards for Epilepsy

3.28 70 per cent of patients should be seizure free two years from initial diagnosis by 1.4.99, this means in the previous 6 months and by 1.4.00 in the previous 12 months (If this is not achieved, then the practice must be able to demonstrate why this is so.)

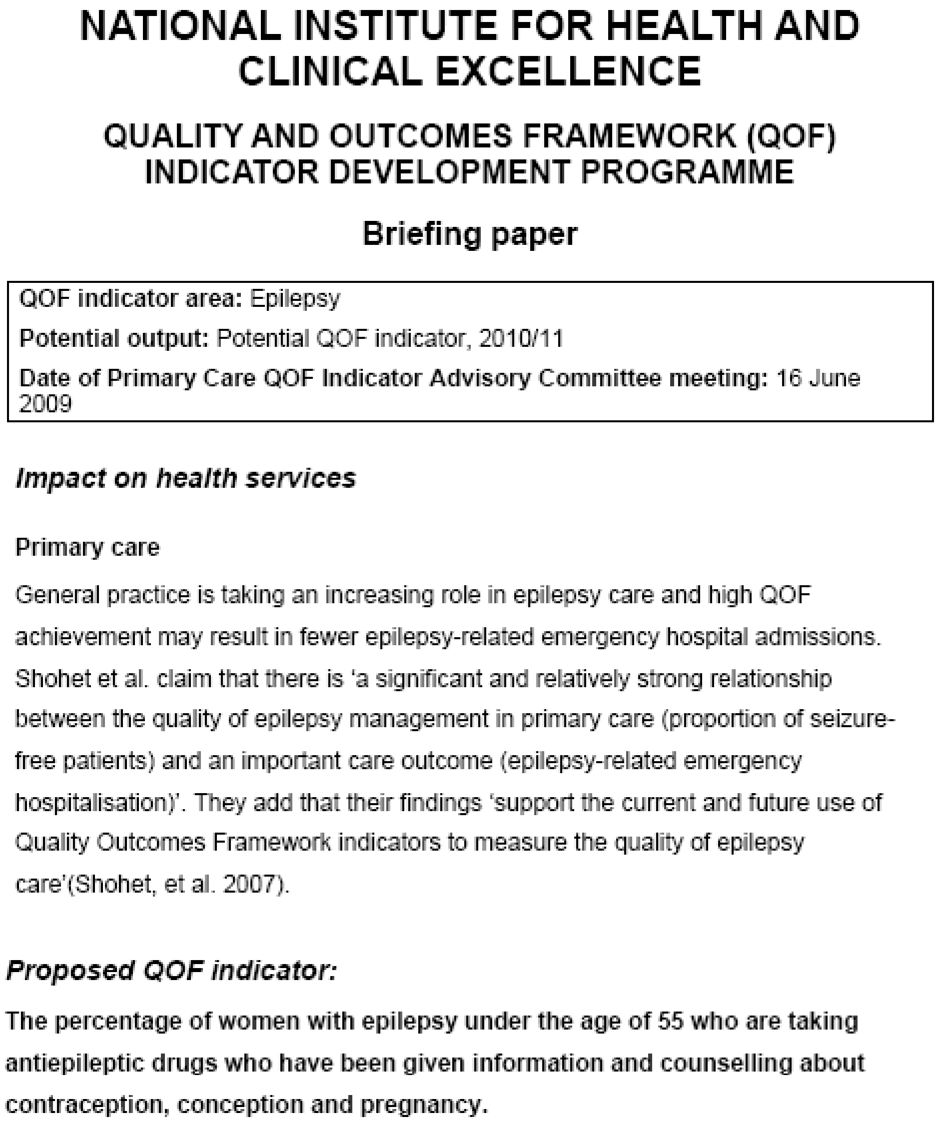
3.29 The review of patients must be annually audited to facilitate optimal care to reduce seizure frequency in all patients.

3.30 There must be evidence of discussion amongst the primary health care team around any critical events.

References

Managing Epilepsy in Primary Care
Epilepsy - A General Practice Problem. Dr Edwin Marton RCGP Clinical Services 1991
Management of Major Epileptics in Adults - BMJ 1990 301:918
Brown S et.al. An Epilepsy Needs Document Seizure 1993; 2:91-103.

4 Involvement of Author in the updating of QOF



NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

QUALITY AND OUTCOMES FRAMEWORK (QOF) INDICATOR DEVELOPMENT PROGRAMME

Briefing paper

QOF indicator area: Epilepsy

Potential output: Potential QOF indicator, 2010/11

Date of Primary Care QOF Indicator Advisory Committee meeting: 16 June 2009

Impact on health services

Primary care

General practice is taking an increasing role in epilepsy care and high QOF achievement may result in fewer epilepsy-related emergency hospital admissions. Shohet et al. claim that there is 'a significant and relatively strong relationship between the quality of epilepsy management in primary care (proportion of seizure-free patients) and an important care outcome (epilepsy-related emergency hospitalisation)'. They add that their findings 'support the current and future use of Quality Outcomes Framework indicators to measure the quality of epilepsy care'(Shohet, et al. 2007).

Proposed QOF indicator:

The percentage of women with epilepsy under the age of 55 who are taking antiepileptic drugs who have been given information and counselling about contraception, conception and pregnancy.

Evidence summary for proposed new indicator

Clinical effectiveness

It is estimated that in the UK 131,000 women with epilepsy are of child-bearing age (12–50 years). Approximately 25% of all people with epilepsy are women of reproductive age, and 1 in 200 women attending antenatal clinics are receiving antiepileptic drugs (AEDs) (Royal Society of Medicine Epilepsy Guidelines Group 2004). Around 2500 women with epilepsy will have a baby each year in the UK. Antiepileptic drugs taken during pregnancy are associated with an increased risk of major congenital malformations (MCMs). Women in the general population have a 1–2% chance of having a baby with an MCM. Women with epilepsy taking one AED have a chance of having a baby with an MCM of slightly over 3.5%, while for women taking two or more AEDs the average chance increases to 6% (Morrow et al. 2006). The risk of MCMs occurring can relate to having epilepsy and to taking AEDs while pregnant.Crawford and Hudson (2003) said: ‘The impact of some commonly prescribed anti-epileptic drugs (AEDs) on female health is well documented. Yet many women continue to experience side effects such as menstrual irregularities, interactions with hormonal contraception/HRT and teratogenicity through lack of awareness or opportunity to discuss problems with a health professional on a regular basis.’

They added: ‘Unfortunately current epilepsy services in the UK are such that many women remain unaware of the issues or risks. Important conversations about contraception and unplanned pregnancy and pre-conception counselling may not take place until it is too late.’

Crawford and Hudson’s survey results show that women are not receiving important information about their condition and the possible effects of AEDs. Only 28% of women aged 19–34 years have received information about oral contraception and epilepsy medication. Of women aged 19–34 years, 71% said that the risk of epilepsy and/or an AED affecting the unborn child is an important issue. Only 46% of women with epilepsy who have had children had been told that their medication might affect their unborn child, which implies that 54% of women who had been through a pregnancy had not been given such information. The vast majority of women surveyed who were considering having children (87%) said that they would like to have more information about epilepsy treatment (Crawford and Hudson 2003).

The Scottish Intercollegiate Guidelines Network (SIGN) guideline states: 'Advice on contraception should be given before young women are sexually active. Women with epilepsy should be advised to plan their pregnancies.' (SIGN 2003)

Cost effectiveness

Relevant cost-effectiveness data was not identified.

Assessment of indicators against current practice

Reduction of health inequalities

There was no evidence identified to directly show that the recommendations outlined in this briefing paper can reduce health inequalities. However, people from black and minority ethnic groups may have different cultural and communication needs and these should be considered during diagnosis and management. The need for interpretation should be considered alongside other means of ensuring that each person's needs are appropriately met.

Will implementation of these recommendations lead to cost-effective improvements in the delivery of primary care?

No evidence was identified to directly show that the recommendations may lead to cost-effective improvements in the delivery of primary healthcare.

The following people were involved in developing this indicator:

1. Kathy Bairstow, Senior Advice and Information Officer, Epilepsy Action
2. Professor Helen Cross, Professor of Paediatric Neurology, UCL Institute of Child Health and Great Ormond Street Hospital
3. Dr Simon Degroot, GP with special interest in epilepsy, Doncaster
4. Professor John Duncan, Professor of Neurology, Institute of Neurology, University of London

5. Bill Hall, GP with interest in epilepsy, Setlle
6. Dr Andy Hansen, GP with special interest in epilepsy, Bradford
7. Dr Karl Rakshi, Consultant General Paediatrician and local lead for children and young people with epilepsy, East Lancashire Health Trust
8. Dr Keith Redhead, GP with interest in epilepsy, Norfolk Primary Care Trust
9. Leone Ridsdale, Senior Lecturer in Neurology and Reader in General Practice, Institute of Psychiatry, King's College London
10. Dr Henry Smithson, Senior Lecturer, University of Sheffield
11. Greg Rogers, GP with special interest in epilepsy, East Kent Primary Care Trust

5 Email from Kent and Medway Public Health Observatory regarding the calculation of trend in mortality rates in England

From: Barlow Julian (EASTERN AND COASTAL KENT PCT)
Sent: 04 October 2012 11:15
To: Rogers Greg (EASTERN AND COASTAL KENT PCT)
Subject: RE: Mortality rate trends for epilepsy

Hello Greg -

I've standardised these deaths for you and added invisible linear trend lines on the charts to give R^2 for these series.

There does indeed appear to be a downwards trend, more noticeable among males than females, with gender rates converging over the period.

There are old and new Excel versions attached. Use the .xlsx version if you can.

I've also included the yearly data sheets in the file, where the arithmetic happens, but I've concealed these, so you'll have to unhide these if you want to work with the underlying data.

I hope this is OK, good luck with the PhD.

Best wishes, Julian

Julian Barlow
Senior Public Health Information Analyst
NHS Kent & Medway
Templar House, Tannery Lane, Ashford, TN23 1PL
Tel: 01233 618366 (direct)
email: julian.barlow@eastcoastkent.nhs.uk julian.barlow@nhs.net

NHS Kent and Medway represents the following primary care trusts (PCTs):
NHS West Kent, NHS Eastern and Coastal Kent and NHS Medway

From: Rogers Greg (EASTERN AND COASTAL KENT PCT)
Sent: 04 October 2012 09:04
To: Barlow Julian (EASTERN AND COASTAL KENT PCT)
Subject: RE: Mortality rate trends for epilepsy
Dear Julian

That would be really great if you would! The area of England and Wales has more external variable factors [different commissioning structures etc] and so ideally just looking at England figures would be preferable however the overall structure is fairly similar as you know.

Again, thank you very much for your help, with best wishes,

Greg

From: Barlow Julian (EASTERN AND COASTAL KENT PCT)
Sent: 03 October 2012 14:57
To: Rogers Greg (EASTERN AND COASTAL KENT PCT)
Subject: RE: Mortality rate trends for epilepsy

Hello Greg –

This shouldn't be very difficult, although I'll have to get the population data in sex/quinary age bands for each year, and that's the time-consuming bit.

If I get a break in proceedings then hopefully I'll get something to you by the end of the week.

In which area are you most interested? England, or England and Wales?

Best wishes, Julian

Julian Barlow
Public Health Information Specialist
NHS Kent and Medway

Templar House
Tannery Lane
Ashford
TN23 1PL

Tel: 01233618366
Email: Julian.Barlow@eastcoastkent.nhs.uk
Email: julian.barlow@nhs.net

NHS Kent and Medway represents the following primary care trusts (PCTs):
NHS West Kent, NHS Eastern and Coastal Kent and NHS Medway.

From: Rogers Greg (EASTERN AND COASTAL KENT PCT)
Sent: 03 October 2012 14:24
To: Barlow Julian (EASTERN AND COASTAL KENT PCT)
Subject: Mortality rate trends for epilepsy

Dear Julian

Hi. Thank you for talking to me on the phone and as we discussed I have attached the file from the ONS ‘Avoidable Mortality in England and Wales, 2010’ and under the bottom page tab for England and Wales there is a list of causes of avoidable death one of which is epilepsy separated by age bands and year.

I took this data and added up each year total and divided it by the population count for that year. This appeared to demonstrate that the unstandardised mortality rates for epilepsy appear to be falling and this seems to have coincided with QOF. If this is the case it would be very useful information and would be something I would share with the RCGP/Epilepsy Bereaved etc

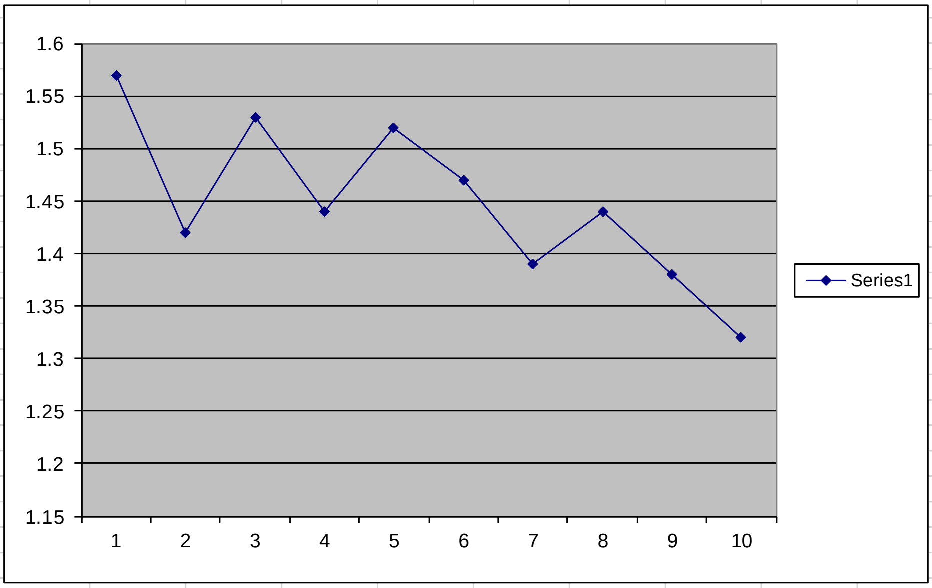
If you could have a look at the data and ideally standardise them etc it would be really helpful and indeed I would owe you a big favour as it will help add weight to my PhD!

With many thanks, Greg

6 Data produced by the author representing non standardised mortality from epilepsy

This data was gather from the document Avoidable Mortality in England and Wales, 2010 produced by the Office for National Statistics which is available but is not summarised being collated in cintiles of 5 years for each year between 2001 and 2010. It covers the populations of England and Wales as well as separate reports for England and Wales. The document is 213 pages long and is not printed in this thesis due to it’s size.

Pop. Eng	50,748.00	50,875.60	50,985.90	51,116.20	51,272.00	51,410.40	51,559.60	51,720.10	51,933.50	52,140.20	52,042.00
Obs Death from Epilepsy			824	825	853	908	885	942	994	918	1010
Death Rate per 100,000			1.62	1.61	1.66	1.76	1.72	1.82	1.91	1.76	1.94
Gross Death Rates											
2001	2002	2003	2004	2005	2006	2007	2008	2009	2010		
1.57	1.42	1.53	1.44	1.52	1.47	1.39	1.44	1.38	1.32		

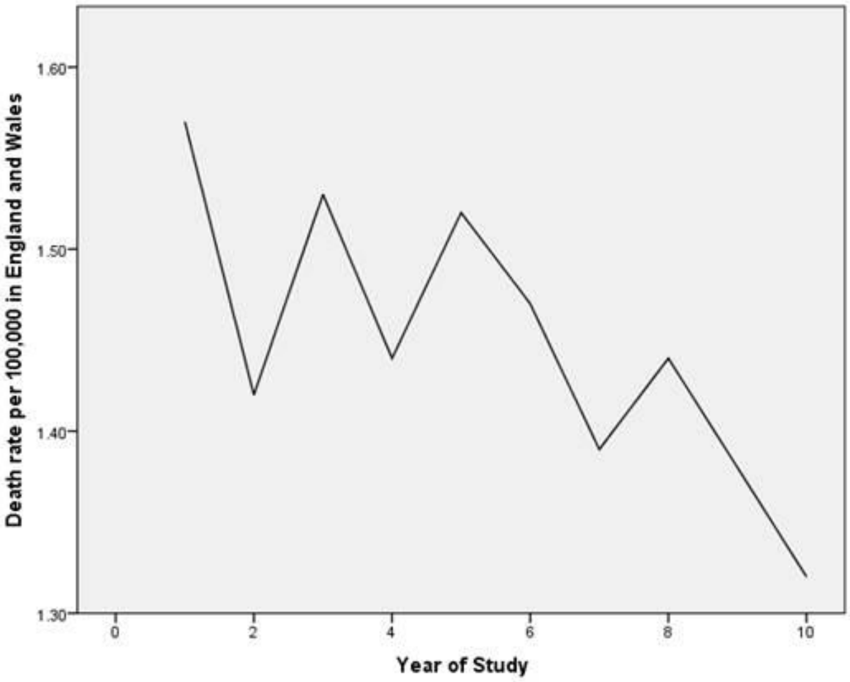


The data further analysed by the author using SPSS statistical software

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	.031	1	.031	11.186	.010[b]
	Residual	.022	8	.003		
	Total	.053	9			

a. Dependent Variable: Death rate per 100,000 in England and Wales
b. Predictors: (Constant), Year of Study



7 Mortality Data sent to the author from the Kent and Medway Public Health Observatory

Directly age-standardised mortality for epilepsy aged under 75, 2001-2010, England

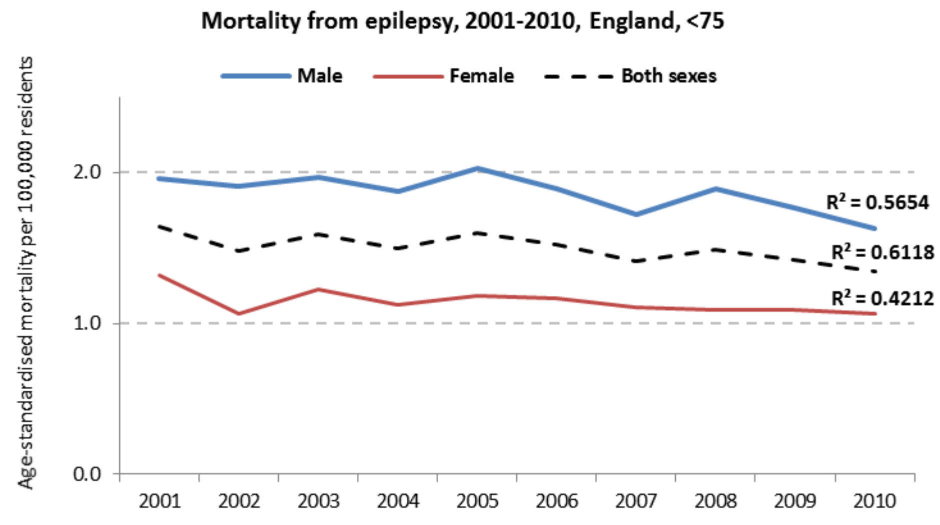
	Year / directly age-standardised mortality per 100,000 residents aged under 75									
Population	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**
Male	1.96	1.91	1.97	1.88	2.02	1.89	1.72	1.89	1.76	1.63
Female	1.32	1.07	1.22	1.12	1.18	1.17	1.11	1.09	1.09	1.06
Both sexes	**1.64**	**1.48**	**1.59**	**1.50**	**1.60**	**1.52**	**1.41**	**1.49**	**1.42**	**1.34**

Source: Office for National Statistics, KMPHO

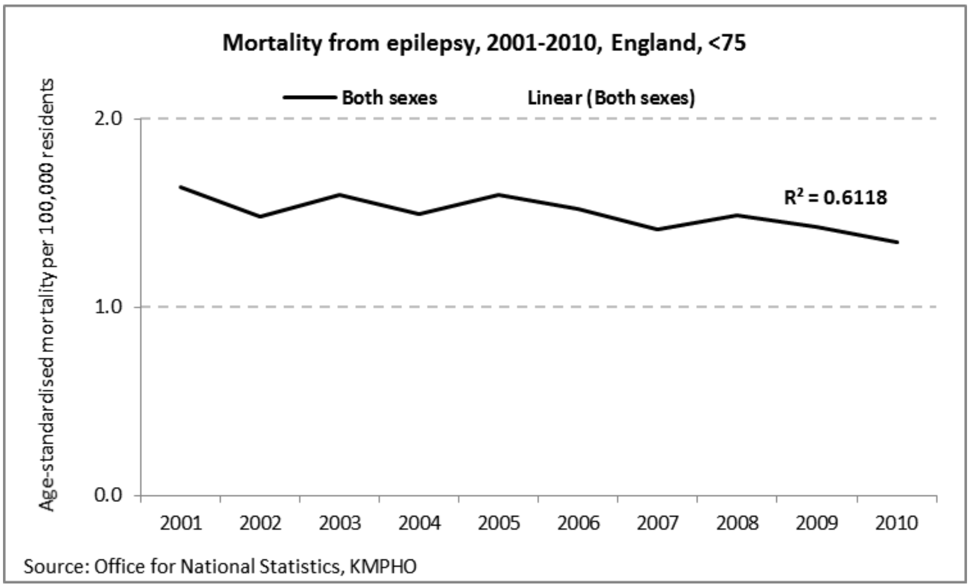
Numbers of deaths from epilepsy, 2001-2010, England

	Year / numbers of deaths aged under 75									
Population	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**
Male	459	449	469	449	489	461	424	468	440	411
Female	317	253	296	274	288	287	275	268	280	269
Both sexes	**776**	**702**	**765**	**723**	**777**	**748**	**699**	**736**	**720**	**680**

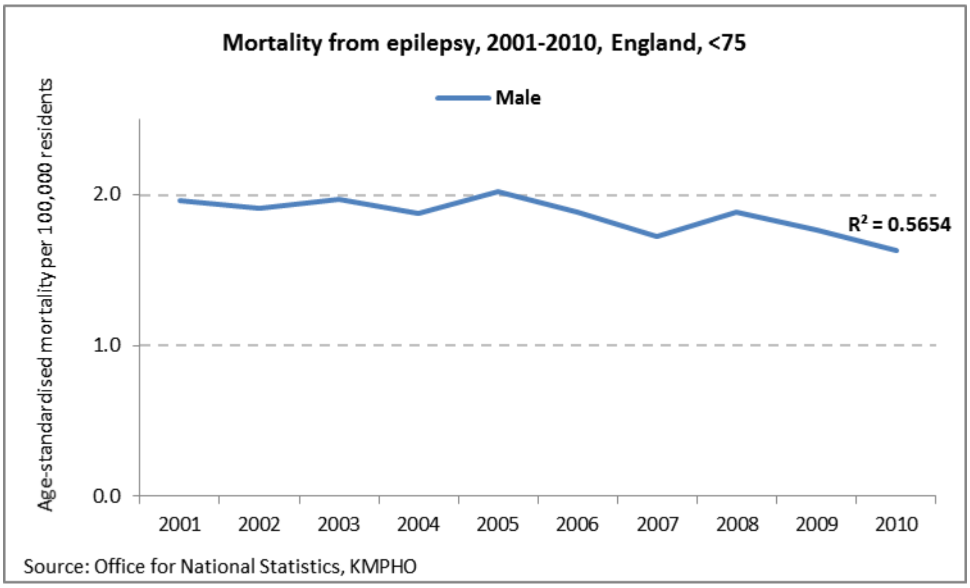
Source: Office for National Statistics, KMPHO



Source: Office for National Statistics, KMPHO



Source: Office for National Statistics, KMPHO



Source: Office for National Statistics, KMPHO

Source: Office for National Statistics, KMPHO

8 PRICCE-2 Raw Data

Number reviewed 2002

Col1	Name	ALL EPILEPSY	% WITH FULL EPILEPSY	FULL EPILEPSY - REVIEWED	% FULL EPILEPSY - REVIEWED
2002	Ashford PCG	363.00	0.39%	354.00	97.52%
2002	Canterbury PCG	205.00	0.13%	195.00	95.12%
2002	East Kent Coastal PCG	107.00	0.14%	102.00	95.33%
2002	Shepway PCG	311.00	0.42%	304.00	97.75%
		986.00	1.08%	955.00	385.72%
			Av = 0.27%		Av = 96.43%

East Kent population in 2002 = 570,100 [ONS population statistics 2002 by Local Authority]

Number seen in PRICCE = 437,232

Number reviewed 2003

Col1	Name	ALL EPILEPSY	% WITH FULL EPILEPSY	FULL EPILEPSY - REVIEWED	% FULL EPILEPSY - REVIEWED
2003	Ashford PCG	445.00	0.44%	433.00	97.30%
2003	Canterbury PCG	783.00	0.49%	741.00	94.64%
2003	East Kent Coastal PCG	986.00	0.54%	936.00	94.93%
2003	Shepway PCG	391.00	0.46%	381.00	97.44%
		2,605.00	1.93%	2,491.00	384.31%
			av= 0.482%		Av = 96.08%

Number Reviewed

2004

Col1	Name	ALL EPILEPSY	% WITH FULL EPILEPSY	FULL EPILEPSY - REVIEWED	% FULL EPILEPSY - REVIEWED
2004	Ashford PCT	477.00	0.45%	465.00	97.48%
2004	Canterbury and Coastal PCT	948.00	0.55%	894.00	94.30%
2004	East Kent Coastal PCT	1,136.00	0.61%	1,080.00	95.07%
2004	Shepway PCT	408.00	0.43%	382.00	93.63%
		2,969.00	2.04% Av = 0.51%	2,821.00	380.49% Av = 95%

Seizure Freedom
2002

Col1	Name	FULL EPILEPSY - SEIZURE FREE	% OF FULL EPILEPSY - FIT FREE
2002	Ashford PCG	267.00	73.55%
2002	Canterbury PCG	140.00	68.29%
2002	East Kent Coastal PCG	78.00	72.90%
2002	Shepway PCG	246.00	79.10%
		731.00	293.84% Av seizure free 73.46

East Kent population in 2002 = 570,100 [ONS population statistics 2002 by Local Authority]

Number seen in PRICCE = 437,232

Seizure Freedom
2003

Col1	Name	FULL EPILEPSY - SEIZURE FREE	% OF FULL EPILEPSY - FIT FREE
2003	Ashford PCG	352.00	79.10%
2003	Canterbury PCG	615.00	78.54%
2003	East Kent Coastal PCG	630.00	63.89%
2003	Shepway PCG	285.00	72.89%
		1,882.00	294.43% Av sz free 73.61

Seizure Freedom 2004

Col1	Name	FULL EPILEPSY - SEIZURE FREE	% OF FULL EPILEPSY - FIT FREE
2004	Ashford PCT	387.00	81.13%
2004	Canterbury and Coastal PCT	692.00	73.00%
2004	East Kent Coastal PCT	719.00	63.29%
2004	Shepway PCT	276.00	67.65%
		2,074.00	285.07%

Av sz free 71.25

Vigabatrin review 2002

Col1	Name	FULL EPILEPSY - VIGABATRIN	FULL EPILEPSY - VIG, VISUAL 6 MONTHS	% OF ON VIG - VIGABATRIN, VISUAL 6 MONTHS
2002	Ashford PCG	1.00	1.00	100.00%
2002	Canterbury PCG	2.00	1.00	50.00%
2002	East Kent Coastal PCG	0.00		
2002	Shepway PCG	2.00	1.00	50.00%
		5.00	3.00	200.00%

Average 66.7%

East Kent population in 2002 = 570,100 [ONS population statistics 2002 by Local Authority]

Number seen in PRICCE = 437,232

Vigabatrin review 2003

Col1	Name	FULL EPILEPSY - VIGABATRIN	FULL EPILEPSY - VIG, VISUAL 6 MONTHS	% OF ON VIG - VIGABATRIN, VISUAL 6 MONTHS
2003	Ashford PCG	4.00	4.00	100.00%
2003	Canterbury PCG	8.00	4.00	50.00%
2003	East Kent Coastal PCG	3.00	1.00	33.33%
2003	Shepway PCG	3.00	1.00	33.33%
		18.00	10.00	216.67% Av = 54.16

PRICCE-2 review 2003

Vigabatrin review 2004

Col1	Name	FULL EPILEPSY - VIGABATRIN	FULL EPILEPSY - VIG, VISUAL 6 MONTHS	% OF ON VIG - VIGABATRIN, VISUAL 6 MONTHS
2004	Ashford PCT	4.00	3.00	75.00%
2004	Canterbury and Coastal PCT	7.00	4.00	57.14%
2004	East Kent Coastal PCT	6.00	4.00	66.67%
2004	Shepway PCT	4.00	1.00	25.00%
		21.00	12.00	223.81% Av = 55.95

PRICCE-2 2004

Number of women reviewed in 2002

Col1	Name	FULL EPILEPSY - PREGNANT IN YEAR	PREGNANT - ON FOLIC	% OF PREGNANT IN YEAR - ON FOLIC	PREGNANT - REFERRED	% OF PREGNANT IN YEAR - REFERRED	PREGNANT IN YEAR - ON VITAMIN K	% OF PREGNANT IN YEAR - ON VITAMIN K
2002	Ashford PCG	7.00	5.00	85.71%	6.00	85.71%	4.00	57.14%
2002	Canterbury PCG	2.00	2.00	100.00%	2.00	100.00%	1.00	50.00%
2002	East Kent Coastal PCG	1.00	1.00	100.00%	1.00	100.00%	0.00	0.00%
2002	Shepway PCG	1.00	0.00	0.00%	0.00	0.00%	0.00	0.00%
		11.00	8.00	285.71%	9.00	285.71%	5.00	107.14%
				Av on folic = 71.43		av refered - 71.43		Av on vit k = 26.79

East Kent population in 2002 = 570,100 [ONS population statistics 2002 by Local Authority]

Number seen in PRICCE = 437,232

Number of women reviewed 2003

Col1	Name	FULL EPILEPSY - PREGNANT IN YEAR	PREGNANT - ON FOLIC	% OF PREGNANT IN YEAR - ON FOLIC	PREGNANT - REFERRED	% OF PREGNANT IN YEAR - REFERRED	PREGNANT IN YEAR - ON VITAMIN K	% OF PREGNANT IN YEAR - ON VITAMIN K
2003	Ashford PCG	5.00	4.00	100.00%	5.00	100.00%	3.00	60.00%
2003	Canterbury PCG	3.00	2.00	66.67%	2.00	66.67%	1.00	33.33%
2003	East Kent Coastal PCG	11.00	7.00	100.00%	11.00	100.00%	4.00	36.36%
2003	Shepway PCG	2.00	0.00	0.00%	0.00	0.00%	0.00	0.00%
		21.00	13.00	266.67%	18.00	266.67%	8.00	129.70%
				Av on folic= 66.67		Av ref = 66.67		Av = 32.43

Pricce 2003

Number of women reviewed in PRICCE 2004

Col1	Name	FULL EPILEPSY - PREGNANT IN YEAR	PREGNANT - ON FOLIC	% OF PREGNANT IN YEAR - ON FOLIC	PREGNANT - REFERRED	% OF PREGNANT IN YEAR - REFERRED	PREGNANT IN YEAR - ON VITAMIN K	% OF PREGNANT IN YEAR - ON VITAMIN K
2004	Ashford PCT	2.00	2.00	100.00%	2.00	100.00%	2.00	100.00%
2004	Canterbury and Coastal PCT	8.00	5.00	75.00%	6.00	75.00%	2.00	25.00%
2004	East Kent Coastal PCT	4.00	3.00	50.00%	2.00	50.00%	1.00	25.00%
2004	Shepway PCT	2.00	2.00	100.00%	2.00	100.00%	2.00	100.00%
		16.00	12.00	325.00 % av= 81.25	12.00	325.00 % av = 81.25	7.00	250.00 % Av = 62.5

Pricce
2004

9 Exception reporting for QOF: Epilepsy

2005/6 Taken from publication 'National Quality and Outcomes Framework Exception Reporting Statistics for England.'[122]

2005/06

6. Exception Reporting 2005/06

6.1 Exception Reporting by Indicator Group

Table 1 shows effective exception rates for the 11 diseases of the clinical domain, and for cervical screening. The exception rates shown are based on the sum of exceptions and the sum of denominators for all indicators within these indicator groups.

Indicator Group	Total Number of Exceptions	Sum of Denominators	Effective Exception Rate
Asthma	671,192	8,404,521	7.40%
Cancer	33,693	346,204	8.87%
Cervical Screening	586,577	12,170,708	4.60%
CHD	1,144,002	14,358,540	7.38%
COPD	279,737	3,700,999	7.03%
Diabetes	1,704,062	26,672,840	6.01%
Epilepsy	76,907	877,973	8.05%
Hypertension	484,122	19,193,570	2.46%
Hypothyroidism	7,343	1,245,224	0.59%
LVD	24,173	271,982	8.16%
Mental Health	25,171	442,085	5.39%
Stroke	430,973	5,295,563	7.53%
All Indicator Groups	5,467,952	92,980,209	5.55%

Table 1: Exception rates by indicator group, 2005/06

Table 1 shows that the overall effective exception rate for England, across all indicator groups, was 5.55%. (Note that the numbers of exceptions and the sum of the denominators refer to patient records associated with indicators, not individual patients. Individual patients can occur in more than one indicator group, and can occur more than once in any specific indicator group when associated with more than one indicator.)

2007/8

This data is available but not included in this thesis as it is in a format which lists every surgery England and is 447pages long

2008/9

NHS
The Information Centre
for health and social care

Quality and Outcomes Framework (QOF) Exception Reporting for April 2008-March 2009, England Exception Rates by Indicator, 2008/09. All available practices in England.

Exception rate = number of exceptions / (number of exceptions + sum of denominators) * 100

Indicator	Total Number of Exceptions	Sum of Denominators	2008/09 Exception Rate
EPILEP06	12,461	313,755	3.82%
EPILEP07	11,728	314,477	3.60%
EPILEP08	52,604	273,545	16.13%

2009/10

Quality and Outcomes Framework (QOF) Exception Reporting for April 2009-March 2010, England
Exception Rates by Indicator, 2009/10. All available practices in England.

Exception rate = number of exceptions / (number of exceptions + sum of denominators) * 100

Indicator	Total Number of Exceptions	Sum of Denominators	2009/10 Exception Rate
EPILEP06	13,015	318,597	3.92%
EPILEP07	12,560	319,048	3.79%
EPILEP08	52,231	279,480	15.75%

2010/2011

Quality and Outcomes Framework (QOF) Exception Reporting for April 2010-March 2011, England
Exception Rates by Indicator (Clinical Domain), 2010/11. All available practices in England.

Exception rate = number of exceptions / (number of exceptions + sum of denominators) * 100

Indicator	Total Number of Exceptions 2010/11	Sum of Denominators 2010/11	Exception Rate 2010/11
EPILEP06	13,549	322,244	4.0%
EPILEP07	13,174	322,594	3.9%
EPILEP08	54,400	281,373	16.2%

10 Email from East Kent Primary Care Trust supplying figures on the number of admissions for epilepsy over the past decade

From: Alison Scantlebury [mailto:Alison.Scantlebury@eastcoastkent.nhs.uk]
Sent: 06 July 2012 13:02
To: Rogers Greg (EASTERN AND COASTAL KENT PCT)
Cc: Felix Robinson
Subject: RE: Information Management - Epilepsy

Hi Greg

Thanks for your email.

I am unable to go back as far as 1995 for EKHUFT activity but I can supply from April 2000 onwards. I have spoken to the public health observatory this morning regarding the mortality data and they have supplied me with data back to January 2002 at local authority level.

Please find 2 files attached. The first contains the inpatient activity at EKHUFT for epilepsy related activity (where epilepsy is the primary diagnosis) for East Kent PCT patients for April 2000 – May 2012. The second contains the mortality information (the file has two tabs – one showing the East Kent local authority areas and the other showing the Kent & Medway PCTs). Public Health have advised that any numbers of 5 or less should not be quoted outside of the NHS due to the confidential nature.

Please let me know if you have any questions or if you would like the inpatient information broken down in more detail (i.e. at locality or practice level).

Regards

Alison

Alison Scantlebury
Client Manager - Business Intelligence
NHS Kent and Medway

Templar House
Tannery Lane

Ashford
TN23 1PL

Tel: 01233658447
Fax: 01233618380
Email: Alison.Scantlebury@eastcoastkent.nhs.uk
Email: alison.scantlebury@nhs.net

NHS Kent and Medway represents the following primary care trusts (PCTs):
NHS West Kent, NHS Eastern and Coastal Kent and NHS Medway.

From: Rogers Greg (EASTERN AND COASTAL KENT PCT)
[mailto:greg.rogers@nhs.net]
Sent: 05 July 2012 13:01
To: Alison Scantlebury
Subject: FW: Information Management - Epilepsy

---Hopefully I have used your correct email address this time!!

From: Rogers Greg (EASTERN AND COASTAL KENT PCT)
Sent: 05 July 2012 12:14
To: alison.scantlebury@eastcoastkent.nhs.net
Cc: Felix.Robinson@eastcoastkent.nhs.uk
Subject: RE: Information Management - Epilepsy

Dear Alison

Hi. I do not think we have met each other but by way of introduction I am a GP in Margate and the clinical lead GPwSi for Epilepsy in East Kent. As there are only a relative few GPs with a specialist interest in epilepsy I have managed to be involved with the epilepsy NICE update and also am on the NICe Epilepsy quality standards group. Working with them I realise that Primary care has been pretty slow in producing scientific papers on epiliepsy care and I am sure we have a significant role in improving the care of people with epilepsy as it is really such a common condition [approx 1% of pop.]

I would be really grateful for you help in obtaining East kent hospital activity relating to Epilepsy for 1995 - to the present. I am finishing my PhD at UCL on health care service delivery and redesign for epilepsy in primary care and this is looking at the impact made on epilepsy care as a result of focused programs of care for epilepsy including PRICCE and PRICCE II in the late 1990's which as you know was the fore runner of QOF, the impact of QOF, the impact then of the Epilepsy LES I and II, and also the impact of the GPwSI service for Epilepsy since 2004.

The value of these services has only poorly been explored for epilepsy and the impact on use of secondary and tertiary care has not been studied in depth for epilepsy. I am hoping also to match this up with the health economics of both the Primary care service contracts and the GPwSI role.

In addition to this would be really helpful to gain access to epilepsy mortality data on a smaller geographical basis that is freely available on the SEPHO website i.e. at district level as some of the schemes were not uniformily adopted and also the PCO boundries have changed during this time. If you could help me with this too it would be really great?

I will be more than happy to do whatever I can to help in this process and would be really grateful for any help you can offer. East Kent has been very pro active in epilepsy care and it would be grate to share any lessons learnt with the rest of the health community.

With many thanks ,

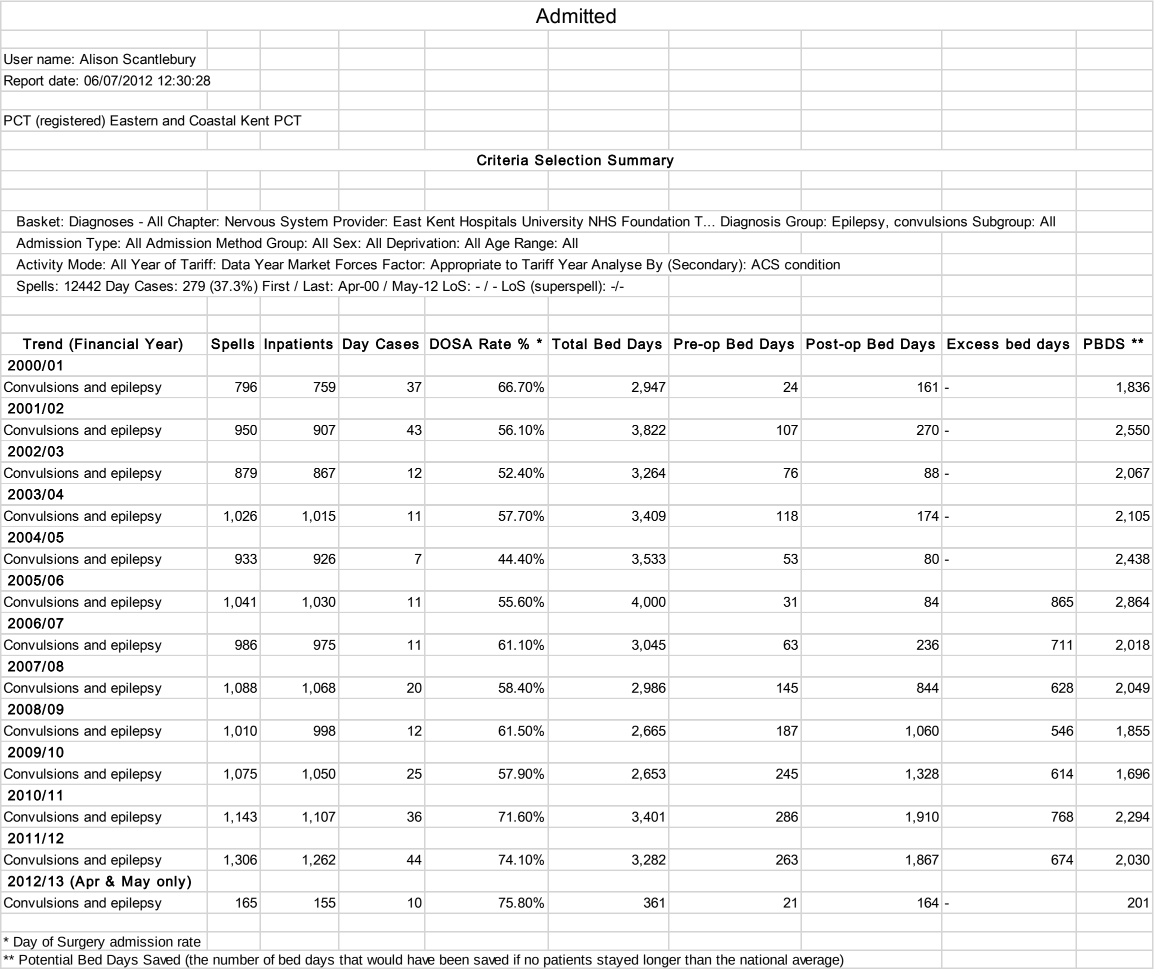
Greg

11 Data received from Eastern and Coastal Kent PCT showing number of admissions for epilepsy from 2000 - 2013

Admitted									
User name: Alison Scantlebury									
Report date: 06/07/2012 12:30:28									
PCT (registered) Eastern and Coastal Kent PCT									
Criteria Selection Summary									
Basket: Diagnoses - All Chapter: Nervous System Provider: East Kent Hospitals University NHS Foundation T... Diagnosis Group: Epilepsy, convulsions Subgroup: All									
Admission Type: All Admission Method Group: All Sex: All Deprivation: All Age Range: All									
Activity Mode: All Year of Tariff: Data Year Market Forces Factor: Appropriate to Tariff Year Analyse By (Secondary): ACS condition									
Spells: 12442 Day Cases: 279 (37.3%) First / Last: Apr-00 / May-12 LoS: - / - LoS (superspell): -/-									
Trend (Financial Year)	**Spells**	**Inpatients**	**Day Cases**	**DOSA Rate % ***	**Total Bed Days**	**Pre-op Bed Days**	**Post-op Bed Days**	**Excess bed days**	**PBDS ** **
2000/01									
Convulsions and epilepsy	796	759	37	66.70 %	2,947	24	161	-	1,836
2001/02									
Convulsions and epilepsy	950	907	43	56.10 %	3,822	107	270	-	2,550
2002/03									
Convulsions and epilepsy	879	867	12	52.40 %	3,264	76	88	-	2,067
2003/04									

Convulsions and epilepsy	1,026	1,015	11	57.70%	3,409	118	174	-	2,105
2004/05									
Convulsions and epilepsy	933	926	7	44.40%	3,533	53	80	-	2,438
2005/06									
Convulsions and epilepsy	1,041	1,030	11	55.60%	4,000	31	84	865	2,864
2006/07									
Convulsions and epilepsy	986	975	11	61.10%	3,045	63	236	711	2,018
2007/08									
Convulsions and epilepsy	1,088	1,068	20	58.40%	2,986	145	844	628	2,049
2008/09									
Convulsions and epilepsy	1,010	998	12	61.50%	2,665	187	1,060	546	1,855
2009/10									
Convulsions and epilepsy	1,075	1,050	25	57.90%	2,653	245	1,328	614	1,696
2010/11									
Convulsions and epilepsy	1,143	1,107	36	71.60%	3,401	286	1,910	768	2,294
2011/12									
Convulsions and epilepsy	1,306	1,262	44	74.10%	3,282	263	1,867	674	2,030
2012/13 (Apr & May only)									
Convulsions and epilepsy	165	155	10	75.80%	361	21	164	-	201
* Day of Surgery admission rate									
** Potential Bed Days Saved (the number of bed days that would have been saved if no patients stayed longer than the national average)									

12 Admission data for East Kent provided by Eastern and Medway PCT using ‘Dr Foster Intelligence’ software.



Admitted

User name: Alison Scantlebury
Report date: 06/07/2012 12:30:28

PCT (registered) Eastern and Coastal Kent PCT

Criteria Selection Summary

Basket: Diagnoses - All Chapter: Nervous System Provider: East Kent Hospitals University NHS Foundation T... Diagnosis Group: Epilepsy, convulsions Subgroup: All
Admission Type: All Admission Method Group: All Sex: All Deprivation: All Age Range: All
Activity Mode: All Year of Tariff: Data Year Market Forces Factor: Appropriate to Tariff Year Analyse By (Secondary): ACS condition
Spells: 12442 Day Cases: 279 (37.3%) First / Last: Apr-00 / May-12 LoS: - / - LoS (superspell): -/-

Trend (Financial Year)	Spells	Inpatients	Day Cases	DOSA Rate % *	Total Bed Days	Pre-op Bed Days	Post-op Bed Days	Excess bed days	PBDS **
2000/01									
Convulsions and epilepsy	796	759	37	66.70%	2,947	24	161	-	1,836
2001/02									
Convulsions and epilepsy	950	907	43	56.10%	3,822	107	270	-	2,550
2002/03									
Convulsions and epilepsy	879	867	12	52.40%	3,264	76	88	-	2,067
2003/04									
Convulsions and epilepsy	1,026	1,015	11	57.70%	3,409	118	174	-	2,105
2004/05									
Convulsions and epilepsy	933	926	7	44.40%	3,533	53	80	-	2,438
2005/06									
Convulsions and epilepsy	1,041	1,030	11	55.60%	4,000	31	84	865	2,864
2006/07									
Convulsions and epilepsy	986	975	11	61.10%	3,045	63	236	711	2,018
2007/08									
Convulsions and epilepsy	1,088	1,068	20	58.40%	2,986	145	844	628	2,049
2008/09									
Convulsions and epilepsy	1,010	998	12	61.50%	2,665	187	1,060	546	1,855
2009/10									
Convulsions and epilepsy	1,075	1,050	25	57.90%	2,653	245	1,328	614	1,696
2010/11									
Convulsions and epilepsy	1,143	1,107	36	71.60%	3,401	286	1,910	768	2,294
2011/12									
Convulsions and epilepsy	1,306	1,262	44	74.10%	3,282	263	1,867	674	2,030
2012/13 (Apr & May only)									
Convulsions and epilepsy	165	155	10	75.80%	361	21	164	-	201

* Day of Surgery admission rate
** Potential Bed Days Saved (the number of bed days that would have been saved if no patients stayed longer than the national average)

13 QOF Achievement tables

QOF Achievement for 2004/2005

Disease Summaries

Quality and Outcomes Framework (QOF) for April 2004 – March 2005, England

Achievement by disease, by Strategic Health Authority with national summary

SHA Code	*Strategic Health Authority Name*	*No. of Practices*	*Epilepsy Total Points Achieved*	*Epilepsy Total Points Achieved /Available %*
Q01	Norfolk, Suffolk and Cambridgeshire	298	4,377.4	91.8%
Q02	Bedfordshire and Hertfordshire	228	3,342.2	91.6%
Q03	Essex	288	3,971.4	86.2%
Q04	North West London	434	6,144.7	88.5%
Q05	North Central London	288	3,971.4	86.2%
Q06	North East London	367	4,818.0	82.0%
Q07	South East London	287	3,746.0	81.6%
Q08	South West London	232	3,188.5	85.9%
Q09	Northumberland, Tyne & Wear	239	3,341.2	87.4%
Q10	County Durham and Tees Valley	176	2,382.7	84.6%
Q11	North and East Yorkshire and Northern Lincolnshire	253	3,556.7	87.9%
Q12	West Yorkshire	359	4,606.1	80.2%
Q13	Cumbria and Lancashire	358	5,052.1	88.2%
Q14	Greater Manchester	548	7,166.4	81.7%
Q15	Cheshire & Merseyside	428	5,626.9	82.2%
Q16	Thames Valley	286	4,288.7	93.7%
Q17	Hampshire and Isle Of Wight	231	3,491.1	94.5%
Q18	Kent and Medway	294	3,979.5	84.6%
Q19	Surrey and Sussex	366	5,337.1	91.1%
Q20	Avon, Gloucestershire and Wiltshire	318	4,675.2	91.9%
Q21	South West Peninsula	248	3,650.2	92.0%
Q22	Dorset and Somerset	177	2,754.6	97.3%
Q23	South Yorkshire	224	2,825.8	78.8%
Q24	Trent	413	5,781.8	87.5%
Q25	Leicestershire, Northamptonshire and Rutland	229	3,267.7	89.2%
Q26	Shropshire and Staffordshire	262	3,679.3	87.8%
Q27	Birmingham and the Black Country	515	6,795.8	82.5%
Q28	West Midlands South	230	3,349.6	91.0%
England	**England**	**8576**	**119,168.3**	**86.8%**

Data source: QMAS database – 2004/05 data as at end of June 2005

SHA codes are used for administrative purposes in local and national databases

QOF Achievement 2005 – 2006

SHA Code	*Strategic Health Authority Name*	*Number of Practices*	*Epilepsy Total Points Achieved*	*Epilepsy Total Points Achieved /Available %*
Q01	Norfolk, Suffolk and Cambridgeshire	292	4,561.9	97.6%
Q02	Bedfordshire and Hertfordshire	223	3,413.9	95.7%
Q03	Essex	282	4,226.7	93.7%
Q04	North West London	432	6,411.1	92.8%
Q05	North Central London	273	4,002.7	91.6%
Q06	North East London	350	5,048.5	90.2%
Q07	South East London	285	4,090.1	89.7%
Q08	South West London	232	3,496.0	94.2%
Q09	Northumberland, Tyne & Wear	233	3,485.6	93.5%
Q10	County Durham and Tees Valley	172	2,562.0	93.1%
Q11	North and East Yorkshire and Northern Lincolnshire	250	3,787.6	94.7%
Q12	West Yorkshire	348	5,033.3	90.4%
Q13	Cumbria and Lancashire	344	5,147.0	93.5%
Q14	Greater Manchester	536	7,794.2	90.9%
Q15	Cheshire & Merseyside	417	6,085.6	91.2%
Q16	Thames Valley	282	4,409.4	97.7%
Q17	Hampshire and Isle Of Wight	230	3,616.5	98.3%
Q18	Kent and Medway	284	4,242.1	93.4%
Q19	Surrey and Sussex	361	5,543.5	96.0%
Q20	Avon, Gloucestershire and Wiltshire	315	4,871.4	96.7%
Q21	South West Peninsula	249	3,866.3	97.0%
Q22	Dorset and Somerset	178	2,827.9	99.3%
Q23	South Yorkshire	222	3,164.0	89.1%
Q24	Trent	407	6,092.3	93.6%
Q25	Leicestershire, Northamptonshire and Rutland	227	3,378.1	93.0%
Q26	Shropshire and Staffordshire	258	3,910.7	94.7%
Q27	Birmingham and the Black Country	498	7,434.5	93.3%
Q28	West Midlands South	229	3,554.4	97.0%
England		**8409**	**126,057.3**	**93.7%**

Data source: QMAS database – 2005/06 data as at end of June 2006

QOF Achievement 2006 to 2007

The high uptake was maintained in 2006/2007 however the Epilepsy 8 standard is lower as previously practices had been unclear whether to only include convulsive seizures however the supporting literature now makes it clear that all seizure types are to be included.

Epilepsy

Quality and Outcomes Framework (QOF) for April 2006 to March 2007, England
Achievement by indicator within this clinical area
Total number of practices = 8,372

	(a)	(b)	©	(d)
Indicator	**Points available**	**Total points achieved**	**Total points achieved / Available %**	**Underlying achievement**
Epilepsy 5	1	8,366.0	99.9%	---
Epilepsy 6	4	32,840.9	98.1%	95.6%
Epilepsy 7	4	32,753.3	97.8%	95.2%
Epilepsy 8	6	43,872.3	87.3%	73.0%
Epilepsy Total	15	117,832.6	93.8%	---

(a) Points available to each practice for this indicator
(b) Sum of points achieved by all practices for this indicator
© Sum of points achieved by all practices / (available points for this indicator * total number of practices) expressed as a percentage
(d) Underlying achievement = (sum of indicator numerators / sum of indicator denominators) * 100

Data source: QMAS database – 2006/07 data as at end of June 2007.

QOF Achievement 2007 – 2008

Basic register and epilepsy surveillance is continued but again seizure freedom for 70% of the population is not reached by approximately a quarter of the country.

Clinical Domain

Epilepsy

Quality and Outcomes Framework (QOF) for April 2007 – March 2008, England

Achievement by indicator within this clinical area
Total number of practices = 8,294

	(a)	(b)	©	(d)
Indicator	**Points available**	**Total points achieved**	**Total points achieved / Available %**	**Underlying achievement**
EPILEP05	1	8,288.0	99.9%	-
EPILEP06	4	32,658.7	98.4%	95.6%
EPILEP07	4	32,595.6	98.3%	95.2%
EPILEP08	6	43,813.5	88.0%	73.2%
EPILEPSY TOTAL	15	117,355.8	94.3%	

(a) Points available to each practice for this indicator
(b) Sum of points achieved by all practices for this indicator
© Sum of points achieved by all practices / (available points for this indicator * total number of practices) expressed as a percentage
(d) Underlying achievement = (sum of indicator numerators / sum of indicator denominators) * 100

Data source: QMAS database – 2007/08 data as at end of June 2008
SHA and PCT codes are used for administrative purposes in local and national databases
For PMS practices participating in the national QOF, achieved points shown are prior to PMS points deductions.

QOF Achievement 2009 – 2010

This year saw a greater emphasis on exception reporting and exception reporting rates between practices was used as a tool to identify some who were too quick to exemption report people with epilepsy who were more of a challenge to help lead to seizure freedom.

Epilepsy

Quality and Outcomes Framework (QOF) for April 2009 – March 2010, England

Total number of practices = 8,305

Indicator	(a) Points available	(b) Total points achieved	© Total points achieved / Available %	(d) Underlying achievement	(e) Exception rate
Epilepsy05	1	8,275	99.6%	-	-
Epilepsy06	4	32,651.4	98.3%	95.3%	3.92%
Epilepsy07	4	32,609.1	98.2%	95.0%	3.79%
Epilepsy08	6	44,394.1	89.1%	74.4%	15.75%
Epilepsy Total	15	117,929.6	94.7%	-	7.82%

(a) Points available to each practice for this indicator

(b) Sum of points achieved by all practices for this indicator

© Sum of points achieved by all practices / (available points for this indicator * total number of practices) expressed as a percentage

(d) Underlying achievement = (sum of indicator numerators / sum of indicator denominators) * 100

(e) Exception rate = number of exceptions / (number of exceptions + sum of denominators) * 100

Data source: QMAS database – 2009/10 data as at end of July 2010
For PMS practices participating in the national QOF, achieved points shown are prior to PMS points deductions.

QOF Achievement 2010 – 2011

The uptake of QOF for epilepsy remains high at around 95.6% of practices working with people with epilepsy for QOF however the achievement of seizure freedom remains fairly static at 73.9%

Epilepsy

Quality and Outcomes Framework (QOF) for April 2010 – March 2011, England

Achievement by indicator within this group, England

	Number of Practices	EPILEP05 Sum of Points	EPILEP06 Sum of Points	EPILEP06 Sum of Numerators	EPILEP06 Sum of Denominators	EPILEP06 Underlying achievement	EPILEP07 Sum of Points	EPILEP07 Sum of Numerators	EPILEP07 Sum of Denominators	EPILEP07 Underlying achievement	EPILEP08 Sum of Points	EPILEP08 Sum of Numerators	EPILEP08 Sum of Denominators	EPILEP08 Underlying achievement
England	8,245	8,229	32,542.5	308,537	322,903	95.6%	32,482.0	307,717	323,251	95.2%	44,269.8	208,267	281,960	73.9%

14 Admissions as a direct result of epilepsy for East Kent

PCT (registered) Eastern and Coastal
Kent PCT

Criteria Selection Summary

Basket: Diagnoses - All Chapter: Nervous System Provider: East Kent Hospitals University NHS Foundation T... Diagnosis Group: Epilepsy, convulsions Subgroup: All

Admission Type: All Admission Method Group: All Sex: All Deprivation: All Age Range: All

Activity Mode: All Year of Tariff: Data Year Market Forces Factor: Appropriate to Tariff Year Analyse By (Secondary): ACS condition

Spells: 12442 Day Cases: 279 (37.3%) First / Last: Apr-00 / May-12 LoS: - / - LoS (superspell): -/-

Trend (Financial Year)	Spells	Inpatients	Day Cases	DOSA Rate % *	Total Bed Days	Pre-op Bed Days	Post-op Bed Days	Excess bed days	PBDS **
2000/01									
Convulsions and epilepsy	796	759	37	66.70%	2,947	24	161	-	1,836
2001/02									
Convulsions and epilepsy	950	907	43	56.10%	3,822	107	270	-	2,550
2002/03									
Convulsions and epilepsy	879	867	12	52.40%	3,264	76	88	-	2,067
2003/04									
Convulsions and epilepsy	1,026	1,015	11	57.70%	3,409	118	174	-	2,105
2004/05									
Convulsions and epilepsy	933	926	7	44.40%	3,533	53	80	-	2,438
2005/06									
Convulsions and epilepsy	1,041	1,030	11	55.60%	4,000	31	84	865	2,864
2006/07									
Convulsions and epilepsy	986	975	11	61.10%	3,045	63	236	711	2,018
2007/08									
Convulsions and epilepsy	1,088	1,068	20	58.40%	2,986	145	844	628	2,049

2008/09									
Convulsions and epilepsy	1,010	998	12	61.50%	2,665	187	1,060	546	1,855
2009/10									
Convulsions and epilepsy	1,075	1,050	25	57.90%	2,653	245	1,328	614	1,696
2010/11									
Convulsions and epilepsy	1,143	1,107	36	71.60%	3,401	286	1,910	768	2,294
2011/12									
Convulsions and epilepsy	1,306	1,262	44	74.10%	3,282	263	1,867	674	2,030
2012/13 (Apr & May only)									
Convulsions and epilepsy	165	155	10	75.80%	361	21	164	-	201

* Day of Surgery admission rate

** Potential Bed Days Saved (the number of bed days that would have been saved if no patients stayed longer than the national average)

15 Locally Enhanced Service documentation to practices

East Kent Coastal Teaching Primary Care Trust

Local Enhanced Service for Epilepsy

Service Level Agreement

Contents

Finance Details

In 2006/2007 each practice contracted to provide this service would receive the following ‘QOF’ points:

Questionnaire to all patients with epilepsy	3
Women with Epilepsy	4
Driving	1
Social	3
Links to secondary care	4
Total:	15

Therefore an average practice would receive 15 x £124.60 = £1869 for full achievement.

This LES is time-limited to 12 months from 1 April 2006.

15.1.1.1.1.1 Note

This contract *may* become invalid if the practice opts to close its list

PAYMENT WILL ONLY BE MADE UPON RECEIPT OF PRACTICE SIGNATURE SHEET

Signature Sheet

This document constitutes the agreement between the practice and the PCT in regards to this local enhanced service.

Please name the doctor who will lead for epilepsy in your practice and tick to confirm that the basic training described below has been received.

Name of GP	Training attended (please tick) ✓

Signature on behalf of the Practice:

Signature	**Name**	**Date**

Signature on behalf of the PCT:

Signature	Name	Date

Background

This local enhanced service is a step to improving the care of epileptic patients in the PCT area.

Further developments are planned which involve the development of greater expertise and further services. Updates to the practice register performed under this LES lay the foundations for future developments.

The objectives set out in this agreement should be achievable by practises which have attended the mandatory basic training that is outlined below.

Service Aims

The aim of this local enhanced service is to:

- Have a named doctor for each GP practice who will take the lead for epilepsy.
- Enhance links with secondary care.
- Begin the process of improving quality and appropriate use of resources.
- Be of benefit to people with epilepsy.

Mandatory basic training

The GP who will be the practice lead for epilepsy must have attended the basic training that is provided as a prerequisite to providing this enhanced service. This is brief detail only, and should take only 1.5 hours. For those who wish to take epilepsy care further, these issues will be dealt with in greater depth later.

The training covers:

- Introductory video session: seizures,
- Epidemiology of Epilepsy
- Basic functional anatomy of the central nervous system
- Overview of Epileptic Syndromes
- Medical Treatment of Epilepsy
- Some imaging techniques used to investigate epilepsy
- Female Issues relating to epilepsy
- Social Aspects of Epilepsy – Quality of life in epilepsy
- Marriage Epilepsy and the family
- Sudden unexpected death in epilepsy
- Employment
- Drivers' licenses

Criteria

This Local Enhanced Scheme has the following criteria:

Development of templates

Practice register

Female issues

Driving

Links with secondary care

Criterion One: Development of templates

The practice should develop (or maintain if they already exist) templates for annual review of all patients [both paediatric and adult] with epilepsy.

Criterion Two: Practice register

The practice's register must be kept up-to-date to show:

- Medication, age and sex of patient (assume if patient on register these are minimum details retained)
- Driving status [target 90%]
- Social Factors [target 80% in year 1 and 90% in year 2]
    - Education issues for paediatric patients
    - Employment status (for links to social services)
    - Social circumstance e.g. lives alone, with family, etc. (as predictor of social morbidity
    - Safety issues e.g. bathing, cooking, etc. See Epilepsy Action's leaflet on safety
    - Stigma (feelings about own condition, attitudes from others)
- Patients who are currently under hospital care – Including the name of the consultant[s] they are under
- List the patients whose medication is not being actively managed

Criterion Three: Women with Epilepsy

This section relates to all females aged 14 – 55

Practices must:

- Be conversant with the list of Anti Epileptic Drugs (AEDs) that interact with the Oral Contraceptive Pill (OCP) – as tabulated in the NICE guideline for epilepsy. [Target 100%]

- Ensure women are on appropriate contraception if required i.e. not on anti-convulsant medication that interacts with ICP, etc.[Target 100%]
- Offer folic acid (5mg) to women likely to become pregnant to help prevent neural tube defects and offer epilepsy action leaflet
- Arrange pre-conceptual advice and provide Epilepsy Action Leaflet
- Record method of contraception

Criterion Four: Links with secondary care

Practices must:

- All known patients that have been seen [within the LES year] in A&E, as a result of a seizure need to be reviewed within 6 weeks and the trigger for the seizure assessed. If this is complex they should be referred to an appropriate service. [Targets Year 1 40%: Year 2 50%; Year 3 60%]
- Ensure that changes to medication etc. suggested by secondary care at outpatient appointment are discussed and, on agreement, started with the patient. This could be in conjunction with a GPwSI in Epilepsy.

16 Patient Questionnaire used for the Locally Enhanced Service for Epilepsy

Patient Questionnaire

You are being asked to complete this questionnaire so that your GP may ensure that all relevant information is added to your records: If you need help completing this questionnaire please contact……………………………………...

About your epilepsy

1. Name:……………………………………………………… Age…………………..

2. Male /Female

3. When did you last see your GP in relation to your epilepsy?........................

4. Have you had any fits/seizures in the last 12 months? Yes No

   If yes please tell us the frequency of your fits/seizures (tick the one that best describes you)

   1 – 12 per year: 2 – 4 per month: 1 - 7 per week: Every day

5. Have you attended Accident & Emergency (A&E) as a result of a fit/seizure within the last 12 months?

   If yes have you been seen by your GP since then to review your epilepsy?

   Yes No

6. What medication do you currently take for your epilepsy?

Medication	Dose	How many times a day

7 Do you drive? Yes No

8 Are you in paid employment? Yes No

9 If not would you wish to be in paid employment? Yes No

10 Do you live alone? Yes No

11 Do you have someone you consider a carer? Yes No

If yes please provide their name and contact number……………………………

…………………………………………………………………………………….

12 Have you been made aware of the safety issues with regards to epilepsy?

Yes No

If no, would you like to receive more information regarding safety issues?

13 Would you like to speak with someone with regard to your epilepsy?

If yes;	would you like medical advice?	Yes No
	From your GP?	Yes No
	From another GP who specialises in epilepsy?	Yes No
	From a specialist nurse?	Yes No
	Would you like emotional advice?	Yes No

14 Are you currently being seen by a hospital consultant for your epilepsy?

Yes No

If yes; please provide consultant name …………………………………….

Which hospital were you seen at?..

When did you last see the consultant?..

This question only applies to the care of children under 16

15 Are you happy with the provision of help from your school with regard to your epilepsy?

Yes No

The following questions only apply to females aged 14 – 55

16 Are you taking a contraceptive pill? Yes No

If no: please state what method of contraception you are using……………

……………………………………………………………………………………

17 Have you received advice if pregnancy is a real possibility for you? Yes No

18 And did this include advice about taking a higher dose of folic acid? Yes No

Thank you for taking the time to complete this information. Please return your completed questionnaire to…………………………………………………………………

17 Epilepsy Local Enhanced Service Monitoring Sheet

Practice List Size @ 31.3.06	
Number of patients with Epilepsy	
Prevalence as % of practice registered population	
Practice Register	
Patients with driving status recorded	
Social Factors numbers of patients with recorded status of: Education issues Employment status Social circumstance e.g. lives alone, with family, etc Safety issues e.g. bathing, cooking, etc. Stigma (feelings about own condition, attitudes from others)	
Number of patients currently under secondary care consultant And number with consultant name recorded	
Women with Epilepsy	
Run report from GP software system of all women aged 14 – 55 with epilepsy, showing all medications and recorded method of contraception	
Links with Secondary Care	
Number of patients with epilepsy attending A&E in year	
Number of these reviewed within 6 weeks	
Number of onward referrals	
Of these number referred to GPwSI	
Access to patient Information Leaflets - please provide evidence of ordering of leaflets through Epilepsy Action	

18 Data obtained for Epilepsy Locally Enhanced Service from Practice A

Monitoring Sheet for 2005-2006

Epilepsy

Practice list size	12891
Patients with Epilepsy:	107

Prevalence: 0.83

Practice Register

Patients with medication, age and sex recorded:	107
Patients with driving status recorded:	57
Patients with Social Factors recorded:	57

Female issues

Femail patients with epilepsy:	52
Of these, the number of child bearing age:	29
Child bearing age and offered folic acid:	2
Child bearing age and offered pre-conceptual advice:	0
Child bearing age where any interaction between their anti-convulsive and contraceptive method has been checked	1

Secondary care

Patients who are currently under hospital care:	34
Of these patients whose medication is being actively managed:	107

Monitoring Sheet for 2006-2007

Epilepsy

Practice list size	13442
Patients with Epilepsy:	100

Prevalence: 0.74

Practice Register

Patients with medication, age and sex recorded:	100
Patients with driving status recorded:	44
Patients with Social Factors recorded:	54

Female issues

Femail patients with epilepsy:	48
Of these, the number of child bearing age:	23
Child bearing age and offered folic acid:	7
Child bearing age and offered pre-conceptual advice:	1
Child bearing age where any interaction between their anti-convulsive and contraceptive method has been checked	6

Secondary care

Patients who are currently under hospital care:	20
Of these patients whose medication is being actively managed:	?

Monitoring Sheet for 2007-2008 was returned blank

Epilepsy

Practice list size	
Patients with Epilepsy:	

Prevalence: 0.00

Practice Register

Patients with medication, age and sex recorded:	
Patients with driving status recorded:	
Patients with Social Factors recorded:	

Female issues

Female patients with epilepsy:	
Of these, the number of child bearing age:	
Child bearing age and offered folic acid:	
Child bearing age and offered pre-conceptual advice:	
Child bearing age where any interaction between their anti-convulsive and contraceptive method has been checked	

Secondary care

Patients who are currently under hospital care:	
Of these patients whose medication is being actively managed:	

19 Data obtained for Epilepsy Locally Enhanced Service from Practice B

Monitoring Sheet 2006-2007

Epilepsy

Practice list size	13786
Patients with Epilepsy:	126
Prevalence:	0.91

Practice Register

Patients with medication, age and sex recorded:	126
Patients with driving status recorded:	76
Patients with Social Factors recorded:	101

Female issues

Femail patients with epilepsy:	61
Of these, the number of child bearing age:	25
Child bearing age and offered folic acid:	3
Child bearing age and offered pre-conceptual advice:	4
Child bearing age where any interaction between their anti-convulsive and contraceptive method has been checked	4

Secondary care

Patients who are currently under hospital care:	37
Of these patients whose medication is being actively managed:	37

Monitoring sheet 2007-2008

Epilepsy

Practice list size	13985
Patients with Epilepsy:	124
Prevalence:	0.89

Practice Register

Patients with medication, age and sex recorded:	124
Patients with driving status recorded:	88
Patients with Social Factors recorded:	96

Female issues

Female patients with epilepsy:	58
Of these, the number of child bearing age:	26
Child bearing age and offered folic acid:	3
Child bearing age and offered pre-conceptual advice:	6
Child bearing age where any interaction between their anti-convulsive and contraceptive method has been checked	11

Secondary care

Patients who are currently under hospital care:	11
Of these patients whose medication is being actively managed:	11

Monitoring sheet 2008-2009

Epilepsy

Practice list size	14172
Patients with Epilepsy:	114
Prevalence:	0.80

Practice Register

Patients with medication, age and sex recorded:	114
Patients with driving status recorded:	90
Patients with Social Factors recorded:	106

Female issues

Female patients with epilepsy:	50
Of these, the number of child bearing age:	24
Child bearing age and offered folic acid:	2
Child bearing age and offered pre-conceptual advice:	7
Child bearing age where any interaction between their anti-convulsive and contraceptive method has been checked	15

Secondary care

Patients who are currently under hospital care:	19
Of these patients whose medication is being actively managed:	19

20 Approval to use pooled data from the Epilepsy Locally Enhanced Service in this study

From: Dodds Peter (MAIDSTONE AND TUNBRIDGE WELLS NHS TRUST)
Sent: 08 June 2012 15:53
To: Chris Greener; Rogers Greg (EASTERN AND COASTAL KENT PCT)
Subject: RE: Permission to use the summary sheet from the Epilepsy LES

Dear Chris and Greg,

I have confirmed my answer with a colleague: if the data is pooled data from which individual patients cannot be identified or indeed individual sets of data cannot be distinguished (or “unpooled”), there is no requirement for ethical or governance approval. It is always worth noting that you should refer to the Data Protection Act for any issues with personal data, but I suspect it will not come into play here. If you have any plans to examine the data in more detail, you should check again before proceeding.

Best regards,

Peter

Dr Peter F. Dodds
RM&G Coordinator

RM&G Consortium for Kent and Medway
No. 6 The Courtyard
Campus Way
Gillingham Business Park
Gillingham
Kent, ME8 0NZ

Temporary phone: 01622 227361
Fax: 01634 262564
e-mail: pdodds2@nhs.net

Please note new contact details. The telephone number is temporary.

The RM&G Consortium for Kent & Medway provides services to NHS Kent and Medway, Kent Community Health NHS Trust, Medway Community Healthcare CIC, Kent & Medway NHS & Social Care Partnership Trust and South East Coast Ambulance NHS Trust

21 Locally Enhanced Service – Read Codes

Epilepsy LES Mark 2

Driving Status (I cannot find a read code that states does not drive, so maybe the questionnaire should be worded slightly differently)

Patient advised about driving	.8CAJ
Patient advised not to drive	.8CA8
Motor Car driver	.OI37
Car Owner	.13C7
Has access to a car	.13C8
Has other personal transport	.13C9
Depends on public transport	.13CB
Driving license	.6673

Social Care

I feel there are too many subsections of social care contributing to one overall target of 80%. This is open to practices doing as much or as little as they wish. Do all questions need to be addressed to fulfil the target, or only 1?

Provision of education needs	.800 (+ appropriate)
Epilepsy impairs education	.667J
Epilepsy restricts employment	.667G
Epilepsy prevents employment	.667H
In employment	.13JV
Employment milestones	.13J (+ appropriate)
Housing dependency scale	.13F (+ appropriate)
Home safety advice	.67IB
Epilepsy associated problems	.6674 (? Could use for stigma question)

Secondary Care

Seen in neurology clinic	.9N1R

Patients whose treatment who is not being actively managed

How on earth do we find these other than a clinician wading through every patients' notes?!

Epilepsy treatment changed	.6678
Epilepsy treatment started	.6679
Epilepsy treatment stopped	.667A

Emergency Treatment

Emergency epilepsy treatment since last appointment	.667W

Leaflets

Epilepsy leaflet given	.8CE7
Epilepsy society member	.13Y9

Contraception (I wouldn't be able to produce the sort of report you are asking for in the LES!!)

Contraception	.61 (+ appropriate)
Pre conception advice	.67IJ
Folic acid advice – pre pregnancy	.6760
Over the counter folic acid therapy	.8BP2

22 Epilepsy Locally Enhanced Service – Patient Questionnaire

About your epilepsy Surgery Number………………

Please tick the appropriate answers.

Name...

Age: .... Sex ....

When did you last see your GP in relation to your epilepsy? ....

Have you had any fits in the last 12 months? Yes ☐ No ☐

If **yes** do you have:- (tick the one that best describes the frequency of your fits)

1-12 fits a year	☐
2-4 fits a month	☐
1-7 fits a week	☐
Daily fits	☐

What medication do you currently take for your epilepsy?

Medication	Dose	How many times a day

Do you drive? Yes ☐ No ☐

Are you in paid employment? Yes ☐ No ☐

Would you wish to be in employment? Yes ☐ No ☐

Do you live alone? Yes ☐ No ☐

Do you someone you consider a carer? Yes ☐ No ☐

If yes, please provide their details

Name ………………………………………

Tel No……………………………………………

Are you aware of the safety issues with regards to epilepsy? Yes ☐ No ☐
(e.g. bathing, cooking etc.)

How would you like to receive more information regarding safety issues?

…………………………………………………………………………..
…………………………………………………………………………..

Would you like to see someone with regards to your epilepsy? Yes ☐ No ☐

If **yes**

Would you like medical advice? Yes ☐ No ☐

Would you like emotional advice? Yes ☐ No ☐

Are you currently being seen for your epilepsy by a hospital consultant?

Yes ☐ No ☐

If Yes, which consultant ……………………………………..

Which hospital ………………………………………

When did you last see the consultant ……………………………..

Only children under the age of 16 years need answer the question below.

Are you happy with the provision of help from your school in regards to your epilepsy?

Yes ☐ No ☐

Only female patients of child bearing age need to answer the questions below.

Are you taking the contraceptive pill? Yes ☐ No ☐

Have you been given advice about pregnancy? Yes ☐ No ☐

Did the advice include taking folic acid? Yes ☐ No ☐

Thank you completing this questionnaire this will help us keep our records up to date and offer the best possible care to you.

23 Targeted Medicines Use Review for Epilepsy

Epilepsy; Targeted Medicine Use Review, in partnership with Boots

Eastern and Coastal Kent PCT

Contents

Executive Summary

- This project seeks to improve the effectiveness of "Medicines Use Reviews" by community pharmacists by focussing for one month on people with epilepsy. Using a 'red flag' template Community Pharmacists will be able to refer to Intermediate Care epilepsy services.
- The red flags will include unscheduled admission to A&E in the previous 12 months, hazardous poor concordance, pre – natal teratogenic risk and uncontrolled seizure. This will only apply to people who are currently not receiving specialist care and aims to reduce unscheduled admissions, improve medication adherence and improve the quality of life for people with epilepsy in Thanet .

Cost Summary:

Total non-recurrent cost (£'000)	Full year recurrent cost (£'000)	Non-recurrent cost (2009/10) (£'000)	Recurrent cost (2009/10) (£'000)	Total cost (2009/10) (£'000)
£2200				

Stages - Planned Completion Dates:

Scope	Design	Select	Implement	Operate
Feb 2011	April 2011	July/August 2011	4 weeks	Sept to October 2011

Localities affected (mark with an 'X'):

Ashford	Canterbury	Dash	Dover	Shepway	Swale	Medway	Thanet
							X

2. Evidence of Need

Community Pharmacists are well placed to address this need as they deliver health care arguably the closest to people with epilepsy when they dispense the patients anti epilepsy drugs[A.E.D.s] This provides the opportunity to ensure the patient is receiving appropriate care and they can identify high risk patients through the epilepsy MUR and where appropriate refer to Intermediate Care.

1. If prescriptions appear to be requested too infrequently the NexPhase pharmacy dispensing software can alert pharmacists to this possibility and offer the patients a Epilepsy Focused MUR.
2. Epilepsy nationally was found to be the 12th most common Healthcare Resource Group [HRG] for a patient to be admitted as an emergency in adults aged 16-74yrs in 2006/7 and has a 28 day readmission rate of 12.7% which places it **7th highest** disease likely to be readmitted. This suggests that current services are not effective at detecting such high risk patients and this project helps to address that need by identifying this patient sub group.
3. For East Kent even a modest 3% reduction in hospital admissions over 24 months for epilepsy would release over £67,013 which would cover the cost of this project if rolled out across the PCT.
4. Medicines Use Reviews are currently not organised to achieve the most effective

outcome as they are ad hoc and tend to be taken up by already well informed and well managed patients. The Pharmacist sends a GP notification list each month and there is a risk of recommendations being lost in the paperwork. If a clinical problem is identified a copy or the MUR is sent to the registered GP but this tends to be in a format that is not particularily user friendly and still can passed over. By allowing Pharmacists to refer directly within agreed parameters to Intermediate care the MUR becomes a dynamic and more effective tool in the hands of a very skilled and arguably currently under utilised pharmacist.

5. Clinical confidence in the management of epilepsy will be enhanced by a day’s educational update in epilepsy for Pharmacists delivered through the Medway School of Pharmacy. Information leaflets on living in epilepsy provided by Epilepsy Action will be available for Pharmacists to use.
6. The project looks to narrow the gap of health inequalities by identifying those at greatest need who currently for any reason are outside of the usual specialist health care provision.

The MUR campaign will run for a Month [Sept to October 2011] and be repeated nine months later to review progress in this group and to re-enforce the educational and supportive elements delivered. It will be also an opportunity to review medicine concordance. Prior to this second campaign an educational half day will run for the Pharmacists involved to revise their epilepsy education.

Outcomes and Benefits

1. This project looks to reduce unscheduled emergency care for this group and to reduce the A&E Admission and Re-admissions principally at the QEQM Hospital.
2. The community pharmacy team are highly trained and dedicated health care professionals who currently contribute a great deal to supporting people with epilepsy however this project looks to maximise this contribution. If successful it may be a model that could be applicable to other long term diseases.
3. We would expect to see people identified who are at high risk of emergency admission and on going seizures. At the end of the project it will be possible to assess if this group have benefited by reviewing admission rates, seizure freedom rates, and concordance estimations.
4. Pre-Natal women who have been identified as being at risk from teratogenic regimes will also be referred to a specialist community clinic.

4. Delivery

This section outlines (a) the changes we expect to put in place in order to achieve the above outcomes and benefits - and (b) the plan and approach we will use in order to deliver these changes.

4.1. Expected changes

GPs will need to welcome community pharmacists as partners to feel confident in their ability to refer patients who appear to have red flag symptoms [as per template] to Intermediate Care. This applies only for people who are currently not under specialist epilepsy services. By offering referral rights to pharmacists this is a significant move into bringing pharmacists under the Primary Care Team and paves the way, if successful, to closer working and collaboration between the two groups.

The communication routes will be simple non IT based initially and will involve a copy of the medicines use review and also where applicable a copy of the pharmacists referral letter to Intermediate Care. This will highlight the area of concern that the pharmacist has for the person with epilepsy.

Another arm of this project is to explore how public – private partnership can be utilised aid to improve the healthcare and indeed the public health of the community. Working in partnership with Boots will allow a co-ordinated campaign and benefit from Boots expertise in marketing the scheme to it’s customers. Bringing care even closer to the patient will inevitably require closer collaboration with the ‘high street’ and given Boots excellent relationship with the NHS is a very appropriate partner to work with.

The pilot will enlist the help of the Kent and Medway R&D Department and the Institute of Neurology in the pilot evaluation.

4.2. Plan and approach

Scope	Design	Select	Implement	Operate
Feb 2011	April 2011	July/August	4 weeks	Sept/October 2011

Key dependencies for this project are as follows :

Other project/activity	Lead	Description of dependency
Discovering how best to explore public – private working to improve community healthcare	Minakshi Odedra	Boots pharmacy chain willing to advertise the epilepsy awareness campaign and use their marketing skills to reach the patient target group.
Secondary Care Specialist providers for epilepsy	Greg Rogers	Ensure care pathways are clearly identified and relationships well maintained to ensure seamless care for people with epilepsy
Epilepsy Specialist Nurses	Greg Rogers and Minakshi Odedra	Ensure care pathways are clearly identified and relationships well maintained to ensure seamless care for people with epilepsy

GPs	Greg Rogers and Minakshi Odedra	Ensure care pathways are clearly identified and relationships well maintained to ensure seamless care for people with epilepsy

4.3. Expected non-recurrent cost

Key elements of non-recurrent cost expected for this project are as follows:

Cost Item	Brief description	Cost (£'000)
Locum Pharmacists costs	Pharmacist locum costs for training 8 Thanet Boots pharmacists	£2,000
Training facilities	Medway School of Pharmacy First Training Day	£200
	Medway School of Pharmacy follow-up Training Half Day	£150
Total non-recurrent cost		**£2350**
Non-recurrent cost (2009/10)		

Expected breakdown of non-recurrent cost by Stage:

Scope (£'000)	Design (£'000)	Select (£'000)	Implement (£'000)	Operate (£'000)
£2350				£2350

4.4. Expected Staffing

Key roles required to deliver the project

Role	Name	Overview of role and time commitment
Pharmacists	Thanet Pharmacies	Invited to participate in the scheme
Boot's Pharmacists	8 Boots Pharmacists Thanet	To be available to implement the epilepsy MURs during the 4 weeks trial with expertise on media management offered by Boots
GP Lead	Greg Rogers	To provide the training for the pharmacists and clinical oversight of scheme
Pharmacist Lead	Minakshi Odedra	To co-ordinate the pilot with Greg Rogers

Pharmacy Academic Lead	Trudy Thomas	To ensure the pilot is in line with current pharmacy development plans for the DH and ensure design is both able to deliver the necessary information to future commissioning and is deliverable

5. Ongoing Operation

This section outlines what it will take to run the services which this project will deliver, on an ongoing basis

5.1. Expected recurrent cost

Key elements of recurrent cost expected for this project are as follows:
NB-

- Arguably patients identified with red flag symptoms of epilepsy will merit referral to specialist care whether the scheme in operation or not and this cost is hard to identify.
- Medicines use reviews are currently already funded by the PCT

5.2. Workforce expectations

Key additional workforce expected in order to operate the proposed service(s) are as follows:

Role type	Brief description of requirement	Expected WTEs
Epilepsy GPwSI	To take referrals for red flag patients identified by Community Pharmacists	
	Not Applicable	

6. Risks

Key risks and proposed mitigating actions are as follows:

Risk and implications	Brief description of mitigating actions

Un-coordinated campaign	Look to Boots expertise in sales and marketing to help devise a well constructed plan
Lack of expertise in Pharmacy team	Will provide appropriate training ahead of the project in the Medway School of Pharmacy
Overload the Intermediate Care Team - Thanet	Unlikely to be a problem as there is ample capacity at present and GPwSIs from outside of Thanet can be drafted in if required to Thanet clinics
Complaints of equality of care from people with epilepsy in other localities in East Kent	Evaluate the pilot quickly to assess size of the problem of unmet need and to estimate feasibility for roll out. Findings will be available at completion of pilot for wider dissemination
Daily and weekly pharmacy workload	To ensure there is protected time for doing the epilepsy MURs

Assumptions

Please list any assumptions upon which the estimates, etc. detailed in this document have been developed:

1. Unmet need exists for people with uncontrolled epilepsy
2. Proactive care will require less resource than reactive emergency care for epilepsy

Stakeholder Engagement and Sign-off

Stakeholder engagement undertaken in defining this project is outlined below:

Stakeholder Group	Overview of engagement.	Signed-off?** (Y/N) & date
PBC	Greg Rogers to discuss with Thanet PBC group and Medway Consortia	
Epilepsy Action	Greg Rogers to liaise with Epilepsy Action in the scoping and design of the project as well as the outcome	
Community Pharmacists in Thanet	Via the “Local Pharmacy Forum” and via direct invitation	
Pharmacy Academia	Meet with Trudy Thomas from the Univ of Kent school of pharmacy and ensure the pilot outline concords with current guidelines for medicines use review and will be in the direction of travel for emerging pharmacy developments	

*** - Meaning approved in principle. A formal pen and ink signature is not required*

24 Attachment 1 – Project Plan and timeline

Project Plan and timeline for Thanet QIPP Project Proposal for Epilepsy; Medicine Use Review campaign

April 2011 – Meeting with Cheryl Clennett
April 2011 – Agree on training day and flyers
April 2011 - Greg Rogers and Minakshi Odedra to meet with GP Consortia
April 2011 – Greg Rogers to meet with Prof. Shorvon
April 2011 – Greg Rogers to meet with Neurologist
May 2011 – Send out flyers to all Thanet pharmacies
May 2011 – Response from all pharmacies by end of May
August 2011 – Full day training at Medway School of Pharmacy
September 2011 – 4 weeks pilot

March 2012 – Refresher training at Medway School of Pharmacy
April/May2012 – Re-run pilot for 4 weeks
May/June 2012 – Disseminate findings with all stakeholders

25 Referral form used by Pharmacists to the GPwSI service for epilepsy

Please fill in all sections of the referral form and email to
bethesda.secretary@nhs.net
or send to the;

Epilepsy Centre,
Bethesda Medical Centre,
Palm Bay Avenue,
Margate
Kent.
CT9 3NR
Tel 01843 209342
Fax 01843 209301

PATIENT DETAILS	
Patient details: ***Please attach label or enter patient's Name , Address and D.O.B.***	**Pharmacist;** **Pharmacy Address;** **Registered GP:**
Patient telephone no: **NHS no:**	**Date:**

Referral Guidance:

1 **All referrals must be 16yrs and over with established epilepsy.**
2 **Referrals will be triaged by GPwSI clinical lead**
3 **Patients are currently not under specialist epilepsy care**

Reason for follow up in Primary Care Scheme:

1. Emergency admission to A&E or treatment by Paramedic Ambulance Service within the past 12months
2. On-going seizures / worsening seizures.
3. Pre-natal hazard identified in women receiving medication which is potentially teratogenic.
4. Hazardous poor concordance of medication [taken as being estimated as less than 80%]

Patient Questionnaire Pre and Post Epilepsy Targeted MUR

26 Pre-MUR questions

Please tick one box for each question

1. How do you rate your understanding of the causes of epilepsy?

Excellent	I can tell you in detail why and how epilepsy occurs	☐
Good	I have a reasonable idea of why and how my epilepsy occurs	☐
Satisfactory	I have a rough idea of why and how my epilepsy occurs	☐
Poor	I don’t really understand why and how my epilepsy occurs	☐

2. How confident are you that you know how to lessen the chance of having a seizure?

Very Confident	I can tell you in detail how I could lessen my chances of having a seizure	☐
Confident	I have a reasonable idea of how I could lessen my chances of having a seizure	☐
Not very confident	I have some idea of how I could lessen my chances of having a seizure	☐
Very unconfident	I don’t know how I could lessen my chances of having a seizure	☐

3. Before today, have you thought about consulting your pharmacist for advice about your epilepsy?

Frequently	I consult my pharmacist regularly about my epilepsy	☐
Now and again	I have occasionally consulted my pharmacist about my epilepsy	☐
Rarely	I haven’t really thought about consulting the pharmacist about my epilepsy	☐
Never	I have never thought of consulting my pharmacist about my epilepsy	☐

After-MUR questions

Please tick one box for each question

1. How do you rate your understanding of the causes of epilepsy?

Excellent	I can tell you in detail why and how epilepsy occurs	☐
Good	I have a reasonable idea of why and how my epilepsy occurs	☐
Satisfactory	I have a rough idea of why and how my epilepsy occurs	☐
Poor	I don’t really understand why and how my epilepsy occurs	☐

2. How confident are you that you know how to lessen the chance of having a seizure?

Very Confident	I can tell you in detail how I could lessen my chances of having a seizure	☐
Confident	I have a reasonable idea of how I could lessen my chances of having a seizure	☐

Not very confident	I have some idea of how I could lessen my chances of having a seizure	☐
Very unconfident	I don’t know how I could lessen my chances of having a seizure	☐

3. After today, how likely are you to consult your pharmacist for advice about your epilepsy?

Very likely ☐

Quite likely ☐

Unlikely ☐

Very unlikely ☐

27 Information sent to Pharmacists taking part

Medicines Use Reviews for People with Epilepsy:
Pilot Project

Pilot Information and Resource Pack for Pharmacists

Dear Pharmacist

Thank you once again for taking part in the training for this pilot project and for agreeing to undertake MURs for people with epilepsy.

This pack describes the next steps in the project and provides some resources so you can start carrying our MURs for people with epilepsy.

This pack includes 12 resources. We include 20 copies of all resources marked * These will also be sent electronically to the email address you supplied to us at the end of the training day. If you require more hard copies please contact Tracy Joseph at the School of Pharmacy on t.joseph@kent.ac.uk

Resource 1: A list of some commonly used drugs used in epilepsy to assist computer search

Resource 2: Sample letter –You need to adapt these letters by printing onto your own headed notepaper and adding your own details. You can either send these out to patients who you identify through the search or give them to patients when they are in the pharmacy. Please feel free to use your own letter. However you must give patients who you wish to include in the pilot a patient participant information sheet. We are not supplying hard copies of this letter but it will be sent electronically to the email address you supplied at the end of the training day.

Resource 3* and 4*: Copy of patient participant information sheet (Resource 3). All patients taking part in the pilot must have an information sheet and complete the consent form and pre-MUR questions (resource 4).

A word about patient consent. We cannot use any patient data for this project (even if it is anonymous) without patient permission. Patients who do not consent for their data to be shared must still be offered an MUR in exactly the same way, however we can't include them in the project.

Patient pre-MUR questions appear on the reverse of the consent form. You will recognise the questions as similar to the ones that you completed yourself before your training. We are using these simple questions (and a similar after-MUR set) to try to assess the 'added value' of the MUR.

However as you will see later we have also incorporated then into the MUR and we think it will be useful for you to see the patient's answers before your start the MUR. If patients do not want to complete them, just record this on the form.

These can also be sent to you electronically as pdfs if you wish to print out your own copies

Resources 5 and 6: Sample MUR form and suggested 'script'. As you know I was anxious at the training day that the evaluation of this service would not involve extra paperwork for yourselves. We think that we have found a way to include the extra pilot only ‘check for referral’ questions into the MUR and this way the data will get captured on the MUR form as you go along. After the training day Greg and I worked though an epilepsy MUR and tried to see where the questions would come ‘naturally’ and so where the information would go on the form. The result is this sample form and suggested script. This is only a suggestion! You will no doubt develop your own words when delivering this service. As long as the pilot referral questions are recorded on the MUR form, then you only need to send us that form for evaluation. If a patient is referred to Greg, you will complete the referral form (resource 8) and we will have a copy of that (via Greg). However many patients will not be referred and the fact that you have asked the questions and have a reason for not referring needs to be captured.

Resource 7: How to do Greg’s assessment of adherence. We need you to do this each time you do an MUR and record it on the MUR form.

Resource 8*: Referral form. We have made some amendments to this since the training session, so please use this most recent version.

Resource 9: Algorithm for referral

Resource 10*: After-MUR question sheet. Please ask patients who have undertaken an MUR to complete this as soon as they have finished the consultation. You should attach it to the consent form/pre-MUR question sheet

Resource 11 and 12: Participant information sheet and consent for you. Remember I threatened you with some qualitative analysis to capture your views on this pilot project. We are planning to run a focus group after you have done your MURs. Details about what this entails, the date, time etc are included here. If you are interested in taking part, then please read the Pharmacist Participant information sheet and complete the Pharmacist consent form and return it to Trudy at the University in the pre-paid envelope.

If you have any questions, comments, suggestions, worries or just want to chat, please get in touch with either Trudy or Greg – details below.

We hope you are really excited about taking part in this project. The eyes of the pharmacy and epilepsy world are on us (so no pressure there). We really hope that you enjoy trying out your new skills and knowledge and we look forward to hearing how it went after the event.

Good luck

Trudy and Greg

Trudy Thomas

t.thomas@kent.ac.uk

01634 883176

Greg Rogers

Email greg.rogers@nhs.net

Phone 01843 209342

What to do next
Familiarisation

- Read through this resource pack and familiarise yourself with everything that is here. Complete the Pharmacist consent to take part in focus group form and return to Trudy if you would like to be involved in this aspect of the project

Identify Patients for MUR

- Carry out a search on your pharmacy computer to identify patients **over the age of 16** with epilepsy. Resource 1 may be helpful here
  NB if you notice that there are a number of patients with the same address, consider that this may be a learning disability care home. We recommend that you do not send letters to each patient, but contact the home manager directly and discuss carrying out MURs for this group of patients.
- Adapt patient invite letter (resource 2) adding your pharmacy address and other details
- Send letter to identified patients

Practice MUR

We suggest you do a ‘mock MUR’ to practice the flow you want to adopt to best carry out the MUR and incorporate the referral questions

Epilepsy MURs (for real)

These can be carried out from 15th September 2011 to 15th October 2011.

For each MUR

- Establish whether the patient is happy to take part in the pilot project by collecting their signed consent form and completed pre-MUR questions – if they do not want to take part, the MUR can go ahead as usual
- For patients that do consent, add the extra information required by this project eg consultant details, adherence check (see resources 5 and 6)
- Complete MUR referral form if referral needed
- At end of MUR ask patient to complete the after-MUR questions
- Attach pre-MUR questions and After-MUR questions for that patient together using a staple. Place into large envelop provided to be returned to Trudy at end of project

Paperwork after a pilot project MUR (where patient consent given)

- Give patient a copy of their MUR as normal
- If referring to Greg – send copy of MUR form and referral to Greg at address indicated on referral form
- If not referring - send copy of MUR form to patient’s GP (only if deemed necessary). If you are referring to Greg this isn’t necessary as Greg’s secretary will contact the patient’s GP.

- Print off **anonomysed** copy of the completed MUR form and store in large envelope provided. This should be returned to Trudy at end of project period.

28 Resource 1 – List of drugs commonly used in Epilepsy

This list may be useful in helping you to search your computer records to identify **adult** patients with epilepsy. It is not exhaustive. Please be mindful that many of these drugs are used for other conditions. We have added a caveat to our sample letter, saying we recognise that patients may not be taking these medicines for epilepsy, but offering those people an MUR anyway. (Time to brush up on your knowledge of neuropathic pain too perhaps?)

Carbamazepine (Tegretrol/Tegretol Retard)
Clobazam (Frisium)
Clonazepam (Rivitril)
Gabapentin
Keppra
Lamictal
Lamotrigine
Levetiracetam (Keppra)
Neurontin
Oxcabazepine (Trileptal)
Phenytoin (Epanutin)
Phenobarbital
Topiramate (Topamax)
Valproate (sodium) (Epilim)
Vigabatrin (Sabril)

29 Resource 2 – Sample letter for patients

Pharmacy headed notepaper or address

Date

Dear *xxxxxx*

I am writing to invite you for a medicine use review (MUR). The MUR is an NHS service and is free of charge. An MUR is a consultation in the pharmacy which lasts about 15 minutes and gives you the opportunity to chat to a pharmacist (chemist) about how you can get the best out of your medicines. You can ask any questions you want and discuss in confidence any medicine related worries or issues.

You have been asked specifically at this time because you take medicines which can be used by people with the condition epilepsy. However we realise that these medicines can be used for lots of different conditions, including chronic pain and you may not have epilepsy. If you do not take medicines for epilepsy, but would like to talk to the pharmacist about these or any other medicines you take please feel free to contact the pharmacy and book an appointment for an MUR.

For people who do take these medicines for epilepsy, we are offering MURs linked to a pilot project in Thanet. The project which starts in September and runs for one month enables the community pharmacist not only carry out an MUR, but if necessary, refer the person with epilepsy directly to a doctor who specialises in this condition. This project is being run in conjunction with the charity Epilepsy Action and has come about because research has shown that many people with epilepsy would benefit from talking to someone about their medicines. Many people may be having seizures unnecessarily.

The enclosed leaflet tells you about the epilepsy project. If you decide to take part in this project you will be asked to answer 3 straightforward questions before you come for the MUR and 3 related questions after the MUR. The before-MUR questions are included with this letter.

If you agree to take part this will also mean that information on the form filled in at your MUR can be analysed by a team from the Medway School of Pharmacy (University of Kent) and the Thanet Consortia (the health body for Thanet). The form will be anonymous; only you and the pharmacist will see your name and address.

If you do not want to fill in the questions and/or share the anonymous information of the form, that isn't a problem, you can still have an MUR with the pharmacist. Just let the pharmacist know that you do not want to be part of the project.

What happens next?

If you would like to book an MUR please ring XXXXX *(Pharmacy name)* on XXXXXXX *(pharmacy number)*.

If you are happy to take part in the pilot project, please bring your completed 3 questions and the attached consent form with you. (The pharmacist will have spares if you forget or change your mind).

We hope that you will be interested on having an MUR and helping the Thanet Consortia to help people with epilepsy in Thanet.

Yours sincerely

Pharmacist

30 Resource 3

Participant information Sheet – to be given to all people who may undertake an MUR

Information for patients

Medicines Use Reviews (MURs) for People with Epilepsy:
A Pilot Project

Your pharmacist has asked you to visit the pharmacy for a medicines use review (MUR). The MUR is an NHS service and is free of charge. You have been asked specifically at this time because you take medicines which can be used by people with the condition epilepsy. Please read this leaflet carefully. It will hopefully answer some of your questions. If there is anything that isn't clear in this leaflet, or if you would like more information, or would like to talk to someone about the project please feel free to contact us. Our details are on page 3 of this leaflet.

Why is this project being carried out?
Epilepsy is the most commonly occurring serious neurological condition in the UK. It affects around 380,000 people in England and Wales. The good news is that with the right treatment around 70% of people with epilepsy could be seizure free. The not so good news is that despite the development of many new and effective medicines for epilepsy, many people have continue to have seizures and a poor quality of life. Thanet has a higher than average incidence of epilepsy. In recent years however there have been a number of local initiatives to try to help people with epilepsy, including the training of general practitioners (GPs) who have a special interest in epilepsy. The new health organisation for Thanet (the Thanet Consortia wants to improve further the care of people with epilepsy and has now trained some pharmacists (chemists) in this condition too.

What is this project about?
In this pilot project these specially trained pharmacists will carry out medicines use reviews (MURs) with people with epilepsy who get their prescriptions dispensed at that pharmacy. An MUR is a pharmacy based consultation available free of charge of the NHS. It lasts about 15 minutes and is designed to help people get the best out of their medicines. In an MUR you can ask any questions you want and discuss, in confidence, any medicine related worries or issues. At the moment anyone who takes regular medicines can have an MUR at their local pharmacy. In this project, the pharmacists will be particularly focussing on people who take medicines for epilepsy. The pilot project will run for one month, starting in September 2011. During this month, the specially trained pharmacists will be able to refer people directly to the Thanet GP with a special interest in epilepsy, if this is appropriate. After the project has finished, the results will be used to develop local services to help people with epilepsy.

What do I have to do?
If you would like to talk to your pharmacist about your medicines, simply ring the pharmacy to book an appointment. If you are happy to take part in the pilot project, then you need to consent to take part. This means confirming that you have read and understood the contents of this leaflet and that you are happy for a copy of your MUR (without your name and address on it) to be shared with the Thanet Consortia and a small project team at Medway School of Pharmacy who

will analyse the project results on behalf of the Consortia. You confirm your consent by completing the enclosed consent form and answering the 3 questions on the reverse of the sheet. You need to take this form to the pharmacy with you when you go for your MUR. The pharmacist will have spare copies.

Do I have to take part in the pilot project?
It is entirely up to you. You are free to change your mind at any time, without giving a reason. This would not affect the standard of care that you receive. If you don't want to take part, you can still have an MUR with the pharmacist if you would like.

Who to Contact about this project
You can get information from; your pharmacist whose details are listed in the covering letter with this leaflet
Thanet Consortia - name
The team at the School of Pharmacy is headed up by Trudy Thomas. She can be contacted via 01634 883150 you can write to her at t.thomas@kent.ac.uk

If you would like to talk to someone impartial about taking part in research like this, you can contact the epilepsy charity, Epilepsy Action on XXXXXXXXX
Of course you can always speak to your GP, nurse or consultant.

What happens if I get referred to the Primary Care Epilepsy Service?
If you are not already under the care of a specialist and the pharmacist thinks it is appropriate, he or she will complete a referral form and refer you to an accredited GP with a Special Interest in Epilepsy. This GP's secretary will offer you an appointment. These consultations will normally take place at the Bethesda Medical Centre in Cliftonville. Your own GP will also be notified.

What happens after the project ends?
The Medway School of Pharmacy team will review the results and write up their findings and make recommendations to the Consortia. You can be sent copies of any aspect of the research that you are interested in. No part of the research that is written up will have any personally identifiable information included.

Are there any risks/disadvantages in taking part?
No

What are the advantages of taking part?
Understanding more about your epilepsy and the medicines you take can help you manage the condition better.

What if there is a problem?
Any complaint about any aspect of the project can be made to the Medway School of Pharmacy or the NHS.

Medway School of Pharmacy
University of Kent
Anson Building
Central Avenue, Chatham Maritime.
Kent ME4 4TB

Resource 4 – Consent form with Pre-MUR questions

Resource 5 – Sample MUR form

Resource 6 – Helpful words to use in your MUR and how to record the Thanet referral questions on the MUR form

Hello Ms Twist

My name is X and I am the pharmacist here at Y Pharmacy

You have been invited to the pharmacy today so that we can have a chat about your medicines. Can I just check that you have had a leaflet about the pilot project being run in Thanet in association with the charity Epilepsy Action. Hopefully the leaflet explained the session today. Is there anything you would like to ask me about anything that you read? I'd also like to ask whether you are happy to have the information that I gather today used (without your personal details on) to see how useful the project has been.

Be prepared to explain again if necessary.

Assuming patient agrees

You are? That's great. Can I just collect your completed consent form. Now on the back of that form there were some questions which we will come to in a minute.

We have got about 15 minutes together today for this medicines use review (MUR). Obviously the focus is going to be the medicines you take for epilepsy, but we may need to look at some of the other medicines you take as well if they are relevant to your epilepsy. Is there anything else specifically to do with any of the other medicines that you would like to discuss today?

Include in MUR if they do

Now the first thing I am going to do is confirm your details

Checks name/address and DOB

Now I want to ask you a little bit about your epilepsy. How long have you had epilepsy? Do you know what type of epilepsy you have?

RECORD ON MUR FORM – in comment section (make note if not known)

Now one of the pre-MUR questions asked you about the causes of epilepsy? How did you rate your understanding?

Use answer to guide where conversation goes next?

a] If they know what type of epilepsy they have e.g. temporal lobe epilepsy or frontal lobe epilepsy you can go on to discuss their seizures using the diagram of the brain in Seizures Explained. If they know they have generalised epilepsy this also is included toward the end of the booklet. The dialogue could progress something like, "I wonder do you know where your temporal lobes are? Don't worry - a lot of people don't. I have this great leaflet here (Seizures Explained) – RECORD GIVEN ON MUR FORM) which shows you just where the temporal lobes are. Sometimes the bit of the brain with the faulty wiring can be as small as a full stop on a page. This booklet also explains the sorts of things that people with your type of seizure can experience – does any of this sound familiar?" (*shows appropriate page of Seizures Explained book)*

b] If they do not know what sort of epilepsy they have and I would imagine most will not, then explain how part of the brain is more prone that it should be to send out nerve signals. The medication acts to settle this down and make it behave more normally. In a sense it is 'faulty brain wiring',

Now the questions also asked about preventing seizures. Do you know what sorts of things trigger a seizure for you?

Right so you have obviously worked out quite a few things that do. There are a few more in this leaflet too. Sometimes if you are having quite a few seizures it is worth keeping a diary. How about you – do you have regular seizures? For example when was the last time you had one? Did you have to go to A&E or was a paramedic called? Have you ever been taken to casualty or had a paramedic called? When was the last time? How would you say your seizures are now compared to say a year ago? Less frequent, about the same, or more frequent RECORD ANSWER – CONSIDER REFERRAL *and explain this*

Who do you see about your epilepsy? Do you see a consultant at the hospital? RECORD ANSWER IN SECTION OF MUR FORM UNDER GP DETAILS – see algorithm

Let's now look at your medicines. Can you tell me which ones you take for epilepsy from your list? So let's start with the first one, Tegretol EC. Can I ask how often you take those each day? When in the day exactly do you take them?

Goes through each of epilepsy medicines in turn

Now some epilepsy medicines are not great to take if you are pregnant. We ask all ladies whether there is any possibility of them being pregnant or if they are contemplating becoming so in say the next 5 years. RECORD ANSWER UNDER AGE ON MUR FORM – CONSIDER REFERRAL IF PREGANT OR PLANNING – Consider giving appropriate Epilepsy Action leaflet as well. Can I just confirm whether you use a method of contraception because sometimes people get the pill from somewhere other than their doctor and we don't always have it recorded.

Check adherence with all AEDs using the Greg Roger's adherence – ometer – see resource 7

Calculate adherence and act as shown

<80% - If they are under specialist care already REFER to usual consultant (this will have to be via GP). If they are not under any specialist epilepsy care offer them a refer to Greg and the intermediate care epilepsy service, using the referral form

80-90% - INVESTIGATE/ADVISE. Ok that's not bad, but you are still missing quite a few – can we have a think about why that might be, because missing these medicines could mean a seizure and seizures can be dangerous, so we like to reduce the number people are having to none if possible! – GIVE A LEAFLET ON SAFETY IN EPILEPSY IF NOT GIVEN ALREADY

90% PRAISE + ENCOURAGE. That's not bad – is there anything we could do to make it even better?

98-100% PRAISE ++

RECORD ADHERENCE ON MUR FORM in comments section. It may well appear in action section too

One of the things we always ask at these reviews is about other medicines that you take from anywhere else? Hospital, dentist, clinic? Do you buy any medicines over the counter? This includes eye drops, inhalers, creams and ointments. What about herbal or homeopathic medicines or anything of the internet? I also need to ask if you smoke? Do you drink alcohol and if so much and I have to ask about recreational drugs? RECORD AS APPROPRIATE ON MUR FORM

Now we have got about 2 minutes left of our time: is there anything you would like to ask me about the medicines we have talked about or anything else to do with your medicines or your health?

Just to summarise – *goes over main points – confirms referral to GPwSI (if appropriate) and how MUR forms are to be used* (1 to patient, 1 to Greg with referral – who will notify patient's GP and anonymised data to University for analysis

Finally can I just ask you to complete 3 questions before you leave – *gives after MUR form*

31 Resource 7 – How to do Greg’s Adherence Check for medication taken for epilepsy

Possible words: Now we all know that people often miss a tablet if they have been taking them for a long time. If we consider all your regular epilepsy medicines together.......Let’s think about the doses you take in the morning – you have three to take in the morning don’t you? On a good week how many of those tablets do you take? *Gives score out of a possible 21 (in this case). Put score in table below*. So what about on a bad week in the morning? – So you pretty much always take those. That’s good.

Let’s move to the lunchtime doses. You only take 1 tablet at lunchtime. Right so even on a good week you miss occasionally? What about the bad week ?– So sometimes they all get missed at lunchtime?

Evening doses – again you take 3 tablets at night – good week? – all of them – bad week? So perhaps one evening missed. Right let me calculate your percentages using my trusty calculator......

	Good week	Bad week	total prescribed/week
Am	21	21	21
Lunchtime	5	0	7
PM	21	18	21
Total taken	47/49	39/49	49
percentage	96%	80%	

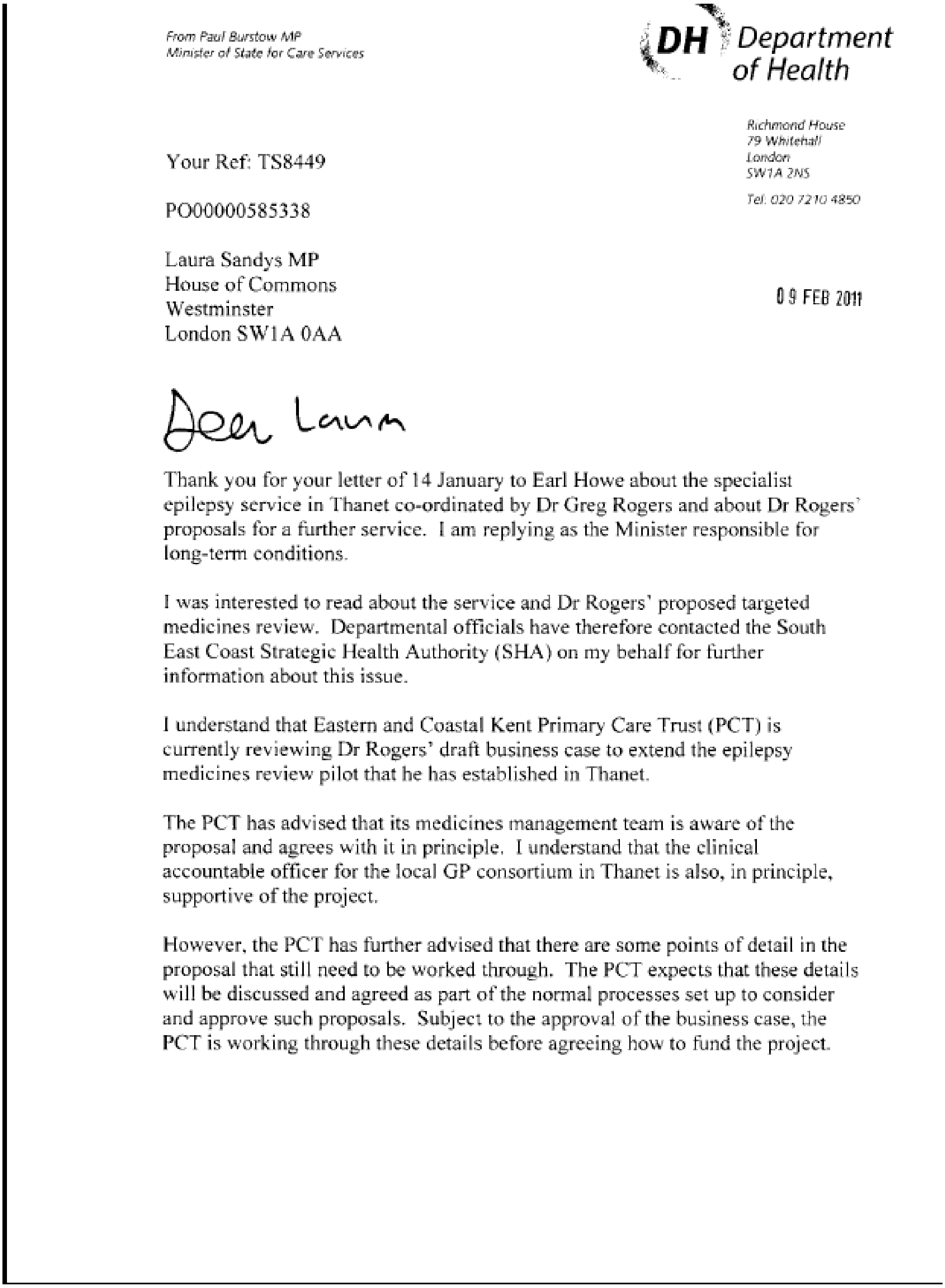
Shows patient

So on a good week you are really hitting the target, but on a bad week that put you in the ‘not so good/could be better’ category. Let’s look at those lunchtime doses again........

Pharmacist explores

NB This patient would not be referred to Greg on adherence alone.

32 Letter from Department of Health



From Paul Burstow MP
Minister of State for Care Services

DH Department of Health

Richmond House
79 Whitehall
London
SW1A 2NS

Tel. 020 7210 4850

Your Ref: TS8449

PO00000585338

Laura Sandys MP
House of Commons
Westminster
London SW1A 0AA

0 9 FEB 2011

Dear Laura

Thank you for your letter of 14 January to Earl Howe about the specialist epilepsy service in Thanet co-ordinated by Dr Greg Rogers and about Dr Rogers' proposals for a further service. I am replying as the Minister responsible for long-term conditions.

I was interested to read about the service and Dr Rogers' proposed targeted medicines review. Departmental officials have therefore contacted the South East Coast Strategic Health Authority (SHA) on my behalf for further information about this issue.

I understand that Eastern and Coastal Kent Primary Care Trust (PCT) is currently reviewing Dr Rogers' draft business case to extend the epilepsy medicines review pilot that he has established in Thanet.

The PCT has advised that its medicines management team is aware of the proposal and agrees with it in principle. I understand that the clinical accountable officer for the local GP consortium in Thanet is also, in principle, supportive of the project.

However, the PCT has further advised that there are some points of detail in the proposal that still need to be worked through. The PCT expects that these details will be discussed and agreed as part of the normal processes set up to consider and approve such proposals. Subject to the approval of the business case, the PCT is working through these details before agreeing how to fund the project.

As you will be aware, the White Paper *Equity and Excellence: Liberating the NHS* proposes that money will follow the patient across the NHS through transparent, comprehensive and stable payment systems to promote high quality care, drive efficiency, and support patient choice. Quality standards will inform the commissioning of all NHS care and payment systems.

Changing the funding system for community pharmacy services to reflect these aspirations will take time and be challenging. Work on this is at an early stage but we are already working closely with the interested parties. Proposals to target medicines use reviews (MURs) to those patients who are likely to benefit from them the most can only be right. So too is ensuring that patients fully understand their medicines from the first time they are prescribed, with follow up support in those early weeks when they are getting used to the treatment and to life with a long-term condition. Evidence suggests that where targeted MURs have been implemented, the use of other NHS services decreases.

As responsibility for commissioning community pharmacy services moves to the NHS Commissioning Board, it makes sense to have national target groups for MURs.

I hope this reply is helpful.

Yours Sincerely

Paul Burstow

PAUL BURSTOW

33 Training with Pharmacists before MURs

Proposed Outline of MURs in epilepsy day

10-10.30 –	scene setting	GR/TT/MO
10.30 – 11.30 –	Classification of epilepsy	GR
11.30 – 11.45 –	Break	
11.45 – 1.30	Session 2 – drugs used in epilepsy?	GR
1.30 – 2.00	Lunch	
2.00 – 2.15	Referring in the East Kent scheme	GR
2.15 – 4.00	Role plays – doing MURs for people with epilepsy 3 case studies (see below)	TT/GR
4.00 – 4.15	Top tips and next steps	TT/GR

Case studies

1. Doing an MUR for someone with an epilepsy drug – where there is high dose drowsiness
    a. TT See attached document
2. Referring – a male patient who has been experiencing a sore tongue – has been nagged into going in by his girlfriend. Has a recent admission to A&E after partying and taking 'E' was referred but DNA
    a. GR to work up
3. Someone on 3 AEDs and rescue (Frisium) – some suggestion of a perimenopausal seizure at one point
    a. GR to work up

34 Response from the Patient Questionnaires – Pre and Post Targeted Epilepsy MUR

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	TOTAL	Average
Question 1																			
Pre MUR	2	3	4	1	3	NQ	1	3	4	3	1	2	2	4	1	NQ	NQ	34	**2.62**
Post Mur	2	4	4	2	3	NQ	2	3	4	3	3	2	2	4	1	NQ	NQ	39	**3**
Question 2																			
Pre Mur	4	1	4	3	3	NQ	1	3	4	4	1	1	3	2	2	NQ	NQ	36	**2.77**
Post MUR	4	3	4	3	4	NQ	1	3	4	4	3	2	3	3	NQ	NQ	NQ	41	**3.41**
Question 3																			
Pre MUR	3	1	1	1	NQ	NQ	1	1	1	1	1	1	1	1	1	NQ	NQ	15	**1.25**
Post MUR	4	4	1	4	4	NQ	4	1	3	1	2	3	4	4	NQ	NQ	NQ	39	**3.25**

Key 4 = highly positive, 3 = positive, 2 = negative, 1= highly negative NQ = No Questionnaire

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