



A resource to help prioritise new research



PATIENTS' PRIORITIES FOR RESEARCH INTO EPILEPSY

A SURVEY OF PATIENT GROUPS 2008

By PatientView, on behalf of

DUETS

and

The James Lind Alliance

in collaboration with the

University of Wales Swansea

and the

University Hospital of Wales

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(The Database of Uncertainties about the Effects of Treatments)

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DUETS 2008 EPILEPSY PATIENT GROUP SURVEY

Introduction

As part of a larger project about future clinical research in the field of epilepsy, DUETs (a component of the NHS National Library for Health) invited relevant patient organisations to respond to a short online survey, sharing their significant knowledge of the needs and wants of the epilepsy patients they represent.

Why this survey?

DUETs wanted to know what questions epilepsy patients have about their treatment—questions that doctors cannot currently answer. In other words, DUETs wished to gather details about those aspects of treatment that patients with epilepsy would like to see addressed by medical research.

The DUETs survey is a first step in giving epilepsy patients/carers a bigger and more potent voice in medical research. Medical research could do a lot more for people with epilepsy. Previously, most research has been primarily designed and conducted by doctors, scientists, and industry—healthcare stakeholders who may not always have an intimate knowledge of the wants and needs of patients. The DUETs survey aimed to find out what epilepsy patients themselves regard as their unmet treatment needs.

How will the survey results create change?

The survey results will feed into a forthcoming DUETs list of uncertainties in the field of epilepsy research—a catalogue that medical science should be addressing. The list will be placed in the public domain, ready to be acted upon by scientists.

About Duets

The Database of Uncertainties about the Effects of Treatments (DUETs) is a unique initiative that determines what specific areas of medical research the public and patients (as well as other interested parties) would like to see undertaken.

About the James Lind Alliance

The Oxford-based James Lind Alliance (JLA) is a non-profitmaking initiative funded by the Department of Health (DoH) and the Medical Research Council (MRC). The Alliance aims to identify the most important gaps in knowledge about the effects of treatments. The JLA brings patients and clinicians together in 'Priority-Setting Partnerships' to identify and prioritise the unanswered questions that they agree are most important—information that then is ranked into a priority order for research, and made available to the funders of health research. The JLA has been maintaining a dialogue with representatives of epilepsy patients for some while, and is at a stage in which many epilepsy 'treatment uncertainties' have been assembled, and could start to be entered onto DUETs.

Administration of the survey

This DUETs survey was funded by the James Lind Alliance (JLA) and conducted between March and July 2008 by PatientView, a Wales-based research and publishing organisation, on behalf of DUETs and the James Lind Alliance, in collaboration with Professor Mark I. Rees, Director of the Institute of Life Science (ILS), and Director of the Wales Epilepsy Research Network (WERN), University of Wales Swansea, and Professor Phil Smith, MD, FRCP, Consultant Neurologist, University Hospital of Wales.

DUETS 2008 EPILEPSY PATIENT GROUP SURVEY

About the DUETs 2008 survey of epilepsy patient groups

The DUETs questionnaire concentrated upon patients' research uncertainties in the following epilepsy subject areas:

- I. Diagnostic tests.
- II. Complementary therapies.
- III. Diets or dietary supplements.
- IV. Prescription medicines.
- V. Neurosurgical interventions.
- VI. Psychological support or psychological treatments.
- VII. Treatments for children with epilepsy.
- VIII. Other treatment areas in epilepsy.
- IX. Non-medical epilepsy services.
- X. Other illnesses.
- XI. Single most-important consideration.

Who took part?

36 different patient organisations with an interest in epilepsy responded to the survey. 35 of them completed the questionnaire (though not all of the 35 answered every question).

16 RESPONDENT ORGANISATIONS WISHED TO BE ATTRIBUTED AS SURVEY PARTICIPANTS IN THE PUBLISHED REPORT

Cambridgeshire Neurological Alliance.
Epilepsy Action (Basildon and Thurrock Branch).
Epilepsy Action (Birmingham Branch).
Epilepsy Action (Brighton and Hove Branch).
Epilepsy Action (North Devon Branch).
Epilepsy Action (Sheffield and District Branch).
Epilepsy Action (Tunbridge Wells Branch).
Epilepsy Connections.
Epilepsy Scotland.
Epilepsy West Lothian.
face2face (North-East Lincolnshire).
Gwent Epilepsy Group.
National Society for Epilepsy, The.
Southampton Community Epilepsy Service.
Southampton University Hospital Trust (Specialist Epilepsy Service).
Sunshine Club, The.

How the results were analysed

In each of the above sections, the respondents' answers were classified into one of several categories of uncertainty (some answers could be classified into more than one category of uncertainty).

Analyses of the survey's results can be found on the next 44 pages.

DUETS 2008 EPILEPSY PATIENT GROUP SURVEY

Patients' priorities for research in the area of epilepsy

*“People often ask me questions about drug treatment.
All I can tell them is that a high percentage of people are controlled by drugs”*

—executive, patient group

DUETS EPILEPSY, 2008: PATIENT GROUPS

SINGLE MOST-IMPORTANT CONSIDERATION

Categories

- (I) Research into better treatments.
- (II) Research into ensuring current treatments are as effective as possible.
- (III) Research into treatments with fewer side-effects.
- (IV) Research into more definitive diagnostic tests for epilepsy.
- (V) Research into potential connections between epilepsy and other medical conditions.
- (VI) Research into stigma associated with epilepsy.
- (VIII) Research into the effectiveness of psychological support.
- (IX) Research into patient information.
- (X) Other: on role of medical research.

I. Research into better treatments

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
63397163	Whether the treatment will prevent seizures from occurring; there is a great need to find treatments for all types of epilepsy that can sense the onset of seizures in the brain and prevent them from occurring in the first place.	For patients with epilepsy, the single most important worry is whether the treatment will prevent seizures from occurring. There is a great need to find treatments for all types of epilepsy that can sense the onset of seizures in the brain, and prevent them from occurring in the first place.	
628869816	Having a 100% proven treatment for epilepsy, if this is possible. That is the ultimate goal for most people	For patients with epilepsy, the single most important desire is to have a 100% proven treatment for epilepsy (if such a thing is possible). That is the ultimate goal for most people with epilepsy.	
614184427	Issues around medication (which are numerous). This would be the most important because it is, in our experience, the subject most frequently asked about. The majority of people with epilepsy are on or are considering medication. So in numerical terms this is the most widely encountered 'treatment'.	For patients with epilepsy, the single most important worry is medication issues (which are numerous). This would be the most important because it is, in our experience, the subject most frequently asked about. The majority of people with epilepsy are on, or are considering, medication. So, in numerical terms, medication is the most widely-encountered 'treatment'.	

II. Research into ensuring current treatments are as effective as possible

601588758	Medical prescriptions - increasing dosages.	Patients with epilepsy would like research into increasing dosages of medical prescriptions.	
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DUETS EPILEPSY, 2008: PATIENT GROUPS

MOST IMPORTANT CONSIDERATION (CONTINUED)

III. Research into treatments with fewer side-effects

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
628774890	The side effects of medication.	For patients with epilepsy, the single most important worry is the side effects of medication.	
627540953	Researching the number of patients who have debilitating side-effects from medicines would be most important. Some patients have few seizures and say that these are easier to cope with than AED side effects. Many of the other issues above are social issues facing people with epilepsy, this is directly related to the medical treatment and the patient's experience of this.	Researching the number of patients who have debilitating side-effects from medicines would be most important. Some patients have few seizures, and say that these are easier to cope with than the side effects of anti-epileptic drugs (AEDs). Many of the other issues above are social issues facing people with epilepsy, and are directly related to the medical treatment and to the patient's experience of the treatment.	
626833046	memory	For patients with epilepsy, the single most important worry is their memory.	
624867399	Side effects of medication	For patients with epilepsy, the single most important worry is the side effects of medication.	
619883916	AED side-effects	For patients with epilepsy, the single most important worry is anti-epileptic drug (AED) side-effects.	
615292546	how side effects of medications may affect epilepsy	For patients with epilepsy, the single most important worry is how side effects of their medications may affect their epilepsy.	
613677577	What epilepsy medications are least likely to cause negative side effects on physical, intellectual and emotional functioning?	For patients with epilepsy, the single most important worry is what epilepsy medications are least likely to cause negative side-effects on physical, intellectual, and emotional functioning?	
600991577	Reviewing of medication for long term effects	For patients with epilepsy, the single most important worry is that medication is reviewed for long-term effects.	
599603280	The effects of antiepileptic medication on cognitive functioning and a patient's academic abilities. This would be a strong reason for some people not to comply with their anti-epileptic medication regime.	For patients with epilepsy, the single most important worry is the effects of anti-epileptic medication on cognitive functioning and a patient's academic abilities. This would be a strong reason for some people not to comply with their anti-epileptic medication regime.	

DUETS EPILEPSY, 2008: PATIENT GROUPS

MOST IMPORTANT CONSIDERATION (CONTINUED)

IV. Research into more definitive diagnostic tests for epilepsy

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
620353646	That there is not a diagnostically certain test.	For patients with epilepsy, the single most important worry is the non-existence of a test that can lead to a certain diagnosis.	
602639750	I felt let down by the electrodes test on my child because it showed no seizure activity, but he fitted two hours later	I felt let down by the electrodes test on my child, because it showed no seizure activity. But my child suffered a fit two hours later.	
604761874	doesn't fall into any of the above but I would like to see research done on identifying babies with the potential for epilepsy whilst still in the womb	This request does not fall into any of the above categories, but I would like to see research done on identifying babies that the potential for epilepsy while still in the womb.	
629403206	Question 1 definitely. Basic diagnosis is essential. every patient should have a basic idea of what is going on and why	For patients with epilepsy, question 1 is the single most important, definitely. Basic diagnosis is essential. Every patient should have a basic idea of what is going on, and why.	

V. Research into potential connections between epilepsy and other medical conditions

602074403	I think there is a strong connection with some types of epilepsy and migraine (Q.8). I worry that medication is prescribed too soon and that there is too little study into allergenic causes/no holistic approach]] This respondent answered question 8 as follows: I worry that causes are not more fully investigated	I think that there is a strong connection with some types of epilepsy and migraine (question 8). I worry that medication is prescribed too soon, and that there is too little study into allergenic causes, and that there is no holistic approach.	
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VI. Research into stigma associated with epilepsy

635879593	no 10 because one is upset that people look on you in a different way] This respondent answered question 10 as follows: what do they think of me (fits) & why do they need to change my pills	For patients with epilepsy, question 10 is the single most important worry, because a person is upset if others look on you in a different way.	
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DUETS EPILEPSY, 2008: PATIENT GROUPS

MOST IMPORTANT CONSIDERATION (CONTINUED)

VII. Research into levels of expertise among the medical profession

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
599103161	This respondent answered question 10 as follows: Practitioners overlooking the other conditions	For patients with epilepsy, question 10 is the single most important worry.	
599124951	Everybody in the medical profession or first aid such as in schools and employers should have knowledge and be trained in Epilepsy. GP's are vital as this is the patients general first point of call.	For patients with epilepsy, the single most important desire is that everybody in the medical profession (or in first aid, such as in schools and places of employment) should have knowledge about, and be trained in, epilepsy. Training for GPs is vital, as they are generally the first point of call for a person with epilepsy.	

VIII. Research into the effectiveness of psychological support

630878832	The efficacy of psychological support to with with epilepsy	For patients with epilepsy, the efficacy of psychological support to people with epilepsy is the single most important worry.	
616977774	Lack of psycho social support in the management of epilepsy. 'Epilepsy' is far more than the occasional seizure, and whilst obviously seizure control is the highest priority, greater 'community' knowledge (other service providers) of the 'effects' of living with epilepsy is required.	For patients with epilepsy, the single most important worry is the lack of psycho-social support in the management of epilepsy. Epilepsy is far more than the occasional seizure, and while seizure control is obviously the highest priority, greater 'community' knowledge (among other service providers) of the 'effects' of living with epilepsy is required.	
629292229	Pscho-social issues	For patients with epilepsy, the single most important worry is psycho-social issues.	

DUETS EPILEPSY, 2008: PATIENT GROUPS

MOST IMPORTANT CONSIDERATION (CONTINUED)

IX. Research on patient information

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
627936845	To have investigations/treatments explained at a level they understand and be given a chance to be an active decision-maker in their careplan (if they are capable). Realistic prognosis given and be made aware of epilepsy charities and benefits]	For patients with epilepsy, the single most important worry is that they get to have investigations/treatments explained at a level they can understand, and be given a chance to be an active decision-maker in their careplan (if they are capable). They would also like a realistic prognosis to be given, and to be made aware of epilepsy charities and benefits.	
614528686	Standard information and services - information empowers people	For patients with epilepsy, the single most important worry is the lack of standard information and services (information empowers people).	
614405966	Referral to appropriate neuroscience centre in order to access specialist in Epilepsy and the right Information, information, information!	For patients with epilepsy, the single most important worry is whether they are referred to an appropriate neuroscience centre in order to access specialists in epilepsy, and the right information.	

X. Other: on the role of medical research

614139330	I don't think that any of these uncertainties can be resolved by medical research - they are all multiple worries and often psycho-social.	I don't think that any of these uncertainties can be resolved by medical research. They are all multiple worries, and often psycho-social.	
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DUETS EPILEPSY, 2008: PATIENT GROUPS

DIAGNOSIS

Categories

- (I) Uncertainties over the limitations and inherent validity of epilepsy diagnostic tests.
- (II) Uncertainties over the frequency of misdiagnosis.
- (III) Uncertainties about potential side-effects of diagnostic tests.
- (IV) Uncertainties about the methodology of diagnostic tests.
- (V) Other.

I. Uncertainties over the limitations and inherent validity of epilepsy diagnostic tests

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
633971639	The tests can not diagnose the type of epilepsy; this appears to still be based very much on eye witness accounts of an observer. If these are not available, the most suitable medication might not be prescribed.	Patients worry that the tests cannot diagnose the type of epilepsy. Diagnosis appears to still be based very much on an observer's eye-witness accounts. If these are not available, the most suitable medication might not be prescribed.	Based on personal accounts of members of our local epilepsy group.
620353646	That there is not a diagnostically certain test.	Patients worry that a test certain to generate a diagnosis does not exist.	
630878832	Tests do not give a definitive answer.	Patients worry that tests do not give a definitive answer.	Patients getting a MRI scan and EEG who get normal results are confused why this is.
627540953	That tests may be inconclusive but they continue to have seizures.	Patients worry that tests may be inconclusive, but they continue to have seizures.	Some people have inconclusive EEGs and MRIs and may disagree with the subsequent positive or negative diagnosis. It would be important to know how many people receive inconclusive tests and are unhappy with the diagnosis and what then happens with their treatment at that point - are they given AEDs or not?
626413844	Categorising type of epilepsy	Patients worry about whether the type of their epilepsy can be categorised.	
614184427	If the tests are 'negative' why does my doctor say I may still have epilepsy (i.e. why can't the tests prove whether I have epilepsy or not).	Patients worry that their doctor may say that they have epilepsy even if the test results are 'negative'. They wonder why the tests cannot prove the presence of epilepsy.	
602074403	worried that sometimes there is no obvious evidence of cause - i.e. there is "nothing showing" on scans but they are still experiencing symptoms	Patients worry that they are still experiencing symptoms even when nothing 'shows' on scans.	
614139330			Patients have a range of worries - ranging from accuracy to understanding results, to thinking they need to have a seizure in order for the EEG to work.

DUETS EPILEPSY, 2008: PATIENT GROUPS

DIAGNOSIS (CONTINUED)

II. Uncertainties over the frequency of misdiagnosis

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
600924133	Correctness of the diagnosis	Patients worry about the correctness of the diagnosis.	The correct diagnosis has a fundamental effect of treatment, and control of events.
599103161	having the right or correct diagnoses and medication.	Patients worry about having the right or correct diagnoses and medication.	
629292229	What the scope and sensitivity of tests is, and whether they'll get a false diagnosis]	Patients worry about the scope and sensitivity of tests, and wonder whether they will get a false diagnosis.	

III. Uncertainties about potential side-effects of diagnostic tests

614528686	That tests will be invasive and painful	Patients worry that tests will be invasive and painful.	
615292546	will test cause seizures	Patients worry that tests may cause seizures.	

DUETS EPILEPSY, 2008: PATIENT GROUPS

DIAGNOSIS (CONTINUED)

IV. Uncertainties about the methodology of diagnostic tests

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
635879593	not knowing what they entail. this is how i felt on odd named tests like 'amitri test' or the MRI	Patients worry because they do not know what the tests entail.	
616977774	Patients think that there IS a conclusive test for epilepsy and often think that a 'normal' eeg means they do not have epilepsy.	Patients who think that a conclusive test for epilepsy exists often believe that a 'normal' EEG means they do not have epilepsy.	
628869816	Will it show that I have epilepsy or something else e.g.brain tumour.	Patients worry that tests may show them to have something other than epilepsy (such as a brain tumour).	This answer comes is from working and talking to clients.
600991577	People with Learning Disability would not understand	People with a learning disability would not understand the testing procedure.	
599626441	People with a profound learning disability can find any new procedure worrying & frightening. Staff must give the reassurance	People with a profound learning disability can find any new procedure worrying and frightening. Staff must give reassurance.	
599124951	Whilst waiting after the test has been done the patient worries thinking have I got Epilepsy or not. Patients need to know the answers a lot wuicker so that action can be done to prevent it getting worse.	Patients who have just been tested worry that they may have epilepsy. Patients need to know test results more quickly, so that action can be taken to prevent their worries from increasing and their condition worsening.	I have experience 5 x EEGs with no result and some MRI scans which showed I have Epilepsy Epilepsy Action have lots of leafets available in many languages and also a Freephone Helpline and a language line. www.epilepsy.org.uk
627936845	That the results and their implication on treatment/lifestyle will not be explained (all too often they are not even told result)	Patients worry that the test results (and implications for treatment/lifestyle) will not be explained to them. All too often, patients are not even told the test result.	A survey at our epilepsy clinic on patient knowledge revealed most patients did not know what their EEG/scan showed or what kind of epilepsy they had We have now introduced a novel patient ID card which specifies results and the patient's type of epilepsy
624867399			Most people that I talk to do not understand the reasoning behind having diagnostic tests and think that the tests will determine whether they have epilepsy or not.

DUETS EPILEPSY, 2008: PATIENT GROUPS

DIAGNOSIS (CONTINUED)

IV. Uncertainties about the methodology of diagnostic tests (Continued)

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
614405966	that they have enough information: e.g. fully informed choices and from a specialist Neurosciences centre and/or specialist consultant in Epilepsy] some patients feel they have not been fully informed of the choices or by the appropriate professionals	Patients worry about whether they have enough information (especially from a specialist neurosciences centre and/or specialist consultant in epilepsy), and are therefore able to make fully-informed choices.	The National Society for Epilepsy (NSE) based in Buckinghamshire could possibly support this as many Epilepsy patients are only ever seen by their GP and rarely by a neurologist who may just have an interest in Epilepsy. And even rarer, do Epilepsy patients see an specialist Epilepsy consultant at a Neurosciences centre such as the Radcliffe, in Oxford

V. Other: user groups

629403206	Basic questions come in plenty, but I feel that many patients have little or no knowledge that NSE or Epilepsy Action exist—and many GPs dont know either. I often get asked " How can I/we get guidance at a moments notice if its badly needed". Reading leaflets is all very well-But talking to a well versed trained Volunteer can help much more. It helped me and Im sure it would help many others.	Basic questions come aplenty, but I feel that many patients have little or no knowledge that the National Society for Epilepsy (NSE) or Epilepsy Action exist—and many GPs do not know about them either. I often get asked: "How can I/we get guidance at a moment's notice, if it is badly needed?" Reading leaflets is all very well. But talking to a well-versed, trained volunteer can help much more. It helped me, and I'm sure that it would help many others.	Its fact-Epilepsy is the most "low profile" even if it is the most common of Neurological condition.
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V. Other: causes of epilepsy

600932266	Knowing the cause of their epilepsy	Patients worry about the cause of their epilepsy, and being able to know it.	Patients find it hard to understand that the current tests don't always find a reason why they have epilepsy.
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V. Other: availability of tests

628774890			Our main concern is about the availability of tests with waiting times for some tests of around 12 months
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V. Other: impact of a diagnosis

613677577			Patients do not seem to have specific worries about the tests although they may worry about receiving a diagnosis of epilepsy following the tests.
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V. Other: value of MRIs

604761874			I have never been advised against any tests re epilepsy for our little girl (now 14) though we were advised against an MRI some years ago
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DUETS EPILEPSY, 2008: PATIENT GROUPS

COMPLEMENTARY THERAPIES

Categories

- (I) Uncertainties about the validity of complementary therapies.
- (II) Uncertainties about the safety of complementary therapies.
- (III) Uncertainties about potential interactions between complementary therapies and conventional medication.
- (IV) Uncertainties about the regulation of complementary medicines.
- (V) Uncertainties about the mechanism of action of complementary therapies.
- (VI) Other.

I. Uncertainties about the validity of complementary therapies

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
633971639	Insufficient research/awareness of how successful/risky the therapy may be. People with epilepsy can be reluctant to try new therapies if they think it might increase their seizures	Patients with epilepsy think that there might be insufficient research into how successful or risky the therapy may be (and insufficient patient awareness of the same). People with epilepsy can be reluctant to try new therapies, if they think these might increase their seizures.	Articles in Epilepsy Today magazine.
626413844	lack of testing	Patients with epilepsy think that there is a lack of testing of complementary therapies.	
620353646	There is a lack of evidence that complementary therapies are of any benefit.	There is a lack of evidence that complementary therapies are of any benefit.	
599603280	Complimentary therapies do not get the same medical/scientific approval or acceptance as a treatment for epilepsy.]	Patients with epilepsy do not believe that complementary therapies get the same medical or scientific approval or acceptance as a conventional treatment for epilepsy.	
628774890			We are not aware of any complementary therapies available on the NHS. Research is needed and then funding into all aspects of complementary therapies to establish what might be beneficial.
629403206	Simply that patients dont know, or quite understand how Complimentary therapy could be of help.	Patients with epilepsy do not know, or quite understand, how complementary therapy could be of help.	Lots of people dont even believe in alternative health practices
614184427	Are Complementary Therapies an effective alternative to medication - can they hurt me and what is the research to support their use as a treatment for epilepsy?	Patients with epilepsy ask: are complementary therapies an effective alternative to medication? Can they hurt me, and what is the research to support their use as a treatment for epilepsy?	People often want alternatives to conventional medicines, and often want to know why CTs have not been investigated as a form of treatment for epilepsy.
613677577	Are the complimentary therapies able to control seizures or do some therapies increase the likelihood of seizures occurring?	Patients with epilepsy ask: are complementary therapies able to control seizures, or do some of these therapies increase the likelihood of seizures occurring?	
603413024	Will they work?	Patients with epilepsy ask: will complementary therapies work?	

DUETS EPILEPSY, 2008: PATIENT GROUPS

COMPLEMENTARY THERAPIES (CONTINUED)

I. Uncertainties about the validity of complementary therapies

(Continued)

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
600932266	knowing whether the treatment is recommended for people with epilepsy.	Patients with epilepsy have difficulty knowing whether the complementary therapy is recommended for people with epilepsy.	
599103161	Authenticity of the treatment.	Patients are worried about the authenticity of the complementary therapy.	
600924133	That they are not effective	Patients with epilepsy worry that complementary therapies are not effective.	More the absence of publications that show benefit.

II. Uncertainties about the safety of complementary therapies

629292229	Which are most effective and which are unsafe	Patients with epilepsy do not know which complementary therapies are most effective, and which are unsafe.	
627936845	Whether it is safe/effective to use them in conjunction with medication - doctors rarely guide people or even suggest complementary therapy, which may be helpful or at least do no harm]	Patients with epilepsy do not know whether it is safe or effective to use complementary therapy in conjunction with conventional medication. Doctors rarely guide people on this subject, or even suggest complementary therapies that may be helpful (or, at least, which do no harm).	Doctors seem set on medication without even considering other options - I think they may fear patients will stop taking their tablets (ie confuse complementary with alternative).
624867399	Are complementary therapies dangerous to have if a person has epilepsy and will it affect their seizures.]	Are complementary therapies dangerous to take if a person has epilepsy? Patients do not know whether these therapies will affect their seizures.	
615292546	little information available about safety of complementary therapies for people with epilepsy	Little information is available about the safety of complementary therapies for people with epilepsy.	
614184427	Are Complementary Therapies an effective alternative to medication - can they hurt me and what is the research to support their use as a treatment for epilepsy?	Patients with epilepsy ask: are complementary therapies an effective alternative to medication? Can they hurt me, and what is the research to support their use as a treatment for epilepsy?	People often want alternatives to conventional medicines, and often want to know why CTs have not been investigated as a form of treatment for epilepsy.
613677577	Are the complimentary therapies able to control seizures or do some therapies increase the likelihood of seizures occurring?	Patients with epilepsy ask: are complementary therapies able to control seizures, or do some of these therapies increase the likelihood of seizures occurring?	

DUETS EPILEPSY, 2008: PATIENT GROUPS

COMPLEMENTARY THERAPIES (CONTINUED)

II. Uncertainties about the safety of complementary therapies

(Continued)

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
614528686	That the complementary medicines are unregulated and could actually make the situation worse.	Patients with epilepsy are worried that complementary medicines are unregulated, and could actually make a patient's condition worse.	
599124951	Boots will not allow TENS machine to be sold to people with Epilepsy. This is the right way. NHS Hospitals and Lloyds Pharmacy give them out to people with Epilepsy, and having looked at the packaging of the one in Lloyds it carries no health warnings at all.	Boots the Chemist will not allow TENS machine to be sold to people with epilepsy. This is the right way. NHS hospitals and Lloydspharmacy, however, give them out to people with epilepsy. I looked at the packaging on the machine in Lloydspharmacy, and saw that it carried no health warnings at all.	I used one supplied by my local hospital for 5 second and was traumatised. Through this encountered problems for my back with a degenerating spine of which I have to now undergo Chiropractic & reflexology to keep me mobile.

III. Uncertainties about potential interactions between complementary therapies and conventional medication

627540953	that the therapy may interfere with their epilepsy medication.	Patients with epilepsy worry that the complementary therapy may interfere with their conventional epilepsy medication.	We get enquiries about using complementary therapies and often the patients are scared into not using them due to advice given by the medical profession. It is our view that complementary therapies can often be of benefit as a complementary treatment when administered by fully trained professionals in the therapy in question.
619883916	Interaction with AEDs - they might do more harm than good	Patients with epilepsy are worried about the potential interaction of complementary therapies with anti-epileptic drugs (AEDs). Complementary therapies might do patients more harm than good.	

DUETS EPILEPSY, 2008: PATIENT GROUPS

COMPLEMENTARY THERAPIES (CONTINUED)

IV. Uncertainties about the regulation of complementary medicines

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
614528686	That the complementary medicines are unregulated and could actually make the situation worse.	Patients with epilepsy are worried that complementary medicines are unregulated, and could actually make a patient's condition worse.	
599124951	Boots will not allow TENS machine to be sold to people with Epilepsy. This is the right way. NHS Hospitals and Lloyds Pharmacy give them out to people with Epilepsy, and having looked at the packaging of the one in Lloyds it carries no health warnings at all.	Boots the Chemist will not allow TENS machine to be sold to people with epilepsy. This is the right way. NHS hospitals and Lloydspharmacy, however, give them out to people with epilepsy. I looked at the packaging on the machine in Lloydspharmacy, and saw that it carried no health warnings at all.	I used one supplied by my local hospital for 5 second and was traumatised. Through this encountered problems for my back with a degenerating spine of which I have to now undergo Chiropractic & reflexology to keep me mobile.

V. Uncertainties about the mechanisms of action of complementary therapies

614405966	I don't think these therapies should or be seen as a form of "treatment" for Epilepsy as non would be likely to have any effect on the brain's neurotransmitter behaviour. However, some do assist the functioning of such! e.g. fatty acids - although this can be achieved through a good diet. And a good diet is essentially the way forward to enhance and support ones various systems, including the neurological and immune systems, in particually when "challenged" by illness.	I do not think that complementary therapies should be seen as a form of 'treatment' for epilepsy, as none would be likely to have any effect on the brain's neurotransmitter behaviour. However, some do assist the functioning of such. For instance, fatty acids—although these can be achieved through a good diet, and a good diet is essential to enhance and support one's various systems, including the neurological and immune systems (in particularly, when 'challenged' by illness).	It is based on fact. Fatty acids improve brain function professor Basant Puri, Hammersmith Hospital and Imperial College, London has done a number of research studies to prove this in a numerous neurological conditions.
601588758	Unmonitored changes in drug doseage to "control" the condition. that after complimentary therapy the required dosage to stabilise patient might change.	Patients with epilepsy worry about unmonitored changes in drug dosage to 'control' the condition. Patients with epilepsy worry that after taking complementary therapy, the required dosage to stabilise the patient might change.	Becausee we provide complimentary therapies at the nerve centre. We do ask for co-operation with GPs but not always a partnership.
626833046			As it's not offered on the NHS as standard treatment gp's etc would be uncertain about additional treatment.

DUETS EPILEPSY, 2008: PATIENT GROUPS

COMPLEMENTARY THERAPIES (CONTINUED)

VI. Other: general comments

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
602074403	Availability.	Availability of complementary therapies.	
635879593	Worry	Patients with epilepsy worry about complementary therapies.	
614139330			Patients are very often worried because of reading scare stories or being put off by their GP's or other healthcare provider. Often there is little cause for alarm but patients should always consult a fully qualified therapist. Patients rarely think of complementary therapies as a treatment for epilepsy, more as an adjunct to treatment or to help with common triggers such as insomnia or stress or side effects of AED's.
604761874			I am unaware of any complementary therapies unless the ketogenic diet is classed as one?
602639750			This has never been mentioned/offered to me
600991577			I know that we have to check out if using reflexology

DUETS EPILEPSY, 2008: PATIENT GROUPS

DIETS OR DIETARY SUPPLEMENTS

Categories

- (I) Uncertainties about the validity of diet and/or dietary supplements as a mechanism of treatment.
- (II) Uncertainties about the safety of changing diet/dietary supplements.
- (III) Uncertainties about the effect of alcohol on seizures.
- (IV) Uncertainties as to whether diets are a sustainable way of treating epilepsy.
- (V) Uncertainties about the existence of a link of diet with epilepsy.

I. Uncertainties about the validity of diet and/or dietary supplements as a mechanism of treatment

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
627540953	that there is not enough research on dietary approaches for adults	Patients with epilepsy worry that there is not enough research on dietary approaches for adults with epilepsy.	The Ketogenic Diet has been used as a successful epilepsy treatment for children - there is currently very little access to this treatment in Scotland and the diet requires rigorous professional support to implement. There has not been a lot of research into dietary approaches for adults.
600924133	Uncertain whether these are helpful	Patients with epilepsy are uncertain whether diets or dietary supplements are helpful.	
615292546	Little solid information available as to how diet may affect seizure control	Little solid information is available to patients with epilepsy as to how diet may affect a patient's control of their seizures.	
599603280	Most people do not have sufficient knowledge of dietary supplements in the treatment of epilepsy, to begin to use them	Most people with epilepsy do not have sufficient knowledge of dietary supplements in the treatment of epilepsy to be able to begin to use them.	
627936845	Re Ketogenic or Atkins diet - public hear about them but I suspect doctors would not in general suggest these to patients or be able to offer them appropriate information/guidance (though I have no direct experience of paediatric cases)	Patients with epilepsy worry about the ketogenic or Atkins diet. The public hears about them, but I suspect that doctors would not, in general, suggest these diets to patients, or be able to offer them appropriate information or guidance (though I have no direct experience of paediatric cases).	
614528686	That they will not be effective	Patients with epilepsy worry that diets/dietary supplements will not be effective.	
629292229	If diet can have an effect on seizures either way and if supplements can help	Patients with epilepsy worry whether diet can have an effect on seizures (either way—good or bad), and wonder if supplements can help.	

DUETS EPILEPSY, 2008: PATIENT GROUPS

DIET AND DIETARY SUPPLEMENTS (CONTINUED)

I. Uncertainties about the validity of diet and/or dietary supplements as a mechanism of treatment

(Continued)

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
614405966	whether they work and the costs involved. Again, through lack of information and informed choices]	Patients with epilepsy worry about whether diets/dietary supplements work, and the costs involved in purchasing. Again, there is a lack of information about the subject , and therefore an absence of informed choice.	Without professional input on any diet and/or dietary requirements/needs one risks the over-medicating and/or undermedicating of these in addition to high costs and no real benefit to health. I suspect there are many [references] to support this view.
614139330			As with complementary therapies they are often misinformed. Patients do not seem to see most diets/supplements as a treatment for epilepsy, with the exception of the Ketogenic and Atkins diet. There is little information and support for patients who want to try the ketogenic diet.

II. Uncertainties about the safety of changing diets and or dietary supplements among people taking epilepsy treatment

628869816	Should I follow a particular diet to help with my epilepsy or avoid any particular foods. Some people are aware that epilepsy medication can prevent their bodies from absorbing certain vitamins and would like to know whether supplements are required. But these are 2 different questions and areas.	Patients with epilepsy worry about whether they should follow a particular diet to help with their epilepsy, or avoid any particular foods. Some people are aware that epilepsy medication can prevent their bodies from absorbing certain vitamins, and would like to know whether supplements are required. But these are two different questions and subject areas.	Again diet and dietary supplements are 2 different areas
628774890	Suitability of the Ketogenic diet for adults.	Patients with epilepsy worry about the suitability of the ketogenic diet for adults with epilepsy.	There is a general lack of information on the influence of variations of a normal diet on epilepsy.
613677577	Is the Ketogenic diet a suitable and effective treatment for adults with epilepsy?	Patients with epilepsy do not know whether the ketogenic diet is a suitable and effective treatment for adults with epilepsy.	
604761874	The diet is only for certain types of epilepsy?	Patients with epilepsy do not know whether a diet is only useful for people with certain types of epilepsy.	
603413024	Will the diet work. Where did the evidence come from and who paid for the research	Patients with epilepsy do not know whether the diet will work. They ask: "Where did the evidence come from, and who paid for the research?"	

DUETS EPILEPSY, 2008: PATIENT GROUPS

DIET AND DIETARY SUPPLEMENTS (CONTINUED)

II. Uncertainties about the safety of changing diets and or dietary supplements among people taking epilepsy treatment

(Continued)

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
614184427	Is it safe to take suppliments if I have epilepsy: what suppliments could affect my epilepsy/epilepsy medication and will suppliments treat my epilepsy?	Patients with epilepsy worry about whether dietary supplements are safe. They do not know which supplements could affect their epilepsy or their epilepsy medication. They do not know whether supplements will treat their epilepsy.	
600932266	There is a need for greater clarity and encouragement about the benefits of trying to exclude substances from the diet systematically to see if there is a reduction in seizure frequency, e.g. food additives which may be excitatory neurotoxins.	There is a need for greater clarity and encouragement about the benefits of trying to exclude substances (for instance, food additives that may be excitatory neurotoxins) from the diet systematically to see if any reduction occurs in seizure frequency.	

III. Uncertainties about the effect of alcohol on seizures

630878832	How drinking alcohol affects their seizures	Patients with epilepsy worry about how the drinking of alcohol might affect their seizures.	
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IV. Uncertainties as to whether diets are a sustainable way of treating epilepsy

626833046			Would they be able to be strick enough to stick to the diet to use it as a long term treatment
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V. Uncertainties of the existence of a link of diet with epilepsy

624867399			In my experience people do not link a poor diet with an increase in seizure frequency.
602639750			This has never been mentioned to me
600991577			Not aware of anything to do with our Service Users.

DUETS EPILEPSY, 2008: PATIENT GROUPS

PRESCRIPTION MEDICINES

Categories

- (I) Uncertainties about the effectiveness of medication.
- (II) Uncertainties about medication side-effects (eg on memory and cognitive processes; over the long term; at differing doses).
- (III) Uncertainties about the necessity for life-long medication.
- (IV) Uncertainties about the impact of dosage increases.
- (V) Uncertainties about the effectiveness of care provided by non-specialists.
- (VI) Other.

I. Uncertainties about the effectiveness of medication and in different types of people

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
629292229	Why don't the doctors know if the medication wil work or not?	Patients with epilepsy worry that doctors do not know if the epilepsy medication will work or not.	Many people with epilepsy are prescribed medication and this is currently largely trial and error rather than a more rational approach. The uncertainty, and the fact doctors cannot give any guarentees is very difficult for a lot of people to accept.
600924133	They may be ineffective	Patients with epilepsy worry whether their medication may be ineffective.	Patients want to have their seizures entirely controlled
628869816	Will the medication definitely control my epilepsy	Patients with epilepsy worry whether their medication will definitely control their epilepsy.	Again working with clients this is the main issue that concerns them. They want control back in their lives and having seizures means lack of control.
599124951			Very frustrating, nerve racking for parents like mine as I was diagnosed at the age of 11 months, now 47, but has taken over 30 years to control.

DUETS EPILEPSY, 2008: PATIENT GROUPS

PRESCRIPTION MEDICINES (CONTINUED)

II. Uncertainties about medication side-effects (eg at all doses; and effects on memory; and cognitive processing)

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
629292229	Side effects!	Patients with epilepsy worry about the side effects of their medication.	
628774890	The extensive side effects with many AEDs. The medication effects can be worse than the condition being treated.	Patients with epilepsy worry about the extensive side effects that occur with many anti-epileptic drugs (AEDs). The side effects of medication can be worse than the condition being treated.	many people call us with stories of difficult to live with side effects. They often feel that living with seizures is easier than living with side effects but are scared to stop their medication or don't feel they are supported to do so.
624867399	The impact of medication on memory	Patients with epilepsy worry about the impact that their medication may have on their memory.	
624798399	Side effects	Patients with epilepsy worry about the side effects of their medication.	
619883916	AED side-effects	Patients with epilepsy worry about the side effects of their anti-epileptic drugs (AEDs).	
615292546	may be adverse side affects	Patients with epilepsy worry that there may be adverse side affects from their medication.	
614528686	That they will have to take them for life and the worries of side-effects	Patients with epilepsy worry that they will have to take medication for life, and worry about side effects.	
613677577	Worries about side effects of medications, particularly negative effects on cognitive processing, attention and concentration	Patients with epilepsy worry about the side effects of their medication, and, in particular, about negative effects on attention, cognitive processing, and concentration.	
604761874	some anti convulsants have an adverse effect on children with complex neurological disorders	Worries exist that some anti-convulsants have an adverse effect on children with complex neurological disorders.	differs from one child to another
602074403	Long term effects	Patients with epilepsy worry about the long-term effects of their medication.	
601588758	Continuing doseage increases of all prescribed medication.	Patients with epilepsy worry about [the effects of continuing increases in the dosage of all prescription medication.	Are all the increases necessary for every patient?

DUETS EPILEPSY, 2008: PATIENT GROUPS

PRESCRIPTION MEDICINES (CONTINUED)

II. Uncertainties about medication side-effects (eg at all doses; and effects on memory; and cognitive processing) (Continued)

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
600932266	The negative effect on cognition and memory.	Patients with epilepsy worry about the negative effect of their medication on cognition and memory.	
599603280	A lot of people worry that their anti-epileptic medication will stop them from being able to concentrate, pay attention and learn. This is especially true of people who are undergoing or want to begin an academic course of study.	A lot of people with epilepsy worry that their anti-epileptic medication will stop them from being able to concentrate, or to pay attention and learn. This is especially true of people who are undergoing (or want to begin) an academic course of study.	
603413024	Are they safe, what are the long term effects especially for children. What side effects are there.	Patients with epilepsy worry about whether their medication is safe, and also about the long-term effects of taking the medication (especially for children). In other words: what side effects are there?	

III. Uncertainties about the necessity for life-long medication

614528686	That they will have to take them for life and the worries of side-effects	Patients with epilepsy worry that they will have to take medication for life, and worry about side effects.	
630878832	Why do they have to stay on the medication even after the seizures are under control	Patients with epilepsy do not understand why they have to stay on their medication even after their seizures are under control.	
614139330			Patients have a range of concerns - if the AED's are lifelong; what the side-effects might be; coming off medication when seizure free; becoming resistant to the AED (i.e. the drug no longer working); pregnancy, birthcontrol and AED's. There is no one concern but many.
600991577			Our main concern has been that we have people on anti-epileptic drugs for years and they are not reviewed

DUETS EPILEPSY, 2008: PATIENT GROUPS

PRESCRIPTION MEDICINES (CONTINUED)

IV. Uncertainties about the impact of dosage increases

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
601588758	Continuing doseage increases of all prescribed medication.	Patients with epilepsy worry about [the effects of continuing increases in the dosage of all prescription medication.	

V. Uncertainty about the effectiveness of care provided by non-specialists

620353646	lack of input from an Epilepsy Specialist Consultant and/or such a referral to a Neurosciences centre for a specialist overview of their type and level of Epilepsy. Most Epilepsy patients are only seen by their GP and rarely seen by a neurologist who although may have an interest in Epilepsy; they are not up necessarily up to date/well informed and they simply are not specialist in Epilepsy!	Patients with epilepsy worry about not getting input from an epilepsy specialist consultant or a referral to a neurosciences centre for a specialist overview of their type and level of epilepsy. Most Epilepsy patients are only seen by their GP, and are rarely seen by a neurologist. Even GPs who may have an interest in epilepsy are not up necessarily up to date or well informed on the subject, and they simply are not specialist in epilepsy!	It is a fact The national Society for Epilepsy based in Buckinghamshire and no doubt, specialist consultants at the Neurosciences centre e.g. the Radcliffe in Oxfor, would have much evidence of thus I state above
599124951	GP's need training on this subject nationally and Epilepsy Action can help out with this. The patients worry is, will this work for me, and the time it takes to find the right medication for the person concerned and the right dose. This can take years like it did for myself.	GPs need training on this subject nationally, and Epilepsy Action can help out with this. Patients with epilepsy worry whether their medication will work for them, and they worry about the time it can take a person to find the right medication and the right dose. The process can take years (it did for myself).	

DUETS EPILEPSY, 2008: PATIENT GROUPS

PRESCRIPTION MEDICINES (CONTINUED)

VI. Other

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
635879593	worry that chemist does not have all pills or right ones	Patients with epilepsy worry that their pharmacist might not have all the prescribed medications available to them.	as they give you a small amount of the pill they might be short of it at a come back date
620353646	That use of a variety of generic preparations may be less effective than using a Brand name preparation.	Patients with epilepsy worry about [the effects of continuing increases in the dosage of all prescription medication.	We are often contacted by members that have been given different versions of medication - always advise to remain on same 'version'.
633971639	That the brand of drug may be changed	Patients with epilepsy worry that the brand of their medication may be changed,	
629403206	People often ask me questions about drug treatment. All I can tell them is that a high percent of people are controlled by drugs. To add to a patients uncertainties, I advise them to keep a "Diary of Events" as this can help towards a Specialists drawing up a diagnosis. Not being qualified means that I can only give information-not medical advice	People with epilepsy often ask me questions about drug treatment. All I can tell them is that a high percentage of people with epilepsy are controlled by drugs. To add to a patient's uncertainties, I advise them to keep a diary of events, which can help a specialist make a diagnosis. Not being medically qualified, I can only give information, not medical advice.	Its the advice I was given-especially about the diary
627936845			Some patients are happy so long as it works, others get despondant and philosphical after trying endless drugs without seizure-freedom (a few then opt for no drugs), for others the side-effects or teratogenic effects are a major worry.
626833046			people are worried about weight gain, memory, and tiredness
614139330			Patients have a range of concerns - if the AED's are lifelong; what the side-effects might be; coming off medication when seizure free; becoming resistant to the AED (i.e. the drug no longer working); pregnancy, birthcontrol and AED's. There is no one concern but many

DUETS EPILEPSY, 2008: PATIENT GROUPS

NEUROSURGICAL INTERVENTIONS

Categories

- (I) Uncertainties about the risk-to-benefit ratio of neurosurgical intervention.
- (II) Uncertainties about the effectiveness of neurosurgical intervention in different types of people with epilepsy.
- (III) Uncertainties about the side-effects of neurosurgical intervention.
- (IV) Uncertainties about the extent to which patients are making informed choices with neurosurgical intervention.
- (V) Other.

I. Uncertainties about the risk-to-benefit ratio of neurosurgical intervention

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
627936845	Will it stop my seizures (without doing me any harm)? or will it be a waste of time?	Patients with epilepsy worry whether neurosurgical intervention will stop their seizures (without doing them any harm). Or will the procedure just be a waste of time?	
620353646	Is the benefit of VNS worthwhile	Patients with epilepsy worry whether the benefit of vagus-nerve stimulation (VNS) is worthwhile.	
616977774	That neurosurgery will leave them severely 'brain damaged'. Often unaware of the actual risk of frequent and/or prolonged seizures.	Patients with epilepsy worry that neurosurgery will leave them severely 'brain damaged'. Patients with epilepsy are often unaware of the actual risk of frequent and/or prolonged seizures.	
614184427	Will it do me more harm than good?	Patients with epilepsy worry that neurosurgical procedures may do them more harm than good.	Many people fear surgery or of having an 'inplant' in their body and want to be convinced that device will work before they consider surgery.
604761874	could further damage be caused? is there sufficient evidence to support the surgeons and the outcome of surgery?...I do not know...our child would not be a candidate for surgery I have been told	Patients with epilepsy worry whether further damage could be caused. They wonder whether sufficient evidence exists to support the surgeons' actions, and the outcome of the surgery. I do not know. Our child would not be a candidate for surgery, I have been told.	
599103161	Resisting in worse situation than before neurosurgical treatment	Patients with epilepsy worry that neurosurgical procedures may result in a worse situation for them than before the neurosurgical treatment.	
633971639			People requiring such treatment are often prepared to do so due to a high level of seizures. Whilst they may be aware that there are risks involved, it is something they are prepared to take to improve their quality of life.
613677577	What patients with epilepsy will these treatments be more effective in controlling their seizures.	What patients with epilepsy worry about is: will these treatments be more effective in controlling seizures?	

DUETS EPILEPSY, 2008: PATIENT GROUPS

NEUROSURGICAL INTERVENTIONS (CONTINUED)

II. Uncertainties about the effectiveness of neurosurgical intervention in different types of people with epilepsy

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
599124951	Again it come down to will it suit me as I know people who have had this done and become worse, having more seizures after having this put in. Some it works.	Again, it comes down to: will neurosurgical procedures suit me, as I know people who have had this done, and become worse—having more seizures afterwards. On some people, neurosurgical procedures work.	
614139330			The majority of patients are unaware of VNS therapy. Some are aware of neurosurgery but are frightened of the possible side-effects of such an operation. Others want neurosurgery but do not understand that they cannot have it if they have generalised seizures.

III. Uncertainties about the side-effects of neurosurgical intervention

629292229	Deficits and death. It not working and visual fields.	Patients with epilepsy worry that neurosurgical intervention may produce deficits, or even death. They worry that the procedure may not work and about its results on their visual fields.	
628869816	Using VNS is in my opinion is not a neurosurgical intervention, as it doesn't involve direct surgery to the brain. If you talk about brain surgery then the main worry is will the surgeons leave me worse off and I will still be having seizures. The risk factors involved	Using vagus-nerve stimulation (VNS) is, in my opinion, not a neurosurgical intervention, as it does not involve direct surgery to the brain. If you talk about brain surgery, then the main worry for patients with epilepsy is that the procedure may leave them worse off, and still having seizures. In other words, patients with epilepsy worry about the risk factors involved.	
616977774	That neurosurgery will leave them severely 'brain damaged'. Often unaware of the actual risk of frequent and/or prolonged seizures.	Patients with epilepsy worry that neurosurgery will leave them severely 'brain damaged'. Patients with epilepsy are often unaware of the actual risk of frequent and/or prolonged seizures.	
615292546	procedures may be dangerous for patient	Patients with epilepsy worry that neurosurgical procedures may be dangerous for them.	

DUETS EPILEPSY, 2008: PATIENT GROUPS

NEUROSURGICAL INTERVENTIONS (CONTINUED)

III. Uncertainties about the side-effects of neurosurgical intervention (Continued)

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
614528686	That treatments involve the brain - which is still largely an unknown area - that treatments could cause other problems with other neurological functions	Patients with epilepsy worry that treatments involving the brain (which is still largely an unknown area) could cause problems with other neurological functions.	
602074403	side effects or, even, a worsening of symptoms	Patients with epilepsy worry that neurosurgical procedures may produce side effects, or even a worsening of their symptoms.	
600924133	That surgery may cause a new deficit: eg of memory, language	Patients with epilepsy worry that surgery may cause a new deficit (for instance, of memory, or of language).	
635879593	no knowing if the problem thats opps & treatment can cause	?	they have more than one epilepsy & surgery but does not cover all

IV. Uncertainties about the extent to which patients are making informed choices with neurosurgical intervention

627540953	that patients feel they are not listened to when they ask about VNS and other neurosurgical interventions	Patients with epilepsy feel that doctors do not listen to them when they ask about vagus-nerve stimulation (VNS) and other neurosurgical interventions.	Some people call us and feel that their neurologists have been dismissive when they have suggested VNS therapy and other neurosurgical interventions.
599603280	Most people do not receive information about neurosurgical interventions from their medical specialists	Most patients with epilepsy do not receive information about neurosurgical interventions from their medical specialists.	
614405966	Probably again the uncertainties develop through lack of information and informed choices that one would otherwise receive from a specialist neurosciences centre specialist centre consultant and/or a centre such as the NSE based in Buckinghamshire (Chalfont St Peters)	Probably again, the uncertainties for patients with epilepsy develop through lack of information and informed choices that they would otherwise receive from a specialist neurosciences centre, specialist consultant, and/or a centre such as the NSE based in Buckinghamshire (Chalfont St Peters).	It is a fact As above: the centres I mention would be able to provide the evidence
629403206	They dont even know what VNS means I can only give very limited info: via leaflets etc	Patients with epilepsy do not even know what vagus-nerve stimulation (VNS) means. I can only give them very limited information about the procedure via leaflets, etc.	people have difficulties with taking drugs, but I feel that most people would accept anything-prescribed-that would help

DUETS EPILEPSY, 2008: PATIENT GROUPS

NEUROSURGICAL INTERVENTIONS (CONTINUED)

V. Other: uncertainties about the impact of delaying operation

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
628774890		Uncertainty about the impact of waiting years for neurosurgical intervention.	Our concerns focus on the availability of the treatment with waiting times of upwards of 2 years.

V. Other: not relevant to us

602639750			This has never been needed for my son.
600991577			NOt aware within this unit or even if it would be considered

DUETS EPILEPSY, 2008: PATIENT GROUPS

PSYCHOLOGICAL SUPPORT OR TREATMENT

Categories

- (I) Uncertainties about the clinical value of different types of psychological support during the patient journey.
- (II) Uncertainties about the effectiveness of psychological support alongside mainstream treatment for different groups of patients.
- (III) Uncertainties about the validity of psychological support for a neurological (rather than a mental health) condition.
- (IV) Uncertainties as to whether stigma poses a barrier to the provision of effective psychological intervention.
- (v) Other.

I. Uncertainties about the clinical value of different types of psychological support during different stages of the patient journey

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
615292546	there is not enough available -nhs treatment often withdrawn after 6 sessions	Patients with epilepsy do not think that enough psychological support is available. NHS treatment is often withdrawn after six sessions.	
599124951	Epilepsy Specialist nurses are the answer to this because at the point of diagnosis the patient need comfort, support and advice and in the clinics at present they do not get that. You are in for 5 minutes if lucky and told see you again in 6 months.	Specialist epilepsy nurses are the answer to this, because, at the point of diagnosis, patients need comfort, support and advice. In the clinics at present, they do not get that. Patients in for five minutes (if they are lucky) and told to return in six months.	Contact Gavin Barlow on this issue at Epilepsy Action.
633971639	A lack of support and understanding at "front line" services, ie where the person first goes to when seizures begin or when epilepsy is first diagnosed.	A lack of support and understanding occurs among 'front-line' services (where the person first goes to when seizures begin, or when epilepsy is first diagnosed).	Rarely do any of our group members come to the group through professional channels such as their GP. Often they have had epilepsy for some time. It is only then that they receive psychological support in some way.
630878832	There is very little or not psychological support in this area	Very little or no psychological support is available for people with epilepsy.	
627936845	I am not aware of any of our local patients being offered psychological support by the medics. However as a 'lay' epilepsy adviser and member of support group many gain a lot from just talking to and meeting others with the condition. Some patients are cagey about coming to support group or conference.	I am not aware of any of our local patients being offered psychological support by the medical profession. However, as a 'lay' epilepsy adviser, and member of a support group, I find that many patients with epilepsy gain from just talking to, and meeting, others with the condition. Some patients, however, are cagey about coming to a support group or to a conference.	
599603280	Not enough knowledge of the efficacy of psychological treatments for epilepsy.	Patients with epilepsy do not have enough knowledge of the efficacy of psychological treatments for epilepsy.	

DUETS EPILEPSY, 2008: PATIENT GROUPS

PSYCHOLOGICAL SUPPORT (CONTINUED)

I. Uncertainties about the clinical value of different types of psychological support during the patient journey (Continued)

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
601588758	Not convinced that talking about it will resolve the issues.	Patients with epilepsy are not convinced that talking about their condition will resolve the issues.	
600924133	Whether it will be of any help	Patients with epilepsy worry whether psychology will be of any help.	

II. Uncertainties about the effectiveness of psychological support alongside mainstream treatment for different groups of patients

614405966	Again, any concerns would be through lack of information and lack of informed choices. In addition, the therapies mentioned in this paragraph cannot be seen as "treatment". As they cannot treat - only be as a part of any treatment plan alongside mainstream medication.	Again, any concerns would be through lack of information and lack of informed choices. In addition, the therapies mentioned in this paragraph cannot be seen as 'treatment'. They cannot treat, only be seen as a part of any treatment plan alongside mainstream medication.	As above, centres specialising in Epilepsy could provide the evidence to support my view
628869816	These are two different questions I think. Support and interventions are separate issues. The main worry about support is where to find the information when newly diagnosed and what services exist. Interventions are used once the client is known to the organisation. Main worry - will it work for me.	These are two different questions, I think. Support and interventions are separate issues. The main worry about support is where to find the information when newly diagnosed, and what services exist. Interventions are used once the client is known to the organisation. The main worry for patients with epilepsy: will it work for me?	Patients do not know whether psychology/psychological support will be effective'
628774890			Psychological support seems to be very limited. Although patients are profiled before surgery the follow up support seems difficult to access. Support for non surgical patients is even harder to find without a sympathetic GP.

DUETS EPILEPSY, 2008: PATIENT GROUPS

PSYCHOLOGICAL SUPPORT (CONTINUED)

III. Uncertainties about the validity of psychological support for a neurological (rather than a mental health) condition

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
614184427	Are they saying I'm mentally ill? I thought epilepsy was a neurological condition, but are they saying I'm 'putting it on' or 'mad'?	Are they saying I'm mentally ill? I thought epilepsy was a neurological condition, but are they saying I'm 'putting it on', or 'mad'?	
614528686	This could imply the condition is 'all in the mind'	This could imply that the condition is 'all in the mind'.	
629292229	That people think they are "mad" or "making it up" and that there isn't adequate support available	Patients with epilepsy worry that people think they are 'mad', or 'making it up', and that adequate support is not available.	
614139330			Patients have MANY worries about psychological support - how to access services; possible stigma attached to accessing psych services; long waiting times for services. Some do not see it as relevant to their condition but we speak to a high proportion of people with epilepsy for whom mental health issues play a large part of their condition.

IV. Uncertainties as to whether stigma poses a barrier to the provision of effective psychological support/intervention

627540953	that there is a stigma involved in accessing psychological services.	There is a stigma involved in accessing psychological services.	
602074403	Being "labelled"	Patients with epilepsy worry about being 'labelled'.	

DUETS EPILEPSY, 2008: PATIENT GROUPS

PSYCHOLOGICAL SUPPORT (CONTINUED)

V. Other: whether psychological support/intervention improve quality of life

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
620353646	Does this help quality of life?	Does this help quality of life?	
599103161	Time to heal.	Time to heal.	

V. Other: general comments on lack of access to services

599626441	The understanding & ability to communicate is very important. Many people with Severe & profound Learning Disabilities have severe barriers to communication. Relationships with people known to the patient are vital.	The understanding and ability to communicate is very important. Many people with severe and profound learning disabilities have severe barriers to communication. Relationships with people known to the patient are vital.	
627540953			Some people say that there are no services in their area, some talk about being worried about asking for psychological help but many people call our helpline looking for counselling services. There is a clear lack of tailored psychological support for people with epilepsy in Scotland.
626833046			Waiting lists are so long most people dont even get offered it.
616977774			People with epilepsy generally feel that there is little psychological support/treatment.
600991577			Not known in this unit
600932266			Patients' only concern is that it takes so long to access psychological services.

DUETS EPILEPSY, 2008: PATIENT GROUPS

TREATMENTS FOR CHILDREN WITH EPILEPSY

Categories

- (I) Uncertainties about the effectiveness and safety of treatments in children.
- (II) Uncertainties about the side-effects of treatments in children.
- (III) Uncertainties about the long-term usage of treatments in children.
- (IV) Uncertainties about whether paediatricians have the skills to deliver effective care.
- (V) Other.

I. Uncertainties about effectiveness of treatments and whether they outweigh safety considerations

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
635879593	does it work & is it going to go away	Worries exist about whether treatment for children with epilepsy will work. Another worry is whether the condition is going to remain present in the child or not.	febrile epilepsy can go at 12 if the child is lucky
600924133	Treatment will not be effective and will have side-effects	Worries exist that treatment for children with epilepsy will not be effective, and will produce side-effects.	
599124951	The worry is the same as it is for adults knowing if it going to work, parents being stressed out, not enough information at point of diagnosis etc.	The worries are similar irrespective of whether the condition affects adults or children: not knowing if treatment is going to work; not enough information at the point of diagnosis; and parents feeling stress.	
628869816	Again will my child's seizures be controlled but at what cost e.g. side effects of medication	Worries exist that treatment for children with epilepsy may control a child's seizures, but at the cost of producing side effects.	Again experience of working with children and their families
627936845	Cognitive effects vs seizure-freedom Also some schools staff refuse to administer rectal diazepam or midazolam - this may worry the parents	Worries exist around the trade-off between freedom from seizures and cognitive side effects. Another worry for parents centres around the fact that some school staff refuse to administer rectal diazepam or midazolam.	
630878832			They [Editor:patients?] often have lots of questions
619883916			How parents will feel is likely to be complex - They are likely to be concerned about side-effects, whether they will control the seizures, effect on child's life etc.

DUETS EPILEPSY, 2008: PATIENT GROUPS

CHILDREN (CONTINUED)

II. Uncertainties about treatment side-effects ...

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
613677577	Concerns over the effects of medication on the child's development, behaviour and education.	Concerns exist over the effects of medication on the behaviour, development, and education of children with epilepsy.	
604761874	side effects of anti convulsants and long term	Worries exist about the side effects of anti-convulsants, and the long-term implications of their use in children with epilepsy.	
599603280	A lot of parents believe that the anti-epileptic medications that are used in the treatment of childrens epilepsy can cause behavioural problems and difficulties with their education	Many parents believe that the anti-epileptic medications used to treat children's epilepsy can cause behavioural problems and difficulties with education.	

... on learning abilities

624867399	Will they affect the child's ability to learn	Worries exist that treatment for children with epilepsy may adversely affect a child's ability to learn.	
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... on behaviour

616977774	The effect of AED's on behaviour	Worries exist that anti-epileptic drugs (AEDs) may have an effect on the behaviour of children with epilepsy.	
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... on development (including cognitive)

615292546	treatment may affect child's development	Worries exist that treatment may affect a child's development.	
614184427	What effect will treatment have on my child's cognitive development, and what are the long-term implications of giving them medication.	Worries exist about what effect treatment may have on the cognitive development of a child with epilepsy, and what might be the long-term implications of giving a child such medication.	

... on neurological functioning

614528686	the long lasting effects of treatments on development, neurological functioning etc.	Worries exist about the long-lasting effects of treatments on the development and neurological functioning of children with epilepsy.	
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DUETS EPILEPSY, 2008: PATIENT GROUPS

CHILDREN (CONTINUED)

II. Uncertainties about treatment side-effects ... (Continued) ... as a result of the the mode of treatment administration

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
602639750	The trauma it may cause to the child	Worries exist about the trauma that treatment may cause to children with epilepsy.	My child was a baby when the seizures began, he was immediately having needles stuck in him and the electrodes stuck on his head were uncomfortable.
628774890			In some areas adult services, especially for specialist testing are used. The procedures used do not accommodate the natural anxieties of a child in this situation. This can have an adverse effect upon the patient.

... as a result of inappropriate dosage

599103161	Overdose	Worries exist about an overdose of medication.	
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III. Uncertainties of the long-term usage of treatments in children

602074403	Long term effects. Also, should the child be given any thing at all as they may grow out of the condition	Worries exist about the long-term effects of treatment in children with epilepsy. Another worry is whether a child be given any treatment—they may grow out of the condition.	From experience with my own child
627540953	that the child will be on anti-epileptic medication for life	Worries exist that children with epilepsy will be on anti-epileptic medication for life.	
627540953			Many parents contact us asking whether AEDs are for life and very concerned about the long term effects of taking medication.
614139330			Parents seem particularly concerned that their child will be on medication for life. If they are told about SUDEP they are really concerned about this and are often unaware of the emergency medication that can be given.

DUETS EPILEPSY, 2008: PATIENT GROUPS

CHILDREN (CONTINUED)

IV. Uncertainties about whether paediatricians have the skills to deliver effective care

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
633971639	That Paediatricians are not specialists in the field of neurological conditions.	The fact that paediatricians are not specialists in the field of neurological conditions is worrying.	I have seen examples where parents have sought specialists privately in order to have their child's epilepsy adequately controlled or "waiting" until their child reaches an age where they then can be seen by a neurologist in adult services.

V. Other

614405966	Again, through lack of information from the appropriate specialist centres and specialist consultants they provide and of course, the NSE, Chalfont St Peters, Buckinghamshire	Patients worry when they lack information. Excellent information is generated by the appropriate specialist centres (and their specialist consultants), and, of course, from the National Society for Epilepsy (NSE), at Chalfont St Peters, Buckinghamshire.	NSE and neuroscience centres have the evidence to support such views
600932266	the cause of their child's epilepsy	Worries exist about the cause of a child's epilepsy.	
629403206			Anything is better than nothing for ones own Child
629292229			We work with adults
601588758			The nerve centre does not have under 18's as members.
600991577			Not working with children

DUETS EPILEPSY, 2008: PATIENT GROUPS

OTHER TREATMENT AREAS IN EPILEPSY

Categories

- (I) Uncertainties about the causes of epilepsy and its epidemiology.
- (II) Uncertainties about epilepsy patients' long-term memory retention (and need for treatment).
- (III) Uncertainties about the causes of sudden unexpected death.
- (IV) Uncertainties about the clinical value of current therapy when put to widespread use.
- (V) Uncertainties about disease progression (day-to-day and long-term) and impact on lifestyle.
- (VI) Other.

I. Uncertainties about the causes of epilepsy and its epidemiology

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
628869816	Problems with memory and more research into possible treatments (if any)	Patients with epilepsy worry about problems with memory. More research into possible treatments (if any) for memory problems is needed.	
615292546	there a huge lack of research done in this area	There a huge lack of research done in this area.	
599124951	I am personally concerned about all issues as GP's have no interest and know nothing about it. Public Sector and Private Sector need traing as Police arrested a person in Birmingham for being drunk and disorderly when all he had was a seizure. Epilepsy Action have volunteers that can provide this service and I am one for the Birmingham and Solihull Areas.	Patients with epilepsy are concerned about all issues in epilepsy. GPs, for instance, have no interest in the condition, and know nothing about it. Similarly, both the public and private sectors need training—particularly the police (one policeman recently arrested a person with epilepsy in Birmingham for being drunk and disorderly, when all that the individual had done was have a seizure). Volunteers from Epilepsy Action provide educational services (I am one for the Birmingham and Solihull areas).	

II. Uncertainties about epilepsy patients' long-term memory retention (and need for treatment)

628869816	Problems with memory and more research into possible treatments (if any)	Patients with epilepsy worry about problems with memory. More research into possible treatments (if any) for memory problems is needed.	
626833046	Alot of people say about their memory problems]	A lot of patients with epilepsy worry about their memory problems.	
616977774	The possible long-term side-effects on memory	Patients with epilepsy worry about the possible long-term side-effects of their treatment on their memory.	
614184427	Some people have great concerns about epilepsy surgery (e.g. resective surgery) and the risks to their memory in particular.	Some people with epilepsy have great concerns about epilepsy surgery (for instance, about resective surgery), and, in particular, about the risks to their memory.	

DUETS EPILEPSY, 2008: PATIENT GROUPS

OTHER TREATMENTS (CONTINUED)

III. Uncertainties about the causes of sudden unexpected death

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
628774890	Research is needed into the causes of SUDEP	Research is needed into the causes of sudden unexpected death in epilepsy (SUDEP).	

IV. Uncertainties about the clinical value of current therapy when put to widespread use

627540953	That one third of patients with epilepsy still have seizures when on AEDs. There is a need for research into new, more effective AEDs with fewer side-effects	Patients with epilepsy worry that one third of them still have seizures when on anti-epileptic drugs (AEDs). Research is needed into new, more effective AEDs that have fewer side-effects.	
614405966	People with Epilepsy can be sectioned under the Mental Health Act and Mental Capacity Act and/or have diverse experiences with the Police. These are areas/patients that could be better served by applying up to date medical research to ensure they do not happen as a consequence of just being affected by the affects of Epilepsy	People with epilepsy can be sectioned under the Mental Health Act and Mental Capacity Act. They tend to have had 'diverse' experiences with the police. These consequences of being affected by epilepsy need not happen if patients were better served by up-to-date medical research.	

V. Uncertainties about disease progression (day-to-day and long-term) and impact on lifestyle

616977774	Patients, following diagnosis, partic when not seen in specialist centre, often come out feeling totally uninformed about their condition and how it is likely to affect them in their day to day lives.	Following diagnosis (particularly when this does not occur in a specialist centre), patients with epilepsy feel totally uninformed about their condition, and know little about how it is likely to affect them in their day-to-day lives.	
629403206	I feel that a patient or more importantly those close to the patient should have at least "Grass roots" info; E.G. limitations in Sport, Driving, etc Safety in the home	Patients with epilepsy (and, just as importantly, those close to such patients) should be given at least 'grassroots' information—such as the effects of epilepsy on driving, sport, safety in the home, etc.	
635879593	educational support	Patients with epilepsy worry about not receiving any/enough educational support.	

DUETS EPILEPSY, 2008: PATIENT GROUPS

OTHER TREATMENTS (CONTINUED)

VI. Other

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
629292229	Psycho-social support, especially financial	Patients with epilepsy worry about not receiving any/enough psycho-social support (especially financial support).	
602639750	That other treatments are not used or overlooked	Patients with epilepsy worry that other treatments are not used or are overlooked.	

NON-MEDICAL SERVICES

Categories

- (I) Uncertainties about the standards and quality of care delivered (including basic understanding of the condition).
- (II) Uncertainties about the ability to self-manage the condition (which may be a consequence of lack of patient information).
- (III) Uncertainties about access to non-medical services.
- (IV) Uncertainties about the extent of stigmatisation.
- (V) Other

I. Uncertainties about the standards and quality of non-medical services (including basic understanding of the condition)

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
629292229	Services don't understand epilepsy and discriminate against them eg Benefits agency, transport, housing, employers etc	Patients with epilepsy worry that services (such as benefits agency, employers, housing, transport, etc) do not understand the condition, and discriminate against people with epilepsy.	
614528686	There is no standard for these services it depends on where you live, if you have other conditions in tandem with epilepsy	No common standard exists for non-medical services—it depends on where patients with epilepsy live, and whether they have other conditions in tandem with epilepsy.	
604761874	ignorance of some schools of the effects of the use of midazolam buccal and innappropriate use!!	One worry is that some schools are ignorant of the effects of the use of midazolam buccal (and innappropriate use).	
614405966	lack of information in these areas e.g. education. Better, frequent and training in information and awareness of Epilepsy and its effects on the person (young and old)	Patients with epilepsy worry about a lack of information about epilepsy among non-medical services (such as education). Better information and frequent training in awareness of epilepsy (and its effects on individuals, whether young or old) are needed.	the NSE and neuroscience centres would be able to support this view with evidence
624798399	Lack of understanding	Patients with epilepsy worry about a lack of understanding of their condition.	
619883916	Lack of knowledge of condition	Patients with epilepsy worry about a lack of knowledge of their condition.	
615292546	many people know little about epilepsy (often less than person with epilepsy themselves) - even those who should e.g. GPs / MPs	Patients with epilepsy worry that many people know little about epilepsy (often less than individuals with epilepsy themselves)—even those who should know about the condition, such as GPs or MPs.	
627540953	that other sectors of the community do not understand epilepsy	Patients with epilepsy worry that other sectors of the community do not understand epilepsy.	Many people face discrimination, inappropriate care during a seizure etc. when outwith their home environment.
		Patients with epilepsy worry about being singled out or labelled—about being seen as different from their peers.	

NON-MEDICAL SERVICES (CONTINUED)**II. Uncertainties about the ability to self-manage the condition
(which may be a consequence of lack of patient informaton)**

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
602639750	That they are not trained properly to deal with the condition and the learning difficulties it can cause	Patients with epilepsy worry that they are not trained properly to deal with the condition and with the learning difficulties that it can cause.	personal experience, people did not know about the condition enough and were very nervous around my child
599124951	Information should be available at all GP practices, clinics in hospitals, carers centres, leisure centres, community centres and it just is not	Information about epilepsy should be available at all GP practices, hospital clinics, carers' centres, leisure centres, community centres—and it just is not.	
600932266	that their child may under-achieve their potential due to under provision of educational support and to lower achievement expectations by teaching and suport staff.	One worry is that children with epilepsy may under-achieve their potential due to poor provision of educational support, and to lower achievement expectations by teaching and support staff.	
614184427	Many people don't know about other support because it is often not readily offered or suggested. So the uncertainty is about what is available.	Many people with epilepsy do not know about other support, because it is often not readily offered or suggested. So the uncertainty is about what is available.	Recent research showed politicians who make decisions about where funding is allocated knew alarmingly little about who many people have epilepsy and what epilepsy is.
599626441	Clear information for Relatives & Staff is important	Clear information about epilepsy for the relatives of people with epilepsy (and for non-medical staff) is important.	
628869816	What information exists in the voluntary sector and how will they help me	Patients with epilepsy would like to know what information about epilepsy exists in the voluntary sector, and how that sector can help people with the condition.	Can medical research resolve this problem? Needs to be more joint working between medical and non-medical services.
627936845	That there is not enough provision and what there is is not known about (they are never told) eg support group they may go 20 years without knowing it exists because nobody tells them or go 20 years without knowing about DLA benefit	Patients with epilepsy worry that there is not enough provision of information and support for people with epilepsy, and what is present is not known about by people with epilepsy (they are never told about such things). Examples might be epilepsy support groups and disability living allowance (DLA) benefit. Patients with epilepsy may go 20 years without knowing that either exists because nobody tells them.	
616977774			Our members often report that they feel that service providers do not know enough about epilepsy.

NON-MEDICAL SERVICES (CONTINUED)

III. Uncertainties about access to non-medical services

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
614139330			Services are not equally spread across the country so access to local services is a big worry, as is funding those services
624867399	Limited access to non-medical support services	Patients with epilepsy worry about limited access to non-medical support services.	

IV. Uncertainties about the extent of stigmatisation

602074403	Being singled out or labelled. Being different from their peers)	Patients with epilepsy worry about being singled out or labelled—about being seen as different from their peers.	
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V. Other: general comments

600991577			I would imagine it would be around the restrictions that are placed upon their lives
628774890	Research is needed into the effect of a) seizures and b) medication on cognitive development and learning. The direct and indirect effect of epilepsy on learning and memory.)	Patients with epilepsy believe that research is needed into the effects of: a) seizures, and b) medication on cognitive development and learning. Research is also needed into the direct and indirect effect of epilepsy on learning and memory.	
626833046	how side effects of drugs will affect ability to study ie memory and tiredness	Patients with epilepsy worry about how the side effects of drugs will affect their ability to study, and their memory and levels of tiredness.	

DUETS EPILEPSY, 2008: PATIENT GROUPS

OTHER ILLNESSES

Categories

- (I) Uncertainties about drug interactions and contra-indications.
- (II) Uncertainties about further ill-health as a consequence of taking epilepsy medication.
- (III) Uncertainties about the rationale of changing medication.
- (IV) Uncertainties about falling prey to another medical condition.
- (V) Uncertainties within pregnancy.
- (VI) Uncertainties about the existence of a link between epilepsy and other medical conditions.
- (VII) Uncertainties about the skills of medical practitioners.
- (VIII) Uncertainties about the long-term effects of uncontrolled epilepsy.

I. Uncertainties about drug interactions and contra-indications

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
633971639	Whether the medication to treat a new condition will counteract their epilepsy treatment.	Patients with epilepsy worry that the medication used to treat a new condition might counteract/interact adversely with their epilepsy treatment.	
629403206	Will tablets I have to take for other problems, clash with my Epilepsy drugs	Patients with epilepsy worry that the tablets they take for other problems might 'clash' with epilepsy drugs.	
629292229	That the treatments clash with their AEDs or will worsen their condition and vice versa. Also lack of understanding of epilepsy from other health professionals eg being denied Anti-depressants, HRT etc	Patients with epilepsy worry that the treatments for non-epilepsy illnesses might 'clash' with their anti-epileptic drugs (AEDs), or might worsen their condition. They also worry about a lack of understanding of epilepsy from healthcare professionals, leading to them, for instance, being denied anti-depressants, HRT, etc.	
627540953	that many anti-depressants interact with epilepsy medication leaving people with severe depression without medical intervention.	Patients with epilepsy worry that many anti-depressants interact with epilepsy medication, leaving people with epilepsy with severe depression and no medical intervention.	Mental health issues such as depression are often concurrent with epilepsy.
626833046	interactions with epilepsy drugs and treatment / medication for other conditions.	Patients with epilepsy worry about interactions between their epilepsy drugs/treatment and medication for other conditions.	
619883916	Drug interactions	Patients with epilepsy worry about drug interactions.	
615292546	will additional treatments affect any treatment they are having for epilepsy	Patients with epilepsy worry that additional treatments might affect any treatment they are having for epilepsy.	
614528686	That it will cause an increase in their epilepsy symptoms]	Patients with epilepsy worry that treatment for non-epilepsy conditions might cause an increase in their epilepsy symptoms.	

DUETS EPILEPSY, 2008: PATIENT GROUPS

OTHER ILLNESSES (CONTINUED)

I. Uncertainties about drug interactions and contra-indications (Continued)

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
602639750	That they may have an impact on the condition and perhaps are responsible for the condition	Patients with epilepsy worry that treatment for non-epilepsy illnesses may have an impact on their epilepsy.	personal experience
602074403	Interaction of medications and possible side effects	Patients with epilepsy worry about the interaction of medications and about possible side effects.	
600932266	the possibility of drug interactions	Patients with epilepsy worry about the possibility of drug interactions.	
600924133	Treatment of the 2 conditions will be conflicting	Patients with epilepsy worry that treatment of the two conditions will be conflicting.	
599603280	The main worry would be that other medication may have an adverse reaction with their anti-epileptic medications.	The main worry for patients with epilepsy would be that other medication may have an adverse reaction with their anti-epileptic medications.	
614184427	What are the contraindications for epilepsy and epilepsy treatment?	Patients with epilepsy worry about not knowing the contra-indications for epilepsy and epilepsy treatment.	
614405966	Any additional medication. Again, lack of information and informed choices	Patients with epilepsy worry about any additional medication. Again, they have a lack of information and informed choices.	The National Society for Epilepsy (NSE) and neuroscience centres would be able to provide the evidence

II. Uncertainties about further ill-health as a consequence of taking epilepsy medication

613677577	Does epilepsy medications cause further ill health conditions, like arthritis, osteoporosis, kidney or liver damage etc.	Patients with epilepsy worry that epilepsy medications might cause further ill health and conditions like arthritis, osteoporosis, kidney or liver damage, etc.	
599124951	Due to my Epilepsy I have encountered urinary problems through Epilim, constipation through Tegretol, and a degenerating spine through all the falling with the tonic clonic seizures I encountered as a child but this did not come out until I was 40. Memory Loss and Learning Disabilities are other problems	My epilepsy has led to a number of health problems. After the age of 40, I have had degeneration in the spine, caused by the falls I had as a child living with tonic-clonic seizures. Memory loss and learning disabilities are other problems. I have also encountered urinary problems through taking Epilim, and constipation through taking Tegretol.	
614139330			Mental health figures highly alongside epilepsy.

DUETS EPILEPSY, 2008: PATIENT GROUPS

OTHER ILLNESSES (CONTINUED)

III. Uncertainties about the rationale for changing medication

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
635879593	what do they think of me (fits) & why do they need to change my pills	Patients with epilepsy worry what members of the medical professional think about them and their fits. They also worry about, and do not understand, changes in the medication they are prescribed.	a pill change done by wrong Drs

IV. Uncertainties about the consequences of falling prey to another medical condition

628869816	How will I cope with having another medical condition and what will this mean for me in the future. What will the future hold?	Patients with epilepsy worry about how they will cope with another medical condition. They worry about the future consequences that a new condition will hold for them.	
599103161	Practitioners overlooking the other conditions	Patients with epilepsy worry about medical practitioners overlooking their other conditions.	

V. Uncertainties within pregnancy

616977774	Pregnancy - often greater than reality perceived risk of inheritance and effect of AED's on foetus	Patients with epilepsy can worry about pregnancy. The risk of inheriting epilepsy is greater than commonly perceived, as is the risk that anti-epileptic drugs (AEDs) may have an effect on the foetus	
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DUETS EPILEPSY, 2008: PATIENT GROUPS

OTHER ILLNESSES (CONTINUED)

VI. Uncertainties about the existence of a link between epilepsy and other medical conditions

Reference	ORIGINAL STATEMENT (UNCORRECTED)	STATEMENT EDITED	ADDITIONAL COMMENTS (UNCORRECTED)
628774890	What is the connection between epilepsy and ME/CFS.	Patients with epilepsy wonder about the connection between epilepsy and myalgic encephalopathy/chronic fatigue syndrome (ME/CFS).	

VII. Uncertainties about the skills of medical practitioners

629292229	That the treatments clash with their AEDs or will worsen their condition and vice versa. Also lack of understanding of epilepsy from other health professionals eg being denied Anti-depressants, HRT etc	Patients with epilepsy worry that the treatments for non-epilepsy illnesses might 'clash' with their anti-epileptic drugs (AEDs), or might worsen their condition. They also worry about a lack of understanding of epilepsy from healthcare professionals, leading to them, for instance, being denied anti-depressants, HRT, etc.	
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VIII. Uncertainties about the long-term effects of uncontrolled epilepsy

600991577			Again I would imagine that it could be around the long term effects on someone whose epilepsy is uncontrolled
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A resource to help prioritise new research

