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**Doctoral Thesis:**

**The experience of seizures: epilepsy and non-epileptic attack disorder**

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## Word Count Statement

<i>Thesis section</i>	<i>Text</i>	<i>Tables, figures, references and appendices</i>	<i>Total</i>
<b>Abstract</b>	249	0	249
<b>Literature Review</b>	7770	11261	19031
<b>Research Paper</b>	7995	9032	17027
<b>Critical Appraisal</b>	3754	5169	8923
<b>Ethics Section</b>	5251	3377	8628
<b>Total</b>	<b>25020</b>	<b>28839</b>	<b>53859</b>

## **Abstract**

This thesis comprises of a literature review, a research paper and a critical appraisal of the research process.

In the literature review, a meta-synthesis methodology was used to identify and synthesise 15 studies that explored the experiences of living with epilepsy. Three themes emerged; 'making sense of epilepsy: "it affects your perception of yourself"'; 'the cost of epilepsy: "getting epilepsy has put me in poverty"'; and 'significance of others in coping with epilepsy: "my family have always helped me"'. Findings are discussed in terms of the impact of epilepsy on identity and self, the losses that individuals have experienced as a consequence of epilepsy, and the ways in which perceived support from others can be helpful or unhelpful.

The research paper utilised interpretative phenomenological analysis, whereby six participants who had received a diagnosis of non-epileptic attack disorder (NEAD) were interviewed, to explore how they had made sense of it. Three themes emerged; "NEAD is a confusing diagnosis; "all it means is it's not epilepsy"; 'Legitimising the illness: feeling "like a bit of a fraud"'; and 'NEAD as a challenge to identity: "I want to be more me again"'. Findings suggest that making sense of a diagnosis of NEAD is a challenging process, which differs from person to person. The clinical implications of these findings are discussed.

The critical appraisal discusses the comparisons between the findings of the literature review and research paper. Reflections about epistemology are offered, alongside reflections on the research process as a whole.

## **Declaration**

This thesis records work undertaken for the Doctorate in Clinical Psychology at Lancaster University's Division of Health Research between June 2015 and April 2016. The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

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## Section One: Literature Review

### A meta-synthesis of the experience of living with epilepsy

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<sup>1</sup> Please note this manuscript was prepared in line with author guidelines for *Seizure- European Journal of Epilepsy* (See Appendix 1A). The word count is in line with University guidelines rather than journal guidelines

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**Abstract**

**Background:** Epilepsy is a condition that has the potential to reduce quality of life, and has been extensively researched with quantitative methods. A sizeable body of qualitative literature now exists on the experience of living with epilepsy which can add to our understanding of this condition.

**Aims:** The aim of this meta-synthesis was to bring together the qualitative literature on living with epilepsy and offer an over-arching interpretation of current findings.

**Method:** A systematic search of qualitative articles was conducted using three databases, which identified 15 studies that met the inclusion criteria. These were synthesised according to Noblit and Hare's (1988) guidance for meta-ethnography.

**Results:** Three themes emerged from the meta-synthesis; Making sense of epilepsy: "it affects your perception of yourself"; The cost of epilepsy: "getting epilepsy has put me in poverty"; and Significance of others in coping with epilepsy; "my family have always helped me".

**Conclusions:** Individuals with epilepsy face complex difficulties. Important clinical implications are drawn from the findings, and suggestions for future research are made.

**Declaration of Interests:** None

**Keywords:** Quality of life, epilepsy, lived experience, qualitative, meta-synthesis

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### **A meta-synthesis of the experience of living with epilepsy**

Epilepsy is a common long term neurological condition, with an estimated 600,000 people living with it in the United Kingdom [1], and 69 million worldwide [2]. Epilepsy is a disease of the brain causing a predisposition to have epileptic seizures [3]. The causes are understood to include birth injury, feverish convulsions, and pre-birth developmental disorders in childhood, and vascular disease, tumours and degenerative diseases in adulthood [4]. However, up to 40% of individuals will have epileptic seizures with no known neurological abnormalities [5]. Epileptic seizures can also take many forms, resulting in a varied impact on the brain [4]. Therefore experiences of seizures are very varied [6] but for many, epilepsy can often lead to psychological, cognitive and social sequelae [7][8].

Epilepsy carries an overall risk of premature death due to various factors such as sudden unexpected death, accidents, injuries and suicide [7]. Individuals living with epilepsy have to adopt management strategies in order to prevent seizures and manage their own condition [9]. Such strategies may include recognising and managing seizure triggers (such as flashing lights), implementing safeguards to avoid seizure related risks (e.g. reducing the risk of being alone during a seizure), informing and educating others on what to do following a seizure, and strategies to comply with multiple medications [1]. Individuals with epilepsy frequently feel underequipped for dealing with the condition and this may be especially important considering that for example up to 40% of individuals with epilepsy in the USA will not gain seizure control and thus will need to manage their condition for the rest of their lives [10].

An estimated four fifths of individuals with epilepsy live in non-western countries [11], and up to 90% of these individuals do not get the medical treatment they require [12]. This has largely been attributed to the limited availability of medication and the subsequent

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reduced ability to gain seizure control [13]. While there may be differences to the medical approaches to epilepsy in western and non-western countries, due in part at least to the different economic, political and cultural contexts, epilepsy negatively affects the lives of people in countries all around the world [14][15][16], although it is notably under-researched outside of the western world [17].

Koutsogiannopoulos, Adelson, Lee and Adermann [18] highlight the necessity to adapt life not only according to the epilepsy presentation itself, but also according to the unpredictable difficulties that often arise from having a diagnosis of epilepsy. The burden of epilepsy can manifest as social and psychological difficulties [19], and is not entirely dependent on whether an individual achieves seizure control or not [20]. A meta-analysis of the quality of life in epilepsy [21] has reported a consistent predictive effect of psychological factors, with a reported 30-35% of the variance in health related quality of life being explained by such factors, more than condition-related factors. In fact, anxiety and depression are thought to be the most important factors impacting upon quality of life in epilepsy [21][22][23].

Other psychological factors impacting upon quality of life in epilepsy include loneliness, loss of independence, fear of seizures, isolation, adjustment, employment difficulties and stigma perception [7][20][24][25][26][27][28]. Recovery time after seizures [29], memory [30], and sleep disturbances [31] are also suggested to impact upon quality of life but to a lesser degree. Taylor et al. [21] further suggests that the psychological factors that reduce quality of life may have a more lasting impact than condition related factors. There are, however, methodological issues reported within the Taylor et al. [21] meta-analysis, with the impact of employment and educational status remaining unclear and methodological quality judged to be poor. Since systematic reviews of other chronic illnesses also report a reduced quality of life [32][33], it is therefore reasonable to propose that overall

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quantitative research supports the notion that epilepsy is a condition that is characterised by a reduction in the quality of life [17].

While the meta-analysis [21] allows us to see the potential predictors of quality of life, it does not increase understanding of how these factors play out in individual's lives. However, qualitative research focuses on making meaning in context [34] which can permit the exploration of experience in depth and highlight the complex and sometimes individual interplay of factors which are not accessible in quantitative research. There is now a growing body of qualitative research into the experience of having epilepsy both in western and non-western countries. Meta-synthesis is an interpretative analysis of qualitative studies which creates a synthesis of those studies which is grounded in empirical data, with conclusions made from the original studies included in the synthesis [35]. The aim of the synthesis is to increase the usefulness and reliability of the findings of the individual studies reviewed and the narratives included. Consequently, findings from meta-synthesis could help inform practice, for example increasing the understanding of a specific phenomenon [35].

Since there is now a sizeable qualitative research base, it seems timely to perform a systematic search of papers and draw them together to provide an in-depth exploration of everyday lived experience of epilepsy, and how individuals cope. A review of qualitative literature on the experience of living with epilepsy has been recently published [36]. However, this review concerns both children and adults and includes only studies from western countries. Furthermore, the review focuses on concepts associated with the impact of epilepsy aimed at informing future clinical trial outcomes, and does not report to follow a specific method of meta-synthesis. As such, the findings in the Kerr and colleagues' review therefore offers breadth in relation to understanding these outcomes but it has not examined the psychological impact and experience of living with epilepsy in depth.

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In contrast, this review utilises the meta-ethnographic method as described by Noblit and Hare [37], which aims to provide a more interpretative literature review, involving a systematic and critical comparison of research. This method is the most commonly cited approach to meta-synthesis [38]. In addition, the current review will also take into consideration several papers that have been published since the previous review in 2011, and will importantly include populations from around the world, both western and non-western. The aim was to create a synthesised understanding of the lived experience of epilepsy from multiple studies.

### **Method**

#### **Research design**

The synthesis was conducted using the principles of meta-ethnography and followed guidance published by Noblit and Hare [37]. Appendix 1B displays a visual representation of the process of synthesis adapted by Moolcharm et al. [39]. This method was considered to meet the aim of the review, which was to explore the contribution of the studies as a whole and to produce higher order themes, while preserving the interpretations of participants' original accounts and their meanings. The meta-ethnography process achieves this through constant comparison of the findings of original studies, allowing similarities and differences in findings to be extrapolated and explored, while preserving original participant experiences. Meta-ethnography consists of six interconnecting and often parallel phases; finding relevant studies, reading and re-reading the relevant studies, determining how studies are related, translating the studies into one another, synthesising the translations and reporting conclusions [37].



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### **Inclusion/exclusion criteria**

Articles that met the following criteria were included in the meta-synthesis: published in a peer-reviewed journal to ensure a minimum quality standard; published in English; focused on an aspect of the lived experience of epilepsy; used adult participants and focused on the experience of adults (those 18 years and over); used qualitative methods and reported qualitative data; included data from individuals with epilepsy, and where data were included from, for example, family or service providers, data and themes from those with epilepsy were clearly distinguishable; provided first-hand experience of living with epilepsy with participant quotations included in the article; were able to be classified within the typology of qualitative findings proposed by Sandelowski & Barroso [40].

The decision was made to include articles using a range of qualitative methodologies as long as they were interpretative and included participant quotations, in order to allow for full representation of qualitative research in the area [40]. This is what Thomas and Harden [41] refer to as ‘conceptual saturation’. Articles that involved the quantification of data (for example content analysis that reported only frequencies) were excluded.

### **Search terms**

Literature searches took place from August 2015 until 31<sup>st</sup> December 2015. The search terms in Table 1 were generated from the EBSCO thesaurus, were combined using Boolean operators and used to search the databases. A specialist librarian at the University offered advice on the most appropriate database to search and search strategies to employ.

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INSERT TABLE 1

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Three databases were searched with these terms; *PsychINFO*, *Pubmed* and *Scopus*. No date restrictions were imposed. Search terms and strategies were adjusted to accommodate database specific indexing systems. Both free text and subject mapping search variants were used. Search terms and strategies can be found in Table 1. Reference lists for the articles included in this review were also scrutinised for additional articles that may be relevant for review, referred to as the ‘pearl growing technique’ [42]. Figure 1 shows a flowchart of article selection.

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INSERT FIGURE 1

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### **Characteristics of studies**

Fifteen studies met the inclusion/exclusion criteria; a summary of their characteristics is available in Table 2. Four studies took place in Sweden, three in the UK, three in the USA, and one in each of Malaysia, Cameroon, Australia and Iran. Two papers used the same sample but it was felt that they had very different foci and were therefore included but were counted as one study (study 7). One article [59] was excluded as it appeared to be a re-analysis of an already included published paper (paper 15) and there was repetition of themes within. To clarify, contact with the author was attempted but unsuccessful. There were 533 participants across the studies, with an age range of 18-69.

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INSERT TABLE 2

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### **Evaluating Quality**

The Critical Appraisal Skills Programme (CASP) qualitative checklist [60] provides a framework to assess the quality of research across ten areas. This was used to evaluate the methods, quality, ethical procedures and research context of the studies (see appendix 1C for CASP scores). The CASP was used with a four point rating scale as adapted from that used by Duggleby et al. [61] and Murray and Forshaw [62]. The first two questions are for screening purposes, asking if a clear statement of aims for the research exists, and that a qualitative approach is appropriate. All articles met this screening criterion. Using this scale, zero points were awarded if a criterion was not reported on, one point if there was little explanation about a criterion, two points if there was some explanation, and three if there was a full explanation. CASP scores ranged from 18-26. A sample of articles and CASP scores were peer audited to enhance the rigour and validity of the ratings. Where there were disagreements, a consensus was reached.

No studies were excluded on the basis of the quality score, with aims of being as inclusive as possible to ensure that relevant studies were not missed [63]. However, the quality of studies guided the order in which they were read and reviewed, with Campbell et al. [64] suggesting that the order in which articles are read gives weight to the overall synthesis as concepts are produced inductively.

### **Analysis and Synthesis**

The method followed Noblit and Hare [37], who suggest some overlap between the phases of the meta-synthesis. The first two have been described above; identifying a research question and carrying out a literature search. The following phases are described below; first reading of the articles, deciding how they are related to each other, translating them into one

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another, and synthesising themes into higher order themes that preserve and represent the meaning of the individual studies.

Articles were read and contextual information such as setting and sample was extracted into a table (Table 2). The articles were analysed by order of CASP score, and those with the same score were analysed by order of publication. According to Noblit and Hare [37] the process of synthesising creates “interpretations of interpretations of interpretations” (p.35), and therefore themes are ‘third order constructs’ [65]. These are created from ‘second order constructs’, i.e. the original author’s interpretations of participants’ interpretations (first order constructs). These second order constructs, or themes, were identified, along with any theme components identified through the reading. Themes, subthemes and quotations illuminating themes were taken from each article and initial judgements were made about how these were related to those in other articles. Themes and concepts from the original articles were constantly compared to the themes generated during this synthesis. Appendix 1D was created to allow tracking of theme development and to check that themes represented the original authors’ themes. Interpretations within and between articles were made; “translating the interpretations of one study into the interpretations of another” [37] (p.32). Appendix 1E shows which papers contributed to themes derived from this meta-synthesis.

### **Findings**

Synthesising the findings of the fifteen studies resulted in three themes, each with subthemes. Participant quotations from the original papers are provided to illuminate the findings. Papers are referred to by their allocated number (see Table 2).

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**Making sense of epilepsy: “It affects your perception of yourself” (paper 4)**

Participants experienced considerable challenges when trying to make sense of epilepsy. Participants described challenges to their sense of self and identity, as well as the different ways they were able to appraise epilepsy in order to be able to live with it.

**Identity.** The psychological impact of epilepsy left some participants feeling that they weren't quite 'normal' in comparison to others; “that's the thing about epilepsy. It's not the seizures, it's the effect of feeling different. It's not the physical reality, it's that psychological effect that just doesn't go away” (paper 8, p.283). This participant was left questioning their sense of self as a result of having epilepsy and there was a very real sense of being different to other people and feeling it in their day to day life. For one participant the difference was evident in terms of ability and speed of working; “I work slower, not clever compare to others” (paper 5, p.23). Feeling different to others left some participants unable to discuss their experiences for fear of how this would be perceived; “I had feelings of de ja- vu at a crossroads and I didn't dare tell my husband in case he'd think I was an idiot” (paper 7a, p.753). Some participants described experiences where it was the reactions of others that made them feel different or abnormal; “The staff looked down on me, as though I was ET [alien]” (paper 5, p.26). This was more direct for a participant in Cameroon; “The people I worked with said I am becoming more and more disturbed, so they send me away” (paper 14, p438).

For many participants, the negative impact of epilepsy and resulting difference to others was evident with descriptions of epilepsy as a label representing disability; “I have still got that tag on me. Disabled. You know it is life changing” (paper 4, p.61). This view was echoed in other papers, with participants referring to themselves as “disabled”, “chronically ill” and “always unwell” (paper 14, p.438). The negativity associated with this was described

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by another participant in terms of accessing social welfare as a result of their condition; “The job went and everything else and I ended up for the first time on the Dole (unemployment benefit)...gutted...still hurts now you know” (paper 4, p.62). For this participant there was a sense of shame at having to access this welfare, suggesting not just the painful comparison to others in terms of ability and disability, but also a difficult change to accept in how they saw themselves.

Other participants also discussed the impact of epileptic seizures in changing how they viewed themselves; “You don’t feel so confident with yourself, it affects your perception of yourself...I got very depressed...it was always on my mind” (paper 4, p. 62). This participant describes losing confidence as a result of the unpredictability of seizures, resulting in being preoccupied with them and spending a lot of time thinking about when a seizure might happen. Some participants experienced significant others in their lives losing confidence in them as a result of epilepsy, resulting in roles being limited; “I was side stepped. My role in the family was affected by epilepsy...Daddy was not always to be trusted” (paper 7B, p.1295). One participant described how epilepsy challenged their role as a parent and subsequently made them feel like a child; “I feel like I am not really grown up, I can-not even walk with the stroller. It is like I am underage...it hurts that I cannot and should not, take the full responsibility” (paper 7b, p.1295). This further led to feelings of inadequacy as a parent; “I feel I am the worst Mum. What will happen if I have a seizure, if it is just me and my children? How will they react...I have a guilty conscience about this” (paper 7b, p.1296). The feelings of being infantilised were evident in other aspects of life, with one participant describing negative feelings in relation to their contact with professionals; “I often feel insignificant” (paper 6, p.393). For another participant, epilepsy challenged their personality and sense of self in a way that made it feel like epilepsy was a battle; “I wasn’t able to accept that I had epilepsy either. I was my own worst enemy...I

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fought it constantly. My personality was always coming up against epilepsy” (paper 3, p.349). For this participant epilepsy did not match their perception of who they were and thus was experienced to be a powerful challenge to identity.

There were, however, examples where participants described how they found a way to maintain their sense of self, or a way to integrate epilepsy into their identity. One participant described “I have never felt like an “epileptic” and I see myself just as valuable as anyone else” (paper 6, p.393). Feeling as valuable as others led to another participant describing no difference between themselves and others; “I can work. [If] other people can do it, I can also do it” (paper 5, p.25). Being able to accept epilepsy and live with it meant that, for one participant, it didn’t have a negative impact on life; “I wouldn’t class it as a disability for me because it doesn’t affect my everyday life at all” (paper 4, p.64).

Aside from these few examples of epilepsy not having such a negative impact on life, there was a real sense that epilepsy left participants feeling as though they were not themselves, with participants experiencing a change in their ability to do tasks, which subsequently impacted on previously established roles. Participants also described a loss of confidence in themselves, as well as the impact of others losing confidence in them. In addition, the unpredictability of seizures led to further challenges to participants’ sense of identity.

**Appraising epilepsy.** In addition to challenges to personal identity, participants also experienced emotional reactions, reflecting a sense of powerlessness and lack of control when trying to make sense of epilepsy; “Periods when I did not have seizures...then I was living...I thought well now the seizures have ceased...but then I had another...I went so completely, yes really completely under...it was so depressing” (paper 2, p.1998). For this participant the unpredictability of seizures challenged their ability to have and maintain faith

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in being able to 'live', constantly living in a place between building up hope and having those hopes dashed. Other participants saw epilepsy as a punishment; "I will never get rid of this crap, it makes me wonder why...what have I done to deserve this?" (Paper 6, p.392). For this person, there was no sense of hope of improvement, suggesting that they felt powerless in the face of their epilepsy. The feeling of powerlessness was reflected in other participants' narratives, who saw epilepsy as a "curse" (paper 1, p.111), as "something that you can't control" (paper 13, p.227) and something which limited an individual's strength; "this is my weakness" (paper 5, p.27).

Some participants were able to accept their epilepsy diagnosis, with some seeing it as "God's will" (paper 15, p.466-471), and subsequently found a way to live with it; "I know that I will always have epilepsy and it feels a bit harsh but one learns to live with it" (paper 6, p.393). Being able to accept that epilepsy was not something that would be cured helped some participants to be confident in themselves and their diagnosis; "well firstly you need to get out and proud about it...it's not going to go away" (paper 11, p.668). This acceptance allowed some participants to embrace their diagnosis; "Yes people can say 'You're epileptic' and I say 'Yes, yes' because I don't have it as something bad...all those feelings have gone" (paper 11, p. 668).

Being able to come to terms with the presence of epilepsy was positive for some participants who saw it as a "blessing in disguise" (paper 12, p. 260). Some participants compared their diagnosis and circumstances to others and felt that having epilepsy was a bit of a "reality check...no-one's infallible" (paper 13, p.226). Making sense of epilepsy in this way led to some participants experiencing growth as a result of their diagnosis in terms of strength and humility; "I had a new attitude towards illness...epilepsy...made it possible for me to imagine myself in other people's misery...I became more humble and had more respect for others...the epilepsy makes you soften up at the same time...not give up" (paper 2,



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p.1997). There was a sense that this acceptance came more easily for some participants than others, with one participant describing “oh I accepted it quite quickly” (paper 11, p.667), and another participant describing how they were determined not to let epilepsy control their life from a young age; “Ever since my childhood I have thought that I must be the one ruling things in life, not the epilepsy” (paper 2, p.1996). Other participants, however, described how time was key in allowing them to take the control of their life back from epilepsy; “once I got rid of the fear, my confidence came back and I was more normal again, I was me again...I could get back to doing what I was doing before” (paper 4, p.63). Participants described both positive and negative aspects of appraising epilepsy, from seeing it as a curse to finding a way to accept it. The variance in these experiences suggest that it is not a linear process, that it is not necessarily time that enables acceptance, but other factors may be important in this.

**The cost of epilepsy: “getting epilepsy has put me in poverty” (paper 1)**

The cost of epilepsy was significant for participants, who described loss as a result of epilepsy within personal relationships, employment and meaningful activities.

**Relationships.** Relationships were a significant area of loss for participants, who described loneliness and isolation as a consequence of this loss; “My husband left me many years ago. I’m basically all alone now” (paper 1, p. 111). As a consequence of loss of relationships, participants described lives of solitude; “Er, well I don’t go out much, I’m like a hermit” (paper 11, p.668). Some participants had chosen not to disclose their condition to friends and worried that they would lose friendships should their epilepsy be discovered; “I worry about that my friends...would...notice something regarding the epilepsy condition and how that would affect my...relation to others” (paper 6, p.392). This was a reality for another participant; “all of my friends disappeared, so yes, my circle of friends is very small”

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(paper 7a, p.755). The expectation that relationships would be lost as a consequence of epilepsy was evident for a participant in Cameroon, who very much related the breakdown of his marriage to the loss of income; “My wife is no longer with me. You should know that with women, when one does not have money she cannot stay with you” (paper 14, p.439). For this individual, the seemingly logical loss of relationships as a consequence of having epilepsy left them accepting their loneliness and isolation.

**Employment.** Employment difficulties were evident throughout the narratives of participants, with employment being a particular area of both loss and negative experiences. Finding employment was difficult for some participants, with one participant describing the need to negotiate various obstacles and manage personal risk; “trying to find employment as a person with epilepsy is like running through a wheat field with a lighted torch” (paper 8, p.281). Rejection at the time of application for jobs was common; “I didn’t get a job because I had epilepsy and it was made very clear that was the reason” (paper 8, p.283). This led to some participants deciding not to disclose their diagnosis of epilepsy to employers, with the sometimes invisible nature of epilepsy aiding this; “You know, it’s not like you’re in a wheelchair or something like that, it’s not visible. It means that people judge you as a person before, you know, it’s not part of their first impression of you” (paper 11, p.668). The consequence of when and if a seizure did occur at work and when colleagues discovered their condition varied, but for one person was particularly severe; “And I had a seizure at work one time, and I go back to work 2 days later, and I got fired” (paper 12, p.259).

Employment difficulties were caused not just by others’ responses to a diagnosis of epilepsy, but by the physical impact of epilepsy on them; “I have no opportunity to advance in the job because of this thing [epilepsy]” (paper 14, p.438). Some participants were physically unable to work, despite a desire to do so; “I really want to work...but my body couldn’t” (paper 5, p.25). The impact of epilepsy in terms of cognitive and memory

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difficulties also limited the ability to maintain employment due to increased fatigue and reduced efficiency; “my superior told me that my work performance is decreasing” (paper 5, p.23). Loss in other domains such as driving, had implications for employment and were seen as a barrier to sustaining employment; “Even if they [employer] give you [me] a job, how are you [am I] going to travel every day? You [I] cannot depend on your brother [always]” (paper 5, p.24).

The implications of difficulties with employment for some participants was huge, particularly for those in countries where social security and health care subsidies were limited, such as the US; “getting epilepsy has put me in poverty” (paper 1, p.110). It also led some participants to work for little in order to maintain employment; “I’m still sitting there, 25, getting paid £100 to do so many hours, and that’s not even £1 or £2 an hour. But at the end of the day you’ve got no choice” (paper 9, p. 171).

Therefore, in summary employment was an area that was difficult both in terms of the interpersonal interactions with colleagues, and in terms of the ways in which epilepsy limited life and abilities.

**Meaningful activities.** Participants described activities that were previously helpful in maintaining quality of life being lost due to epilepsy; “I then got this list of things that I couldn’t do...so I would say that a major, major part of my quality of life was stripped out almost straight away” (paper 4, p.63). Loss of previously enjoyed activities made life less enjoyable for some participants; “It’s a lot harder to live my life. Which has taken away from me, it’s taken away my enjoyment of just everyday life simplicity” (paper 4, p.62). This loss of enjoyment in everyday life was also experienced as a consequence of necessary changes within roles, with one participant describing not feeling at ease when caring for their child; “I

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bite my tongue all the time I am with my baby. If I will carry her or if I am walking with the stroller, it is really frightening...I sense that this is something I must do” (paper 7b, p.1295).

One consequence of epilepsy was that many participants were no longer able to drive. This had major implications for participants within various life domains, including employment as mentioned previously. For some participants, transport represented freedom; “If you can’t drive, well to me that was my independence” (paper 4, p.62). While not all participants had held a driving licence, the loss of this was significant to many. This loss left them relying on others for transport, limiting their engagement in other activities; “I mostly depend on my in-laws who live here to get me where I need to go...I can’t ask them all the time...I do what I can do...going where I can go” (paper 1, p.111). Loss of transport also led to increased worry for participants, leaving them feeling that daily activities were more effortful and perhaps not worth doing; “concerns about transportation have been an issue too...I lived 20 miles away from school and work and everything. It may not take long by the freeway, but then if I had to take a bus, it could take a lot longer” (paper 12, p.259). For this participant, not being able to drive and having to rely on public transport meant that time was also lost.

The inability to engage in previously enjoyed activities also left participants feeling that they had lost normality. For some participants, the loss of normality was evident through what they could no longer do; “it’s just annoying, because all my friends take drugs and go out and drink, and I really shouldn’t be doing that” (paper 13, p.226). The loss of normality also meant participants found themselves constantly considering what would happen if they had a seizure, and adopting strategies in case this were to happen: “people will change them [babies] up there without thinking. It won’t occur to everyone ‘what’s going to happen if I have a seizure’ because it’s not what you think about all the time” (paper 10, p.62).

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**Significance of others in coping with epilepsy: “My family have always helped me”****(paper 15)**

Participants described ways in which they were supported by others and the importance of this in consequently being able to cope with epilepsy. One participant described how others can be reassuring and how this was something that they particularly valued; “I need to hear other people say that I’m normal, and treat me that way...even if I have a difference in my brain- all people are different aren’t they?” (paper 6, p.393). For this participant, having support from others was important in terms of reducing their sense of being different (see theme 1). For another participant, the importance of others’ reactions extended to the workplace, where one participant described a supportive environment; “in my office, my colleague will help me. They will look after me because they knew about my epileptic condition” (paper 5, p.27). Many participants referred to relationships and emotional support as key factors in being able to cope; “my family...I think without that all my quality of life would suffer” (paper 4, p.61). The role of the family was a finding represented across all the studies, with a participant in Iran stating; “My family have always helped me...they give me such comfort that I feel better and the disease does not matter to me anymore” (paper 15, p. 468). Significant others were also important in terms of encouraging and empowering some participants; “I feel really safe with him [partner]. And he pushes me to take risks...whereas I would say...I will stay in...he will say you have got to get up and live, so let’s go” (paper 4, p.64).

The level of support from significant others and how this was interpreted varied, with some describing how it could be frustrating and overbearing; “She told me that: “you go out and then you fall down somewhere”...they are scared [that] anything will happen to me” (paper 5, p.27). This was also experienced by another participant who felt that reactions of family members were extreme and overprotective; “They worry all the time...for example if

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something falls down hitting the floor, at once they come running, asking me what is happening, am I alright?" (paper 2, p.1997). For some participants, having to rely on others could leave them feeling as though they were a burden at times; "I feel bad as I make a mess for those around me, always being a bother to other people" (paper 6, p.393).

Other participants described how the significance of spirituality and feeling that they were loved and cared for by a god were important in terms of coping with epilepsy. One participant described that going through a difficult time with epilepsy benefitted them in terms of bringing them closer to god; "apart from all the terrible effects that it leaves on me, the disease has benefitted me, in that it gets me closer to God" (paper 15). Another participant in the same paper described that "only prayers pacify" in their struggle with epilepsy. A relationships with god also provided peace in life for some participants; "whatever God plans, he's the best of all plans" (paper 14). For these individuals, relying on their spirituality or religion was important in being able to accept and live with epilepsy.

Overall, while it could be frustrating at times, the support of others was important to the participants in terms of being able to cope and live with epilepsy day to day. This included both practical and emotional support, and within a range of settings including social, employment, and family.

### **Discussion**

The aim of this meta-synthesis was to bring together the qualitative literature on living with epilepsy, in order to offer an over-arching interpretation. The synthesis of the findings of the 15 papers resulted in three themes, which suggest that epilepsy is a condition with the potential to impact on identity and one which can result in feelings of loss, with significant others playing an important role in coping.

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Epilepsy has been written and spoken about for over 4000 years [66] with many misconceptions being made within this time, ultimately making it a condition which carried much stigma and prejudice. According to de Boer [66], while understanding has evolved, epilepsy remains a label that is stigmatising throughout the world. Stigma has the potential to reduce an individual “from a whole and usual person to a tainted, discounted one” [67](p.3), resulting in feelings of being less important or valuable than others. Participants in the current meta-synthesis described feelings of reduced confidence and self-esteem as a consequence of experiences or perceptions of stigma which impacted on their identity. Furthermore, feelings of inadequacy in comparison to others in society has been linked to increased levels of anxiety and depression in the general population [68], and indeed anxiety and depression are reported to be the greatest predictors of reduced quality of life in individuals with epilepsy [21]. Participants in this meta-synthesis described feeling ‘depressed’, low in mood and anxious.

Stanton and Revenson [69] suggest that the course of chronic disease can move from health to illness, or ability to disability. Disability is a construct which, like epilepsy, is associated with prejudice and stigma from society [70]. The label of disability was important in the current meta-synthesis, with participants interpreting others’ reduced confidence in them as a consequence of being ‘disabled’. Imposing labels on individuals has the potential to challenge their self-image, especially when they are viewed negatively by the remainder of society [71]. Within the current meta-synthesis, the labels and stigma associated with epilepsy and disability contributed to some participants isolating themselves. This adds to the understanding of the link between epilepsy and loneliness/isolation that has been reported within the quantitative literature [7][20][24][26][27].

Furthermore, Charmaz [72] suggests that a fundamental form of suffering within chronic illness is the erosion of the pre-ill self through an accumulated loss of previously

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satisfying self-images. Participants within this meta-synthesis described changes in various domains of their lives, including life-roles, employment and driving, resulting in reduced independence and feelings of inadequacy. Many of the changes discussed within this meta-synthesis were caused by others, such as when individuals lost their job or when relationships were lost as a consequence of having epilepsy. The role of others within the erosion of the self is important, since the self is developed and maintained through social interactions [72]. Within this meta-synthesis there were descriptions of positive social support (mainly from family members but also from spirituality) which may suggest that the self can also be maintained through such interactions. However, individuals also described negative interpersonal experiences that added to the burden of their illness, and contributed to feelings of loss and descriptions of isolation.

Wedlund et al. [20] reported that the burden of epilepsy is not necessarily dependent on whether or not an individual achieves seizure control, yet the findings of this meta-synthesis suggest that the unpredictability of seizures is an important factor in the experience of epilepsy. The unpredictability of seizures left participants within this meta-synthesis feeling powerless in relation to their seizures, which further impacted upon their identity. One participant described how the unpredictability of seizures challenged their ability to 'live', with both social (in being able to go out) and personal (in thinking they were seizure free) identity implications. These feelings are consistent with research on chronic illness, with Anjoulat, Luminet and Deccache [73] describing that a sense of powerlessness can threaten individual's social and personal identities.

However, Anjoulat, Marcolongo, Bonadiman and Deccache [74] and Bury [75] describe that individuals with chronic illness can be empowered and manage their illness, and this is a double process. This process involves maintaining previous self-representations and roles while learning to control the disease on the one hand (thus differentiating one's self



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from illness), and on the other hand letting go and relinquishing control (thus integrating illness to self) [74]. Within this meta-synthesis there are both descriptions of not feeling like an 'epileptic', thus not integrating the illness with their sense of self, and of accepting the practical limitations and consequences of epilepsy on their lives (this integrating illness to self). These individuals subsequently described being more positive about having epilepsy and better able to cope with it. However, the overall narrative was that of powerless, suggesting that for the samples contained within this review managing the burden of their illness did not appear to be attained, or for some, attainable.

As previously highlighted with regards to stigma, others can play a negative role in the experience of epilepsy. This exacerbated participants' sense of powerlessness in relation to seizures, resulting in them isolating themselves as a consequence of being afraid they would have a seizure in public. However, participants described relationships and significant others as key in reducing the negative consequences of epilepsy. According to Caplan [76] social support consists of "continuing social aggregates that provide individuals with opportunities for feedback about themselves and for validations of their expectations of others" (p.4). The role of social support within the findings of this meta-synthesis were complex. For some individuals, having supportive relationships helped them maintain their sense of worth. For others, however, the support offered by others was too much, leaving them feeling overprotected and contributing to the feelings of lost independence discussed previously.

Quantitative research has suggested that reduced social support is associated with reduced quality of life in individuals with epilepsy [77][78]. Charyton et al. [78] further emphasised that this is specifically related to perceived affectionate support, which they define as feeling loved and wanted. The findings from this meta-synthesis support the suggestion of Charyton et al. [78], but also suggest that there are further complexities to this

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relationship. Taylor [79] suggests that social support can, for some, come at a cost. Indeed, as the current meta-synthesis supports, Shumaker and Hill [80] suggest that overly intrusive social support networks can actually make things worse. Whether or not such support is experienced as helpful can depend on several factors, including how large the social network is, whether the support provided is appropriate to meet the individual's needs at that time, and whether the right support comes from the right person [78]. Indeed for some individuals within this meta-synthesis, the level of support was appropriate to meet their needs and helped them cope with living with epilepsy.

### **Clinical Implications**

The findings of this review suggest that individuals continue to experience stigma and lack of understanding from others in society. While understanding of epilepsy has progressed in many countries, it still carries with it stigma and negative associations. These findings highlight the need for more education for the public, increasing understanding of what epilepsy is, and that epileptic seizures are not something to be 'feared'. Clinical psychologists are key in challenging the discrimination of individuals with disabilities in society and can do this by researching issues that are relevant to these individuals [81]. Indeed, Rhodes [82] suggest that the role of psychologists extends beyond researching these issues, but involves advocacy in order to implement the findings at the local and national level. Ultimately, influencing policy is becoming part of the long term enterprise of this profession [82].

The findings of this meta-synthesis further highlight the process individuals go through in terms of questioning their sense of worth and identity. Understanding this impact may mean that specific types of interventions could be useful, taking into consideration how an individual's identity is impacted. A Cochrane review of psychological treatments for

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epilepsy and their effects on seizure reduction and quality of life measures [83] suggest that there is little conclusive evidence for any one psychological intervention. Bearing in mind the findings of the current meta-synthesis, an intervention which would help an individual accept the existence of epilepsy while focusing on their values and who they want to be, such as Acceptance and Commitment Therapy (ACT, [84]), may be beneficial for some individuals with epilepsy. Indeed significant improvements in seizure frequency and quality of life for individuals with epilepsy who are treated with ACT have been reported [85][86].

Finally, this meta-synthesis highlights the value of social support and how some individuals saw relationships as key in reducing the negative impact of epilepsy in their lives. Elafros et al. [87] reported that attendance at epilepsy support groups reduced internalised stigma, thus highlighting the potential value of such resources. These are important considerations for all persons involved in the care of individuals with epilepsy, in order to signpost them to local support. It would be worthwhile for services to consider providing support groups as standard, considering their potential benefit. This has been found to be beneficial even as an online resource [78]. These could help to normalise the existence and experiences of epilepsy, in addition to offering advice and reassurance. Individuals within the current review were worried about sounding 'insane', but being able to share experiences in a group of individuals who truly understand could be vital. Furthermore, Walker et al. [9] highlight that epilepsy plays a large role not just in shaping the life of the individual with epilepsy, but also for those who support them. This is also something important for those working with individuals with epilepsy.

### **Limitations and future research**

There are limitations to the current meta-synthesis. While both western and non-western populations were included in the meta-synthesis, these were not evenly weighted and

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indeed there were more western studies included. This is likely to have resulted in a western finding bias in the results, again highlighting the lack of non western research [17]. More research is needed in non-western countries in order to better understand their specific experiences and needs.

The literature review by Kerr and colleagues [36] was completed with both adults and children (although did draw more from the adult population than the child population), but it would be interesting and useful to complete a meta-synthesis on children alone and see the difference, if any, between that population and the adult population used in this meta-synthesis. It would also be useful to look at the experiences of family members of individuals with epilepsy.

The CASP tool used indicated that many studies could have been improved in terms of reporting quality. It is important to consider that the contribution each study makes to a meta-synthesis depends on its quality, in particular in the results section. In order to account for any shortcomings in reporting quality the current meta-synthesis gives more weight to the studies that were of higher reporting quality than those of poorer quality. One major area of poor reporting quality was in relation to reflexivity, with none of the included studies directly discussing their epistemological position. While it is also important to consider the restrictions implemented when submitting to academic journals for publication, and not assume that because it was not mentioned in the journal, that it was not considered. Studies were therefore not excluded based on their CASP scores, but the tool was used to prompt consideration of the strengths and weaknesses of each study.

## **Conclusion**

This meta-synthesis has explored the experience of living with epilepsy and has shown that there are complex difficulties that individuals face. The main themes identified

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included trying to make sense of the illness in the context of the individual, the costs of epilepsy, and the importance and value of social support. There are clinical implications drawn from this, and suggestions for future research made.

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Database	Free Text- Epilepsy (S1)	Free Text – Methodology (S2)	Subject Mapping- Epilepsy (S3)	Limiters
PsychINFO	“Epilepsy” OR “epileptic seizures” OR “grand mal” OR “status epilepticus” OR “epileptic” OR “seizure”	“qualitative” OR “phenomen*” OR “interview” OR “experience” OR “thematic” OR “interpretative” OR “discourse” OR “grounded theory” OR “focus group” OR “survey” OR “narrative”	DE “epilepsy” OR DE “epileptic seizures” OR DE “experimental epilepsy” OR DE “lennox Gestaut syndrome” OR DE “epileptic seizures” OR DE “experimental epilepsy”	Scholarly (Peer Reviewed) Journals Language: English
PubMed	As above	As above	As above (MESH major topic)	Language: English
Scopus	As above	As above	-	Language: English Document type: Article/article in press Exclude: child/adolescent/ preschool/infant

*Table 1: Details of Searches Relating to Database Specific Indexing Systems*

## THE LIVED EXPERIENCE OF EPILEPSY

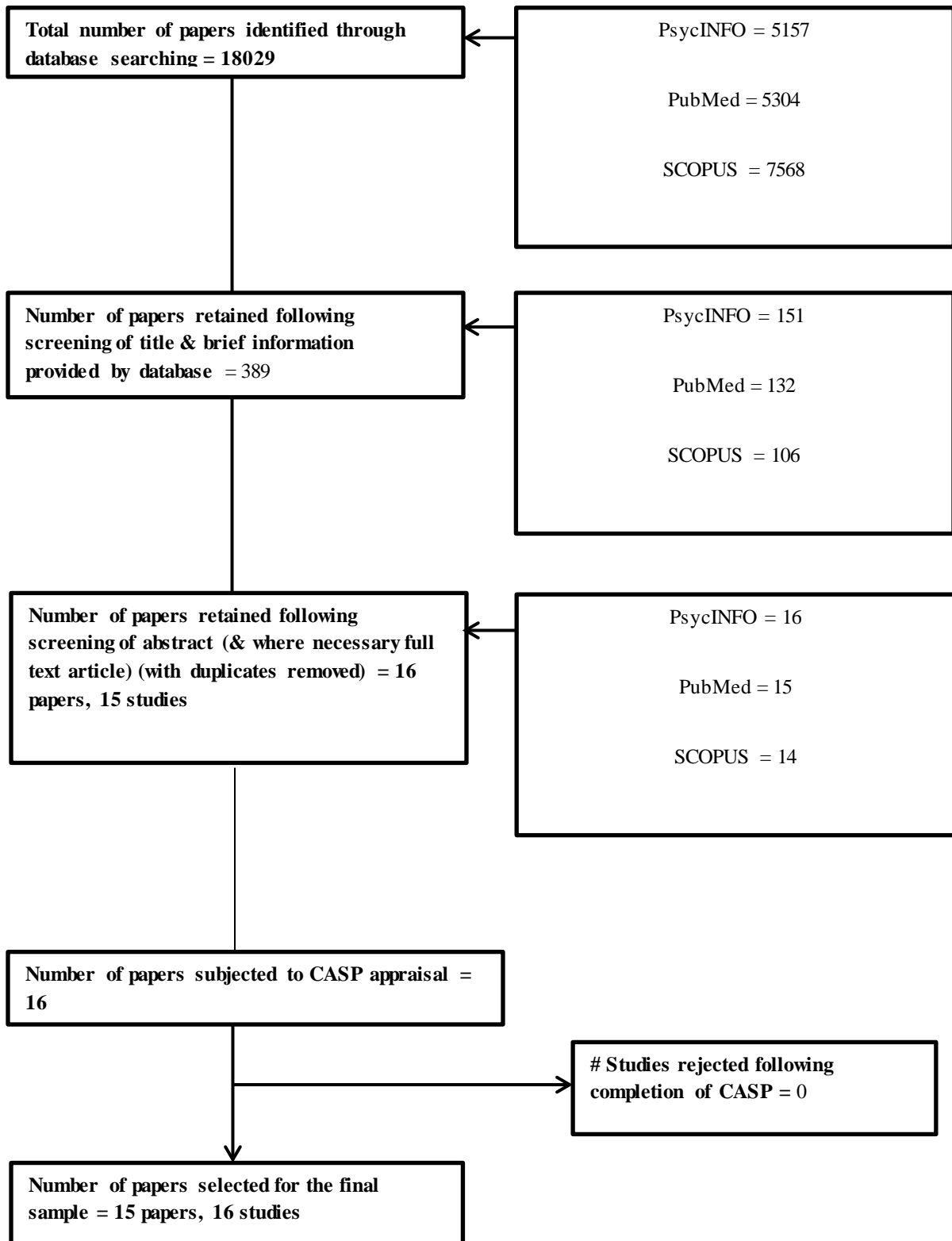


Figure 1. Figure showing process used to identify relevant studies

## THE LIVED EXPERIENCE OF EPILEPSY

Paper	Author	Date	Research Aim	Sample size	Age range	Country	Data collection and analysis
1 [43]	Paschal, Ablah, Wetta-Hall, Molgaard, Liow	2005	Exploring the attitudes and behaviours of African-American females with epilepsy	10	29-58	USA	Unstructured interviews Grounded theory
2 [44]	Raty, Wilde-Larsson	2011	To describe how patients with epilepsy perceive living with epilepsy	19	20-65	Sweden	Semi-structured interviews Phenomenographic approach
3 [45]	Wedlund, Nilsson, Tomson, Erdner	2013	To identify the issues experienced as essential in the rehabilitation for persons with epilepsy	17	25-69	UK	Focus group interviews Qualitative content analysis
4 [46]	Jacoby, Ring, Whitehead, Marson, Baker	2014	Exploring the utility of the concept of loss and loss replacement as a means of gaining understanding of the implications of epilepsy on quality of life	67	24-65	Sweden	Structured interviews Thematic analysis
5 [47]	Chen Mun Wo, Lim, Yuen Choo, Tin Tan	2015	Explore the positive and negative factors affecting the employability of patients with uncontrolled seizures	21	21-47	Malaysia	Semi-structured interviews IPA
6 [48]	Raty, Soderfeldt, Larsson	2007	Illuminate the impact of epilepsy on daily life in young adulthood	95	18-27	Sweden	Open ended survey questions Qualitative content analysis

## THE LIVED EXPERIENCE OF EPILEPSY

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7 [49][50]	Gauffin, Flensner, Landtblom	2011, 2015	<b>A.</b> Explore the experience of living with epilepsy and subjective cognitive decline <b>B.</b> Describe aspects of what it means being a parent who has epilepsy	14	18-35	Sweden	Focus groups Content analysis
8 [51]	Bishop	2002	Explore employment-related challenges and successes	14	20-50	USA	Focus groups Content analysis Focus groups Qualitative analysis
9 [52]	Small, Ismail, Rhodes, Wright	2005	Examine how Bradford's Pakistani Muslim community experience living with epilepsy	20	18-68	UK	Semi-structured interviews Framework analysis
10 [53]	Thompson, Thomas, Solomon, Nashef, Kendall	2008	Explore what it is like for women who have epilepsy, with a focus on reproductive health	15	20-40	UK	Semi-structured interviews Grounded theory
11 [54]	Kininc, Campbell	2009	Explore the concept of felt stigma in today's society	52	-	UK	Semi-structured interviews Phenomenological approach
12 [55]	Chung, Liu, Ivey, Haung, Chung, Guo, Tseng, Ma	2012	Evaluate quality of life in people with epilepsy in the San Francisco Bay Area, USA	36	24-65+	USA	Focus groups Content interpretative analysis
13 [56]	Velissaris, Wilson, Saling, Newton, Berkovic	2007	Explore the psychosocial adjustment following a newly diagnosed seizure	90	18-65	Australia	Semi-structured interviews IPA

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## THE LIVED EXPERIENCE OF EPILEPSY

14 [57]	Allotey, Reidpath	2007	Explore the relationship between the social, cultural and environmental context and the experience of living with epilepsy in Cameroon	42	25-35	Cameroon	Structured and semi-structured interviews Grounded theory
15 [58]	Hosseini, Sharif, Ahmadi, Zare	2010	Identifying coping strategies employed by Iranian adults with epilepsy	21	18-65	Iran	Semi structured interviews Qualitative content analysis

*Table 2.* Summary of studies that were included in the review



# SEIZURE - EUROPEAN JOURNAL OF EPILEPSY

## AUTHOR INFORMATION PACK

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ISSN: 1059-1311

## Chapter 2 **DESCRIPTION**

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*Seizure - European Journal of Epilepsy* is an international journal owned by [Epilepsy Action](#) (the largest member led epilepsy organisation in the UK). It provides a forum for papers on all topics related to **epilepsy** and **seizure disorders**.

*Seizure* focuses especially on **clinical** and **psychosocial** aspects, but will publish papers on the basic sciences related to the condition itself, the differential diagnosis, natural history and epidemiology of **seizures**, as well as the investigation and practical management of seizure disorders (including drug treatment, neurosurgery and non-medical or behavioural treatments).

The journal reflects the social and psychological burden and impact of the condition on people with epilepsy, their families and society at large, and the methods and ideas that may help to alleviate the disability and stigma, which the condition may cause. The journal aims to share and disseminate knowledge between all disciplines that work in the field of epilepsy.

## Chapter 3 **AUDIENCE**

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Epileptologists, neurologists, epilepsy specialist nurses, clinical neurophysiologists, pharmacologists, psychiatrists.

## Chapter 4 **IMPACT FACTOR**

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## Chapter 5 **ABSTRACTING AND INDEXING**

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The body of the text of these articles should be limited in length to 4,000 words, and there should be a maximum of 6 figures or tables. Additional figures, tables and other material (such as associated videos) can be submitted as online only Supporting Information (see section 'preparation of manuscripts' for further details). Full length research articles should be preceded by an abstract. The body of the text of the article should be clearly structured into 1) Introduction, 2) Methods 3) Results, 4) Discussion, 5) Conclusion and 6) References.

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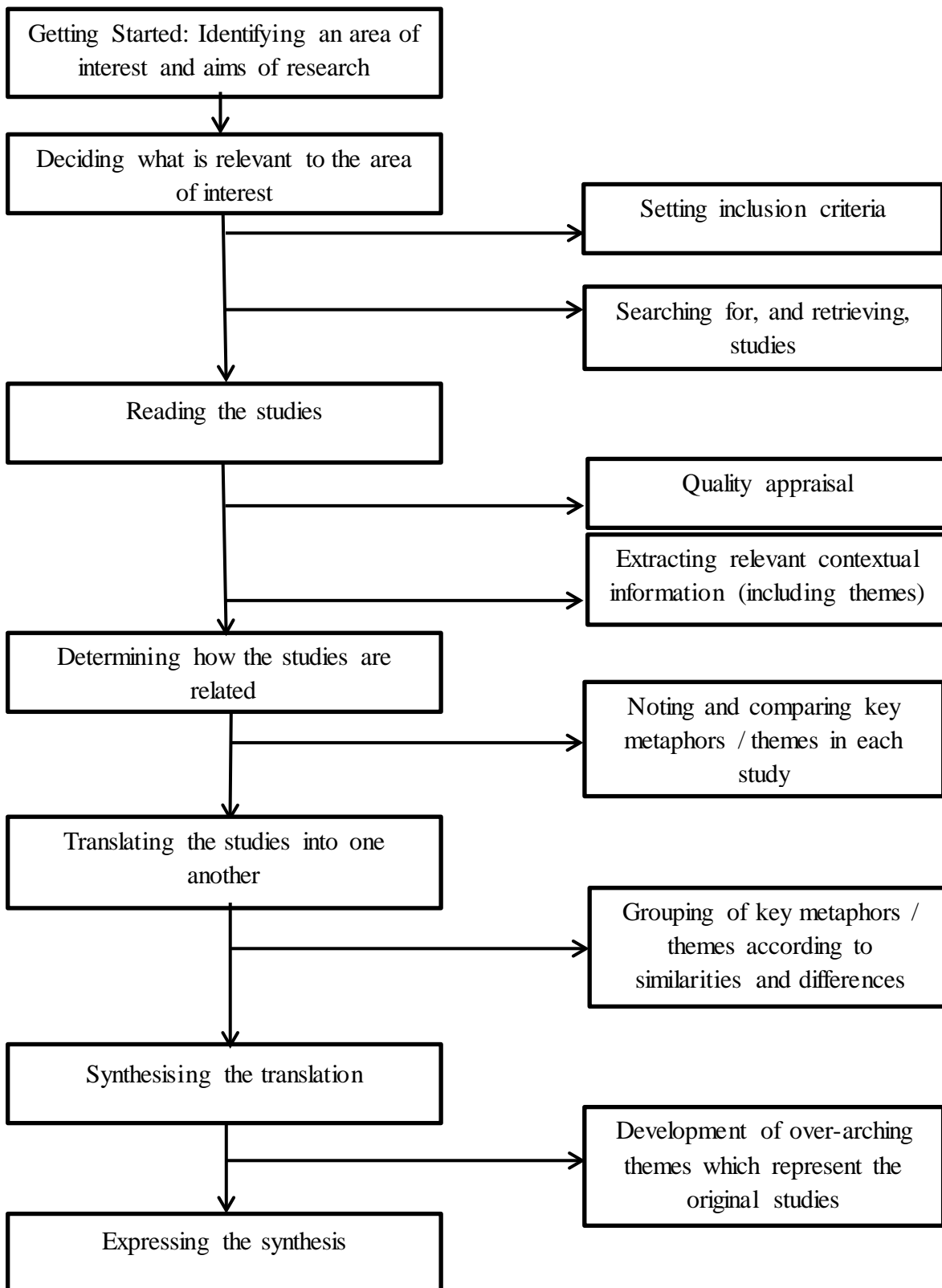
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Appendix 1B

Figure showing stages of meta-synthesis in accordance to guidance provided by Noblit and Hare (1988).



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## Appendix 1C

## CASP scores for the included studies

Study	Clear statement of aims	Qualitative methodology appropriate	Research Design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research	Total
1	3	3	3	3	3	0	2	2	3	2	24
2	3	3	3	3	3	0	3	3	3	3	27
3	3	3	2	3	2	1	2	3	3	3	26
4	3	3	1	2	3	0	2	2	3	2	21
5	3	3	3	3	2	0	2	3	3	3	25
6	3	3	3	1	1	0	1	2	2	2	18
7a	3	3	2	1	2	0	2	3	3	2	21
7b	3	3	3	2	2	0	3	3	1	2	22
8	2	3	2	2	3	0	1	2	3	3	21
9	3	3	2	3	2	0	2	2	2	3	22
10	3	3	1	1	2	0	2	2	2	2	18
11	3	3	3	3	2	0	1	3	3	3	24
12	3	2	3	3	3	0	1	3	2	2	22
13	3	3	2	3	2	1	2	1	2	3	22
14	3	3	2	3	2	1	3	3	3	2	25
15	3	3	3	3	3	1	3	3	3	2	26

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## Appendix 1D

Table demonstrating how the themes and quotations from each study contribute to Theme One: Making Sense of Epilepsy

Paper	Original Themes	Supporting quotations
1	Knowledge about epilepsy	“unlike me, he has those...terrible seizures”
2	Living with epilepsy means living a normal life- gaining and maintaining control – <i>Taking on the challenge</i> <i>Accepting the person with epilepsy</i> Giving up hope of recovery, accepting loss of control	“I thought I must be the one ruling things in life, not epilepsy”  “I gave up...what is the point in living”
3	Life with epilepsy: experiences through emotions	“I wasn’t able to accept that I had epilepsy either. I was my own worst enemy”
4	Explaining QOL impacts- the linkage between psychological and social losses	“you don’t feel so confident with yourself. It affects your perception of yourself”
	Restoring ‘normality’ and regaining good QOL	“my confidence came back and I was more normal again, I was me again”
	Factors exacerbating loss	“I wouldn’t class it as a disability for me because it doesn’t affect my everyday life”
5	Ability to work: self-perceived ability to work	“I can work. [if] other people can do it, I can also do it”
	Support and stigma at the workplace: a reflection on epilepsy disclosure	“The staff looked down on me, as though I was an ET [alien]”
	Disclosure of epilepsy	“Cannot let people know I have this disease...this is my weakness”

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6	Basic emotions: hope	“I find it important to keep up hope that [epilepsy] could grow away”
	Negative basic emotions related to experiences in daily life: despair	“I will never get rid of this crap...what have I done to deserve this?”
	Self-evaluating emotions: being valuable; being insignificant	“I have never felt like an epileptic and I see myself just as valuable as anyone else” “I often feel insignificant”
7a	Difficulties with personal development and fulfilment of dreams	“It feels like everyone else is pass you by, everyone else can get ahead...I can’t do that”
	Feelings of alienation	“I have never met anyone with this, so you feel that, no, I’m the only one”
	Meeting ignorance in society	“people are so incredibly ignorant and they know nothing about epilepsy”
7b	A Feeling of inadequacy- of not being able to take full responsibility for one’s child	“I was side stepped...Daddy was not always to be trusted”
	A feeling of guilt: of not being able to fulfil one’s expectations of being the parent one would like to be	“I feel I am the worst Mum”
8	Epilepsy in the application process	“That’s the thing about epilepsy. It’s not the seizures, it’s that effect of feeling different”
9	Maintaining employment with epilepsy Making sense of illness- words used to describe epilepsy	“And there really is nothing that I cannot accomplish or that I can not do” “Your brain just stops functioning and then just starts again”
	Making sense of illness- perceptions of cause	“It’s written for you, there’s nothing you could do about it...it’s in God’s hands”
	Negotiating meaning and significance- managing stigma	“they think it’s jinn”

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## THE LIVED EXPERIENCE OF EPILEPSY

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10		
11	Misconceptions versus ownership of epilepsy	“There’s a stigma about it. That there’s some sort of em connection with mental illness and that epileptics are slow people”
	Avoiding versus sharing epilepsy	“I’ve got quite good at hiding it”
	Embarrassment versus normalising epilepsy	“I don’t feel as confident as I used to”
12	Difficulties living with epilepsy: barriers to obtaining and sustaining employment	“You experience a lot of discrimination”
	Difficulties living with epilepsy: invisibility of epilepsy/need to prove existence of condition	“Epilepsy is not something that you can see...they’re [other people] like well you’re relatively articulate, so you’re just making this up”
	Difficulties living with epilepsy: stigma toward PWE	“A lot of times, us that have epilepsy, they don’t look at us as normal”
	Difficulties living with epilepsy: psychological burden	“It’s hard to keep your head up high”
13	Grappling with uncertainty	“For me to sit here today and not know that in half an hour I might have a seizure...is difficult”
	Sense of vulnerability	“no-one’s infallible”
	Diminished self of self	“it makes me feel like a second rate person”
14	Understanding epilepsy- the epileptic identity	“I hardly go out, and when I do I can only go as far as the cock crows”
	Impact of epilepsy on daily activities	“This illness has greatly paralysed me”
	Impact of epilepsy on relationships with others	“The neighbours treated me like a mad person”

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THE LIVED EXPERIENCE OF EPILEPSY

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15	Accepting the disease as God's will	"Whatever happens to me, I consider it God's will"
	Fighting the disease	"I did everything I could, but I did not get any better"
	Defending oneself against the disease	"I always say to myself that I am quite healthy and there is no difference between others and me"
	Concealing the disease	"I will not tell them I am suffering from epilepsy because I feel ashamed"

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## THE LIVED EXPERIENCE OF EPILEPSY

## Appendix 1E

## Contribution of each study to the meta-synthesis themes

Meta-synthesis theme	Study															
	1	2	3	4	5	6	7a	7b	8	9	10	11	12	13	14	15
1. Making sense of epilepsy	X	X	X	X	X	X	X	X	X	X		X	X	X	X	X
2. The cost of epilepsy	X	X	X	X	X	X	X		X	X	X	X	X	X	X	X
3. Significant of others in coping with epilepsy	X	X	X	X	X	X	X		X	X		X		X	X	X

**Section Two: Research Paper**

How do individuals understand a diagnosis of non-epileptic attack disorder?

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### Abstract

**Background:** Non-epileptic attack disorder (NEAD) is a condition that presents difficulty in terms of diagnosis both for the professional and the individual. How an individual makes sense of a diagnosis is important in terms of how they cope and engage in treatment.

**Aims:** The aim of this research was to explore what it is like to make sense of a diagnosis of NEAD.

**Method:** Six participants took part in semi-structured interviews which were audio recorded. Interpretative phenomenological analysis (IPA) was utilised for analysis of the interviews.

**Results:** Three themes emerged from the analysis: NEAD is a confusing diagnosis: “all it means is it’s not epilepsy”; Legitimising the illness: feeling “like a bit of a fraud”; and NEAD as a challenge to identity: “I want to be more me again”.

**Conclusions:** Sense making in NEAD is a complex process and one which varies from individual to individual. Clinical implications are drawn from the findings, and suggestions for future research are made.

**Declaration of Interests:** None

*Keywords:* Interpretative phenomenological analysis, non-epileptic attack disorder

## MAKING SENSE OF NEAD

### **How do individuals understand a diagnosis of non-epileptic attack disorder?**

Non-epileptic attack disorder (NEAD) is a condition in which individuals experience events that resemble epileptic seizures but these have no electrophysiological correlate or clinical evidence to support a diagnosis of epilepsy [1]. For a diagnosis of NEAD to be given, there must be no obvious alternative physical explanations for the seizures and thus, the diagnosis of NEAD currently relies on the exclusion of other conditions rather than it being a positive diagnosis in its own right [2]. Estimates of NEAD within the general population have been suggested to be in the range of 2-33 per 100,000 people [3], and it has been most commonly reported in females with a peak reported in the age range of 15-24 years [1]. Individuals with NEAD make up 12-18% of those newly presenting specifically with seizures in neurology clinics [4], making it the most common functional (or medically unexplained) condition within neurology clinics [5].

The underlying mechanisms giving rise to NEAD are still not well understood [6]. Proposed models suggest a plethora of psychological, social and neurobiological factors may be involved in the causation, development and maintenance of NEAD [7][8]. Such factors include previous trauma, difficult familial experiences and emotional difficulties, as well as organic factors and poor cognitive functioning, coupled with particular personality styles, illness perceptions, emotional regulation and coping styles [1][8]. The interplay of these factors may be complex and vary between individuals with a differential impact in the causation, development, and maintenance of NEAD [1].

Many terms exist for describing NEAD within the literature, including psychogenic non-epileptic seizures, pseudo-seizures, psychogenic seizures, somatoform disorder, and historically, hysteroepilepsy, with no international consensus on which term to be used [9]. The numerous terms used may indeed add to the complexity of this relatively poorly

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understood condition. Throughout this research paper, the term NEAD will be used, as it is the term most frequently used within the reviewed literature and also within some clinical services [10]. However, the term is not without criticism [11].

Although the differential diagnosis of epilepsy and NEAD has improved in the past 30 years [1], NEAD is still frequently diagnosed at specialist epilepsy clinics, even though the vast majority of individuals will not have concurrent epilepsy [12]. This suggests that there continues to be a lack of diagnostic clarity, and indeed that misdiagnosis of the condition is still common [13]. Indeed, Reuber, Fernández, Bauber, Helmstaedter and Edger [14] propose that the average time for the correct diagnosis of NEAD is over 7 years, often due to a misdiagnosis of epilepsy. Furthermore, it often means that individuals will be treated with antiepileptic medication (AEM) [14], with research indicating that up to 80% of people with NEAD are treated with AEMs [15]. This is concerning as AEMs produce changes in the central nervous system, having both positive and negative effects on mood [16]. They also have cognitive and behavioural consequences, impacting on all aspects of how an individual interacts with the world around them [17] and thus negatively influencing quality of life. In addition to the physical and emotional harm they cause, treatment with antiepileptic medication could also further strengthen a person's belief that they have a condition other than NEAD.

A positive diagnosis delivery (i.e., a conclusive diagnosis where functional diagnoses are given rather than other diagnoses being excluded) is key for individuals with functional disorders, including NEAD [18][19]. In fact, the neurologist delivering the diagnosis can be all the treatment that an individual may require, helping them see the signs of their condition, reassuring them that there are no other causes of their presentation, that nothing has been missed in the medical examinations, and offering some ways for an individual to alter the

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way they respond to their condition [19][20][21]. For those individuals who do require further psychological or therapeutic input, if the diagnosis has been delivered in a clear and positive way, success in further treatment is more likely and the diagnosis can act as a first step in the therapeutic journey [19][22]. Indeed, Quinn, Scofield & Middleton [23] explored therapists' experiences of successfully treating individuals with NEAD and reported that those whose clients did not have significant trauma were successfully treated for NEAD with sensitive delivery of the diagnosis and brief cognitive therapy.

Despite there being little reliable evidence to support any particular treatment approach [22][24][25], in practice some form of psychotherapy is usually recommended. However, to engage and remain engaged in psychological therapy, individuals have to perceive some potential benefit and be willing to explore the possibility of a psychological explanation [26]. Engagement barriers are also compounded by the fact that reducing seizure frequency in NEAD requires considerable levels of motivation and effort [27]. It is therefore vital to understand the needs and expectations of individuals with NEAD in order to help them adjust to living with a different diagnosis than perhaps they anticipated, and to enable them to be in an informed position to choose whether to engage in psychological treatment. Wyatt, Laraway and Weatherhead [28] found that individuals with NEAD who engaged in psychological therapy found therapy powerful, but also immensely difficult and this was compounded by a continued sense of uncertainty over the diagnosis.

Indeed, illness perceptions are of potential importance in relation to accessing treatment, coping and clinical outcomes [29]. Green, Payne and Barnitt [30] successfully applied an adapted version of Leventhal's self-regulation model to individuals with NEAD, and found acceptance and understanding of the illness, from both the perspective of the individual and by others, are important in the illness representations of NEAD, alongside

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previously identified domains of illness identity, cause, consequence, timeline and cure/controllability of the illness. Interestingly, Stone, Binzer and Sharpe [31] found that individuals with NEAD thought that psychological factors were less important in their illness than those with epilepsy did. They also found that individuals with NEAD were more likely to deny the existence of stressful life events, and reported that those with NEAD had a greater external locus of control when compared to individuals with epilepsy. Furthermore, Dickinson et al. [2] reported that individuals with NEAD who adopted epilepsy as an illness prototype had less effective treatment expectations in comparison to individuals who incorporated other illness prototypes, such as anxiety attacks. Conversely, those individuals who explored a psychosocial basis for their illness were more open to, or even demanding of psychotherapeutic interventions [2]. Stone and colleagues [31] suggest that illness beliefs are of importance with regards to treatment, as if an individual holds beliefs that a condition is uncontrollable or permanent it is likely that these beliefs will hamper rehabilitation and psychological treatment.

Moreover, a small study exploring the experiences of receiving a diagnosis of NEAD suggested that the meaning an individual makes of the diagnosis and the subsequent impact of this upon engagement in treatment is of importance [32]. However, meaning making emerged as one theme in this study, and consequently was not explored in great depth. Furthermore, the research study sample was solely female and was completed within one specialist neurosciences service, where neurologists had specialist interests in seizure disorders. It might therefore not be representative of the experience of being given a diagnosis by neurologists who are not specialists in seizure disorders, and arguably this could impact on how people view their condition. A further study exploring what it is like for individuals to have a diagnosis of epilepsy changed to NEAD supported the findings of



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Thompson et al. [32] further suggesting that that communication of the diagnosis is key in treatment motivation and ability to cope [33].

Another small qualitative study [2] also explored how individuals make sense of illness experiences with NEAD, through the use of a standardised semi-structured interview schedule (McGill Illness Narrative Interview Schedule [34]), and specifically explored three distinct forms of reasoning with regards to illness experiences in a deductive manner. The findings suggest the potential impact of illness prototypes and perceived explanatory models on individuals' illness experiences, including treatment expectations and quality of life.

Dickinson and Looper [6] suggest that more qualitative research into the topic of NEAD is needed, highlighting that a goal of qualitative research is to make sense of a phenomenon in terms of the meanings individuals bring to it. Thus, the current research aimed to explore what it is like to make sense of a diagnosis of NEAD. However rather than a deductive approach exploring particular types of reasoning such as Dickinson et al. [2], it took a phenomenologically informed approach [35], exploring inductively the sense making process in the context of individuals' lives. It focused on individuals who had not started psychological therapy, and thus had minimal psychoeducation or other therapy, and also aimed to include male participants, whose voices are seldom heard in NEAD research [36][37].

## **Method**

### **Design**

This study utilised a qualitative design using semi-structured interviews to explore participants' sense making of a diagnosis of NEAD. IPA was used to analyse the data as this methodology is dedicated to the examination of how people make sense of major life

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experiences [38]. It is a phenomenological approach which “aims to clarify situations lived through by persons in everyday life” ([35], p.26), and allows the researcher to analyse what people have said from a psychological perspective, revealing meaning that may not have otherwise been evident [35]. Hermeneutics are of particular importance to IPA, due to its interpretative nature [38]. Smith and Osborn [39] suggest that IPA involves a double hermeneutic in that the researcher is making sense of the participant’s account, and the participant is in turn making sense of the phenomenon being studied within their own life, in this case NEAD. Given the complexity of most human phenomena, IPA studies usually benefit from a concentrated focus on a smaller sample of cases [38] and thus a minimum of six participants was sought.

Interviews were based on a semi-structured interview schedule, (see ethics section, p4-45), informed by previous research (for example [30][32][40]), which was flexible and allowed the interview to be shaped by the experience of the participant. The schedule was designed in consultation both with the field supervisor and an expert patient, who was engaged in psychological therapy at the service and who agreed to give comments and feedback on all documents included in the research (interview schedule, participant information sheets, opt in sheets, consent forms and debrief forms). They completed a feedback sheet about each individual form and this was considered and additions made before submission to ethics.

### **Research approvals**

The research was reviewed and approved by the National Research Ethics Service (see ethics section for approval letter [p. 4-50] and other documents), before being approved by the relevant Research and Development Departments (R&D), (see ethics section for approval letters [p. 4-54] and other documents). Ethical protocols were established to

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provide guidance should participants become distressed (with contact details provided for support organisations) and if a participant had a seizure during the interview (see ethics section 4-48).

### **Participants**

Potential participants were individuals who were on the waiting lists for psychological therapy at one of two neuropsychology departments at hospitals in the North West of England. All participants took part before official therapeutic input started, although some had received a screening appointment from the service to assess their eligibility and determine urgency of treatment required. Individuals were invited to participate if they had a diagnosis of NEAD that had been given by a neurologist, self-identified as struggling to make sense of this diagnosis, did not also have epilepsy, and were not currently in psychological therapy for NEAD.

Potential participants received participant packs either through the post, or in their screening/assessment appointment. These packs contained a participant information sheet, opt in sheet and return envelope (see ethics section, p.4-39, 4-42). Participants were asked to opt in via these packs.

A total of eight participants opted to be contacted by the researcher. The researcher then called them to ensure they met the inclusion criteria and to answer any questions about the research. Six participants then agreed to arrange interviews. One participant changed their mind about participating due to feeling that it was too much of a commitment and the researcher was unable to contact the eighth person. A total of three men and three women took part in the research, all of whom were White British and all of whom were working age adults. Length of time since symptom onset ranged from two years to more than 20 years.

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All participants came from the same research site and no participants opted in to the research from the second site.

### **Data collection**

Interviews were completed between November 2015 and February 2016 and were conducted either on University premises or within the neuropsychology department. The participant and researcher went through the participant information sheet, with the researcher answering any questions. Both the researcher and the participant then considered and signed the informed consent form (see ethics section, p. 4-43). Each interview was audio recorded and later transcribed verbatim. Interviews lasted between 25 and 45 minutes.

### **Data analysis**

IPA guidelines devised by Smith and colleagues [38] were followed. The process of data analysis was done on a case by case basis, with each transcript being looked at in detail before moving onto the next, starting with the interview that the researcher found the most detailed [38].

*Step 1. Reading and re-reading.* The interview transcript was read and re-read in order for the researcher to become immersed in the data. The first reading of the transcript was done alongside listening to the interview in order to ensure that the participant became the focus of the analysis. A reflective journal was kept during the initial reading of and listening to transcripts (see appendix 2B for an extract of this).

*Step 2. Initial noting.* Exploratory comments were made in the margins of transcripts, with descriptive, linguistic and conceptual comments being highlighted by colour coding (see appendix 2C for a transcript extract with exploratory comments in the right margin).

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*Step 3. Developing emergent themes.* The exploratory notes were read again in order for them to be turned into themes. Themes not only included original participant's quotes, but also the researcher's interpretations (see appendix 2C for a transcript with emergent themes in the left margin).

*Step 4. Searching for connections across emergent themes.* The emergent themes were written on post-it notes and spread across a large table, in order for them to be easily moved around. Patterns and connections were searched for, with similar themes being grouped (abstraction [38]) together while opposite themes were placed far away from each other (polarisation [38]). This led to the identification of superordinate themes (subsumption [38]). Appendix 2D displays an example of identification of a superordinate theme for an individual participant.

*Step 5. Moving to the next case.* After the first transcript was read, noted upon, and superordinate themes identified, the researcher moved onto the subsequent transcripts one at a time. It was key for the researcher to treat each case in its own right, allowing new themes to emerge with the new cases. Steps 1-4 were repeated for each subsequent transcript.

*Step 6. Looking for patterns across cases.* The superordinate themes identified from each participant's transcript were written on post-it notes and these were laid out on a large surface. This enabled the researcher to look through and compare the cases, identifying connections and creating final superordinate themes (see appendix 2E for cross-participant super-ordinate themes relating to the entire dataset). An example of this was in drawing the superordinate themes of 'NEAD makes me nuts', 'NEAD is hard to understand' and 'It could have been worse' together to create theme one, 'NEAD is a confusing diagnosis'.

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### **Validity and Reliability**

While the idea of judging quality of qualitative research is contested [41], Elliott, Fischer and Rennie [42], and Yardley [43] have proposed guidelines in order to enhance quality in qualitative analyses. These were consulted in order to improve the validity and reliability of the current research.

The first interview transcript was read by one supervisor in order to offer feedback regarding the content and direction of questioning. The analysis of themes was done in consultation with supervisors experienced in both IPA and in neurological conditions, including NEAD [43]. A transcript was also read by one supervisor when forming emergent themes to ensure the process of theme development was both transparent and grounded in the data [42][43]. A second supervisor with experience and knowledge in the area of NEAD also offered advice and insight into theme development. Further, in order to enhance transparency of the analytic procedure, the report also includes verbatim extracts from the transcripts [42]. Furthermore, contextual information is provided in that the recruitment method is reported [43].

### **Findings**

The aim of the research was to explore sense making following a diagnosis of NEAD. Three themes were created using IPA, which were relevant to the research question. The first theme considers what it meant for participants to try to understand the diagnosis (*NEAD is a confusing diagnosis*). The second theme considers the rationale and processes that participants went through in order to legitimise the diagnosis (*Legitimising the illness*). The final theme considers the participants' interpretation of the many changes in their lives as a consequence of NEAD (*NEAD as impairing life and impacting on identity*).

## MAKING SENSE OF NEAD

**NEAD is a confusing diagnosis: “all it means is it’s not epilepsy”**

While all participants did acknowledge that NEAD was a diagnosis that fitted the experience of their symptoms, they also discussed the difficulty in understanding the diagnosis of NEAD and what sense they made of it in terms of the comparisons and conclusions they drew, as well as their experience of the diagnostic process. The comparison between epilepsy and NEAD was a strong narrative throughout, particularly when previously misdiagnosed with epilepsy, and the (potential) degree of control of the condition was important.

All participants expressed the view that NEAD was a diagnosis that was poorly understood, by themselves, the public, and at times the medical profession. The terminology used for the condition was one source of confusion, both for the participant’s own understanding and in communicating it to others. One term led one participant to feel that other people would interpret their illness as being factitious: “they’ve been called pseudo-seizures...[which] basically means putting it on” (P2). While this was not the participant’s own interpretation of the term, they feared others would misinterpret NEAD based on this terminology and they would be viewed as malingering. Other terminology (e.g., non-epileptic) also did not add clarity when trying to work out what the diagnosis meant, or explain it to others; “the word epilepsy is in there, so they go, ‘so you’ve got epilepsy’ and you say, ‘no’... all it means is it’s not epilepsy isn’t it?” (P6).

In fact, five of the six participants had had a diagnosis of epilepsy at least suggested before they were diagnosed with NEAD, with three participants (P1, P2 & P6) being treated for epilepsy for some time before being told it was actually NEAD that they had. There were acknowledgements that NEAD was far from a “black and white” diagnosis (P1, P2, & P3), and it was not always easy for medical professionals to distinguish it from epilepsy. The

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comparison between epilepsy and NEAD was discussed by all participants as they tried to explain their condition; “with epilepsy you feel like umm just blame my brain, it’s tangible, blame your brain, whereas with NEAD...it’s not tangible” (P1).

Another participant concluded that the difference between epilepsy and NEAD was related to the level of symptom control; “if it’s non-epileptic they [medical professionals] say then you’ve probably got more control over it” (P4). It was apparent that this participant felt some aspect of culpability regarding the condition in that following his diagnosis he perceived that others thought he was in control of his symptoms to some degree. Indeed, the concept of control and culpability was evident in all participants’ narratives, though in different ways. One participant described being questioned about their level of control over seizures from social contacts; “even people say ‘well can’t you stop them?’” (P6), even though from this person’s perspective the seizures were uncontrollable. However, believing that the seizures could be controlled (at least in the future) was comforting and empowering to some participants who felt that control was given back to them through their diagnosis; “you have the power to stop all of this...it’s something I can actually make a difference to by myself” (P5). For others, however, seizure control was not something they could easily envisage and trying to exert a level of control over their seizures resulted in worsening symptoms; “if you fight them you find they come on worse and they last longer” (P6). While most participants hoped for seizure control in the future, one participant perceived seizures to be completely unstoppable and viewed NEAD as a fight that they were losing, which resulted in them feeling like a burden to those around them; “well you can’t stop it, so you just have to try and get on with it...the less fuss you make about it the better” (P4). This led to feelings of helplessness and resignation that the seizures were out of his control.



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In addition to seeing seizures as uncontrollable, being diagnosed with NEAD could be frightening for the participant themselves as it often represented a move from a physical explanation to a psychological explanation; “to be told ‘no you’re actually going to see a psychologist’...was a bit scary to be honest” (P3). Both the idea of seeing a psychologist and the understanding that NEAD had a psychological explanation meant that participants equated NEAD with being ‘mad’; “I’m a nut job now, officially a nutter”, (P3); “nuts is a much better word”, (P4); “Oh I’m mad, I must be mad” (P1).

While being diagnosed with NEAD could be frightening for some, it was simultaneously perceived as reassuring. Participants were relieved that they did not have something perceived as more serious; “it meant that I wasn’t dying” (P5). Participant 5 explained; “if it’s not the obvious thing that causes seizures is it going to be something really bad...like...a brain tumour or something” (P5). Another participant also referred to fears of a brain tumour; “there’s a history in my family of tumours...so that was the big scare for me” (P3). For this participant, however, it was of utmost importance that NEAD had a ‘cure’; “the biggest thing I’ve clung to, yes I’ve got an illness, yes it can be cured” (P3), they were unable to comprehend life where the prognosis was not a cure. This was echoed by another participant who “very much refused to acknowledge” (P5) the possibility that seizures could get worse or treatment would not work. For all of the participants having a diagnosis of NEAD ruled out something more ‘serious’, and thus was of some degree of comfort. This was particularly true for those who perceived the condition as treatable, even though it remained a relatively confusing diagnosis.

### **Legitimising the illness: feeling “like a bit of a fraud”**

This theme represents the processes that participants went through to try to legitimise the diagnosis of NEAD for themselves. Participants found themselves feeling fraudulent

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when comparing their symptoms to others with the same condition, as well as questioning the legitimacy of NEAD as an illness. Participants explored their understanding of the cause associated with NEAD and how this impacted on whether or not they felt they were entitled to have the illness.

Participants tried to legitimise their experience by comparing their symptoms and even the causation of NEAD to others, and often drew conclusions that they were not as entitled to have the diagnosis. All participants felt that their symptoms were not as bad as others; “everyone I talk to seems to have worse symptoms than I do” (P3). Most of these comparisons occurred through online support groups, with participants feeling “like a bit of a fraud” (P3) as a result of the comparisons. For one participant this was in relation to aspects of life that they had managed to keep hold of, such as driving, “I could still drive, and I wasn’t going to face the risk of losing my job” (P5). Participants also felt that they were able to cope better because their symptoms were less severe; “it’s not having as much impact on my life” (P1), and they were able to appreciate that they were almost lucky in comparison to others as they only had NEAD; “everybody I seem to talk to...not only have this non-epileptic attack disorder but they also have...PTSD [post-traumatic stress disorder] or some sort of schizophrenia or something as well” (P5).

Another aspect of feeling like a fraud was in relation to the cause of NEAD. This was especially relevant for two participants, who thought that finding the exact cause would be of utmost importance in being able to legitimise their diagnosis. For one participant, a comment from a medical professional that “most people [with NEAD] have had sexual abuse” (P2) led her to believe that NEAD may be because of a repressed distressing childhood experience. For this participant, if she were not able to legitimise the diagnosis in this way during her therapy, she thought she may “get the feelings of the diagnosis being less valid because it was

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not down to that” (P2). The importance of finding the cause was also important to another participant who stated that NEAD would not be a tangible explanation for their symptoms; “without more clarification...from a professional” (P1). Although they had been offered some explanation from a neurologist, this participant hoped for an explanation of the root cause of their NEAD during their psychological therapy. However, for another participant, exploring the specific cause of NEAD was something to be avoided; “[finding a cause would] just bring everything to the surface...I think that would be quite frightening” (P6). Instead she wanted the treatment to focus on the here and now.

Further to the desire to find the cause of their NEAD, it was also important to participants that NEAD was a ‘legitimate medical condition’. One participant expressed the view that; “I’ve had it pointed out to me, it’s not a medical condition...it’s up to you to work around it and plug your head back in” (P4). This participant believe NEAD was a “self-inflicted illness” (P4), thus not deserving of the time and effort from professionals that a more ‘medical’ condition might attract. However, other participants appeared to legitimise NEAD through seeing it just as any other medical condition; “there is something wrong with you but it can be fixed with, it’s just a different kind of medicine” (P1). Another participant saw the physical and psychological closely linked and legitimised the diagnosis in this way; “your brain is ill just like any other part of your body” (P5). This sense of NEAD being similar to any other medical condition was echoed in the language of other participants, with participants talking about something that can be ‘fixed’ by appropriate treatment; “it’s this and it’s curable...at some stage in the future I won’t have these seizures” (P3). Hearing more about the diagnosis and what it meant in the screening appointment was legitimising for one participant; “I felt like someone understood for the first time ever” (P6).

## MAKING SENSE OF NEAD

**NEAD as a challenge to identity: “I want to be more me again”**

This theme presents participants’ perceptions of the impact of NEAD on their identity and subsequently how this impaired their life. Participants saw NEAD as responsible for changes in life roles, experiences of discrimination and infantilisation, and a changed sense of self.

Participants felt that changes had occurred to their sense of self as a result of a diagnosis of NEAD. For one participant this was in relation to no longer being able to drive and instead he had to rely on his partner for transport, which made him question his role in the relationship;

“I’m depending on my wife to do all the driving, and call me old fashioned in some respects...if we are both in the car I would sooner be driving...I open the door for my wife, I do all those sorts of things, I think it should be me that transports her around and not the other way around” (P3).

For this participant, NEAD meant the loss of a key role and a negative change in his self-concept, in which driving seemed of utmost importance. This participant was very focused on there being a ‘cure’, as discussed previously, and his inability to consider a life without being ‘cured’ may reflect a fear of permanence of these changes to self-concept, which would be difficult to come to terms with; “I don’t want to say I’m never going to drive...if that’s not going to happen then I need to seriously think about it and try to get my head around it and I suspect that might be quite difficult” (P3).

Loss in terms of driving was also important to another participant in terms of their role as a parent; “[Following treatment] I could get back to things like driving, which would be really good, especially with my little boy...I’m finding those things really hard” (P2).

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NEAD left participants struggling to be independent, describing feelings of being infantilised; “I’m here [at the interview] on my own, my Dad’s probably worried and so is my fiancé”

(P6). This sense of being chaperoned or supervised was also suggested by other participants and created a sense that NEAD made it harder to live a life of independence;

“my wife won’t let me go out on my own, even though I’m out on my own today [at the interview], she’s text[ed] me 6 or 7 times just to make sure I’m alright...I just want to be able to do things on my own” (P3).

Loss of independence also impacted on social roles, with one participant describing trying to organise a social meeting with other individuals with NEAD; “because it’s [NEAD] so unpredictable...trying to get people to turn up is another problem because usually they have to bring someone” (P6). This participant alluded to the fact that individuals with NEAD often have to fit their schedule and social arrangements around other ‘well’ people who have to accompany them. For another participant however, they felt “vulnerable” (P6) when not accompanied, and another explained; “I used to walk around on my own quite happily...ever since I’ve felt a bit on edge...a little bit more vigilant” (P2). Again this links to the sense of a loss of independence, with these vulnerabilities leading to other feelings of childlikeness and a changed sense of self.

Participants also perceived that NEAD had led to loss in relationships, employment and social support, which challenged their self-perceptions. Some participants experienced loss of relationships as a result of NEAD and interpreted themselves as being difficult to be around; “other friends who I used to share hotel rooms with...are like actually no we’re not going to share hotel rooms with you anymore” (P5). The seizures meant that some participants perceived they had become an object of discomfort or even fear to others. Friends did not want to be around them as “they find it too distressing” (P5), or “people

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around you think ‘bloody hell what’s going on here?’ (P1). For others, NEAD had led to a loss of employment due to an inability to work, which also impacted on their role; ‘I used to work...all that’s gone, all of it’ (p6).

Other participants described that NEAD was something they had to manage on their own, reflecting loss of support, in addition to a sense of isolation from others; ‘I’ve gotta manage this, it’s the same with anything isn’t it. You got a cold you’ve gotta get your own tissues and stuff’ (P4). This led to perceptions of being alone with NEAD, in addition to a loss of hope for the future; ‘I don’t like thinking about the future. I can’t see a future’ (P4). This participant did not see a time when he would not have seizures and had little hope for improvement of the condition. This left him to perceive the future with NEAD as a frightening and unpredictable place.

## Discussion

The purpose of this research was to examine the experience of making sense of a diagnosis of NEAD. The major findings suggest that NEAD is perceived as a confusing diagnosis, both for participants themselves and for other people, and which participants tried to legitimise. NEAD was viewed as significantly affecting ability to maintain life roles and responsibilities which impacted on identity. However, in an attempt to make sense of their diagnosis, all the participants in this study acknowledged that they felt NEAD was a diagnosis that did fit with their symptoms, regardless of whether or not they found it hard to understand.

Feeling that NEAD was a diagnosis that did fit with their symptoms when also feeling that NEAD was a difficult diagnosis to understand highlights the complexity that individuals experienced with regards to this diagnosis. Thus, in line with previous research, [2][28][32]

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an overarching finding from the current study is that NEAD was experienced as a confusing and poorly understood diagnosis. The numerous labels in existence used for the condition contributed to the lack of clarity and increased confusion surrounding the diagnosis for participants. Indeed, the experiences of the participants represent the impact that a lack of uniformity in the terminology adopted by medical and health professionals [9] has on individuals diagnosed with NEAD. Interestingly, Stone et al. [18] explored the perceived offensiveness of terminology used for NEAD and found that many of the terms adopted were perceived to be offensive to varying degrees, even those which had been adapted to try to be less stigmatising. Furthermore, Plug, Sharrack and Reuber [44] highlighted the importance of paying attention to an individual's choice of label, proposing 'seizure' as the preferred label for the condition within their study.

The majority of participants had been previously treated for epilepsy, and given the similarity of symptoms it was unsurprising that participants compared NEAD to epilepsy most often in terms of illness models. This was in line with previous research highlighting the comparisons between NEAD and epilepsy in illness prototypes [2][28], and symptom experiences [31]. Within the current research, participants continued to talk of their diagnosis as a physical condition, and although most understood the potential psychological basis, the language used both demonstrated and suggested more medical underpinnings. This may suggest that whilst individuals often accept the psychological basis of NEAD, they also use a medical prototype to frame their illness. This further highlights the difficulty in the process of sense making of a diagnosis that has been previously misdiagnosed as a medical condition, which presents in a way that closely resembles the medical condition, and that is delivered in a medical setting.

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However, at the same time as discussing NEAD as a medical condition, participants made references to 'madness'. In addition, they were relieved, to some degree, that they had NEAD and not something more 'serious' or life threatening, supporting the findings of Thompson et al. [32]. This contrasts with the findings of Wyatt et al. [28] who suggested that the understanding of a psychological basis of NEAD felt more distressing than an organic cause. This interesting contrast may be attributable to differences in sample. Participants in the Wyatt et al. [28] study were engaged in psychological therapy, thus the reality of this implication may have been more prominent than those awaiting this input.

Within the current study the sense that the illness may have a psychological basis, however, did bring into question the level of control participants had and this had implications in terms of self-blame. Previous studies have suggested that individuals with NEAD have a greater external locus of control than those with epilepsy do, indicating that they may experience life events, including seizure experiences, as out of their control and completely unpredictable [31][45]. The current study also identified control as an area of importance but its meaning to participants was more complex and varied between individuals. Five participants interpreted a diagnosis of NEAD as meaning that seizures could, in theory, be controlled to some degree. While for one participant the idea of being able to control their seizures was empowering, the other participants did not talk about seizure control as something that they could easily envisage at the time of interview, although all but one did hope for this in the future, perhaps suggesting a more internal locus of control than Stone et al. [31] and Goldstein et al. [45] found.

However, an increased sense of control was not viewed as completely positive. The possibility of controlling the seizures led to some participants feeling that their illness was self-inflicted in some way and felt that others would judge them to be in control of them and



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using them for self-gain. This fits with Shaver's [46] writings on blame and responsibility, which suggest that when factors establishing personal control are increased (in this case the acknowledgement that NEAD means that seizures are potentially controllable), self-blame attributions are intensified. This was subsequently one reason that participants felt they needed to try to legitimise their diagnosis of NEAD, in an attempt to reduce feelings of self-blame.

Nettleton [47] suggests that an unsteady or uncertain clinical confirmation of a condition can lead individuals to question whether or not they are fabricating their symptoms. However, this was not found reported in the current research, with participants confident in the authenticity of their symptoms regardless of whether or not they felt legitimised to have them. Participants described further attempts to legitimise their diagnosis and increase certainty, for example via social comparison (see for example Charmaz's study of chronic illness [48]). As Charmaz [48] suggests, this did go some way to increase some participants' sense of certainty in the diagnosis of NEAD as they read descriptions that they could relate to. However, while increasing feelings of certainty in their condition, for some participants these social comparisons also led to feelings of being a fraud and risked de-legitimising their experiences of having NEAD, and led to questions about the cause of it.

Illness perceptions have been suggested to be of importance in relation to coping with an illness and eventual outcomes [29]. Green et al., [30] explored illness beliefs in individuals with NEAD and suggested that a clear illness identity and understanding of the mechanisms that cause seizures may be fundamental to successful management of symptoms. Greenberg et al. [49] suggest that prior to seeing a professional for diagnosis, individuals do not always report an explicit cause with regards to illness, but do view cause as one of the most important pieces of information for the professional to explain with regards to a

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diagnosis. Furthermore, Benyamini, Leventhal and Leventhal [50] suggest that symptoms and diagnoses that are often unexpected may have threatening implications and thus stimulate the search for a cause. In this study, participants were mixed in their desire to find the specific cause of their illness. While some already had a clear hypothesis about the cause (such as an ex-army serviceperson who had witnessed trauma in service), another acknowledged the cause was likely to be psychological but was frightened to explore the past and find the specific causal events, and another wanted evidence of a cause in order to legitimise the diagnosis. Wyatt et al. [28] suggested that participants found it helpful and rewarding to explore the cause within psychological therapy. The findings of the current study suggest that such exploration may not be desired by all, or may need to be approached very sensitively and carefully.

NEAD was experienced as a threat to participants within this study who felt that their role and self-concept were challenged as a result of their condition. Bury [51] suggests that illness, and in particular chronic illness, can be a biographical disruption, something that affects the structures of everyday life and the forms of knowledge that reinforce them. To some extent, the current research would support Bury's [51] writings on chronic illness, where illness is seen as a disruption to self-concept. However, within the current research many participants did not perceive their illness as chronic, despite some having lived with symptoms for some time and therefore were hopeful that they could still return to their pre-illness state. These hopes manifested in the sense of NEAD being potentially 'curable', which was important for some participants as it gave them hope that they could be their pre-ill selves.

Charmaz [52] also writes on the "crumbling away" (p. 168) of the former self as a consequence of chronic illness, resulting in restricted lives, social isolation, being discredited

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and being a burden onto others. This was supported by the current research, with one participant almost resigning themselves to living in isolation with NEAD, consumed by thoughts that they were 'mad' and that it was 'self-inflicted'. However, both those who were determined that they would be cured and those who felt resigned to living with NEAD were willing and optimistic to engage in psychological therapy, indicating that there was a hope for some level of improvement in symptoms. Again, this might suggest that individuals saw their condition as a time-limited condition, while hoping for a cure and a return to their pre-ill selves, thus did not lose their self-concept to the extent that those who identify with chronic illnesses may do [51][52].

### **Clinical Implications**

In this study, the process of sense making was complex and individualised. However, all participants were trying to understand more about their condition, which supports recent review findings suggesting psychoeducation is an important part of treatment [7][24][25][53]. This need not be delivered by a psychologist or therapist, for some individuals a concise and explicit delivery of the diagnosis (for example by a neurologist) can be all the treatment that is required [53][54]. This is important considering that only 65% of neurologists in the UK are able to refer all their clients for psychological treatment [10]. However, the participants in this study had not experienced a concise and explicit delivery of the diagnosis. Participants may have struggled to take the information in, perhaps not surprising since 40-80% of information provided in a consultation is immediately forgotten [55], and half of what is remembered is incorrect [56]. Information may therefore need to be given slowly and over several consultations [19][57][58].

However, Dworetzky [59] suggests that only 10% of epilepsy experts explain the possibility of NEAD as a diagnosis when it is relevant, suggesting that even for professionals

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who should be familiar with this diagnosis it is still not perceived to be easy to discuss. In addition, the perceived psychiatric nature of NEAD can lead neurologists to feeling underequipped in managing the condition, making it a difficult topic for them [10][23]. The need for continuing research and education in the area of communicating the diagnosis to an individual with NEAD has been highlighted [59]. Research into delivering a diagnosis of NEAD suggests that providing the diagnostic information alone is insufficient, but rather standardised, structured feedback and psychoeducation can potentially reduce seizure frequency and is perceived by individuals with NEAD to be satisfactory [60][61], and can increase treatment motivation [33]. This appears to be in contrast to Stone's [54] suggestion that a clear diagnosis alone can be all the treatment required, although may continue to highlight the variation in treatment needs for individuals with this condition. The findings of this research paper do not suggest that a satisfactory communication method was experienced by participants.

Furthermore, while some participants sought to explore the cause of their illness, others did not. This supports the writing of Brown et al. [62] that a "one size fits all" model of treatment does not work for individuals with NEAD. Psychological interventions remain the treatment of choice [7][62], but the lack of conclusive recommendations for any particular treatment approach [7][25][53] adds credence to the findings of this study that interventions may need to be individualised to each person. Jimenez et al. [63] suggest that clinical psychologists can be a key speciality within multidisciplinary teams in terms of offering specialist advice and individualised formulation for NEAD. Such person centred formulations can set up appropriate person centred interventions [64]. The individual's own sense making needs should be taken into account, bearing in mind that increasing a sense of control over seizures can also lead to self-blame. Furthermore, individuals differ in their

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preference to explore cause of their illness in depth, which is an important consideration when working therapeutically with someone.

### **Limitations and Future Research**

There were, of course, limitations for the current research. The differences between the current findings and previous similar studies may represent the type of participants that opted into the current study. The participants were on a waiting list for psychological screening or treatment, and thus were therefore likely to have been open to the possibility of a psychological cause. It is likely that those who were not open to a psychological explanation would make sense of their illness in different ways. The current sample also all came from the same psychology service, however they had been referred to that service from various different sources, including neurologists and GPs, in contrast to previous research where all participants had seen specialist neurologists [32]. The sample was also limited in terms of diversity. While recruitment took place in a culturally diverse area, all participants who opted into the research were of white British origin. This raises questions on why other ethnicities did not opt into the research, and would be something that future research could try to address in terms of sampling. Furthermore, six participants may be seen to be a small sample, which cannot be representative of the experience of everyone who receives a diagnosis of NEAD. However IPA aims to provide an in-depth exploration of the experiences of individuals, exploring commonalities and differences and the sample size is commensurate with recommendations [38].

Dickinson and Looper [6] highlight the need for more qualitative research into the topic of NEAD. Future research could explore the sense making processes for those who do not feel that the diagnosis is one that they can accept. This could be interesting and beneficial in supporting such individuals in getting whatever input they require, if any. It may also be

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useful to explore the various treatment interventions and add research to this area in terms of understanding specifically what individuals want from treatment. Outcomes from treatment are still variable [7][25][53], therefore there is much work to be done in finding what works for whom. It would also be interesting to explore what it is like from a clinical psychologist's point of view, with regards to working with individuals who have a diagnosis of NEAD, especially if the individual continues to struggle to make sense of it. A study of experiences of therapists who 'successfully treated' individuals with NEAD has been completed [23], but there is little other research including this population, and including experiences of those who were not 'successfully treated'. Finally, it is clear that the terminology used is difficult and research could help identify an acceptable and useful name for the condition.

### **Conclusion**

The findings of this research provide understanding of the impact that a diagnosis of NEAD has on an individual, specifically in terms of how they make sense of it. This research highlights the difficult and complex process of making sense of a diagnosis that is often poorly understood, and highlights the importance of tailor made interventions for individuals with NEAD.

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Appendix 2A.

Guidelines for authors for *Seizure*

Author guidelines for *Seizure- European Journal of Epilepsy*



# SEIZURE - EUROPEAN JOURNAL OF EPILEPSY

## AUTHOR INFORMATION PACK

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## Chapter 2 **DESCRIPTION**

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*Seizure - European Journal of Epilepsy* is an international journal owned by [Epilepsy Action](#) (the largest member led epilepsy organisation in the UK). It provides a forum for papers on all topics related to **epilepsy** and **seizure disorders**.

*Seizure* focuses especially on **clinical** and **psychosocial** aspects, but will publish papers on the basic sciences related to the condition itself, the differential diagnosis, natural history and epidemiology of **seizures**, as well as the investigation and practical management of seizure disorders (including drug treatment, neurosurgery and non-medical or behavioural treatments).

The journal reflects the social and psychological burden and impact of the condition on people with epilepsy, their families and society at large, and the methods and ideas that may help to alleviate the disability and stigma, which the condition may cause. The journal aims to share and disseminate knowledge between all disciplines that work in the field of epilepsy.

## Chapter 3 **AUDIENCE**

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Epileptologists, neurologists, epilepsy specialist nurses, clinical neurophysiologists, pharmacologists, psychiatrists.

## Chapter 4 **IMPACT FACTOR**

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2014: 1.822 © Thomson Reuters Journal Citation Reports 2015

## Chapter 5 **ABSTRACTING AND INDEXING**

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## Chapter 6 **GUIDE FOR AUTHORS**

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*To find out more, please visit the Preparation section below.*

## **INTRODUCTION**

### **Types of articles**

*Seizure - European Journal of Epilepsy* publishes the following types of article:

#### **1.1 Peer-reviewed articles**

##### **a. Full reviews.**

*Seizure* welcomes comprehensive reviews on all subjects relating to epilepsy and other seizure disorders. Authors planning/proposing are invited to discuss their ideas with Editor-in-Chief prior to submission. Full reviews should be preceded by an abstract. Full reviews should not exceed 7,000 words, include no more than 6 figures or tables and 150 references.

##### **b. Focused reviews.**

*Seizure* is keen to publish focused reviews, especially on the latest developments in particular fields or on topics which are currently debated by clinicians and researchers. Authors are welcome to approach the Editor-in-Chief with their idea for a focused review prior to submission. Focused reviews should be preceded by an abstract. Focused reviews should be 1,500-2,500 words, and include no more than 3 figures or tables and 50 references.

##### **c. Full-length original research articles.**

The body of the text of these articles should be limited in length to 4,000 words, and there should be a maximum of 6 figures or tables. Additional figures, tables and other material (such as associated videos) can be submitted as online only Supporting Information (see section 'preparation of manuscripts' for further details). Full length research articles should be preceded by an abstract. The body of the text of the article should be clearly structured into 1) Introduction, 2) Methods 3) Results, 4) Discussion, 5) Conclusion and 6) References.

##### **d. Short communications.**

Comprise a number of different kinds of previously unpublished materials including short reports or small case series. Short communications should be preceded by an abstract. The body of the text is limited to 1,400 words. There are no more than 12 references, and 2 figures or tables (combined).

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**e. Case reports (Clinical Letters)**, see also *Interactive Case Insights* below  
Seizure will also publish particularly instructive case reports in the format of Clinical Letters. Clinical Letters will not be preceded by an abstract. The word count is limited to 1,000 words. Clinical Letters can only include a maximum of 4 references and 2 figures or tables (combined), authors may include additional reading as supplementary material.

### **f. Letters to the Editor**

Letters containing critical assessment of papers recently published in the *Seizure - European Journal of Epilepsy* will be considered for publication in the correspondence section. Letters should not exceed 1,000 words including references as necessary, one table or one figure. Letters should be typed in double spacing, should have a heading and no abbreviations. If related to a previously published article, the article should be identified by title, author(s), and volume/page numbers. All letters are subject to editorial review. At the Editor's discretion, a letter may be sent to authors of the original paper for comment, and both letter and reply may be published together.

### **1.2 Editorially-reviewed material**

Other contributions than original research or review articles will be published at the discretion of the Editor-in-Chief, with only editorial review. Such material includes: obituaries, workshop reports and conference summaries, letters/commentary to the Editors (500 word limit, exceptionally including figures or tables), special (brief) reports from ILAE Commissions or other working groups, book reviews and announcements.

### **1.3 Supplements/Special Editions**

The Editor-in-Chief invites ideas for supplements or special editions of *Seizure* including meeting abstracts. Such materials may be published, but only after prior arrangement with the Editor-in-Chief. Supplements will incur a charge. The page rate for proposed supplements can be negotiated with the Editor-in-Chief. Special editions are issues of *Seizure* wholly or partially dedicated to one particular topic. They may be edited or co-edited by internationally recognised experts in their field. Such experts do not need to be members of the Editorial Board of *Seizure* and are welcome to approach the Editor-in-Chief with their ideas. Special editions of *Seizure* would be expected to contain the same kind of manuscripts which are published in normal editions.

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## MAKING SENSE OF NEAD

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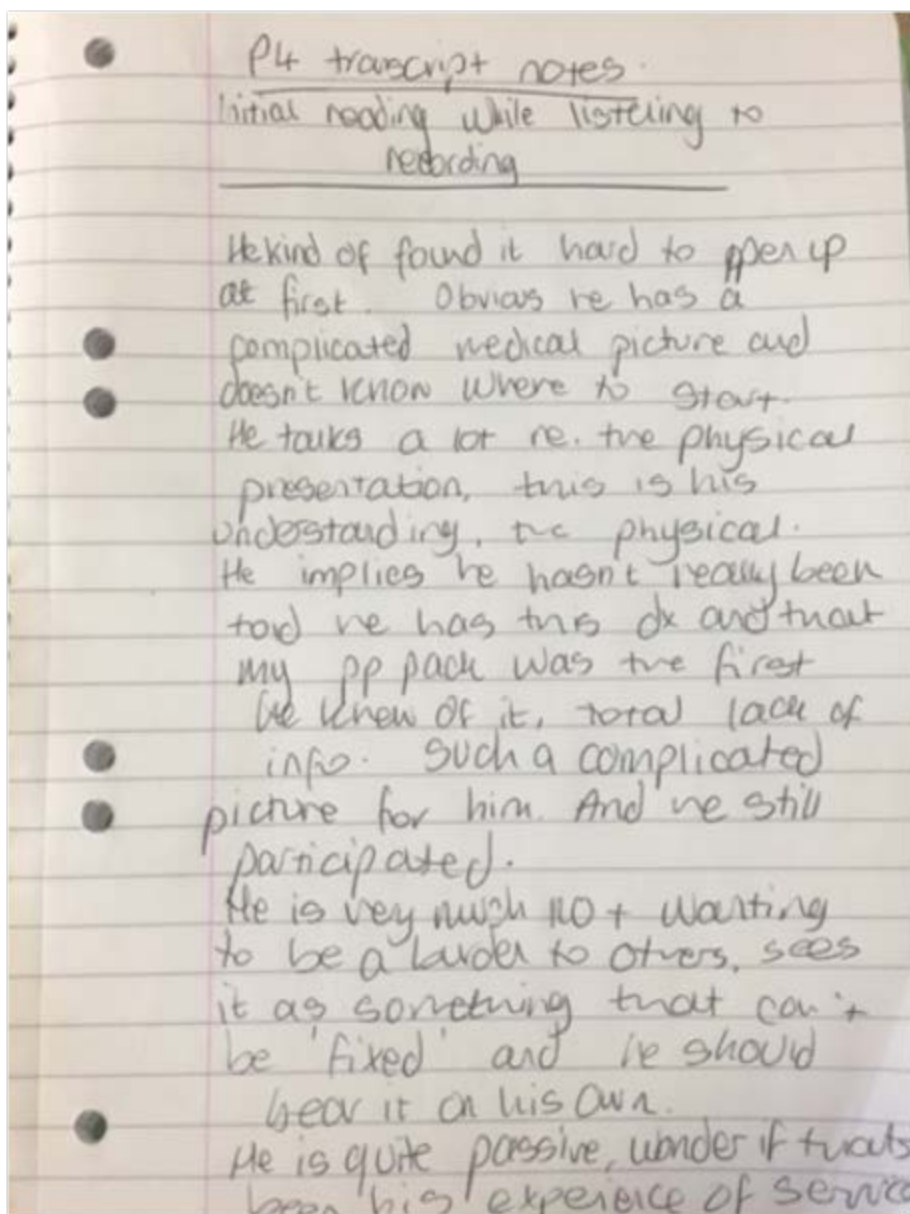
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## Appendix 2B

## Reflective journal extract



## Appendix 2C

Table showing examples of exploratory comments (developed in step two of analysis) and emergent themes (developed in step three of analysis) for a section taken from the transcript of the interview with P3

Emergent Themes	Transcript	Exploratory Comments
Relationships as key	<p>P2: Umm, it's hard to say really, it was only 2 weeks ago so I'm still trying to get everything, you know, in a way I can understand it, umm like I say, we had a, I was open and frank and we had a good discussion about what it wasn't and he actually explained to me about what he thought It was, my wife was in with me as well, my wife has been a rock to be perfectly frank, and she showed him some videos of me having these episodes and that kind of confirmed really his thinking. Umm, it was almost as if I was disembodied in some respects, I was sat there, I know I was sat there, but I was looking at it from afar not quite understanding what was going on, it took me some time really to filter down to where we were at and it was all a big quick and a bit, I think I was in there about 35 minutes or something like that but it didn't seem that, it seemed like minutes, umm and it was a bit, I was like rabbit in the headlights kind of thing</p>	<p>It's hard to understand NEAD</p> <p>Discussions help His wife is key in coping The proof is in the videos</p> <p>Overwhelming process</p> <p>Feeling in danger?</p>
Not understanding/hard to understand	<p>I: And two week ago you didn't know anything about non epileptic attacks?</p>	<p>Treated for epilepsy Not heard of non-epileptic Fraudulent</p> <p>A surprise, unexpected</p>
Epilepsy versus NEAD	<p>P2: No I mean up to seeing the consultant neurologist, I'd been treated for epilepsy so we weren't sure what it was, I'd never heard of non epileptic, in some respects it made me feel a fraud when they said non epileptic, well hang on a minute if it's not epileptic what is it, is it the same thing or similar thing I should say, its only since reading up about it that I now understand a</p>	<p>Repetition of "I know"- almost as if reassuring himself, still feeling fraudulent Everyone is worse shouldn't be feeling this way-not as bad as others- invalidating</p>
NEAD as a shock		



## MAKING SENSE OF NEAD

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Validity linked to severity	little more about it but at the time it came as a bit of a bolt out of the blue	Self-talk, don't understand but trying to make sense
Trying to make sense	I: have those feelings of being a fraud gone now? P2: not really cos I still feel there's this, I know I've got this problem I know I have, I know people out there and have talked to people on facebook and on the internet as well, but everyone I talk to out there seems to have worse symptoms than I have, so I'm thinking hang on a minute why am I thinking I'm this bad when I'm not, seeing other people out there, similar symptoms but a little bit more frequent or they have other problems as well.	Social comparisons aren't helpful, still feels like everyone is worse than him
Social comparisons	So I mean everybody I seem to talk to on facebook or online not only have this non epileptic attack disorder but they also have like umm PTSD or some sort of schizophrenia or something as well, and I'm like well hang on a minute that's not me, not quite sure what's going on here, I don't understand it but, so...	Repetition of I don't know, uncertainty, NEAD causes him to be unsure/uncertain Medical talk, absences
Epilepsy versus NEAD	I: So that's the part that makes you feel like a bit of a fraud? P2: A bit yeah cos I'm, it's almost as if I've got a small amount or whatever or what everyone else has got, umm, and that makes me feel a fraud	Invalidating, being tired for 30 minutes makes him not as bad as others Comparisons reinforce fraudulent feelings
Invalidating social comparisons	I: And in terms of symptoms, is it because of the presentation of the non epileptic attacks and their severity, or more in the comorbid PTSD. P2: Uh I think it's in both ways, I mean I have absences where I don't know where I am, and shaking only down one side as well, so I don't quite know where I'm at with it, it's all quite new in that respect, umm, but yeah like I say the absences I'm, 30 minutes afterwards I don't know much of anything, I can't remember the immediately prior to the start of it so I don't know what triggers and then like I say 30 minutes after it I'm not quite sure where I am. So talked to other people and them saying no they're wiped out for days afterwards, I'm tired and sore but I'm nowhere near that level and that makes me feel somewhat fraud.	Sounds like it makes him question what he has, he thought it made sense but talking to others makes him query this Trying to justify it? Feeling like the measures of anx and dep might prove that he is justified to have it?

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MAKING SENSE OF NEAD

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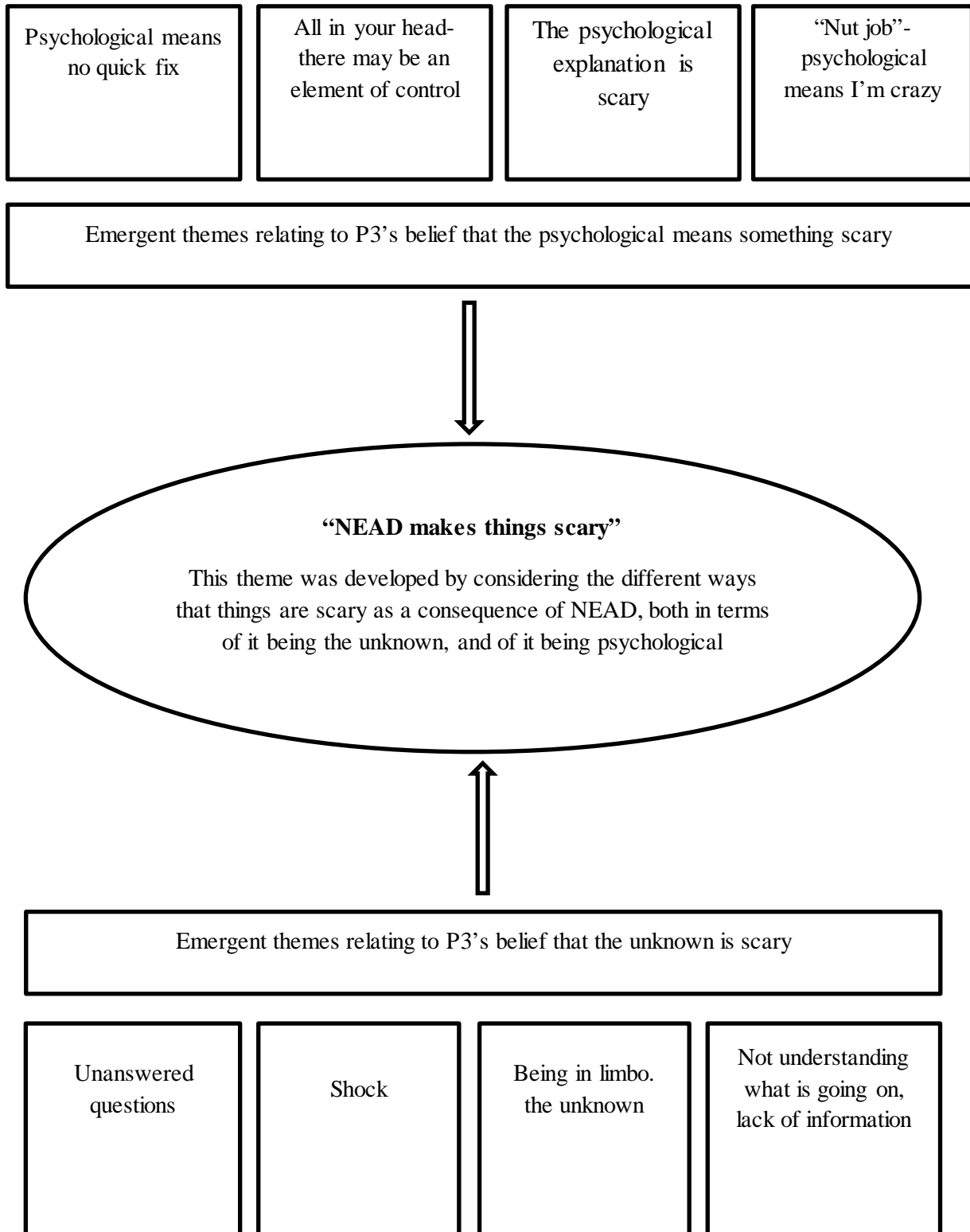
I: So a bit of social comparisons there

P2: Yeah I'm like, oh if I've got this what's everyone else like with this, when you talk to them then you're like hang on a minute I'm nowhere near as bad as they are. Whether that's me thinking I'm nowhere near as bad and comparing it, or whether that is actually true, I don't know but like I say I do have, when I did the depression and anxiety scores for XXX, I came up as moderate on both of those. Now whether that's because I'm worried about what's going on I don't know

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**Appendix 2D**

Figure showing the development of a super-ordinate theme for participant 3 (step four of analysis)



## MAKING SENSE OF NEAD

## Appendix 2E

Table demonstrating how individual super-ordinate themes for each transcript contribute to the development of the super-ordinate themes for the entire dataset (step six of analysis)

<b>Super-ordinate Themes for Entire Dataset</b>	<b>Participant</b>	<b>Individual Super-ordinate Themes Contributing to Super-ordinate Themes for the Entire Dataset</b>	<b>Supporting quotes from original transcripts</b>
Theme One: NEAD is a confusing diagnosis: “all it means is it’s not epilepsy”	P1	NEAD makes everything seem unclear	“well this is the thing, it’s always been really sketchy...there’s never been a black and white conclusive one [diagnosis]”
	P2	NEAD is confusing	“I was in limbo...they might be they might not be...some might be epileptic some might not be”
	P3	NEAD makes things scary: physical vs medical	“to be told no you’re actually going to see a psychologist...was a bit scary to be honest”
	P4	NEAD makes things seem complicated	“If it’s not epilepsy...I assume it was some nervous thing or whatever”
	P5	The unknown is scary	“it wasn’t epilepsy which in one sense made it a bit scarier because I was like well what can it be then”
	P6	It’s not understood	“as soon as you say you’ve got NEAD, the word epilepsy is in there”

## MAKING SENSE OF NEAD

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Theme Two: Legitimising the illness: feeling ‘like a bit of a fraud’	P1	Seeking legitimacy in the illness	“[I’d need] the delivery of a concrete diagnosis, a really sound sort of definition”
	P2	I’m not as bad as others	“he said that usually it’s someone with a history of abuse or sexual abuse”
	P3	I’m a fraud in comparison to others	“the general feeling is that most people think of you as a fraud”
	P4	NEAD is not a legitimate medical illness	“I’ve had it pointed out to me, it’s not a medical condition”
	P5	Brain as any other part of your body	“it’s not something that can be treated with medication but it can be treated”
	P6	Feeling like finally someone understood	“I felt like someone actually understood for the first time ever”
Theme Three: NEAD as impairing life and impacting on identity: “I want to be more me again”	P1	NEAD is invisible and makes me invisible	“it’s not tangible, you can’t see it you can’t, you don’t know why”
	P2	NEAD leads to unpleasant experiences	“I had an experience on a bus where someone cut off my hair”
	P3	It stops you being who you want to be	“I want to be more me again”
	P4	NEAD means that I’m a burden	“I don’t want to waste people’s time at the end of the day, just get on with it.”

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## MAKING SENSE OF NEAD

P5	NEAD limits my life	“what can I do I can’t force them to share a hotel room with me”
P6	My independence is limited as a result of NEAD	“I look back now at what I used to do...all that’s gone, all of it”

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### **Section Three: Critical Appraisal**

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In this critical appraisal I will present a review of the research process. First I will offer a summary of the findings of the literature review and research paper to orientate the reader. I will then discuss the strengths and limitations of the research process, focusing on the difficulties encountered with recruitment, while offering reflections on conducting research within the NHS and particularly within the requirements of a Doctorate in Clinical Psychology thesis. I will go on to highlight comparisons between the findings of the empirical paper and of the literature review. I will expand further on the choice of using interpretative phenomenological analysis (IPA), including a discussion of the epistemology. Finally, I will then provide personal reflections on conducting the research.

### **Summary of findings**

The literature review aimed to explore the lived experience of epilepsy. The findings suggest that epilepsy is a condition that has the potential to change identity, while also resulting in loss in various life domains. It is a condition where the right level of social support can be helpful, while the wrong level can be detrimental. Three themes were identified through the meta-synthesis of 15 studies; ‘making sense of epilepsy’, ‘the cost of epilepsy’ and ‘significance of others in coping with epilepsy’.

Participants discussed how epilepsy had the potential to impact on their sense of self, with discussions around being different to others and what this meant. There were descriptions of powerlessness in relation to epilepsy, with various explanations being given for having the illness, including it being a curse. Some participants saw epilepsy as a blessing in disguise, although these were in the minority. Overall, it was seen as a negative challenge to participants’ identities.

Epilepsy was also described as a costly illness, with descriptions of loss in relationships, employment and meaningful activities. Participants described how their lives had changed as a result of epilepsy, and how this was difficult to come to terms with at times.



Driving was a further important loss for participants, which resulted in reduced independence.

Participants did, however, describe how significant others could help them cope with epilepsy. This was both in relation to social support and spirituality. There was a delicate balance, however, between helpful support and unhelpful support, with descriptions provided of both. Overall, epilepsy was described as a condition with the potential to change many aspects of life and this resulted in some participants describing that it was difficult to cope with.

The aim of the empirical research project was to explore the sense making process for individuals with a diagnosis of non-epileptic attack disorder (NEAD). The findings suggest that it is a difficult diagnosis for individuals to make sense of, and one that has implications on feelings of legitimacy and identity. Three themes were identified through the interpretative phenomenological analysis of the interview transcripts; 'NEAD is a confusing diagnosis'; 'Legitimising the illness'; and 'NEAD as a challenge to identity'.

Participants described that NEAD was a poorly understood diagnosis from a variety of perspectives, including from themselves, from professionals that they had come into contact with, and indeed from society as a whole. Participants' accounts reflected confusion about the labels used to describe NEAD and the impact that these had on the understanding of the condition, including the fact that the term "non-epileptic" includes the word 'epilepsy', thus adding to the confusion. Indeed, epilepsy was a common illness model to which NEAD was compared, and many participants were misdiagnosed with this in the first instance. The psychological nature of NEAD was described as a relief to some, that they could have had a life threatening diagnosis but they had instead received something that was potentially 'curable'. This led to discussions about the perceived control of NEAD, and what this meant to participants.

Participants went to various lengths to legitimise NEAD as an illness. For some participants, NEAD was not a 'medical' condition and thus was not a legitimate illness. Some participants struggled with the idea that NEAD, a psychological illness, was legitimate for them. This was especially relevant when participants engaged in social comparisons, most commonly through online interactions. Here, participants felt like a fraud in comparison to others whose lives were severely limited, whose seizures were interpreted to be much worse, and who were perceived to have more of a justification for their illness. This led on to discussions about the cause of NEAD. Again some participants felt that in comparison to individuals who had experienced traumatic life events, seen as possible causes of developing NEAD, they did not have an obvious attributable cause for their condition. Other participants thought they may have suppressed the real cause and hoped to explore this in therapy, while one participant saw the idea of finding a cause as frightening.

The impact of NEAD upon participants' lives varied but all participants described that the impact of NEAD on their life challenged their identity and sense of self. Participants described a change in their self-perception, both through changing of roles and through feelings of not being able to be who they wanted to be or not being able to be who they previously were. For some, the idea that these changes could be permanent was difficult to come to terms with. In addition, participants described the other ways that NEAD had impacted on their life, and how this resulted in a change in identity. Loss was described in various life domains, including driving, independence, employment and relationships.

In summary, the findings of this research paper have highlighted that individuals find NEAD a diagnosis that is difficult to comprehend and one that impacts on various aspects of life.

**Strengths and limitations of the research process**

A major limitation of this research was that the participants all came from the same research site. While this was not the original intention, and indeed ethical approval was gained for two research sites, it proved very difficult to access participants at the second site. This was due to staffing problems within the neuropsychology department, which meant that relatively few individuals with NEAD were being seen by clinicians. Consequently, only a small number (less than five) of research packs were distributed at this site.

Thomas, Turpin & Meyer [1] suggest that clinical research within the profession of clinical psychology is under threat, and as such, the profession risks losing its research credentials as a result. One suggested explanation for this is cuts to NHS clinical psychology posts resulting in an increased burden on other staff in post [2]. A recent policy document, outlining the vision for research in the NHS, describes that each and every patient within the NHS should be offered the opportunity to take part in research [3]. While at one research site all eligible participants were offered the opportunity to participate in this research, this did not happen for the second research site and more eligible participants are likely to have been identified had resources been available within the service. The paper further suggests that the NHS should be open to research, and while the department within the second research site was open to the research, the aforementioned limitations acted as a barrier to this. This could have been compensated for with the inclusion of another research site, however difficulties within the ethical approval process and time constraints meant this was not feasible.

Thompson and France [4] suggest that the ethical approval process within the NHS needs to be streamlined, highlighting the need for staff training and clarity in guidance. This was also highlighted by the BPS [5] who suggested that the NHS research and ethics governance pose problems for research by clinical psychologists, which subsequently has the potential to limit the development of the knowledge base underpinning psychological

healthcare in the United Kingdom. Indeed, the ethical process for this research project was difficult, with advice being inconsistent in the planning stages. The project was submitted for proportionate review in the first instance, which was upon the advice of the appropriate research and development (R&D) committee. Subsequently this was deemed not appropriate and as a result the project went to the next available research ethics committee (REC) meeting, which was some distance away. This impacted upon the researcher's ability to attend the REC meeting in person, and subsequently delayed the ethical approval process.

Furthermore, while at the main research site participation packs were distributed to all eligible participants, only six of a possible 23 participants opted in the research. It could be that those individuals who did not wish to take part in the research felt more overwhelmed by their diagnosis, or were less open to psychological treatment. Moreover, there is a population that was missed within the current research; those that are diagnosed with NEAD but refuse a referral to psychology. Future research could recruit participants through neurology clinics, capturing the experiences of individuals who are unsure or even opposed to psychological therapy. Thought would have to be given to recruitment as these individuals are likely to be 'hard to reach'. However, understanding more about their experience of making sense of a diagnosis of NEAD would be valuable, especially since NEAD is a heterogeneous experience [6].

However, the research has also filled a previous gap in the literature in that it included male participants, whose voices are seldom heard within research on NEAD [7][8]. The very varied sense-making experiences of participants highlight the need for individualised care, and should individuals wish to engage in psychological therapy, tailor-made approaches.

### **Comparisons between the literature review and research paper findings**

It is interesting to compare the findings of the literature review with those of the research paper. While epilepsy and NEAD are different conditions in terms of their

underlying mechanisms, there were many similarities between how they were experienced by participants.

Research into the quality of life in epilepsy has highlighted that there are high levels of anxiety and depression in individuals with epilepsy, which negatively impacts upon their quality of life [9][10][11][12]. Similarities within the experiences portrayed in the literature review and those in the research paper may suggest that individuals with NEAD are also likely to experience anxiety and depression, in addition to a reduction of quality of life. Indeed, Szaflarski et al. [13] reports that the quality of life is significantly lower in individuals with NEAD than those with epilepsy, while Asmussen, Kirilin, Gale & Chung [14] report specifically on levels of depression and suggest that these do not differ between individuals with NEAD and individuals with epilepsy.

Control was an area of commonality across the papers, with participants discussing the level of control that could be gained over seizures. The difference between this, however, was that within the empirical research individuals were hopeful for a 'cure' and of being able to control seizures, whereas those with epilepsy felt more powerless, with narratives suggesting that there was an acceptance that it was not something they would get 'cured' of. Perhaps these similarities are not surprising since other studies have highlighted the negative impact of factors such as loneliness, loss of independence, fear of seizures, isolation, adjustment and stigma perceptions within individuals with epilepsy [15][16][17][18][19][20], and aspects of these factors are reported on within the literature on NEAD [13][21][22][23][24].

Participants in the empirical research reported that NEAD was a confusing diagnosis, comparing it most often to epilepsy, a condition some perceived as more tangible. Participants within the literature review reported that epilepsy caused them to feel different, with some describing that epilepsy had made them disabled. In common, participants from

both papers discussed how their respective conditions made them feel less confident in themselves, caused changes in their roles and also meant adapting their sense of self.

While participants with NEAD tried to legitimise their illness in terms of its presence and legitimacy as an illness, those with epilepsy tried to make sense of what they had done to deserve their illness. Participants in both papers discussed feelings that things could have been worse, although the negative impact of each condition was evident throughout narratives.

Another interesting similarity between the findings on NEAD and epilepsy was the perceived stigma associated with each condition. Participants within the empirical research experienced thoughts and situations where they were judged negatively as a consequence of having NEAD as opposed to having epilepsy (for example when querying levels of control over their condition), and there was an opinion that epilepsy was a more legitimate and less negative illness. However, in the literature review negative experiences from others as a consequence of stigma associated with epilepsy were evident (for example [25][26][27][28][29]). Dekkers and Domburg [30] suggest that NEAD carries the same stigma that individuals with epilepsy did in former times, but stigma was experienced by participants in both papers. Epilepsy is a condition that has received high levels of historical stigma, and the literature review supports the findings that it remains a stigmatising condition [31].

### **The use of IPA**

IPA has been recommended for research exploring how an individual makes sense of an event in their lives [32]. One to one interviews were conducted, allowing participants to think, speak and be heard, to offer an in-depth and personal discussion [33]. While there is a common misconception that IPA is merely a descriptive methodology [34], it is not an “easy option” [35] (p.103), but rather a methodology that has the potential to be very powerful in

that it concentrates on specific individuals as they deal with a specific event in their life [35].

IPA offers psychologists the opportunity to learn about individuals' experiences from the experts- the individuals themselves [33].

In attempting to retain this idiographic focus, IPA recommends smaller sample sizes [32][33]. Smith and Osborn [36] suggest that IPA is committed to the detailed case by case analysis of individual transcripts rather than focused on generalisability, making it time consuming and more akin to smaller samples. Thus, in the current research, six participants was felt to be adequate to explore the sense making process of individuals with NEAD, especially as it was felt that they offered in-depth discussions. Further, Smith et al. [32] this sample has been recommended for professional doctoral theses.

### **IPA and my epistemological position**

The emphasis of the empirical paper was on the experience of individuals who had received a diagnosis of NEAD, and it employed an IPA approach. IPA does not claim a distinctive epistemological position, but describes itself as “part of a stable of closely connected approaches which share a commitment to the exploration of personal lived experience” [37] (p.41). According to Nightingale and Cromby [38], qualitative research requires an “awareness of the researcher’s contribution to the construction of meaning throughout the research process, and an acknowledgement of the impossibility of remaining ‘outside’ of one’s subject matter while conducting research” (p.228). It is therefore important that a researcher reflects upon their own epistemological position within the research, and what impact their life experiences have on the research process.

Epistemological positions can be understood to lie on a continuum, with positivism positioned at one end, and social constructivism at the other. I most closely identify with a critical realist perspective, which lies somewhere in the middle of the aforementioned continuum [39]. Critical realism accepts that our ability to understand reality is necessarily

influenced (or even constrained) by our own views and contexts, and that there is no one single correct understanding of the world [40].

Critical realism allows for generation of more widely applicable knowledge while refraining from claims to the absolute 'truth' [41]. Therefore, I feel that critical realism is a stance that is well-suited to this particular research project. Furthermore, I feel that IPA allows for a focus on the reflections and observations of the individual (the empirical), while considering how these experiences related to unobservable, underpinning mechanisms. IPA also complements a critical realist stance due to the shared acknowledgement of the influence of the relationship between the researcher and the research.

### **Personal reflections on the research and why I chose this topic**

**Reflexivity.** Kleinsasser [42] suggests that reflexivity is "the process of crucial self-reflection on one's biases, theoretical predispositions and preferences...an acknowledgement of the inquirer's place in the setting, context and social phenomena [s]he seeks to understand" (p.155). Being a researcher grants a lot of power due to the potential to influence the collection and interpretation of data [43]. Finlay and Gough [44] suggest that researchers have therefore come to value reflexivity within their research in order to transform their subjectivity of the qualitative data from a problem into an opportunity.

I found the use of a reflective journal was key in being aware of my own personal biases, predispositions and preferences, valuing the participant's expertise and allowing the interpretations made to be about their experience. It is also important within the process of reflexivity to consider my motivations for choosing the topic.

**Why I chose this topic.** I chose this topic following a placement in a neuropsychology setting where I had the opportunity to work therapeutically with individuals with NEAD. Prior to this, I had never heard of NEAD as a condition, nor did I know much about epilepsy. However, I found extremely interesting that the body can react in such a way



to psychological stress/distress, although I do not believe that NEAD is always as a consequence of these things. I also came across individuals who either did not know when they were having an epileptic or non-epileptic seizure, or did not believe that the diagnosis of NEAD that they had been given was correct. I began to wonder what it was about the diagnosis that makes it complicated, and soon realised how complex the situation surrounding NEAD as a condition is.

I remember subsequently asking a friend, who is a medical doctor, what they knew of individuals with NEAD, to which they responded “it means they are faking it”. Upon doing some literature searches, I realised that NEAD has been and is a condition that carries the stigma of being ‘fake’ (e.g. [45]). Furthermore, I learned that other terms had been used to describe NEAD, including pseudoseizures (e.g. [46][47]). While I did not assume that individuals with NEAD were ‘faking it’, I was aware that pseudo means ‘not genuine’ [48], and that this can lead to misunderstandings, included perhaps by medical professionals.

I was also interested in the lack of a conclusive diagnosis given to individuals, and the ‘wondering’ as opposed to concrete diagnoses evident in many individuals’ referral letters. There is literature on the importance of the delivery of a diagnosis of NEAD (e.g. [49][50][51]), yet this does not appear to have been consistently implemented in practice in many settings.

During the course of conducting this research I returned to the neuropsychology placement to complete a specialist placement. Again, I worked therapeutically with individuals with NEAD and continued to hear stories, both in the therapeutic and research setting, of individuals who were marginalised and who had had negative experiences as a consequence of having NEAD, something that they could not control. These experiences added to my enthusiasm to contribute to the literature, to further the understanding of these

experiences, and to highlight treatment implications, with the hope that ultimately NEAD becomes a condition that is less stigmatised as a whole.

Vogel and Wade [52] suggest that clinical psychologists have a role to play in reducing public stigma about mental health difficulties. They outline the methods which clinical psychologists can achieve this; through protest, education and contact. This research project adds to the literature on NEAD, highlighting the complexities surrounding the diagnosis of NEAD, and how it impacts on individual's lives. I feel that this is an initial step in my journey with NEAD, acknowledging that it is not enough to show compassion or empathy to individuals who are experiencing discrimination and suffering, but future action is needed. Gerber [53] suggests that "just as words and values are needed to sustain our compassion and humanity, so is responsible action" (p.57).

**Reflections on conducting the research.** I found the process of this research both rewarding and challenging. The planning stages were difficult and I found myself having to make adjustments that I did not necessarily feel entirely happy about, in order to meet the requirements of a rather risk adverse REC committee. An example of this was that as the REC had expressed some concern about potential participants' safety and well-being following participation in my research, they requested that I write to participants' GPs to let them know of their participation. I was quite uncomfortable with this, feeling that it breached the confidentiality of taking part in my research. In reality, however, none of the participants were opposed to this.

I realised the importance of developing good relationships with members of the neuropsychology departments in order to facilitate recruitment. This was in many ways made much easier as I was on placement at one research site, although I doubt recruitment would have been successful without the dedicated and helpful administrative team. There were limitations in terms of building this relationship at the second research site, although perhaps

better efforts could have been made to establish these relationships. At this site, however, recruitment was set up through clinical contact rather than through the administration team due to limitations within the service. Although one meeting was set up with other clinical members of the team in order to talk about my research, further relationships could have been established and strengthened with these individuals in order to ensure the research was remembered and prioritised.

In many ways I think that being on placement within the department and regularly working with individuals with NEAD made me much more relaxed about conducting the research interviews. This was especially the case with regards to feeling comfortable managing the potential that talking about NEAD could potentially trigger a seizure, although this did not happen. I found it relatively easy to build rapport, and found that participants were open to exploring their experiences. I debriefed after research interviews and continued taking notes in my reflective journal throughout, which helped me to deal with the sometimes emotional content of the interview.

### **Conclusion**

In conclusion, this research highlights the complex process of sense making that individuals with NEAD can experience. It also highlights that this is not a 'one size fits all' experience, but that different individuals want and need different things with regards to their illness. The importance of professionals bearing this in mind when working with individuals with NEAD is emphasised. Overall the project was interesting and the findings will influence my future clinical practice.

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**Section Four: Ethics Section**

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## ETHICS SECTION

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

**Please enter a short title for this project** (maximum 70 characters)

How do individuals understand of a diagnosis of NEAD?

**1. Is your project research?**

Yes  No

**2. Select one category from the list below:**

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

**If your work does not fit any of these categories, select the option below:**

Other study

**2a. Please answer the following question(s):**

- a) Does the study involve the use of any ionising radiation?  Yes  No
- b) Will you be taking new human tissue samples (or other human biological samples)?  Yes  No
- c) Will you be using existing human tissue samples (or other human biological samples)?  Yes  No

## ETHICS SECTION

**3. In which countries of the UK will the research sites be located?** *(Tick all that apply)*

- England
- Scotland
- Wales
- Northern Ireland

## ETHICS SECTION

**3a. In which country of the UK will the lead NHS R&D office be located:**

- England  
 Scotland  
 Wales  
 Northern Ireland  
 This study does not involve the NHS

**4. Which review bodies are you applying to?**

- HRA Approval  
 NHS/HSC Research and Development offices  
 Social Care Research Ethics Committee  
 Research Ethics Committee  
 Confidentiality Advisory Group (CAG)  
 National Offender Management Service (NOMS) (Prisons & Probation)

*For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.*

**5. Will any research sites in this study be NHS organisations?**

- Yes  No

**5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?**

- Yes  No

*If yes and you have selected HRA Approval in question 4 above, your study will be processed through HRA Approval.*

*If yes, and you have not selected HRA Approval in question 4 above, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).*

**5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.**

- Yes  No

*If yes, you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before submitting other applications. If you have selected HRA Approval in question 4 above your study will be processed through HRA Approval. If not, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).*

**6. Do you plan to include any participants who are children?**

- Yes  No

**7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?**

- Yes  No

*Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory*

## ETHICS SECTION

*Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.*

**8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?**

Yes  No

**9. Is the study or any part of it being undertaken as an educational project?**

Yes  No

Please describe briefly the involvement of the student(s):  
The thesis for a doctoral programme in Clinical Psychology

**9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?**

Yes  No

**10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?**

Yes  No

**11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?**

Yes  No

Chapter 1 Integrated Research Application System  
**Application Form for Research involving qualitative methods only**

  
Health Research Authority

**Application to NHS/HSC Research Ethics Committee**

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

**Short title and version number:** (maximum 70 characters - this will be inserted as header on all forms)  
How do individuals understand of a diagnosis of NEAD?

## ETHICS SECTION

Please complete these details after you have booked the REC application for review.

**REC Name:**  
 [REDACTED]

**REC Reference Number:**  
 15/ES/0136

**Submission date:**  
 05/08/2015

**PART A: Core study information**

**1. ADMINISTRATIVE DETAILS**

**A1. Full title of the research:**

How do individuals understand a diagnosis of non-epileptic attack disorder?

**A2-1. Educational projects**

Name and contact details of student(s):

**Student 1**

	Title Forename/Initials Surname
	Mrs Nicola Tikare
Address	Department of Health and Medicine School of Psychology, Furness Building Lancaster University
Post Code	LA1 4YG
Email	n.tikare@lancaster.ac.uk
Telephone	01524 592970
Fax	

Give details of the educational course or degree for which this research is being undertaken:



## ETHICS SECTION

Name and level of course/ degree:  
 Doctorate in Clinical Psychology

Name of educational establishment:  
 Lancaster University

Name and contact details of academic supervisor(s):

**Academic supervisor 1**

	Title Forename/Initials Surname
	Dr Fiona Eccles
Address	Department of Health and Medicine School of Psychology, Furness Building Lancaster University
Post Code	LA1 4YG
E-mail	f.eccles@lancaster.ac.uk
Telephone	01524 592970
Fax	

Please state which academic supervisor(s) has responsibility for which student(s):

*Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.*

Student(s)	Academic supervisor(s)
------------	------------------------

**Student 1** Mrs Nicola Tikare

Dr Fiona Eccles

*A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.*

**A2-2. Who will act as Chief Investigator for this study?**

- Student  
 Academic supervisor  
 Other

**A3-1. Chief Investigator:**

	Title Forename/Initials Surname
	Mrs Nicola Tikare
Post	Trainee Clinical Psychologist
Qualifications	BSc (Hons) Psychology with Criminology MSc Forensic Psychology
Employer	Lancashire Care NHS Foundation Trust
Work Address	Faculty of Health and Medicine Furness Building, Lancaster University Lancaster
Post Code	LA1 4YG
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## ETHICS SECTION

\* Personal E-mail                      nicla.tikare@live.co.uk  
 Work Telephone                        01524 592970  
 \* Personal Telephone/Mobile 07989164394  
 Fax

*\* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*

*A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.*

**A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?**

*This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.*

	Title Forename/Initials Surname
	Ms Debbie Knight
Address	Research Ethics Officer, Research Support Office B58 Bowland Main Lancaster University
Post Code	LA1 4YT
E-mail	ethics@lancaster.ac.uk
Telephone	01524592605
Fax	

**A5-1. Research reference numbers.** *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version:

Version 1

Protocol Date:

27/07/2015

Funder's reference number:

Project website:

**Additional reference number(s):**

Ref.Number	Description	Reference Number
------------	-------------	------------------

*Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.*

**A5-2. Is this application linked to a previous study or another current application?**

Yes     No

*Please give brief details and reference numbers.*

**2. OVERVIEW OF THE RESEARCH**

## ETHICS SECTION

**A6-1. Summary of the study.** *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

The study will investigate the experience of having a diagnosis of non-epileptic attack disorder (NEAD). In particular it will focus on those who are struggling to make sense of this often confusing diagnosis. NEAD is a condition which is often only diagnosed following a lengthy illness history and which often is misdiagnosed in the first instance. It can be difficult for individuals to accept a psychological explanation for what feels a very physical condition, and this has implications in terms of engagement in psychological treatment. It would be useful to find out more about the experience of coming to terms with this diagnosis, particularly for those who are struggling with this process. Learning more about individuals' experiences may help inform therapeutic approaches, particularly for those who find the condition difficult to understand or accept.

**A6-2. Summary of main issues.** *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

*Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.*

**Purpose and design:**

To understand what it is like to try to come to terms and make sense of a diagnosis of NEAD it is necessary to gain the expertise of the individuals themselves who have experienced this first hand. Thus, a qualitative methodology seems to be most appropriate, which will allow a rich and detailed account of the participants' experiences. Semi-structured interviews ensure that the participant is able to guide the content of the interview, as well as covering specific topics which are informed by previous research. A service user was involved in the development of this proposal, in addition to being advised by research staff at Lancaster University and clinicians at ██████████ Hospital Neuropsychology service and Neurology department, and ██████████ Hospital Neuropsychology service.

**Recruitment:**

Initial identification of and contact with potential participants will be carried out by staff within the services and who have permission to access medical records as part of their current role. A recruitment pack will either be sent out to the individual's home address or will be given to the individual at the initial screening/assessment appointment. Participants will be reassured by the clinician that their decision as to whether or not to participate will not be known by the service and will not affect their care. No incentives will be offered for taking part in the research, but travel expenses up to the value of £20 will be reimbursed. Exclusion criteria: individuals who have a dual diagnosis of NEAD and epilepsy will be excluded from the study as this would be experienced differently to having NEAD alone.

**Consent:**

Potential participants will be provided with the participant information sheet as part of the recruitment pack. If they express an interest in taking part in the study, the Chief Investigator will ring the potential participant and discuss the information sheet with them in detail, allowing time for questions to be answered. Before the interview takes place, the Chief Investigator will go through the information sheet again and ask participants if they have any further questions. They will be reminded that they can withdraw their consent without giving a reason, up until two weeks after the interview. Participants will then be asked to sign a consent form, which will include their consent for the interview to be audio recorded. Participants will also be asked to give consent for their home address to be known by the researcher, if they wish to receive a copy of the report, or their email address if they wish to have the findings emailed to them.

**Risks and benefits:**

Receiving a diagnosis of NEAD can be a distressing experience and discussing this process of feeling uncertain about this diagnosis may be difficult for participants. It is also acknowledged that many individuals who receive a diagnosis of NEAD may have had previous traumatic life experiences. Although these will not explicitly be included in the interview questions, it is possible that participants will talk about them or think about them. To ensure that the risk of distress is minimised, participants will be informed that they can withdraw or take a break from the interview at any point. Participants will also be given a time to discuss any difficult emotions brought up by the interview during the debriefing stage, and will receive a debrief sheet which will signpost them to relevant services. Participants will also be made aware of the limits to confidentiality prior to the interview.

It is possible that talking about the diagnosis could trigger a non-epileptic attack. Participants will be asked during the consent process at ██████████ how best they would like to Chief Investigator to react if they did experience such an attack, and this will be followed. At ██████████, if an attack happened on site the departmental protocol would be followed. Should the participant sustain an injury which would require medical attention either in the

## ETHICS SECTION

community or within the service locations, the respective neuropsychology service protocols would be followed.

The study does not intend to provide any therapeutic benefits to individuals taking part. However, it is hoped that the information gained through the research could help improve the care provided to individuals who struggle to come to terms with their diagnosis of NEAD.

## Confidentiality:

The "Caldicott Principles" and the Data Protection Act (1998) have been consulted during the design of this research. No personal information will be recorded until an individual opts in to the research. Interviews will be audiotaped and transcribed – both the audio recordings and transcriptions will be kept on a password protected account on the Lancaster University network. Recordings will be deleted off the audio recorder upon transfer, and deleted from the network upon submission of the project. Transcriptions will be anonymised. Participants will be allocated a pseudonym which will then be used within the transcripts and in all subsequent analysis and reporting. Transcripts will be kept for ten years following completion or publication of the thesis, whichever is longer. Participants will be informed prior to the interview that confidentiality may have to be broken if the Chief Investigator deems the participant or others to be at significant risk. In this situation, the Chief Investigator would seek advice from the relevant field supervisor, taking the participant's preference into account where possible.

**A6-3. Proportionate review of REC application** *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

Yes - proportionate review     No - review by full REC meeting

*Further comments (optional):*

*Note: This question only applies to the REC application.*

### 3. PURPOSE AND DESIGN OF THE RESEARCH

**A7. Select the appropriate methodology description for this research. Please tick all that apply.**

- Case series/case note review
- Case control
- Cohort observation
- Controlled trial without randomisation
- Cross-sectional study
- Database analysis
- Epidemiology
- Feasibility/pilot study
- Laboratory study
- Metanalysis
- Qualitative research
- Questionnaire, interview or observation study
- Randomised controlled trial
- Other (please specify)

**A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.**

How do people understand a diagnosis of NEAD?

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**A11. What are the secondary research questions/objectives if applicable?** *Please put this in language comprehensible to a lay person.*

N/A

**A12. What is the scientific justification for the research?** *Please put this in language comprehensible to a lay person.*

Non-epileptic attack disorder (NEAD) is characterised by the presence of seizures that may resemble those of an epileptic nature, but have no electrophysiological correlate or clinical evidence that would support a diagnosis of epilepsy (Bodde et al, 2009). The importance of early diagnosis of NEAD has long been recognised (Moore & Baker, 1997), yet the erroneous diagnosis of epilepsy in the first instance is relatively common (Benbadis, 2005) and has a negative impact on long term prognosis. This is further complicated by the large number of labels used when referring to this condition (Scull, 1997), which can cause confusion to both client and practitioner alike.

Non-epileptic attack disorder is a condition where seizures are unconsciously produced. Unless clients accept and understand the diagnosis, they will generally not engage with recommendations and this will ultimately have a negative impact on treatment (Carton, Thompson & Duncan, 2003). Nettleton (2006) describes that diagnoses with an organic basis can prove to be a positive experience for individuals in terms of legitimisation of their symptoms but a diagnosis that correlates with medically unexplained symptoms delegitimises the experience of individuals and makes it difficult for them to accept. It can be difficult to get clients to accept a psychological explanation to what they feel is a very physical problem, which can lead to feelings of confusion and anger following diagnosis, not feeling that their symptoms have been legitimised (Carton, Thompson & Duncan, 2003). Furthermore, with various diagnostic labels for the symptoms of NEAD and a tendency for professionals to misdiagnose, the diagnosis may not be delivered in a concrete manner.

Increasing our understanding of the sense making process for people who have received a diagnosis of NEAD and who are struggling to make sense of it would be helpful in finding the best way to support these clients, who still require a level of support and input. Giving such individuals a voice could help determine the best ways to offer them support, not assuming or demanding that clients must accept the psychological cause of their diagnosis in order to engage fully in therapy.

**A13. Please summarise your design and methodology.** *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

A qualitative methodology was deemed appropriate as the study aims to illuminate the first hand experience of individuals. Semi structured interviews were chosen to gather the qualitative data as this allows the researcher to include areas highlighted by previous research, but ultimately to be guided by the participant.

**Population:**

Potential participants will be recruited from the waiting list within the [REDACTED] Neuropsychology Service and the assessment stage in the [REDACTED] Neuropsychology service. Individuals who have been given a diagnosis of NEAD by a neurologist and who self identify as struggling to make sense of it will be included. Individuals with a dual diagnosis of NEAD and epilepsy will be excluded.

**Recruitment:**

Potential participants will be provided with a copy of the participant information sheet and an opt-in form. If the potential participant expresses interest in the study through returning the opt in form or phoning/emailing the Chief Investigator, they will receive a call from the Chief Investigator who will discuss the participant information sheet with them, discuss the inclusion criteria, and answer any questions. If the individual is willing to participate, a time, date and location for interview would be agreed. For participants at the [REDACTED] Hospital site, a cover letter from the service lead, [REDACTED], will be sent with the other documentation to those on the waiting list via post.

**Interview:**

Participants will be asked to take part in one interview which will last approximately one hour. Before beginning the interview the researcher will discuss the participant information sheet with the participant and again answer any questions. A written consent form will be completed at this point. This will include consent for the interviews to be audiotaped. It is anticipated that these interviews will be conducted between July and November 2015.

During the interview, participants will be asked questions in line with the interview schedule. This schedule is semi structured so that participants can discuss issues which they feel is pertinent to the research question. At the end of the interview, the participant will be given time to discuss anything brought up by the interviews and will be provided with a debrief sheet. This will thank the participant for taking part in the study and point them towards independent sources of support.

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After all interviews have been completed, the Chief Investigator will analyse the transcripts using interpretative phenomenological analysis, with support from the academic supervisor. The final report will be prepared from November 2015 and submitted as part of the Chief Investigator's Doctorate in Clinical Psychology in February 2016.

**A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?**

- Design of the research  
 Management of the research  
 Undertaking the research  
 Analysis of results  
 Dissemination of findings  
 None of the above

*Give details of involvement, or if none please justify the absence of involvement.*

A service user advisor read and commented on the supporting participant documents, including the information sheet, opt in form, informed consent, debrief and interview schedule.

**4. RISKS AND ETHICAL ISSUES**

**RESEARCH PARTICIPANTS**

**A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).**

Potential participants will have received a diagnosis of non-epileptic attack disorder from a neurologist and will self identify as struggling to make sense of this diagnosis.

**A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).**

Potential participants must not have major comorbid neurological problems, for example concurrent epileptic seizures.

Potential participants will not have begun formal psychological therapy (although may have had screening appointments)

**RESEARCH PROCEDURES, RISKS AND BENEFITS**

**A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.**

Please complete the columns for each intervention/procedure as follows:

- Total number of interventions/procedures to be received by each participant as part of the research protocol.
- If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
- Average time taken per intervention/procedure (minutes, hours or days)
- Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Telephone call from Chief Investigator to discuss Participant Information Sheet, answer questions and arrange interview	1		20 minutes	Chief Investigator by phone
Seeking consent	1		15 minutes	Chief Investigator NHS Trust site or appropriate community venue

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Interview	1	60 minutes	Chief Investigator NHS Trust site or appropriate community venue
Debrief	1	10 minutes	Chief Investigator NHS Trust site or appropriate community venue

**A21. How long do you expect each participant to be in the study in total?**

Up to 60 minutes

**A22. What are the potential risks and burdens for research participants and how will you minimise them?**

*For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.*

Participants will be asked to discuss their experience of receiving a diagnosis of NEAD which they are struggling to make sense of. Receiving such a diagnosis can be an upsetting and confusing experience, and this may result in participants becoming upset during interviews. To minimise this risk, participants will be informed prior to the interview that they are able to take a break or stop the interview at any point. They will also be provided with a debrief sheet which gives details of relevant organisations should they feel that they require further support. Participants will have time after the interview to discuss any difficult emotions. If the Chief Investigator is concerned for the participant's safety (or that of others), they will explain to the participant that they must breach confidentiality and discuss this with a supervisor, subsequently taking appropriate action if necessary.

**A23. Will interviews/questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?**

Yes  No

*If Yes, please give details of procedures in place to deal with these issues:*

Interviews will include topics that may be distressing to participants, in particular their experiences after receiving a diagnosis of NEAD. The Chief Investigator is a trainee clinical psychologist who has experience working with individuals in highly emotive situations. The other members of the researcher team are qualified clinical psychologists with extensive experience of working with risk, and will be available to provide support for the Chief Investigator.

If participants disclose any information which identifies concerns over a clinician's practice, the Chief Investigator will discuss this immediately with their academic supervisor.

**A24. What is the potential for benefit to research participants?**

There are no direct therapeutic benefits anticipated for participants taking part in the study, although the process of talking about their experiences may be a positive experience.

**A26. What are the potential risks for the researchers themselves? (if any)**

If the researcher is conducting an interview at community locations they will follow the fieldwork guidance provided by Lancaster University.

This will involve the researcher informing a peer trainee clinical psychologist from the Lancaster University cohort (to be identified and agreed prior to interview being arranged) of her destination, time of arrival and estimated time of return. This includes giving the peer trainee an envelope containing details of the interview, which would be destroyed after the interview if not needed. This information could also be given to the peer clinical psychologist in an emailed password protected file which would be more convenient for interviews arranged at short notice. The researcher would then contact the peer trainee clinical psychologist by telephone to confirm they are safe. If the researcher does not get in contact at the estimated time of return, emergency policies would be employed. Should the researcher be conducting multiple interviews, frequent telephone calls should be placed to keep the peer up to date on her progress and where exactly she is.

The Chief Investigator recognises that completing the interviews is likely to be emotionally challenging at times. She will seek regular supervision and support from other members of the research team, or a peer trainee clinical psychologist, to minimise this risk.

## RECRUITMENT AND INFORMED CONSENT

*In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.*

**A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?** For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).

Potential participants will be identified by a member of the research team who currently works within the neuropsychology service as a member of the direct care team.

Waiting lists and referral information will be screened for inclusion and exclusion criteria. Should it be necessary, medical records will be accessed at this stage to further screen for the inclusion and exclusion criteria. This will be done by a member of the research team, who has access to medical records as part of their clinical duties.

**A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?**

Yes  No

*Please give details below:*

The medical notes of potential participants may be screened to ensure that they meet the inclusion criteria. This will be carried out by a member of the research team who is also a member of the direct care team in the service.

**A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?**

Yes  No

**A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?**

Yes  No

**A29. How and by whom will potential participants first be approached?**

Participants will either be given participant packs by the Clinical Psychologist in the respective service at a screening appointment, or for the [REDACTED] site only, will be sent the information sheet and opt in form via post with a covering letter by the service lead whilst they are on the waiting list.

**A30-1. Will you obtain informed consent from or on behalf of research participants?**

Yes  No

*If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.*

*If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.*

Potential participants will be provided with a written information sheet within their recruitment pack which provides comprehensive information regarding the research and their role. They will have the opportunity to discuss this before opting to take part in the study and again immediately before the interview. At this time, the information sheet will be verbally explained by the researcher, and participants will be given time to ask any questions. They will then be asked



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to sign a consent form, which will be kept by the researcher.

In accordance with the Department of Health's guidance for social scientists on the Mental Capacity Act, capacity will be assumed by the act of consenting to participate. However, the Chief Investigator will use her judgement to determine whether the individual has fully understood the information provided and has been able to make a free decision. The Chief Investigator is a trainee clinical psychologist who has experience of seeking consent from a range of individuals in clinical practice.

Potential participants will be informed that participation is entirely voluntary and accepting or declining to participate will not affect their care in any way.

*If you are not obtaining consent, please explain why not.*

Please enclose a copy of the information sheet(s) and consent form(s).

**A30-2. Will you record informed consent (or advice from consultees) in writing?**

Yes  No

**A31. How long will you allow potential participants to decide whether or not to take part?**

There will be no specified time limit stated but potential participants will be accepted into the research on a first come first served basis with interviews being conducted until this is no longer feasible either due to time constraints or participant numbers being reached.

**A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters)**

Unfortunately there are not funds available to support the use of interpreters. It may also be difficult to fully engage with the sense-making focus of interpretative phenomenological analysis when language is interpreted.

**A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.**

- The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- The participant would continue to be included in the study.
- Not applicable – informed consent will not be sought from any participants in this research.
- Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

*Further details:*

Participants' capacity will be assessed immediately prior to the interview.

Shortly after the interview transcripts will be produced which use pseudonyms and do not include identifiable information and audio recordings will be destroyed.

*If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.*

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

#### Storage and use of personal data during the study

**A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?** (Tick as appropriate)

- Access to medical records by those outside the direct healthcare team
- Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data with other organisations
- Export of personal data outside the EEA
- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
  - Manual files including X-rays
  - NHS computers
  - Home or other personal computers
  - University computers
  - Private company computers
  - Laptop computers

*Further details:*

Participants' personal address will be used by the direct care team in some cases to provide them with recruitment packs. Participants will also be offered the opportunity to receive a brief report of the findings of the study. If they wish to receive this, they will be asked to provide verbal consent for the researcher to keep a record of their address, email address or telephone number.

Direct quotations from participants used in publications will be anonymised using pseudonyms. Participants will be asked to provide consent for their interview to be recorded using an audio device. These files will be transferred to and stored on a password protected computer and will be destroyed following transcription and analysis.

**A38. How will you ensure the confidentiality of personal data?** Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

Personal data will be handled in accordance with the confidentiality model described in the NHS Code of Confidentiality (protect, inform and provide choice).

Data will be kept securely. No personal data will be kept, unless a participant wishes to be informed of the findings of the study as mentioned described above.

Audio recordings will be transferred onto the secure university network with original recordings being deleted upon transfer. Recordings will be transcribed and anonymised. Recordings will be deleted upon submission of the thesis. Consent forms will be scanned onto the university network and stored securely for 10 years following submission or publication of the thesis, whichever is longer.

Anonymised quotes may be used when disseminating the research findings. Participants will complete a consent form which allows them to state whether they are happy for their personal data to be used in an anonymised format within publications.

**A40. Who will have access to participants' personal data during the study?** Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.

Personal data will be accessed by members of the direct care team during the recruitment process. The Chief

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Investigator will have access to personal data if the individual opts into the study and provides this information via an optin form, thus indicating consent for this information to be shared with the Chief Investigator.  
Participants will be advised as to who will have access to their personal data within the participant information sheet.

## Storage and use of data after the end of the study

**A43. How long will personal data be stored or accessed after the study has ended?**

- Less than 3 months  
 3 – 6 months  
 6 – 12 months  
 12 months – 3 years  
 Over 3 years

## INCENTIVES AND PAYMENTS

**A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?**

- Yes  No

*If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.*  
Participants will receive reimbursement of travel expenses from Lancaster University, up to a maximum of £20.

**A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?**

- Yes  No

**A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?**

- Yes  No

## NOTIFICATION OF OTHER PROFESSIONALS

**A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?**

- Yes  No

*If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.*

## PUBLICATION AND DISSEMINATION

**A50. Will the research be registered on a public database?**

- Yes  No

*Please give details, or justify if not registering the research.*

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The research is in partial fulfillment of an educational doctoral research programme, and no suitable database exists.

*Registration of research studies is encouraged wherever possible.*

*You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.*

**A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:**

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- Publication on website
- Other publication
- Submission to regulatory authorities
- Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- No plans to report or disseminate the results
- Other (please specify)

Feedback to the services involved

**A53. Will you inform participants of the results?**

- Yes     No

*Please give details of how you will inform participants or justify if not doing so.*

Participants will be given the opportunity to consent to receive a brief report which will highlight the main findings and implications of the research.

**5. Scientific and Statistical Review**

**A54. How has the scientific quality of the research been assessed? Tick as appropriate:**

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's institution or host organisation
- Review within the research team
- Review by educational supervisor
- Other

*Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:*

The research question has been reviewed by the research department at Lancaster University doctorate in clinical psychology. Both the educational and field supervisors have reviewed the research proposal

*For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.*

*For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/institution.*

**A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.**

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Total international sample size (including UK): 0  
Total in European Economic Area: 0

Further details:

Between 6 and 12 participants will be recruited

**A60. How was the sample size decided upon?** *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

A purposive sampling technique will be adopted to ensure that the participants are best positioned to enable our research question to be explored. A minimum sample size of 6 participants was chosen to ensure that a rich understanding of each individual's experience can be achieved. It was felt that a maximum of 12 participants should be sought, alongside interpretative phenomenological analysis guidelines (Smith, Flowers & Larkin, 2009).

**A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.**

Interpretative phenomenological analysis (IPA) is a qualitative approach committed to the examination of how people make sense of their major life experiences (Smith, Flowers & Larkin, 2009). It has therefore been selected as an appropriate analysis for this research which aims to understand how people make sense of their non-epileptic attacks and having a diagnosis of NEAD. According to Smith, Flowers and Larkin (2009), IPA researchers are engaged in trying to make sense of the participant who is trying to make sense of what is happening to them. IPA is committed to the detailed examination of the particular case, striving to know in detail what the individual person's experience is like and what sense the individual person is making of it (Smith, Flowers & Larkin, 2009). For this reason, IPA studies generally have relatively small sample sizes, with interviews being semi-structured with a flexible interview schedule, giving the participant an important stake over what is covered in the interview. Transcripts are subsequently analysed individually and systematically.

6. MANAGEMENT OF THE RESEARCH

**A63. Other key investigators/collaborators.** *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
Post	[Redacted]		
Qualifications			
Employer			
Work Address			
Post Code	[Redacted]		
Telephone			
Fax			
Mobile			
Work Email	[Redacted]		
Post			

Qualifications	[REDACTED]
Employer	[REDACTED]
Work Address	[REDACTED]
Post Code	[REDACTED]
Telephone	[REDACTED]
Fax	
Mobile	
Work Email	[REDACTED]

#### A64. Details of research sponsor(s)

##### A64-1. Sponsor

###### Lead Sponsor

- Status:  NHS or HSC care organisation  
 Academic  
 Pharmaceutical industry  
 Medical device industry  
 Local Authority  
 Other social care provider (including voluntary sector or private organisation)  
 Other

Commercial status:

*If Other, please specify:*

###### Contact person

Name of organisation Lancaster University  
 Given name Debbie  
 Family name Knight  
 Address Research Ethics Officer, Research Support Office, B58 Bowland Main  
 Town/city Lancaster University  
 Post code LA1 4YT  
 Country UNITED KINGDOM  
 Telephone 01524592605  
 Fax  
 E-mail ethics@lancaster.ac.uk

###### Is the sponsor based outside the UK?

- Yes  No

*Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.*

##### A65. Has external funding for the research been secured?

- Funding secured from one or more funders
- External funding application to one or more funders in progress
- No application for external funding will be made

What type of research project is this?

- Standalone project
- Project that is part of a programme grant
- Project that is part of a Centre grant
- Project that is part of a fellowship/personal award/research training award
- Other

Other – please state:

**A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?**

- Yes  No

*Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.*

**A68-1. Give details of the lead NHS R&D contact for this research:**

	Title	Forename/Initials	Surname
	[REDACTED]		
Organisation	[REDACTED]		
Address	[REDACTED]		
	[REDACTED]		
Post Code	[REDACTED]		
Work Email	[REDACTED]		
Telephone	[REDACTED]		
Fax	[REDACTED]		
Mobile	[REDACTED]		

*Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>*

**A69-1. How long do you expect the study to last in the UK?**

Planned start date: 01/07/2015

Planned end date: 19/02/2016

Total duration:

Years: 0 Months: 7 Days: 19

**A71-2. Where will the research take place? (Tick as appropriate)**

- England
- Scotland

- Wales  
 Northern Ireland  
 Other countries in European Economic Area

Total UK sites in study 2

**Does this trial involve countries outside the EU?**

- Yes  No

**A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:**

- NHS organisations in England 2  
 NHS organisations in Wales  
 NHS organisations in Scotland  
 HSC organisations in Northern Ireland  
 GP practices in England  
 GP practices in Wales  
 GP practices in Scotland  
 GP practices in Northern Ireland  
 Social care organisations  
 Phase 1 trial units  
 Prison establishments  
  
 Independent hospitals  
 Educational establishments  
 Independent research units  
 Other (give details)

Total UK sites in study: 2

**A76. Insurance/indemnity to meet potential legal liabilities**

*Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland*

**A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.**

*Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.*

- NHS indemnity scheme will apply (NHS sponsors only)  
 Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

*Please enclose a copy of relevant documents.*

**A76-2. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as**



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applicable.

*Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.*

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)
- Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

**A76-3. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?**

*Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.*

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- Research includes non-NHS sites (give details of insurance/indemnity arrangements for these sites below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

**PART C: Overview of research sites**

**Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites.** For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site	Investigator/ Collaborator/ Contact
Institution name Department name Street address Town/city Post Code	
Institution name Department name Street address Town/city Post Code	

<b>PART D: Declarations</b>
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**D1. Declaration by Chief Investigator**

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
  - <sup>Ra</sup> Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
  - <sup>Ra</sup> May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
  - <sup>Ra</sup> May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
  - <sup>Ra</sup> Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
  - <sup>Ra</sup> May be sent by email to REC members.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

**Contact point for publication** *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

- Chief Investigator
- Sponsor

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- Study co-ordinator
- Student
- Other – please give details
- None

**Access to application for training purposes** (*Not applicable for R&D Forms*)

*Optional – please tick as appropriate:*

I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Mrs Nicola Tikare on 05/08/2015 11:40.

Job Title/Post:            Trainee Clinical Psychologist  
Organisation:            Lancaster University  
Email:                      n.tikare@lancaster.ac.uk

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**D2. Declaration by the sponsor's representative**

*If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.*

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

*Please note: The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by An authorised approver at ethics@lancaster.ac.uk on 05/08/2015 14:11.

Job Title/Post: Research Support Officer  
 Organisation: Lancaster University  
 Email: s.c.taylor@lancaster.ac.uk

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**D3. Declaration for student projects by academic supervisor(s)**

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

**Academic supervisor 1**

This section was signed electronically by Dr Fiona Eccles on 05/08/2015 12:01.

Job Title/Post:	Lecturer in Health Research
Organisation:	Lancaster University
Email:	f.eccles@lancaster.ac.uk

**RESEARCH PROTOCOL****How do individuals understand a diagnosis of NEAD?**

Principal Investigator Trainee Clinical Psychologist Nicola Tikare

Field Supervisors: [REDACTED]

Research Supervisor: Lecturer in Research Methods Dr Fiona Eccles

**Introduction**

Non-epileptic attack disorder (NEAD) is characterised by the presence of seizures that may resemble those of an epileptic nature, but have no electrophysiological correlate or clinical evidence that would support a diagnosis of epilepsy (Bodde et al, 2009). The importance of early diagnosis of NEAD has long been recognised (Moore & Baker, 1997), yet the erroneous diagnosis of epilepsy in the first instance is relatively common (Benbadis, 2005) and has a negative impact on long term prognosis. This is further complicated by the large number of labels used when referring to this condition (Scull, 1997), which can cause confusion to both client and practitioner alike.

Non-epileptic attack disorder is a condition where seizures are unconsciously produced. According to Reuber, Howlett, Khan and Grunewald (2007) a number of interacting predisposing, precipitating and perpetuating factors exist, including biographical factors (such as abuse or trauma), biological factors (such as gender), psychological factors (such as dissociative tendencies), psychiatric morbidity, neurological comorbidity (such as epilepsy), social aspects (such as friendships), broader cultural factors and opinions or cognitive styles (such as illness perceptions).

Benbadis (2005) suggests that one of the most vital steps in initiating treatment in NEAD is the delivery of the diagnosis, due to the complex and often sensitive reactions on the part of the client<sup>1</sup>. However, it is thought that unless clients accept and understand the diagnosis, they will generally not engage with recommendations and this will ultimately have a negative impact on treatment (Carton, Thompson & Duncan, 2003).

According to Nettleton (2006) obtaining a diagnosis can, with reference to people with conditions such as chronic pain, be a means of legitimising symptoms and illness experience, in addition to facilitating communication with others about the condition. Nettleton (2006) goes on to describe that individuals who obtain an organic basis for their symptoms are more inclined to feel relieved and justified, whereas those who could not

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obtain this concrete diagnosis and who were diagnosed with medically unexplained conditions, felt profound de-legitimisation. It can be difficult to get clients to accept a psychological explanation to what they feel is a very physical problem, which can lead to feelings of confusion and anger following diagnosis of NEAD, a condition with no organic basis, leaving individuals not feeling that their symptoms have been legitimised (Carton, Thompson & Duncan, 2003). Furthermore, with various diagnostic labels for the symptoms of NEAD and a tendency for professionals to misdiagnose, people who then finally receive a diagnosis are understandably confused.

Thompson, Isaac, Rowse, Tooth & Reuber (2009) explored what it is like to receive a diagnosis of NEAD. Their findings suggested that the meaning the client makes of the diagnosis and their understanding of the seizures is important as it impacts upon attitude towards, and engagement in, treatment. However, their sample included only female participants and they were drawn from one neuropsychology service and had seen a neurologist with special interests in seizure disorders. It is reported that NEAD clients are a heterogeneous group (Bodde et al, 2009), suggesting that such limitations in terms of sample, in addition to one recruitment site, make it difficult to transfer these findings to other groups, such as male participants or those seen by different neurologists and from other services. This research will aim to fill this gap in the existing literature.

Green, Payne and Barnitt (2004) examined illness perceptions among people with NEAD in relation to Leventhal's self-regulation model and reported that illness perceptions play an important role and have implications for adjustment to the illness, acceptance of treatment and treatment outcomes. This suggests that understanding the process of sense making of a diagnosis of NEAD could be vital in engaging clients in psychological therapy, in addition to finding the best way to support them.

Wyatt, Laraway and Weatherhead (2014) explored the experience of engaging in psychological therapy while adjusting to a diagnosis of NEAD and found that clients continued to voice uncertainties about their diagnosis while they were in psychological therapy. Although this has implications for engagement in and success of psychological therapy it excludes those who are on the waiting list for psychological therapy and who are trying to make sense of the diagnosis without psychological input. It was also based on a sample from one NHS site and included only one male participant. This research study will focus on the sense making process of people who have received this diagnosis but are on the waiting list for psychological therapy in order to add understanding specifically to what it is like to make sense of this diagnosis, the process that participants may go through, and



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how best they can be supported through this.

Increasing our understanding of the sense making process for people who have received a diagnosis of NEAD and who are struggling to make sense of it would be helpful in finding the best way to support these clients, who still require a level of support and input. Giving such individuals a voice could help determine the best ways to offer them support, not assuming or demanding that clients must immediately accept the psychological cause of their diagnosis in order to engage fully in therapy. Therefore this research will aim to interview people who have received a diagnosis of NEAD, but are struggling to make sense of it. The data will be analysed using interpretative phenomenological analysis as this is methodology dedicated to the examination of how people make sense of major life experiences (Smith, Flowers & Larkin, 2009).

## Method

### **Participants**

Participants will be individuals who have received a diagnosis of NEAD from a neurologist and who self identify as struggling to make sense of this diagnosis. 6-12 participants will be individually interviewed in line with interpretative phenomenological analysis guidelines (Smith, Flowers & Larkin, 2009).

Inclusion criteria:

- Participants will have received a diagnosis of NEAD from a neurologist and self identify as struggling to make sense of this diagnosis.
- Participants will be on the neuropsychology waiting list. Those who have had initial screening or assessment appointments with the neuropsychology department will be eligible

Exclusion criteria:

- Those who have a dual diagnosis of NEAD and epilepsy will be excluded

Participants will be recruited throughout the [REDACTED] areas. The services involved in this research are both neuropsychology departments within general hospital sites, namely [REDACTED] and [REDACTED]. For [REDACTED], participants will be recruited from the psychology waiting list. For [REDACTED], participants will be undergoing the assessment appointments and recruited from here, before beginning formal psychological therapy.

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neurology service receive referrals from the neurology department. Potential participants will either be on the screening waiting list or will have had a screening appointment with the neurology service and be placed on the waiting list. The screening appointments involve giving out some psychoeducation but not any direct therapeutic intervention.

neurology service also receive referrals from the neurology department, but some clients receive video-telemetry to confirm their diagnosis of NEAD. While this is seen as the 'gold standard' in diagnosis, it is still only used for a small percentage of clients as it is expensive, and not all hospitals have access to this facility. Therefore participants will be included regardless of the means used to reach their diagnosis. At neurology service clients have up to two assessment appointments with a clinical psychologist before beginning formal psychological therapy. These assessment appointments may also involve administering psychoeducation, but do not involve any direct therapy.

### **Materials**

A semi-structured interview will be conducted, with questions not being pre-determined but broad topic areas being identified in order to guide questioning (see appendix 4-E for the interview schedule). These topic areas are in line with previous research (Thompson, Isaac, Rowse, Tooth & Reuber, 2009; Green, Payne & Barnitt, 2004; Carton, Thompson & Duncan, 2003) and include: the path to diagnosis, length of time since first symptoms, any previous medical investigations, how participants understand their symptoms and how/whether they try to make sense of them, thoughts on what might be helpful to support the participant and hopes for the future.

### **Procedure**

Participants will be given the participant information sheet (see appendix 4-A), an expression of interest form (see appendix 4-B) and a stamped addressed envelope. These documents will be given out in person by members of the neurology departments at the screening or assessment appointments. These sheets may also be sent to those on the neurology waiting list at a covering letter (appendix 4-F) from the service lead (Consultant Clinical Neuropsychologist). Participants will be asked to contact the researcher in order for her to answer any questions, to ensure that the inclusion criteria are met, and for potential participants to 'opt in'. The researcher will then arrange a suitable time for interview. Contact details will include a university supplied mobile number, university email, or postal address to the

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university site. If more participants than necessary reply (more than 12), participants will be accepted on a first come first served basis.

Interviews will take place on NHS sites where possible, depending on the locality of interviewees, in order to facilitate participation that is most convenient to the participant. Where necessary, interviews may take place in agreed community settings if requested by participants, and Lancaster University fieldwork guidance will be put in place in such instances. This will involve the researcher informing a peer trainee clinical psychologist from the Lancaster University cohort (to be identified and agreed prior to interview being arranged) of her destination, time of arrival and estimated time of return. This includes giving the peer trainee an envelope containing details of the interview, which would be destroyed after the interview if not needed. This information could also be given to the peer clinical psychologist in an emailed password protected file which would be more convenient for interviews arranged at short notice. The researcher would then contact the peer trainee clinical psychologist by telephone to confirm they are safe. If the researcher does not get in contact at the estimated time of return, emergency policies would be employed. Should the researcher be conducting multiple interviews, frequent telephone calls should be placed to keep the peer up to date on her progress and where exactly she is.

Participants will be administered consent forms at interview which highlight that they do not have to participate, and can withdraw their participation up to two weeks after their interview takes place (see appendix 4-C). Debrief forms (appendix 4-D) will be administered following participation. Participant's GPs will be informed of their participation (appendix 4-H).

Interviews will be recorded using digital audio recorders, and subsequently transferred onto the university server, either directly or via a VPN, with original recordings being deleted upon transfer. Electronic recordings will be stored on the university server until submission of the project and then deleted. Interviews will be transcribed and anonymised.

Electronic transcripts of interviews will be stored on the secure University network for 10 years after submission or publication, whichever is longer, and then destroyed by administrative staff. Anonymised paper copies will be kept in a secure box in my home and destroyed upon submission of the report. The consent forms will be scanned to the secure University network and stored by administrative staff for a period of 10 years after submission or publication, whichever is longer. They will subsequently be destroyed by the programme's administrative staff. Paper copies of consent forms will be destroyed as soon as they are scanned to the secure

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network.

### **Proposed analysis**

Interpretative phenomenological analysis (IPA) is a qualitative approach committed to the examination of how people make sense of their major life experiences (Smith, Flowers & Larkin, 2009). It has therefore been selected as an appropriate analysis for this research which aims to understand how people make sense of their non-epileptic attacks and having a diagnosis of NEAD. According to Smith, Flowers and Larkin (2009), IPA researchers are engaged in trying to make sense of the participant who is trying to make sense of what is happening to them. IPA is committed to the detailed examination of the particular case, striving to know in detail what the individual person's experience is like and what sense the individual person is making of it (Smith, Flowers & Larkin, 2009). For this reason, IPA studies generally have relatively small sample sizes, with interviews being semi-structured with a flexible interview schedule, giving the participant an important stake over what is covered in the interview. Transcripts are subsequently analysed individually and systematically.

### **Service user/public involvement**

A service user with a diagnosis of NEAD who was engaged in psychological therapy at the [REDACTED] site provided feedback on the information sheet, informed consent, debrief and opt in forms, as well as the interview schedule and title of the project.

### **Chapter 2 Practical concerns**

Room booking for interviews will be made through the reception staff at the identified building. Photocopying and printing costs will be covered by Lancaster University's Doctorate in Clinical Psychology programme.

Travel expenses, not expected to exceed £20, will be paid to participants where necessary.

### **Ethical concerns**

Identified ethical issues include recovering potentially stressful and difficult times for participants. This has been tackled in terms of including contacts to help with any distress following the project on the debrief forms. As a trainee clinical psychologist I would be able to contain any distress in the interview, pausing and potentially terminating the interview if requested. Contact details of relevant support would be given to participants if they felt distressed following the interview. There is a risk that talking about the diagnosis could trigger a non-epileptic attack. Crisis protocols will be followed in this instance (appendix 4-G). Participants will be asked at the

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beginning of their interview how they would like me to respond if they do have a non-epileptic attack and this will be followed unless the participant is injured in a way that would require medical attention, in which case protocol for the respective neuropsychology department would be followed. At the [REDACTED] site, if a non-epileptic attack is triggered on site, the departmental protocol will be utilised. In a community setting I would continue to follow the participant's wishes where possible, or call 999 if they were injured in a way that would require medical attention.

Should any risks of participants' harm to themselves or others be identified during interview, I would advise participants that the confidentiality agreed at the beginning of the interview would have to be broken in order to seek advice from my respective field supervisor and then I would take appropriate action. This would also be explained during the consent process.

### **Timescale**

Data collection will commence once the necessary approvals are in place (anticipated as the beginning of July 2015). It is hoped that interviews will have been conducted by the end of November 2015. The project will end in February 2016, when it will be submitted. Results will be fed back to participants upon request following submission of the final report.

### **Dissemination**

Research findings will be written up and fed back to both services, and also disseminated via academic presentation at the University of Lancaster. It is intended to submit the findings for publication in an academic journal. The project will be written up and submitted as my academic thesis as part of my DClinPsy course.

### **Project management**

Supervision will be managed through set meetings, in addition to the trainee contacting her research supervisor when in need of advice or support. The field supervisors are also available for general queries regarding contacting participants.

**Timescale**

July- September 2015: obtain ethical approval

September 2015: 1<sup>st</sup> draft of literature review

October 2015-Dec 2015: Collection and analysis of data

October 2015: 2<sup>nd</sup> draft of literature review

January 2016: 1<sup>st</sup> draft research paper

February 2016: 2<sup>nd</sup> draft research paper

February 2016: critical appraisal

Submission February 2016

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**REFERENCES**

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Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.

Thompson, R., Isaac, C., Rowse, G., Tooth, C., & Reuber, M. (2009). What is it like to receive a diagnosis of nonepileptic seizures? *Epilepsy and Behavior*, 14, 508-515. Doi. 10.1016/j.yebeh.2008.12.014

Wyatt, C., Laraway, A., & Weatherhead, S. (2014). The experience of adjusting to a diagnosis of non-epileptic attack disorder (NEAD) and the subsequent process of psychological therapy. *Seizure*, 23, 799-807.

Doi. <http://dx.doi.org/10.1016/j.seizure.2014.06.012>



Appendix 4-A  
Participant Information Sheet

**How do individuals understand a diagnosis of non-epileptic attack disorder?**

My name is Nicola Tikare and I am required to undertake a project as part of my clinical psychology training course. I invite you to take part in the following study. However, before you decide to do so, I need to be sure that you understand firstly why I am doing it, and secondly what it will involve if you agree. I am therefore providing you with the following information. Please read it carefully and be sure to ask any questions you might have and, if you want, discuss it with others including your friends and family. I will do my best to explain the project to you and provide you with any further information you may ask for now or later.

**What is the study about?**

I am interested in finding out more about the experience of making sense of a diagnosis of non-epileptic attack disorder. Some people find this a confusing diagnosis to receive and I am interested in finding out what you think of this diagnosis.

**Do I have to take part?**

No, it is completely your decision. If you decide not to take part you will not hear from me again. Your decision will in no way affect your clinical care.

**What will I be asked to do if I take part?**

If you do decide you would like to take part, you can contact me via email or phone, or alternatively return the enclosed 'opt in' form in the stamped addressed envelope, and I will contact you to discuss the research and arrange participation.

If you do decide you would like to take part, we would make arrangements to meet and complete an interview for approximately 60 minutes at [REDACTED] Hospital, or in a community location if it is more convenient for you.

Travel expenses of up to £20 will be reimbursed upon receiving receipts. The interview will be audio recorded and transcribed (i.e. I will make a written version of it).

**Will my data be confidential?**

The information you provide is confidential. The data collected for this study will be stored securely and only my academic supervisor (Dr. Fiona Eccles) and I will have access to this data:

- Signed consent forms will be scanned onto the secure University network and stored for a period of 10 years after submission or publication, whichever is longer. The paper copies will be destroyed once they have been scanned onto the University network.
- Audio recordings will be transferred onto the secure University network, with originals being deleted upon transfer. Audio recordings will be destroyed once the project has been submitted for examination
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- Anonymised electronic transcripts will be kept for a period of 10 years after submission or publication, whichever is longer, and destroyed by administrative staff.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

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I will inform your GP and clinical psychologist that you are participating in this study, so that if you do require support following the interview they will know that you have been part of the study. As mentioned previously, however, this study is completely separate to your medical care.

### What will happen to the results?

The results will be summarised and reported in an academic project (thesis) and may be submitted for publication in an academic or professional journal. They may also be presented at conferences.

### Can I change my mind?

You can withdraw your consent from the study, without giving a reason, up until 2 weeks after interview. In this instance your data will be destroyed and not used. Your psychologist will not know of your decision to withdraw (unless you tell them) and your decision will in no way affect your clinical care.

### Are there any risks?

There is a possibility that you may feel distressed during or following the interview. If you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

### Are there any benefits to taking part?

There are no direct benefits in taking part.

### Who has reviewed the project?

The [REDACTED], which has responsibility for scrutinising all proposals for medical research on humans in the UK, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from [REDACTED] Foundation Trust, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected. The research proposal has also been reviewed and approved by the local Research and Development departments at [REDACTED] Hospital.

### What should I do next?

If you wish to take part, or for more information on the research, please follow the instructions on the enclosed 'expression of interest form' form. If you do not wish to take part, please ignore this information.

### Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact:

The main researcher:

Nicola Tikare

[n.tikare@lancaster.ac.uk](mailto:n.tikare@lancaster.ac.uk)

(University supplied number  
to be inserted)

Academic supervisor:

Dr Fiona Eccles

[f.eccles@lancaster.ac.uk](mailto:f.eccles@lancaster.ac.uk); 01524 592807

Field Supervisors:

[REDACTED]

[REDACTED]

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### Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Name: Dr Jane Simpson (Research Director)  
Tel: (01524) 592858  
Email: [j.simpson2@lancaster.ac.uk](mailto:j.simpson2@lancaster.ac.uk)  
Division of Health Research  
Furness College  
Lancaster University  
Lancaster  
LA1 4TY

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Professor Roger Pickup  
Tel: +44 (0)1524 593746  
Associate Dean for Research  
Email: [r.pickup@lancaster.ac.uk](mailto:r.pickup@lancaster.ac.uk)  
Faculty of Health and Medicine  
(Division of Biomedical and Life Sciences)  
Lancaster University  
Lancaster  
LA1 4YG

Thank you for taking the time to read this information sheet.

### Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

- [nonepilepticattackdisorder.org.uk](http://nonepilepticattackdisorder.org.uk) – a website set up by others' who have NEAD for information and support
- <https://www.epilepsy.org.uk/> a website for people with epilepsy but also with information for those with NEAD
- <http://www.nonepilepticattacks.info/index.html>: a website set up by professionals for those with NEAD
- The Samaritans on 08457 909090 – a charity offering support to those experiencing distress
- Alternatively, if you feel you would benefit from support with distress or mental health difficulties, then you may wish to speak to your GP about access to local services.

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Appendix 4-B  
Expression of interest form

- If you might be interested in taking part, please contact me by email or telephone (see details below), or fill in this form and return to me in the supplied stamped addressed envelope as soon as possible.
- I will contact you directly to discuss the research and answer any questions you may have.
- You can then either take more time to make up your mind, decide it's not for you, or we can make arrangements for you to take part.

Many thanks  
Nicola Tikare

You can contact me directly via telephone or email:

Tel: 07508375663

Email: n.tikare@lancaster.ac.uk

Alternatively, if you prefer, you can complete below and return it to be in the supplied envelope.

I give permission for Nicola Tikare to contact me directly:

Name(s):

Contact details:

Telephone number:

Email address (if applicable):

Signature:

Notes (please give any details you feel are relevant regarding your contact details): E.g. times or days that are not suitable to call or any other preferences regarding communication.

--

## ETHICS SECTION

Appendix 4-C  
Participant consent form**Study title: How do individuals understand a diagnosis of non-epileptic attack disorder?**

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to Nicola Tikare.

Please initial box after each statement

1. I confirm that I have read the information sheet, asked any questions that I wanted to ask and fully understand what is expected of me within this study
2. I understand that my interview will be audio recorded and then made into an anonymised written transcript, with audio recordings being kept until submission of the project.
3. I understand that my participation is voluntary and that I am free to withdraw any time up to two weeks after interview, without giving any reason, without my medical care or legal rights being affected.
4. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published
5. I consent to confidential information and quotations from my interview being used in reports, conferences and training events. I understand that my information will be confidential unless there is thought to be a risk of harm to myself or others
6. I give permission for you to advise my GP and clinical psychologist of my participation
7. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished or been published, whichever is longer.
8. I consent to take part in the above study

Name of Participant \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

Name of Researcher \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

Appendix 4-D  
Debrief form

**Debrief form**

Thank you for taking part in this research.

**What happens next?**

As we discussed, once the study is complete, Nicola will provide you will a summary of the findings of this research if you have requested this.

**What happens with my travel expenses?**

If you travelled by car all that is needed to claim your travel expenses back is your mileage, which Nicola will ask you about either before or during the interview process.

If you travelled by public transport you will need to provide receipts of your travel. You may need your receipt for your return journey. In this case you will be given a travel expenses form to complete and a freepost envelope to return the form and your receipts to the University.

**What happens if I feel I need support after the interview?**

There are a number of online support and information services available:

- nonepilepticattackdisorder.org.uk – a website set up by others' who have NEAD for information and support
- <https://www.epilepsy.org.uk/> a website for people with epilepsy but also with information for those with NEAD too
- <http://www.nonepilepticattacks.info/index.html> : a website set up by professionals for those with NEAD
- The Samaritans on 08457 909090 – a charity offering support
- Alternatively, if you feel you would benefit from support with distress or mental health difficulties, then you may wish to speak to your GP about access to local services.

Thank you again for your contribution to this research. Please do not hesitate to contact me should you require any further information.

Nicola Tikare

Telephone: University supplied telephone number to be inserted

Email: n.tikare@lancaster.ac.uk

## ETHICS SECTION

Appendix 4-E  
Interview scheduleTitle: **How do individuals understand a diagnosis of non-epileptic attack disorder?**

## Introduction:

Thank you for meeting with me today. My name is Nicola. You might remember from the information sheet that you received that I have a few questions I would like to ask you. It should take approximately 30-60 minutes. If you would rather not answer some questions, this is absolutely fine. If you would like to stop at any time, please let me know and we will stop. What we will talk about will be kept confidential. However, if you tell me that you or someone else is at risk of harm, I will have to report this to a relevant member of staff either at the University or my field supervisor [REDACTED] to keep you or them safe.

I have a digital recorder here to record our interview. This is to make sure I get everything that you say right. Before we start we will go through the information sheet and if you have any questions you can ask them. After that, I will ask you to sign two consent forms, one of which you will keep, which makes sure you understand what is involved in taking part in this research and to clarify that you consent to this.

**General Topics\*:**

- Path/context to diagnosis

For example: when did you first notice symptoms?

What was your path to diagnosis like ie. were you diagnosed with this straightaway, or was it a long path to diagnosis?

Who gave you the diagnosis of non-epileptic attack disorder

What was this experience like?

- Feelings around the diagnosis and basis for uncertainty of it

For example: What do you understand by the diagnosis of non-epileptic attack disorder?

How do you think it fits for you? What made you come to this conclusion?

How do you explain it to others?

Do you know anyone else who has this diagnosis?

- Thoughts on what might be helpful

For example: Do you have any thoughts on what might help with non-epileptic attack disorder?

- Hopes for the future

For example: Can you imagine a time when this will feel like an acceptable diagnosis for you?

Is there anything else that you think would be helpful for me to know?

## ETHICS SECTION

In the information sheet it mentioned that you would be asked if you would like to receive a summary of the research, if this is the case these could be by post, email or telephone, and would be in April or May 2016. Can I please confirm your details if you would like to receive this information.

Thank participant for their involvement in the project.

\* Although general topic questions have been devised to guide the interview, questions will be in response to participant's narratives as per Interpretative Phenomenological Analysis guidance.



## ETHICS SECTION

Appendix 4-F  
Covering letter from main research site

Dear (insert name)

I am writing to tell you about a research project that is currently being conducted within our department by a trainee clinical psychologist, Nicola Tikare. It is a project for people who have received a diagnosis of non-epileptic attack disorder, hence I am sending you the enclosed information to see if you wish to participate.

The project is separate from your treatment. It is entirely your decision whether you choose to take part in the research. Your clinical psychologist will not know your decision (unless you choose to tell them) and your decision to participate or not will in no way affect your treatment or place on the waiting list. It is being completed by a trainee clinical psychologist at Lancaster University, and being supervised within the department here at [REDACTED] Service.

This letter has been sent out from the Neuropsychology Service and the trainee clinical psychologist will not have access to your details unless you choose to contact her.

If you would like further information and may wish to participate please follow the instructions enclosed. If you do not wish to participate please ignore this letter.

Thank you for taking the time to consider this research.

Yours sincerely

[REDACTED]

Consultant Clinical Neuropsychologist

**Crisis protocol** **Seizure protocol:**

Participants will be asked how they would like the researcher to respond should they have a non-epileptic seizure. They will be advised that this will be followed where possible. The researcher will ask how long seizures usually last for. Should a seizure occur the researcher will ensure that the area is safe, removing any dangerous objects, cushioning the head where possible, and speaking in a calm and reassuring voice.

Should a seizure last for a prolonged period of time, which is considered to be in excess of 5 minutes as per departmental guidelines, the emergency services will be contacted.

**Distress protocol:**

Should the researcher have concerns over the participant's safety, or the safety of others, researcher will contact the relevant field supervisor to discuss. The appropriate additional service would then be contacted if this was felt necessary, which may involve contacting the GP for additional support. If there was an immediate emergency, the emergency services would be contacted.

## ETHICS SECTION

## Appendix 4-H

## Letter to GP

Mrs Nicola Tikare  
Trainee Clinical Psychologist  
Doctorate in clinical psychology  
Faculty of Health and Medicine  
Furness College, Lancaster University  
Lancaster  
LA1 4YG  
(Date to be inserted)

**Doctors address to be inserted**

Dear Dr...

**Re: (insert participant name)**

I am a trainee clinical psychologist who is undertaking some research into non-epileptic attack disorder as part of my doctoral training at Lancaster University. I have recruited participants from [REDACTED] [REDACTED] Neuropsychology Departments.

The above named participant, who is a patient of yours, has agreed to participate. As these types of research projects can sometimes provoke some distressing thoughts and feelings, the research ethics committee has requested that I inform you of this person's participation.

I include the participant information sheet for your records, including contact details should you have any queries.

The participant is aware that I have sent you a letter informing you of their participation.

Many thanks

Nicola Tikare  
Trainee Clinical Psychologist

cc. [REDACTED]

Appendix 4-I  
REC approval

Mrs Nicola Tikare  
 Trainee Clinical Psychologist Lancashire Care  
 NHS Foundation Trust Faculty of Health and  
 Medicine Furness Building, Lancaster  
 University Lancaster  
 LA1 4YG

Date: 22 September 2015  
 Your Ref:  
 Our Ref:




Dear Mrs Tikare

Chapter 3 Study title: How do individuals understand a diagnosis of non- epileptic attack disorder?  
 REC reference: 15/ES/0136  
 IRAS project ID: 174747

Thank you for your letter of 16 September 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, 

#### Chapter 4 Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised](#), subject to the conditions specified below.

#### Chapter 5 Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Chapter 6 You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host

## ETHICS SECTION

organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

#### Chapter 7 Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

Chapter 8 It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

#### Ethical review of research sites NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Chapter 9 Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS

## ETHICS SECTION

research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

## Chapter 10 Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper [Covering letter]		31 July 2015
Covering letter on headed paper [Covering letter]	Version 2	16 September 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		20 July 2015
GP/consultant information sheets or letters [Letter to GP]	1	16 September 2015
Interview schedules or topic guides for participants [Interview schedule]	1	27 July 2015
IRAS Checklist XML [Checklist_05082015]		05 August 2015
IRAS Checklist XML [Checklist_21092015]		21 September 2015
Letters of invitation to participant [IRAS invitation [REDACTED]]	1	27 July 2015
Other [Debrief]	1	27 July 2015
Other [Expression of interest]	1	27 July 2015
Other [Letter to Nicola/Fiona from sponsor]		29 July 2015
Other [Professional indemnity]		04 August 2015
Other [employers liability]		
Other [Debrief]	Version 2	16 September 2015
Other [Crisis protocol]	1	16 September 2015
Participant consent form [Informed consent]	1	27 July 2015
Participant consent form [Informed consent]	Version 2	16 September 2015
Participant information sheet (PIS) [Participant information sheet]	1	27 July 2015
Participant information sheet (PIS) [Participant information sheet]	Version 2	16 September 2015
REC Application Form [REC_Form_05082015]		05 August 2015
Referee's report or other scientific critique report [Critique]		03 August 2015
Research protocol or project proposal [TIKARE thesis protocol]	1	27 July 2015
Summary CV for Chief Investigator (CI) [Nicola Tikare CV]		
Summary CV for supervisor (student research) [Fiona Eccles CV]		

## Chapter 11 Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

## ETHICS SECTION

## Chapter 12 After ethical review

Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

## Chapter 13 User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

## Chapter 14 HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>15/ES/0136</b>
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<b>Please quote this number on all correspondence</b>
-------------------------------------------------------

[REDACTED]

[REDACTED]

Email: eosres.tayside@nhs.net

Enclosures: “After ethical review – guidance for researchers” [SL-AR2]

Debbie Knight, Lancaster University [REDACTED]

[REDACTED]

Appendix 4-J  
R&D approvals

Dear Nicola

<b>R&amp;I</b>	<b>IRAS Ref 174747 (non-portfolio)</b>
<b>Stud</b>	How do individuals understand a diagnosis of non-epileptic attack
<b>REC</b>	

Thank you for submitting the above study for NHS R&I permission. [REDACTED] NHS Foundation Trust is the host site for this non-NIHR portfolio study.

I am pleased to confirm that the Research Office has now received all necessary documentation, and the appropriate governance checks have been undertaken. This letter is issued subject to the research team complying with the attached 'conditions of permission', Trust SOPs, the DH Research Governance Framework, and any other applicable regulatory requirements.

Chapter 16 **List of documents reviewed as part of the Trust permission process:**

Document	Date
REC Application Form	05 August 2015
GP/consultant information sheets	16 September
Interview schedules	27 July 2015
Letters of invitation to participant	27 July 2015
Debrief	16 September
Crisis protocol	16 September
Research protocol	27 July 2015
Participant consent form	16 September
Participant information sheet (PIS)	16 September
NRES Favourable Opinion Letter	22 September
GCP Certificate_Nicola Tikare	22 May 2015

Our agreed recruitment target is 6 participants, to be achieved by 19 February 2016. Should you wish to over-recruit, this needs to be agreed in advance with the sponsor, and the Research Department kept informed.

To meet Department of Health benchmarks for recruitment, you will be expected to recruit the 1<sup>st</sup> patient within 30 days of the date of this letter, i.e. **14 November 2015**

I would like to take this opportunity to wish you well with your research.

Yours sincerely



[REDACTED]

[REDACTED]

[melanie.keeling@lthtr.nhs.uk](mailto:melanie.keeling@lthtr.nhs.uk)

[REDACTED]

[alec.laraway@lthtr.nhs.uk](mailto:alec.laraway@lthtr.nhs.uk)

Dr Fiona Eccles  
Department of Health and Medicine School of Psychology, Furness  
Building Lancaster University





ETHICS SECTION

Chapter 18 I have read the general terms and conditions above and agree to conduct my research in accordance with Trust policies for the conduct of research.

Name of PI (please print): Nicola Tikare

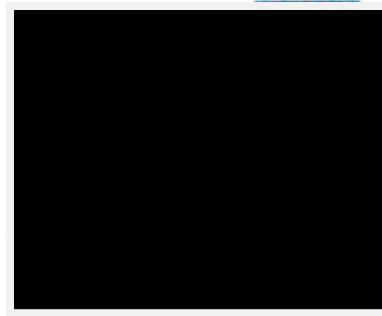
Signed:

.....

..... Date:



**Research & Development Director:** Professor Bill Ollier  
**Research & Development Associate Director:** Rachel Georgiou  
**Research & Development Lead:** Natalie Garratt



### NON-INTERVENTIONAL RESEARCH

24<sup>th</sup> September 2015

Mrs Nicola Tikare  
 Trainee Clinical Psychologist  
 Lancashire Care NHS Foundation Trust  
 Faculty of Health and Medicine  
 Furness Building, Lancaster University  
 Lancaster LA1 4YG

Dear Mrs Tikare

**Study Title:** How do individuals understand a diagnosis of non-epileptic attack disorder?  
**REC Reference:** 15/ES/0136  
**EuDraCT Reference:** N/A  
**IRAS Reference:** 174747  
**R&D Reference:** 2015/133NEURO

### RECRUITMENT OF FIRST PARTICIPANT BY NO LATER THAN 15<sup>TH</sup> OCTOBER 2015

Thank you for providing all the study documentation for the above mentioned study.

I am pleased to inform you that the above study has been given **NHS permission** to start at [REDACTED] Trust.

**This Trust has adopted performance management of recruitment to time and target for all research receiving NHS permission and you are responsible for ensuring that recruitment targets are met and recorded within R&D.**

**As this is a non-interventional study, the Trust expects the first subject to be recruited within 70 days from receipt of a valid application. When the first subject is consented to enter this study please notify R&D Governance Team at [REDACTED]**  
**If there is a delay in your recruitment, please contact us straight away. we can offer advice and escalate issues if needed.**





Permission is granted in accordance to the Research Governance Framework (2005), Medicines for Human Use (Clinical Trials) Regulations 2004, and [redacted] Foundation Trusts local policies.

Whilst you are conducting this study at [redacted] Trust the conditions of this **NHS permission** is that you are compliant with local Trust Policies and Mandatory Training. It is also conditional that any required research passports and letters of access for the research team are in place before you come on site at [redacted] Trust to conduct this research.

On completion of the study you are required to submit a 'Declaration of End of Study' form to the main REC, which should also be copied and forwarded to the R&D office at the address shown in this letter.

Good Luck with recruitment



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ccles  
y

