

Ruby J. Hooper

Extended Proposal

Young People with Epilepsy's Illustrations of Their Narratives: An Arts-Based Approach

What connections can be made between their narratives in the context of these three perspectives? seizures, anti-seizure medications and social perceptions.

Word count: 11,446

Abstract

This is an extended proposal asking epileptic young people, with some guidance from the researcher, to illustrate their narratives of being epileptic. There will be three contexts provided for them, to begin to create their expressions: seizures, anti-seizure medications and social perceptions. Much of the current research focuses on seizure activity so, the focus here will be on a balance of all three. Why these are chosen is explored further here, as all three are in-depth subjects. What connections can be found between the imagery once created, will then be explored from a phenomenological perspective.

Contents

Chapter 1 Introduction	846
<u>Part A Extended Review of the Literature</u>	
Chapter 2 Literature Review the Topic	4079
2.0 – Introduction	
2.1 – Research with young people with epilepsy	
2.2 – Anti-seizure Drugs	
2.3 – Social perceptions	
2.4 – Seizures	
2.5 – Art and epilepsy	
Chapter 3 Literature Review the Conceptual Framework	2924
3.0 – Listening	
3.1 – A Gap in the Literature	
3.2 – Identity and Disability	
3.3 – Phenomenology	
<u>Part B The Research Proposal</u>	
Chapter 4 The Research Proposal	545
Chapter 5 Research Design, Research Methods and Methods of Analysis	2586
5.0 – Research Design	
5.1 – Phase 1 Building Confidence	
5.2 – Phase 2 Building Relationships	
5.3 – Phase 3 Generating the Art	
5.4 – The Three Context: Seizures, Anti-epileptic Medications and Social Perceptions	
5.5 – Inclusion Criteria and Recruitment	
5.6 – Ethical Considerations	
5.7 – Consent Process	
5.8 – Phase 4 Data Analysis	
5.9 – Dissemination of Findings	
<u>Postscript</u>	
Narrative Critical Reflection	466
<u>References</u>	
pp. 33-36	
<u>Appendices</u>	
Appendix 1 Louise Bourgeois link to artwork	

- Appendix 2 Mary, aged 19
- Appendix 3 Johnny, aged 20
- Appendix 4 Jono, aged 22
- Appendix 5 Valerie, aged 20
- Appendix 6 Mary, aged 28
- Appendix 7 Johnny, aged 20
- Appendix 8: Ethical Appraisal form

Chapter 1 **Introduction**

This dissertation will take the form of an extended proposal, focused on epileptic young people's life experiences expressed through art. Epilepsy is a chronic neurological condition that can affect anyone, at any age, from any walk of life (WHO, 2024). However, it more commonly develops in children and young people. Around 1 in 200 school-aged children (5-19 years old) in the UK have epilepsy (Young Epilepsy, 2023). Here we will be focusing on young people aged 16-18. There is a gap in the literature, and according to leading UK charities, neurology is known to be severely underfunded (Epilepsy Action, no date). Finding other ways of enabling the voices of young people (YP) with epilepsy to be heard needs to be found.

The rationale for this proposed research is, firstly, I have epilepsy myself and was diagnosed as a young person. The auto-ethnographical aspect of my chosen topic allows me to exercise the perspicacity I have gained through my experiences as an epileptic young person, in a way that may have helped me at that age. Secondly, epilepsy is a fascinating example of a dichotomy of disability and the social expectations of normality or 'ability', within one individual. This is highly unusual. It is to an extent an invisible disability. A person has a choice to tell or not to tell those around them about their epilepsy but must live with the consequences. If, and when seizures choose to show, it is somewhat out of the control of the person experiencing the seizure, and this leads to a spectrum of emotions, both from those with the disease, those close to them and the public. It is often diagnosed while young and regardless of cultural or social background this is an important time for confidence building and identity formation.

This extended literature review aims to provide the reader with a richer background understanding of what can be gained from asking YPs about their experiences of being epileptic, and exploring what might be preventing the more conventional methods, quantitative medical approaches of exploration, from working so well in the past. Art production is a means to communicate these experiences unobtrusively but substantially. Enabling YP to communicate their experiences of being epileptic rather than being asked to express something through words they may not have yet, to doctors they do not know very well. I am an artist before I am an academic, and having access to this space has been beneficial in helping me communicate, without the expectations of conversation, the feelings, and sensations I

experience during different kinds of seizures. My degree is in drama and technical theatre, where I made puppets and built sets. I am still regularly drawing, painting and creating. I am employing this skill base by using art creation as a tool.

Giving children a voice resonates across the E822 module. Finding different ways to help children and young people express their voices has always been of interest to me. I have found that art has been an excellent form of expression both for myself, and as a way of attracting and absorbing others into what I, or they, are doing, especially when it comes to working with children (Kanwal, 2012). Goodley & Runswick-Cole's, (2018) work on the worlds of disabled children in E808 rings true across the research I have been doing in the world of young people with epilepsy. They explore how disability has been conceptualised through the lens of medicalisation and investigate the political and theoretical responses. This started me looking into identity and disability within the context of epilepsy. I found E809 (Robb, Montgomery, and Thomson, 2019) elaborative on this space, by focusing on the importance of rooting professional practice in children and young people's perceptions of their needs and interests. Having been a professional working with children and young people with disabilities, many of whom had seizures, and an epileptic young person myself, led me onto explorations of self-reflection of myself as a professional in the different contexts I've worked in, and in turn into a wider exploration of phenomenology.

Reading Stafstrom and Havlena's (2003) work on self-image and children with epilepsy using drawings is where I began to develop ideas about using art in academic research. I was excited by this prospect and moved by the imagery the children had created. I realised I had experienced some of what the children were drawing, the elongated limbs stood out. The author's observation of there being many underrecognized psychological challenges, reflects my own experience, both of being epileptic and of working with those who have seizures. This is an observation, that is often reflected in many of the studies of people with epilepsy and in turn, why this may be, is reflected in more detail throughout this dissertation. I agree with Stafstrom and Havlena's (2003) conclusion, that artwork is a powerful tool, allowing the expression of things that may be difficult to express verbally, especially for children. The children's artwork reminded me of the artwork of Louise Bourgeois (Appendix 1) and so inspired, I began preparing the project I am proposing here.

Chapter 2

Literature Review the Topic

2.0 – introduction

This chapter will review the relevant literature on the chosen topic regarding young people's experiences of being epileptic in modern Western society today. This section has been split into five subsections. Each section has been chosen with a specific focus keeping the young person at the centre.

2.1 – Research with young people with epilepsy

Baheerathan, Khan, and Whitehouse, (2012) propose an innovative way of researching and supporting epileptic young people. They offer that those with epilepsy can be better helped by the development of a 'transition of care' into the adult care system that focuses on the needs of epileptic young people as they move from the paediatric care system, and with it into adulthood. The expectations placed on these young people, in terms of responsibility and ownership of their condition, change quite dramatically in the adult services compared to within the paediatric services. Baheerathan, Khan, and Whitehouse, (2012) explore how the evolving social, behavioural, medical, and academic difficulties of the teenage years pose challenges for all, but many young people with epilepsy feel 'dumped' or 'left in the dark' once transferred. They often encounter problems, having no idea where to turn for support or information. Baheerathan, Khan, and Whitehouse, (2012) suggest slowly building a relationship early on with the adult team, where the transfer of care begins, and happens between the two teams. The young people and their families are prepared for the absence of certain services in the adult system and are given the opportunity to put plans in place to reduce potential distress. The idea that these prospective clinics are based around education and social integration and that a structured protocol could be developed to make sure every aspect of a young person's epilepsy care is covered, in one place is an important one and a much-needed reality. Baheerathan, Khan, and Whitehouse, (2012) talk with optimism, recognising the transition period as a critical time. It is important to recognise the young person's vulnerability as a potential opportunity for positive intervention by healthcare professionals to support these adolescents through a complex stage of life. They acknowledge that substantial evidence is not available to prove the

benefits of a 'transition programme' over the current 'transfer system'. However, they claim it is widely accepted that it should be established that in all centres it is resources, staff and know-how that prevent progress, despite the enthusiasm from both adult and paediatric neurologists and epilepsy nurses, patients young and old, including myself. Such emphasis is placed on listening to our young people's voices across this master's in childhood and youth. Yet here they are telling us quite clearly what it is they need, to quote 'Older teenage boy' from Lewis and Noyes, (2013) research

“I think personally it would be a good idea to have an in between one (centre) for teenagers so they wouldn't have to sit with all the little kids, but they wouldn't be sitting with the adults and getting intimidated either”

p. 18. Older teenage boy, Case 1 children's services, (2013)

Lewis and Noyes, (2013) present an in-depth mixed-method systematic review that also supports current epilepsy transition models not working well. What stood out alongside their support of change in the current system was their focus on health literacy as a tool of enablement for children and young people. They used synthesising evidence to develop a theoretical framework to inform their qualitative study. They aimed to address a critical research gap by exploring communication, information needs and experiences of knowledge exchange in clinical settings by young people and their parents during this time of transition. This is an informative paper and the methods used are complex. The knowledge exchange between healthcare professionals, young people and their families is a fundamental enquiry of this project. The actuality of condition-specific knowledge not being enough to support quality adherence to long-term self-management of epilepsy for a young person is an important one. For example, a strong matched pattern found that many of the young people thought they would grow out of their epilepsy and that this misconception was often experienced by their parents as well. One father interviewed for the research realised his daughter thought she was on a course of treatment for two years and would then get on with her life, cured of her epilepsy (p. 14, Lewis and Noyes, 2013). Here, health literacy is talked about in the context that children and young people have

'the motivation and capacity to obtain, process and understand basic epilepsy-specific self-care and management information ... to make appropriate decisions about their medicines management and lifestyle adjustments.'

p. 3, Lewis and Noyes, (2013)

They found that when the healthcare professionals anticipated and identified the health literacy of the young people, their epilepsy, lifestyle-related knowledge, and information needs, then provided targeted age-appropriate information and support, the young people were better educated about their epilepsy: this was also applicable to their parents and equally as important. Lewis and Noyes, (2013) post-hoc theory development showed the health literacy of the young people involved played a valued role in decisions made when faced with complex life choices; gender-specific care, or lack of it, is a good example of this. Most of the girls could not remember or were yet to receive any information about contraception or pregnancy, they were aged between 13-18 years. Four of the older teenage girls were pregnant during the interviews. Two were due to the failure of their oral contraception. Some are known to interact with certain anti-epileptic medications (AEDs). One girl had stopped taking her epilepsy medication without consulting anyone, knowing it would harm her unborn baby but without understanding the risks such an action posed to herself. None were sure if their babies would inherit epilepsy (p. 15, Lewis and Noyes, 2013).

2.2 – Anti-Epilepsy Medications

How much epilepsy differs for women is underestimated. In June 2023 the International Bureau for Epilepsy hosted an online conference specifically focused on this issue (IBE, 2023), including a panel of experts both medical and by experience. The opening account by Liz de Wiki is sadly like that of the teenagers in the section above and my own. She talks about having two planned pregnancies, however, even a decade later, once pregnant her choices were still limited to stopping all medications or taking more. Dr Pinnell shows with great skill, how much more women have going on during their life cycle hormonally than men (20.08 mins, IBE, 2023). From an auto-ethnographical perspective, it has introduced me to catamenial epilepsy, where seizure patterns are related to a woman's menstrual cycle. Dr Herzog introduced these ideas (23.14 mins, IBE, 2023). Dr Pinnell talks in some detail about the interactions between AEDs, pregnancy, and contraception. She states that 50% of all pregnancies are unplanned (33.59 mins, IBE, 2023), so more care needs to go into what medicines are being used and to

minimise the long and short-term effects of these while maintaining seizure control. During the conference, it was also refreshing to hear women being spoken about in a context other than motherhood and this was pointed out as well by Maria Teresa Ferrtti (58.08 mins, IBE, 2023). Puberty, the menstrual cycle, and the menopause are complex times for someone with epilepsy and more research needs to be done. However, it was agreed that the implementation of what evidence there is not getting translated into an accessible format that empowers patients globally and, women with epilepsy in poorer countries face an array of other difficulties on top of this.

Here in the UK supported by the Epilepsy Society, Epilepsy Action and Young Epilepsy the results of the 2021 online nationwide survey (Swanborough, 2021), explore the understanding of epilepsy in the wider community. It found that 83% of over 1000 participants said they were concerned or very concerned about the stigma attached to being epileptic and the lack of awareness and education about it. Participants talked about losing work due to claims they were unsafe, despite being on stable medication; 63% said the government and 55% said the general public were areas that had the most power to improve understanding and increase the support available. The article ‘Women still unaware of the risks around epilepsy medicines in pregnancy – a charity survey finds’ (Swanborough, 2021a) on the results of just part of this survey shows how deep the consequences run. Women are still unaware of the proven risks around taking Sodium Valproate, an anti-epileptic drug (AED), during pregnancy and the risks of birth defects, and developmental and learning delays. These women include 11% of those already on the drug. There are measures, such as an annual risk acknowledgement form and a pregnancy prevention plan in place, but neither are enforced. These results show, that it is less an individual’s inability to cope with the disease itself, but other people’s reactions or potential professional inaction that can be distressing for those living with epilepsy. The World Tonight has just this year 2024, released a programme on Radio 4 focused on the effects of Epilim, Sodium Valproate an anti-seizure medication and pregnancy (*The World Tonight - BBC Sounds*, 2024). They claim that those affected can claim financial help. This shows just how deep the consequences of these inactions run.

Gus Baker (IBE, 2023) during the conference, specifically brings up the importance of a good transition service for all young people, and how these would create a space where information relevant to what is happening in their lives could be communicated and how a space to ask questions makes all the difference in the care received. Not knowing what questions to ask or

where to ask them, can greatly influence social perceptions and how young people perceive themselves.

2.3 – Social perceptions

It is crucial that healthcare professionals recognise the importance of social perceptions of young people with epilepsy, and that these will have an influence on their care from them. Austin *et al.*, (2015) conducted the first study primarily focusing on the challenges of diagnosis disclosure, all revolving around social perceptions; the desire for normality; that epilepsy can be easily hidden; dealing with the negative responses epilepsy provokes; the complexity of trying to explain epilepsy and dealing with the pre-conceptions of epilepsy. I also chose this paper because I have an interesting auto-ethnographical perspective on it, being diagnosed at 13 with epilepsy in the Republic of Ireland where the study was conducted. I then moved to London at 16 in 2003. That this research is undertaken in Ireland is only mentioned once. It is often assumed that Ireland is the same as the UK, especially from the UK side, it is not. Not having a national health service makes a big difference to the medical journey an individual will undertake. Things become reliant on insurance and in turn money, this can still be the case across the globe today (2:32.01mins, IBE, 2023). Rural infrastructure is often different, things like the distance from hospitals and the availability of drugs and different treatments can be an issue (Wood, 2024) (2:32:48mins, IBE, 2023). Calling out an ambulance when someone has a seizure for the first time, or any injury is a good example of this. You may be expected to pay for the ambulance but also timing-wise it may be quicker to drive to an accident and emergency department, either drive yourself, a family member or a friend. It can be stressful to make this decision and the journey. Then, there is a culture of religions, in the Republic of Ireland it would be the Catholic Church. In more modern times, it has been seen to align its ownership of land with the Government's valued health and educational assets, which has come under public controversy (Boylan, 2022). These things create a context around being epileptic that distinguishes it from others, certainly enough for it to be mentioned. Especially in the current climate here in the UK with the state of the NHS, we do not want to lose that. I think to open with a statement such as 'being the first', however true, Austin *et al.*, (2015) have a responsibility to create a stronger context. In the context of social perceptions, it wasn't until I noticed the names 'Aoife', 'Ryan', 'Colm' and that some would say 'like' (a colloquialism in Ireland) in odd places in the transcript of their interviews that I thought to check where the research was based officially.

There are many social perceptions around epilepsy, and they are complex enough for Austin *et al.*, (2015) to focus on disclosure alone. They chose to do a qualitative exploratory study consisting of individual interviews with 29 children with epilepsy aged 6 – 16 years old. How Austin *et al.*, (2015) recruit their participants is a good example of why it helps if a study is contextualised. If a participant lived in Millstreet, for example, access to public transport to the ‘neurology department of a pediatric hospital’ based in Dublin, where the study’s participants were referred from, would be harder. In addition, intermittent internet access would cause problems for gaining potential participants. Although I no longer live there this has been verified by continued visits to see friends and family. Austin *et al.*, (2015) countered this by interviewing their participants at a time and place of their choice. They conducted semi-structured interviews lasting approximately 20-40 mins, exploring the direct experiences of disclosing (or not) their epilepsy diagnosis to those external to their nuclear family. In particular, telling others about, or concealing from others, their diagnosis, or selective disclosure and why the participants made these choices. Section ‘3.2.1 The invisibility of epilepsy’ stands out in the context of social perceptions. Selena aged 11 comments

“you don't have to look it, you could just have it on the inside and be normal on the outside.’ And she was like, ‘oh ok, how?’ And I was like, ‘I don't know...’”

p.86 Austin *et al.*, (2015)

This is continually reflected throughout the comments from the other participants. What is also there is a strong desire for normalcy, not wanting to be singled out. This anxiety is exacerbated by having little or no interaction with others with epilepsy, and no space to deal with any preconceptions or responses to the condition. Their inability to define their epilepsy with words in these interviews creates good reasoning to try and get young people to use imagery creation to describe their complex neurological condition.

2.4 – Seizures

The emotional impact of having seizures, especially for young people, should not be underestimated. Ryan and Raïsañnen, (2012) state that the emotional element was not the original focus of their work here but was so strong they were able to produce this piece and acknowledged that more work is needed. They open with pathology, diverse manifestations

and attached social understandings that contribute an emotional dimension to epilepsy that takes little consideration in existing research. They undertook a qualitative study involving in-depth interviews with 37 young people aged 16-28 years diagnosed with epilepsy. They used a two-tiered interviewing approach with broad open-ended questions to begin. Then the participant was further queried about the issues raised in their initial narrative. Anger, confidence, embarrassment, happiness, frustration, and sadness appeared as codes through an iterative process as the transcripts were read and re-read, with fear appearing as the core category: 31 of the 37 participants discussed fear without prompting. Seizures were the focal point for this fear, while the other participants did not have this initial cause to be afraid, such as no recollection of their seizures. It is a complex fear, related to different aspects of the seizure process: the anticipation, experience, uncertainty of when and where it could happen, potential harm, emotional and physical after-effects, some talked about the fear others experienced and the fear associated with the diagnosis. Three key themes emerged within this: harm, temporality, and action.

Some participants talked about fear in an immediate physical sense of harm. These included sudden unexplained death in epilepsy (SUDEP), and status epilepticus; status epilepticus is when a seizure lasts a long time or when you have one seizure after another without recovering in between, loss of control and in turn the potential for harm to the body, and the internal fear of harm to the brain. Suppose a person is conscious while having a seizure, then fear can be part of the seizure, as well as about it; Mary, aged 19, describes this well (Appendix 2). Hallucinations and imagery during a seizure can create fear of the next seizure. A threat to the sense of self comes from the potential neurological damage to the brain, where the self is conceptualised, caused by seizure activity and the medications used to try and control them. It is clear in Ryan and Raïsañnen's, (2012) research that the fear was not of dying, but of a transformed self; Johnny, aged 20, (Appendix 3). It was also found that a temporal dimension ordered some people's fearfulness.

Some participants in the study had no predictable seizure patterns, or triggers that could be avoided, and in turn, lived in fear, unable to navigate their lives. Even those who were able to anticipate having a seizure at certain times heightened, limiting behaviour patterns and management strategies. Anticipation leads to ordering life around the event and heightened emotions and paranoia when it is delayed; Jono, age 22, (Appendix 4). Seizure type and the way they manifest themselves can change over time creating a new potential source of fear.

Valerie, aged 20, (Appendix 5), description captures well the range of experiences, experienced in a short seizure, and that changes to one's epilepsy can be a new source of fear, as it is the unknown. The way participants responded to their seizures and the action they took, had an impact on their fearfulness. Some identified triggers and tried to avoid these. This was not always possible, with the external influence of stress being the main culprit. Whether people with epilepsy are treated with surgery or medication, both bring on a complexity of emotions; Mary, age 28, (Appendix 6).

Some decided on surgery, some on medication. Brain surgery, however, is a scary prospect, and its suitability will depend on the context of the situation and the complexity of the emotion felt there. It was found that fear increased during times of change or contemplation of potential risk. Medication changeovers last a long time, a year or more, like surgery, with no guarantee of getting it right. Home often becomes a safe place through fear of harm for those with epilepsy. Ryan and Raïsaïnen, (2012) sum up fear and epilepsy well by saying

'Fear is more than a worry of having a seizure, or a concern of disclosure and other people's negative reactions to this. It is an emotion that is actively negotiated and made sense of in the short- and long-term trajectories of people's lives.'

p. 222 (Ryan and Raïsaïnen, 2012)

They argue that for those with epilepsy, potential harm to the brain is the dominant fear. Ryan and Raïsaïnen, (2012) acknowledge that the complexity of the experience of fearfulness is largely overlooked in research, I would like to extend that to the complexity of the experience of epilepsy in general. This is another good reason to use art when working with young people with epilepsy as imagery of this kind is easier to interpret than describe, especially for younger people with less developed language.

2.5 – Art and epilepsy

Little has happened, despite their positive results. Sixteen years passed between Stafstrom and Havlena, (2003) the first publishing of their work, on children with epilepsy, and art and the second paper, a 20th-anniversary celebration for the journal *Epilepsy & Behaviour* (Stafstrom, 2019) today.

‘Artwork is a valuable and underutilized technique for exploring the self-esteem and psychological challenges facing children and adolescents with epilepsy and other chronic diseases.’

p.1 (Stafstrom, 2019)

Whilst art is now well recognised as a therapeutic tool (Magsamen and Ross, 2023) and there may have been a push towards a change in attitude towards this ideal in more recent years, it is access to the benefits it creates society struggles with. Relying on charities such as Epilepsy Action and Epilepsy Society here in the UK, and others abroad there is little out there with professional backing that I can use here with art as a context.

Stafstrom and Havlena, (2003) show that children with epilepsy exhibit psychological difficulties in excess of the general population: depression, anxiety, social and emotional adjustment disorders, low self-esteem, increased vulnerability and lack of control over their environment and life events are commonplace among them. They also talk about the adjustments these children need to make regarding quality of life, and the unpredictability of seizures, embarrassment, taking medication, side effects and stigma.

Drawing could have provided a useful tool to help deal with these things on several levels. Stafstrom and Havlena, (2003) asked 105 children with epilepsy, aged 5- 18 years, over three years to draw a picture of what it is like to have a seizure. They were invited to take part based on their ability and willingness to complete the task. They were provided with a pencil and paper, later with coloured pencils and given unlimited time. Stafstrom and Havlena, (2003) invited a paediatric epileptologist and an art therapist to perform an independent analysis of the drawings. The paediatric epileptologist noted features of the seizure; motor activity, face, head, limbs and accompanying symptoms; drooling or evidence of an altered mental state. The art therapist looked at the representation of the self: developmental level, body composition and outline, interrelationship within the drawing, thematic content, and suggestions of vulnerability and helplessness. First, themes and features of the entire group are considered, later, pictures are divided into groups of drawings. They obtained important insight into the psychological well-being and self-concept of the children and the child’s self-perception of the seizure and its meaning to them. The imagery obtained is powerful. Stafstrom and Havlena, (2003) say they only use indicators that are well backed by research for analysis and commentary, for example, distortion of the body representing low self-concept. They do acknowledge that

distortion of the body could be a creative attempt to render symptoms as well as self-image. They claim that their study favours those who can recall their systems, and so in turn who have a certain level of consciousness during their seizures. I have experienced several kinds of seizures and believe there was no need for this. More guidance was needed for those with no other experience, and as has been explored earlier here, a range of emotions are often experienced on either side of a seizure that could be interestingly expressed, especially if colour is used. At the very least there was no reason to rely on others' recollections of the experience.

There are some excellent renditions of the experience of being epileptic from the perspective of researchers and specialists participating in the 2020, Latin American Summer School on Epilepsy (Carrizosa-Moog, J., Mameniskiene, R., and Puteikis, K., 2020). I wanted to include this briefly because the young people I will be working with will be adults soon and it will be this generation of professionals that they will be engaging with. I feel that by potentially sharing these works with these young people it may help to humanise the medical profession, which is much needed. However, I will wait to see the dynamic of the young people I may be working with, if their confidence is there for example, before making that decision, as some of the imagery could be moving. I was genuinely impressed by the effort put into the work. Three main interpretations of epilepsy were outlined: identity schism, a loss of control and it is a complex condition. I found the image of epilepsy being a composite phenomenon in terms of its neural origin and its multidisciplinary requirements a strong one, and the imagery chosen respected this. The epilepsy specialists also showed an ability to empathise with their patients and a willingness to create new treatments was also observed. Paediatric to adult care transition is also briefly mentioned. Care for those with epilepsy is multidimensional and consists of many components which cannot yet be easily resolved. This project is an interesting glimpse into how the other side, the medical professionals see epilepsy and one I hope to use. I also agree with Carrizosa-Moog, Mameniškienė and Puteikis, (2020) that it is a useful perspective from a specialist viewpoint, that could be used more often.

Chapter 3
Literature Review
The Conceptual Framework

3.0 Listening

I wandered along the grey-brown outstretched expanse of Winchelsea beach. As I approached the cliffs, I came upon a group of children playing. As I walked past, they stopped, gazed at me or the ground and drew in a little, only to carry on once I had continued past. I remembered realising that I was now perceived as an adult by others and had grown up. The significance of this dream has always stayed with me, although how it has made me feel has changed over the years. Whatever researchers try they will never find their way back to the playful spaces that, as children they so naturally inhabited. Ways can be found of helping, sorting, and educating but not of ever fully understanding a child or young person. Listening is perhaps the strongest tool we have as grownups, and we need as much practice at it as we can get. The concept of how practitioners listen to children and young people (CYP), is fundamental to increasing practitioner understanding of how best to enable the positive development and well-being of CYP. An epistemological approach to the process of adults listening to CYP would be beneficial to prompt the practitioner to reflect on and question what they, as adults hear. Understanding the power of perspective is vital. A good working practice example of this is The Mosaic Approach (Carr, Clark and Moss, 2011) explores how a practitioner can expand their concept of communication. By learning to listen to the variety of interactions between young children and adults with more than their ears and begin to genuinely involve the children they are working within the decision-making process. Through the exploration of whether the responsibility of well-being can or should be extended to children, a range of social topics are touched upon by considering equalising the value gap between the voice of the adult and that of the child. Its namesake is reflective of the picture built up of each child through the variety of choices and preferences offered to them and, the range of strategies employed when working with children. The array of results lends itself to the crystallisation rather than the triangulation of data (Richardson, & St. Pierre, 2008), reflective of a multi-dimensional individual and the world around them. It works to fill the gap between child and adult perspectives through the

practical use of three key themes: methodology, rights, and modes. The methodology involves adults and children creating knowledge together and co-constructing meanings, rather than an adult extracting knowledge from a child. The rights and status of seldom-heard groups are acknowledged through challenging dominant discourses about whose knowledge counts, and by providing a context for individuals' experiences rather than adults speaking for them. The mode referred to is a multi-dimensional process of viewing the world, that acknowledges the way implicit views about childhood influence the way adults interact with young children. It does this through constructing knowledge using different forms of communication. Although the focus is on younger children, when exploring concepts like 'Attunement', in practical applications of the methodology like in the 'The Listening Project' (*The Open University*, 2008), it was met with a positive response from the staff and teachers, it was expanded the following year to include Attunement to parents, as part of the training process. I find this very encouraging in the context of young people as it means it could be expanded to include young people as part of their training process, with the potential for peer education programmes in the future. I would like to go as far as to extend this way of listening and working to *all* those with disabilities; I have successfully used it working with those with complex physical needs and Autism both here in the UK and India. But disability is a broad field and epilepsy does not sit comfortably within it. It leaps back and forth as discussed in Chapter 2, depending on a variety of things including an individual's mood, time of month, hormone, or stress levels, living situation or up-and-coming exams, and for some, these triggers may always exist. In the context of research, it is only in more recent years that young people with epilepsy have begun to be considered as an independent group. In my research, I found it particularly difficult to find research that focuses on epileptic young people and their experiences specifically. Carpenter, Chew, and Haase, (2017) found a similar issue when conducting their research project, which had a very broad inclusion criterion. This article shows a clear gap in the literature on treating young people with epilepsy as an independent group.

3.1 A Gap in the Literature

Those aged 16 years and above are often used as part of a wider statistic, including much younger children. This is the case across the majority of the articles I have used here but also goes beyond these choices. In Carpenter, Chew, and Haase, (2017) systematic review of 501 qualitative studies, they ask the question 'What are young people's experiences of epilepsy?'. Their inclusion criteria were limited to young people aged 13 to 18 years diagnosed with

epilepsy; qualitative data collection methods; studies published in English language peer-reviewed journals and grey literature. Despite this broad set of criteria, out of the 501 citations identified, only 17 studies met the full inclusion criteria. They aimed to explore the extent young people's perspectives were examined using qualitative and mixed-methods research designs, to summarise research findings and draw out any implications that came with these for the use of social work practice, and finally, to identify gaps in the literature for future research potential. Although all three aims are relevant, this paper has identified a huge gap in the literature when it comes to age, and this is one of the main reasons why I have chosen to work with young people aged 16 to 18 years old. Carpenter, Chew, and Haase, (2017) talk about much of the work on the impact of epilepsy in childhood using quantitative methodologies, which offer little understanding of the experiences of living with the condition.

Beazley *et al.*, (2009) in their paper, make a similar point from an ethnographic perspective. Their paper also affirms that most thematic issues of social science journals concentrate on the research results, with methods only being a means to an end. They however offer a tangible solution; turning concentration onto how such research is carried out, rather than on the results. The motivation for their article came from the twentieth anniversary of the date of adoption by the General Assembly of the United Nations, of the Convention of the Rights of the Child (UNCRC, 1989). Beazley *et al.*, (2009) use the articles in this special issue of 'Children's Geographies' (*Children's Geographies — Vol. 7 Issue 4, 2009*) to rationalise the rights children have to be properly researched. Beazley *et al.*, (2009) felt that much had moved forward in the last twenty years in the development of rights-based research with children, that attention should be brought to it, and that space could be offered to explore some of the challenges remaining. The research they chose consists of work with people, ungendered, aged 10 – 17 years as they felt that this group is both important and often neglected. They delineated the right to be properly researched by consolidating provisions from four articles from the UNCRC: Article 12; the right to provide opinions, Article 13; the right to freedom of expression using a medium of children's own choice, Article 36; the right to protection from forms of exploitation not addressed in other articles, and Article 3.3; the right to the highest possible standards being used in work with children. Approaching research from a rights-based perspective helps researchers recognise a diverse range of childhoods. By doing so it becomes harder to construct a single universal childhood, to move away from creating potential social 'problem groups' such as AIDS orphans or child soldiers, or from a Global Northern/Southern: ultimately Western perspective, the idea of 'the youth'. Thus, importantly dispelling this idea

that there is a ‘normal’ childhood to be had. The concept that children live real childhoods rather than social constructs gathered importance for me. Beazley *et al.*, (2009) acknowledge the importance age differences play in childhood and how these can outweigh other discriminatory factors, like gender, ethnicity, or religion, whose importance begins to take over as age increases. The main criticism I would have of this paper is that although the focus here is wide, ranging across the ethnographical aspects of the Global North and South, neither disability nor young people as independent groups are often mentioned. I suspect that both groups would respect ‘The right to be properly researched’. Although perhaps ‘properly’ is the operative word, that will never work fully in the context of identity, disability, and young people.

3.2 Identity and Disability

A paper that links the ideas of disability, identity and epilepsy together nicely is Rhodes *et al.*, (2008) paper. Although they used adults to develop this work, as I have said before, for the young people I am proposing to work with it will only be a year or two before they step into the world as adults. A thought-provoking idea Rhodes *et al.*, (2008) presents is how living with epilepsy provides

‘exemplary illustrations of the medical and social models of disability’

pp.1&2, (Rhodes *et al.*, 2008)

within one individual. Traditionally the social and the medical models of disability are presented as polarised ideals, with the interests of each opposing the other. To support those with disabilities the social model of disability looks to change the environment and the attitudes of society. In contrast, the medical model of disability looks to treat the individual impairment and fit that individual into the established environment. I believe there is a space for these established models to work in partnership when looked at in the context of epilepsy and young people. I could not find much literature to expand on this idea specifically but feel that it is a very valid and underexplored one. Epilepsy, as both an identity and a disability, challenges the traditional boundaries of the concept of disability when looked at from the perspectives of both the social and medical models. Rhodes *et al.*, (2008) article regards identity as being fluid and malleable with a contingent element, and disability as having various constructed meanings, depending on the context, holding a different relevance to different people at different times.

They explore the social understanding around the concept that an ill person should be tucked up in bed and a disabled person working, with adjustments, and how epilepsy fits into neither expectation. Rhodes *et al.*, (2008) ideas around language are weighty. Few people think of epilepsy as a brain disease, yet it is. Rhodes *et al.*, (2008) talk about the language of disability as having a similar influence as that of illness and disease. Cultural, personal, moral, and political contexts all play an important role in creating a way of seeing, a form of understanding (John Berger, 1972). This is why there are likely to be different understandings of disability in circulation and not all will be compatible or mutually exclusive. Rhodes *et al.*, (2008) consider the term ‘epilepsy’ as polysemic in doing more than bridging the divide between illness and impairment, it becomes more than a clinical disorder; it also develops into a social label.

In terms of the social stigma surrounding epilepsy, Rhodes *et al.*, (2008) suggest that it often develops from a fear of the unknown. In some cases, the cause of epilepsy is medically identifiable but in most the cause is idiopathic. In society in general epilepsy is associated with the brain and in turn, even in the not-too-distant past, as a form of madness: many epilepsy drugs are developed from psychiatric drugs, and many are still used for both. These ideas are quite ingrained in society and hard to uproot and separate. Rhodes *et al.*, (2008) talk about a ‘moral weight’ that is worse than just having seizures, which has developed from having to engage with a society that does not yet know how to cope with those with epilepsy. They explain that paradoxically, it is often those with the least visible, yet greatly stigmatised impairments, who are least likely to want to identify as disabled. The disabling effects of epilepsy are neither primarily social nor physical but will be different for every individual, depending on the different contexts or times in their lives. A person’s epilepsy will have a different salience depending on the context they find themselves in. Rhodes *et al.*, (2008) ideas on seeing different perspectives on disability as competing and antagonistic and rather seeing them as potentially complementary and offering different insights is a refreshing one, but not when the paper is written is considered. Then how far society has come in the last fifteen years is disappointing. More needs to be done to demystify the epileptic experience, as it is such a common one. A quote from this paper rounds up their work nicely and has stood out for me. It would be one I’d be tempted to use when working with young people with epilepsy.

‘accepting a diagnosis of epilepsy does not necessarily entail accepting the label ‘disabled’.’

p. 2, Rhodes *et al.*, (2008)

From an auto-ethnographical perspective, the comment made by an unnamed contributor, to a disability discussion, in the Epilepsy and Disability section rings true: ‘we are eyed suspiciously by both disabled and non-disabled communities and welcomed by neither’ (p.390, Rhodes *et al.*, 2008). I have found we are often not so sure about what to do when meet each other. I have also experienced resistance when meeting others with epilepsy due to uncertainty about their life choices. This uncertainty is something that I would aim to break through and I believe that supporting epileptic young people to have a stronger sense of identity as a group is important. Rhodes *et al.*, (2008) are right in stating that epilepsy can result in ‘almost total physical incapacity’ (p.390, Rhodes *et al.*, 2008). This can be a challenge to watch: despite having a video of myself having a seizure I have never been brave enough or felt supported enough to watch it and to live with the consequences. Johnny, aged 20 (Appendix 7) talks about not having cried in years and ‘really crying’ when being showed himself having a seizure as a young person and nothing about any further support was offered. I was shocked at this. Despite my fear of seeing myself have a seizure, I have found a great deal of professional pride in working with others who have been incapacitated by seizures in several different contexts.

3.3 Phenomenology

Lastly, the proposed methodological approach for this research will be based predominantly on phenomenology (Smith, 2018). I was drawn to this philosophy but have lacked the time to explore it in great depth. Even the etymology of its name: phenomenon, a thing appearing to view, I liked, as it reminded me of having a seizure. My ontology used to include a space for the potential solidity of scientific knowledge without understanding, having experienced the benefits and extreme negatives of taking epilepsy medication, but I have always encountered difficulties in translating this into an assessable format for others to understand with ease. This led naturally to the epistemology of interpretivism, that there is not a correct way of ‘knowing’. With some further exploration, I found the phenomenological focus on understanding and communicating lived experiences a relevant one and accommodating the ideas explored here in an interesting way. This was a pleasant surprise to me. The school of phenomenology was established in the late 19th century by Edmund Husserl (1859-1938) an Austrian-German philosopher and mathematician. He claimed that there is no cognition without consciousness and that this (invisible consciousness, sensual perception, and object constitution) is always bound to something that is recognised. Husserl developed the concept of ‘lifeworld’. This is

the world of what he referred to as ‘lived experience’ inhabited by our consciousness. How this took the shape of phenomena (events, objects, emotions) in our everyday life. This term is used regularly in humanities sciences today. I felt this was an interesting way of beginning to incorporate the complex experience of being epileptic and the multiple experiences of having seizures and the different kinds of seizures more into the everyday. The reflexivity expected is also reflected in my choice of a narrative approach. For example, from an auto-ethnographical perspective, which is where a lot of my initial inspiration came from, what I like to eat and how my body responds to food on each different medication I take for my epilepsy changes. Some repressed my appetite, some do the opposite, some speed up certain processes etc. I am on drug number five, I am 37 years old, and my experience with epilepsy medications is average. Eating is just one aspect, but it incorporates all three phenomena (events; mealtimes, objects; food, emotions; there is a wealth of work that has linked mental health and food) and this is constantly being influenced by an external source; the medication. The process of eating must be engaged with to gain independence. The academic in me could write a whole dissertation on just this one aspect and the artist could create endless imagery. I will talk more about the importance of art in the next section, but epilepsy and art are so interestingly individual that my experience of these will inform the project well.

Chapter 4

The Research Proposal

The research title ‘**Young People with Epilepsy’s Illustrations of Their Narratives: An Arts-Based Approach**’ has developed from the purpose of the research. This research design takes a qualitative multi-phased narrative approach. As I am epileptic myself, I have experienced many similar things to these young people. I was surprised to find little had changed in the last twenty years since I was a young person, or was any different across European countries. People with epilepsy are rarely asked about what their perceptions are during, before or after a seizure, or what it is like to live with epilepsy, especially as a young person. There is often excellent paediatric care but as children get older the support focusing on their needs as older teenagers dwindles (Baheerathan *et al.*, 2013). Children are asked by professionals, and expected to offer, a description of sensations that I have struggled to describe with access to a full thesaurus. Children are often intimidated by the presence of medical professionals and unable to understand the medical jargon used by them. This often leads to them shutting down and not sharing at all, even with friends their own age. This is made easier with epilepsy being, to an extent, a hidden disability (Bertsche, *et al.*, 2020). My research aims to create more confidence in YPs talking about their experiences.

I have found that correlating the series of sensations experienced to relatable imagery, colours, or feelings is a good way of communicating an experience that is difficult to describe to those who have never been through it. Beyond the tonic-clonic seizure commonly portrayed in the media, how seizures manifest themselves is different for every person and only ever similar to the last one and never the same. That there are different kinds of seizures cannot be assumed to be general knowledge, although there is a push for awareness. A recent study found that one of the most important things that people with epilepsy wanted the general public to know is that seizures are not all like the ones seen on Casualty, (the TV show) (Swanborough, 2021). Although the general public may not be my main audience, when working with teenagers, it must be respected that they will always be theirs.

There are many personal changes during the teenage years, particularly the development of communication skills, self-awareness and the expectations placed on young people with a

chronic illness. I enjoyed the realisation that the experience can be shared, potentially more clearly, in a non-verbal, visual way (Stafstrom and Havlena, 2003), (Magsamen and Ross, 2023).

The depth of the three contexts, seizures, anti-seizure medications and social perceptions, I have chosen to base the art creation around shows why they may be important to a young person with epilepsy. Epilepsy is a complex subject, but it is a genuine one and much more common than society acknowledges (WHO, 2024). If well executed, the data gathered could be translated into a format understood by medical professionals, academics, and other epileptics, old and young. These YPs narratives will be short but already in-depth and interesting. I would like to help them unravel them a little and see ...

What connections can be made between their narratives in the context of these three perspectives? seizures, anti-seizure medications and social perceptions.

Chapter 5 **Design Methods and Analysis**

5.0 Research Design

The research design is a qualitative multi-phased narrative approach. The theories introduced in Chapter 3 around listening and the Mosaic Project (Carr, Clark and Moss, 2011), the gap in the literature surrounding young people with epilepsy, and identity and disability are all included in my chosen paradigm position. This is phenomenological (Smith, 2018), with a firm grounding in interpretivism. The more detailed concepts introduced around Husserl's phenomena are inclusive of the lived experiences of young people with unseen disabilities such as epilepsy and autism (Huws and Jones, 2008), (Beck, Huws and Jones 2013).

The research design is concentrated on gathering the data through the participants' artwork. This is similar to the way in which, Stafstrom and Havlena, (2003) worked, they asked their participants to draw a picture of what it was like to have a seizure, but here instead, there will be a wider focus. The focus here is on the participants' understanding and experiences of having epilepsy in the everyday world, not just on having a seizure. The methods for data collection have been divided into four phases. The first focus is on preparing the researcher and those supporting them to feel confident about working with young people with epilepsy, who may have seizures during their time together. The next is about forming relationships between the researcher, and the participants. The third is about collecting the data itself. The final phase focuses on how the data may be analysed.

5.1 Phase 1

Building confidence

Before starting work on the project, any support staff working with the researcher should be offered an opportunity to withdraw from it, as seeing others having seizures can be frightening. This is to enable a sense of calm and non-judgment for the participants in the research space and to ensure that all involved are capable of coping, as there is the potential for a seizure to occur. They will also be asked if they can make use of their observation skills while in the

research space and make note of participants' potential self-regulated learning behaviours, task avoidance behaviours, non-verbal cues, or other things of interest.

5.2 Phase 2

Building Relationships

I intend to use my epilepsy and my experience as an epileptic young person as a tool to engage with these epileptic young people, and as is referred to in (Jones, Huws and Beck, 2013), taking on the role of an 'expert interpreter'. This is also reflective of the paradigm position. As the researcher and an adult, I cannot gain direct access to the participants' worlds. I can, however, offer a unique insider perspective. My interpretations of these young people's experiences will be less biased, or more positively biased than someone without epilepsy (Huws and Jones, 2008). I feel that if I am open about my salience to the insider-outsider perspective, the participants will perhaps be happier to engage with me and the research.

Taking time with introductions at the first meeting will help develop trust and rapport within the research space. Many participants may not have met someone else with epilepsy before, as was true in Austin *et al.*, (2015) study, and in my experience. The internet is changing this, offering spaces where people with epilepsy can meet without needing to travel or worry about seizure activity. Yet, many in this study may not have been epileptic for very long and so may just not have had the chance to, or wanted to, reach out to others just yet. It is in the teenage years when many social anxieties begin to develop for all, so spending time here is important.

5.3 Phase 3

Generating the Art

As discussed in Chapter 3, the researcher and participant will co-construct communicable meaning relevant to that young person, rather than it falling to the researcher to extract meaning from the participant (Carr, Clark, and Moss, 2011), (Richardson and St. Pierre, 2008). Gill Adams, (2022) talks about the importance of enabling others to clarify and articulate their stories to take ownership of them. If this skill can be shared, especially when living with a chronic illness, the results can be invaluable and last a lifetime. Art is increasingly being used as a tool for people with chronic health issues, such as in preventative medicine, symptom relief and psychological support (Magsamen and Ross, 2023). Adams's (2022) caution against the

power imbalances that can often develop between researcher and participant when engaging in mutual storytelling, is one I would benefit from taking on board. Her reassurance as to what is appropriate to share became easier as time went on in her storytelling project. The increase in her knowledge was reassuring for me as mutual storytelling is a tool that would work well here.

The beginning of each session will take the form of an unstructured narrative interview. The researcher will use open-ended questions focused on one of the three specified contexts per session: seizures, anti-epileptic drugs (AEDs) and social perceptions. This will lead to the guided art creation. There will be three sessions, each an hour long, one for each of the three contexts. I would be mindful of not making the one-hour timing too strict, in case of a participant having a possible seizure.

There is a wide variety of art creation methods at the disposal of the researcher. Unfortunately, it is genuinely difficult to determine at this stage which ones will work best, but this will become obvious as the project unfolds. It is recommended for the researcher to have a collection of arts-based activities to hand in case something does not work, a participant does not respond well or completes an activity more quickly than planned.

There are the more traditional methods of art creation such as pencils, charcoal, and paints. The participants will be able to get some clear and distinct imagery using these methods. At the opposite end of the spectrum, the imagery created through play is messy but informative. Play is an important and underestimated form of expression (Brown and Vaughan, 2009). Collage is another possible medium; through the break-up of others' work, old magazines etc or even their own work, the participants can create new imagery. Physical pieces gathered in a frame and taken photographs of can also provoke an emotive reaction. Whilst the participants will experience this as an art project, it will offer valuable insight to the researcher and the existing body of knowledge.

It is recommended that a pilot study be carried out with different young people with epilepsy of similar age, focusing on their art activity choices, to gain insight into which ones may work best in this context. It is also here that I would like to employ or offer my skills.

5.4 The Three Contexts: Seizures, Anti-epileptic Medications and Social Perceptions

These have been chosen because many of the researchers who have worked with young people and epilepsy, focus mainly on seizure activity. If they do look at anti-epileptic drugs, they look at them in a quantitative and medical context. Rarely are the consequences of the side effects of the medications or the social perceptions of such a common neurological disease examined.

Seizures will be the first choice of context introduced. There are many kinds of seizures. Often the person experiencing them does not remember the most dramatic parts of the larger ones. These form the basis for what most people think of when the word seizure is mentioned. The person having the seizure can become very involved in the seizure itself and reliant on those around them, and can feel very isolated. Their experiences are often not what others perceive them to be.

The second context is the anti-epileptic drugs. The intention here is to make the distinction between the drugs taken to control the seizures, and the seizures themselves. This offers a space to reflect on not only the negative aspects of the drugs, of which there are many, but also to look at the positive aspects they can offer, such as independence and the potential this offers.

Lastly, there are the social perceptions of epilepsy, such as the way in which epilepsy can be hidden, yet how complex it can be to explain to others who have not experienced it. Epilepsy can still produce such negative responses from some, who may argue that it is in the name of self-protection that they react in such a way. Ryan and Raïsañnen, (2012) suggest that fear is a powerful tool working on all sides. There are subtler social perceptions in spaces like language. Epilepsy is defined as a brain disease; this provoked a cartoonish disgust reaction from me when I found out that this was how epilepsy was defined, and it has stayed with me ever since. What imagery the participants use in response to this would be interesting to see.

5.5 Inclusion Criteria and Recruitment

An inclusion criterion for the study is that the participants be having seizures reasonably regularly. This is because, in order to explore something as intense as this confidently, epilepsy needs to be an active experience in one's life. Memories can be easily distorted and for those with epilepsy, memory is more of a problem due to seizures, medication and social perception.

The study will be carried out in the National Hospital for Neurosurgery and Neurology in Queens Square, London. Being here will enable the researcher to conduct the study in a safe environment surrounded by trained professionals who are confident in dealing with any difficulty that may occur because of someone having a seizure. The likelihood of more participants participating in the study is higher, if it has the support of an epilepsy nurse, the neurology department and the NHS. The researcher would be more likely to find a gatekeeper here who would support the work here as well.

Advertisements for epileptic young people to get involved in this research project could be placed on the UK epilepsy charity websites Epilepsy Action and Epilepsy Society, the NHS website, the WHO website, local GP practices and their websites, and sixth-form colleges. Times of potential stress for participants, such as exams, and important occasions, will be avoided.

5.6 Ethical considerations

The specified age group is 16-18 years old. I was initially drawn to this age group as there are fewer parent and carer permissions involved, which gives a certain amount of autonomy to both the researcher and participant. This space to work was inviting and I have experience with this age group. However, after a small amount of research, I soon found a large gap in the literature where young people with epilepsy are so often lumped into statistics with much younger children, and rarely asked about their experiences as an independent group (Carpenter, Chew and Haase, 2017). I was genuinely surprised by this. So, not only do these young people have to deal with the normative but difficult, day-to-day adjustments of the teenage years, they have the challenges of managing a sporadic chronic seizure condition and all that comes with that. Why are we not exploring this area more?

At this time the research proposal is not gender specific, but this would be an interesting area to consider looking into this if it moved the research forward. The effects of hormones on seizure frequency (Bertsche *et al.*, 2020), (IBE, 2023), the interaction of epilepsy and birth control medications (BBC, 2024) and the lack of clear information out there had me considering this, from both male and female perspectives (Swanborough, 2021).

5.7 Consent Process

The consent for this research will be based on informed and ongoing consent (Hemple-J Orgensen, 2022). Before they start, the participants will be offered information on how their artwork and the data generated will be used. This will be done by using accessible language and avoiding academic jargon. The importance of health literacy language in relation to young people with epilepsy was discussed in Chapter 2 (Lewis and Noyes, 2013).

I propose the endorsement of two consent forms. Both are presented at the beginning. One is signed then. The second explained it will be brought out at certain points during the time together; like the beginning of each session for example, to check that all is well and that both are still on track and signed at the end. The second will have a structure like the one used by Liz Chamberlain and Alison Buckler, but adapted to the specifics of this project, in their research with girls in Zimbabwe (Buckler and Chamberlain, 2022). By using this structure, the participants can tick their levels of consent and the researcher can make sure they understand what is being done with their artwork. It will also be made clear before starting that the participants may be identifiable by their artwork so there may only be so much privacy to be had (Cremin, 2022). This is another reason why I have chosen to work with 16-18-year-olds as they may be able to negotiate this space better than younger teenagers, although this would not be taken for granted. It is imagery creation they are working with so there is the possibility that the young person may not like the work they produce and wish to withdraw their permission to use it further. This reiterates the importance of the second form and the levels of consent offered. For example, this may enable the work to be used for analysis, but not to be displayed publicly. There are also ways of getting them involved in the anonymity process and making it fun. For example: they can choose or be offered pseudonyms (Cremin, 2022) before they enter the session, like artists or rappers have.

5.8 Phase 4

Data analysis

In order for the researcher to make distinctions and connections between the imagery under the three subheadings, the images will be presented on three separate papers. These may not be the only works created, but the images will be chosen by the participants to represent that subheading and context. The development of the content analysis needs to capture both the bigger picture and the detail within (Cohen, Manion and Morrison, 2017). The concern raised

by Rose, (2007), (p. 704), argues that different people view images in different ways. This will be countered, to an extent, by allowing the artists to guide their viewers, by describing their works themselves on the tape recording or in a short piece of writing, possibly vignette style if they choose to. This time is also an opportunity for the support staff to be asked for their opinions on potential narratives and connections they see between the images.

Once work on their art has finished, the participants will be offered the opportunity to either come and collect their work or have it sent to them. It would be good if they were able to produce a small booklet of the artwork and personal explanations. If this were a possibility, it would create many opportunities for the future, like fundraising, raising awareness and peer education.

5.9 Dissemination of Findings

The findings of this research will be of interest to many fields of study. Dissemination of the information would be in the form of a journal article. It could also be offered at the next International Burro for Epilepsy conference, like the one referenced here (IBE, 2023). This way it would be accessible online in a positive context as well. Like in the work of Lewis and Noyes, (2013) with small adjustments, a project like this could be amended to include young people with other long-term health conditions.

Narrative Critical Reflection

My journey as a researcher has developed greatly. From reading through my learning journals and notes, I have found that I can now cope with much larger amounts of literature for a single project. These amounts of literature come in kinds more varied in approach yet more focused on a single topic. I can skim-read titles and abstracts, and pick out what might be more useful to read further, just from this information. I do this much better than I could at the beginning of this process and with more confidence. I'm not so intimidated by the language or length of a paper and enjoy using more complex language myself. I am not so bothered by my dyslexia as I know there will be help there if I need it. I can sit and work for much longer periods than I could do before. I still work in twenty-minute slots to remind myself to take breaks eventually, that has definitely been a useful tool.

A big reason I had initially come back to university was to be more sociable, but the opposite has happened. During my time with the Open University, my health changed dramatically. My epilepsy medications stopped working and I am on my fourth drug in four years. I had never considered that my life might change to the extent that it has. I chose epilepsy as the topic for my dissertation because it is rare that one has the opportunity in life where one can combine such an earth-shattering experience with something so productive and grounding as studying. However, what I have gained is the ability to work independently and a huge amount of confidence in my own academic work. I certainly didn't have nearly as much as this a few years ago. I now know that to an extent I can still study and be happy regardless of the state of my health, that is a hugely empowering feeling.

It would still be good for me to do some work with people. I point out in my notes at different points that I often get excited, rush ahead and sometimes miss the basics. This has always been reined in, when I have had people around me to bounce ideas off or compare things with, in a productive way. Or to tell me to just slow down a little. As I have been thinking about inspiration, this reminded me of elements of what I enjoyed about my first degree doing puppetry and set design in the theatre. These practical things are far removed from the academic things I also enjoy doing now, and if I had been told then, that I would be doing an academic masters and considering carrying on this work further I probably would have just laughed.

Bibliography

Adams G., (2022) 'Audio 6.17 Narrative (biographical): research focus and design' Available at URL: <https://learn2.open.ac.uk/mod/oucontent/view.php?id=1946347§ion=3.7>

Accessed: 14/5/24).

Austin, J., Benson, A., Gallagher, P., Lambert, V., and Shahwan A. (2015) "I don't want them to look at me and think of my illness, I just want them to look at me and see me": Child perspectives on the challenges associated with disclosing an epilepsy diagnosis to others', *Epilepsy & Behavior*; vol: 53, pp. 83-91. Available at URL: [https://www.epilepsybehavior.com/article/S1525-5050\(15\)00541-7/abstract](https://www.epilepsybehavior.com/article/S1525-5050(15)00541-7/abstract) (Accessed: 14/5/24).

Baheerathan, A., Khan, A., and Whitehouse, W., (2012) 'Transition of children with epilepsies to adult care' *Acta Paediatrica*. 102 (issue 3), pp. 216-221 Available at URL: <https://onlinelibrary.wiley.com/doi/abs/10.1111/apa.12097> (Accessed: 22/5/24).

Beazley, H., Bessell, S., Ennew, J., and Waterson, R. (2009) 'The right to be properly researched: research with children in a messy, real world' *Children's Geographies*, 7 (issue 8), pp. 365-378. Available at URL: <https://libezproxy.open.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=46722510&site=ehost-live&scope=site> (Accessed: 17/5/24).

Beck, G., Hews, J. and Jones, R. (2013) 'I'm not the only person out there': insider and outsider understandings of autism', *International Journal of Developmental Disabilities*, 59 (issue 2), Available at URL: <https://libezproxy.open.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=c8h&AN=104172095&site=ehost-live&scope=site> (Accessed: 14/5/24)

Berger, J. (1972) *Ways of seeing*. Available at URL: <https://www.vlebooks-com.libezproxy.open.ac.uk/Product/Index/661959?page=0&startBookmarkId=-1> (Accessed: 22/5/24).

Bertsche, A., Bertsche, T., Pauschek, J., Neiniger, M. P., Jeschke, S., Woltermann, S., and Kiess W. (2020) 'Why do children and adolescents with epilepsy disclose or not disclose their condition to their friends?' *European Journal of Pediatrics*, 179 (issue 10), pp. 1627-1633. Available at URL: <https://doi.org/10.1007/s00431-020-03661-0> (Accessed: 22/5/24).

Boylan, P. (2022) 'Catholic Church role in health and schools can no longer be funded by State', Available at URL: <https://www.irishtimes.com/opinion/2022/11/22/church-ethos-and-role-in-healthcare-or-education-can-no-longer-be-funded-by-state/> (Accessed: 14/5/24).

Braun, V. and Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3 (issue 2), pp. 77-101 Available at URL: <https://libezproxy.open.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=20391875&site=ehost-live&scope=site> (Accessed: 22/5/24).

Brown, S. and Vaughan, C. (2009) *Play, How it Shapes the Brain, Opens the Imagination, and Invigorates the Soul*, Penguin Groups Ltd. ISBN: 978-1-58333-333-4.

Buckler A. and Chamberlin, L. (2022) 'Audio 8.8 Case study Zimbabwe – ethical issues' URL:<https://learn2.open.ac.uk/mod/oucontent/view.php?id=1946356§ion=4.6>(Accessed: 22/5/24).

Carpenter, J., Chew, J. and Haase, A. M. (2017) 'Young People's Experiences of Epilepsy: A Scoping Review of Qualitative Studies' *Health & Social Work*, 43 (issue 3), pp. 167-176. Available at URL: <http://academic.oup.com/hsw/article/42/3/167/3854672/Young-Peoples-Experiences-of-Epilepsy-A-Scoping> (Accessed: 22/5/24).

Carr, M., Clark, A. and Moss, P. (2011) 'Listening to Young Children: The Mosaic approach' *National Children's Bureau*, Available at URL: <http://ebookcentral.proquest.com/lib/open/detail.action?docID=912526> (Accessed: 22/5/24).

Carrizosa-Moog, J., Mameniskiene, R., and Puteikis, K. (2020) 'Painting epilepsy – The essence of disease by participants of the Latin American Summer School on Epilepsy (LASSE XIII)', *Epilepsy & Behavior*, vol:104, Available at URL: <https://www.sciencedirect.com/science/article/pii/S152550501931217X> (Accessed: 22/5/24).

Cohen, L., Manion, L. and Morrison, K. (2017) 'Research Methods in Education Research Methods in Education', *Taylor & Francis Group*, Available at URL: <http://ebookcentral.proquest.com/lib/open/detail.action?docID=5103697> (Accessed: 14/5/24).

Cremin, T. (2022) 'Audio 8.9 Experimental design (RCT) – ethical issues' Available at URL:<https://learn2.open.ac.uk/mod/oucontent/view.php?id=1946356§ion=4.6>(Accessed: 22/5/24).

Curran, T., Liddiard, K., and Runswick-Cole, K. (2017) 'The Palgrave Handbook of Disabled Children's Childhood Studies', *Palgrave Macmillan UK*, Available at URL: <http://ebookcentral.proquest.com/lib/open/detail.action?docID=5131248> (Accessed: 14/5/24).

Epilepsy Action (no date) 'Epilepsy facts and terminology', Available at URL: <https://www.epilepsy.org.uk/press/epilepsy-facts-and-terminology> (Accessed: 22/5/24).

Goodley D., and Runswick K. (2020) 'Three, Disability, childhood and young people' *Children and young people's worlds*. pp. 41-55 Available at URL: https://library-search.open.ac.uk/permalink/44OPN_INST/la9sg5/alma9952797414402316 (Accessed: 22/5/24).

Hemple-J Orgensen, A. (2022) 'Audio 8.11 Longitudinal design – ethical issues' Available at URL:<https://learn2.open.ac.uk/mod/oucontent/view.php?id=1946356§ion=5.2> (Accessed: 14/5/24).

Huws, J., C. and Jones, R. (2008) 'Diagnosis, disclosure, and having autism: An interpretative phenomenological analysis of the perceptions of young people with autism' *Journal of Intellectual & Developmental Disability*, 33 (issue 2), pp. 99-107, Available at URL: <https://libezproxy.open.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=ejh&AN=34478500&site=ehost-live&scope=site> (Accessed: 14/5/24).

IBE (2023) 'Women & Epilepsy, Why is Epilepsy Different for Women?' *International Bureau for Epilepsy*, Available at URL: <https://vimeo.com/840438195> (Accessed: 22/5/24).

Kanwal, M. (2012) 'Giving children a 'voice': arts-based participatory research activities and representation.' *International Journal of Social Research Methodology*, 15 (issue 2), pp. 149-160. Available at URL: <https://libezproxy.open.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=71959968&site=ehost-live&scope=site> (Accessed: 14/5/24).

Lewis, S., A. and Noyes., J. (2013) 'Effective process or dangerous precipice: qualitative comparative embedded case study with young people with epilepsy and their parents during transition from children's to adult services', *BMC pediatrics*, 13 (issue 1), pp. 169–169, Available at DOI: 10.1186/1471-2431-13-169.

Magsaman, S. and Ross, I. (2023) *Your Brain on Art: How the Arts Transform Us*. Available at URL: <https://go-gale.com.libezproxy.open.ac.uk/ps/i.do?p=LitRC&sw=w&issn=00000019&v=2.1&it=r&id=GALE%7CA737039756&sid=googleScholar&linkaccess=abs> (Accessed: 22/5/24).

Rhodes, P., Nocon, A., Small, N., and Wright, J. (2008) 'Disability and identity: the challenge of epilepsy', *Disability & Society*, 23 (issue 4), Available at URL: <https://libezproxy.open.ac.uk/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=cul&AN=32708446&site=ehost-live&scope=site> (Accessed: 14/5/24).

Richardson, L. and St. Pierre, E. (2008) 'Chapter 38, Writing, A method of inquiry', *Collecting and Interpreting Qualitative Materials*. 3, pp. 959-978. Available at URL: <https://depthpsychotherapy.pbworks.com/f/Writing+A+Method+of+Inquiry.pdf> (Accessed: 14/5/24).

Robb, M., Montgomery, H. and Thomson, R. (2019) *Critical practice with children and young people*. 2nd ed. Bristol: Policy Press in association with The Open University.

Ryan, S. and Räisänen, U. (2012) "The brain is such a delicate thing": an exploration of fear and seizures among young people with epilepsy, *Chronic Illness*, 8 (issue 3), pp. 124-224. Available at URL: <https://journals-sagepub-com.libezproxy.open.ac.uk/doi/epub/10.1177/1742395312449666> (Accessed: 14/5/24).

Smith, D., W. (2018) 'Phenomenology', *The Stanford Encyclopedia of Philosophy*, (Summer 2018 Edition). Available at URL: <https://plato.stanford.edu/archives/sum2018/entries/phenomenology/> (Accessed: 22/5/24).

Stafstrom, C. E. (2003) 'Seizure drawings: insight into the self-image of children with epilepsy', *Epilepsy & Behavior*, 4 (Issue 1), pp. 43-56. Available at URL: <https://www.sciencedirect.com/science/article/pii/S1525505002006844> (Accessed: 14/5/24).

Stafstrom, C. E. (2019) 'Using artwork to understand and address the psychosocial challenges facing children and adolescents with epilepsy', *Epilepsy & Behavior*. 101, Available at URL: <https://www.sciencedirect.com/science/article/pii/S1525505019310169> (Accessed: 22/5/24).

Stonehouse, R. (2023) 'File on 4 - The Epilepsy Drug Scandal - BBC Sounds', Available at URL: <https://www.bbc.co.uk/sounds/play/m001nvs4> (Accessed: 22/5/24).

Swanborough, N. (2021) 'It's all about you - survey results | Epilepsy Society', Available at URL: <https://epilepsysociety.org.uk/latest/news/its-all-about-you-survey-results> (Accessed: 22/5/24).

Swanborough, N. (2021a) 'Women still unaware of risks around epilepsy medications in pregnancy – a charity finds.', Available at URL: <https://epilepsysociety.org.uk/news/women-still-unaware-risks-around-epilepsy-medicines-pregnancy-aug2020> (Accessed: 14/5/24).

Swanborough, N. (2021b) 'Concerns around Sodium valproate | Epilepsy Society' Available at URL: <https://epilepsysociety.org.uk/about-epilepsy/sodium-valproate/concerns-around-sodium-valproate> (Accessed: 14/5/24).

The BBC (2024) 'The World Tonight - Thousands harmed by pelvic mesh and sodium valproate "should get urgent financial help"', Available at URL: <https://www.bbc.co.uk/sounds/play/m001w184> (Accessed: 22/5/24).

The Open University (2022) 'The Listening Project at the Rachel McMillan nursery', *E809-20J Critical practice with children and young people*, Available at URL: <https://learn2.open.ac.uk/mod/oucontent/view.php?id=1638584§ion=4> (Accessed: 14/5/24).

UNCRC (1989) 'United Nations Convention on the Rights of the Child', Available at URL: <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child> (Accessed: 14/5/24).

Waple, K. (2024) 'Epilepsy medication shortage 'making me anxious', sufferer says', *BBC News*, Available at URL: <https://www.bbc.com/news/articles/c6pqp5p9y2o> (Accessed: 14/5/24).

Wood, G. (2024) 'Medicine shortages becoming 'new normal'', *Epilepsy Action*, Available at URL: <https://www.epilepsy.org.uk/medicine-shortages-becoming-new-normal> (Accessed: 22/5/24).

World Health Organisation, WHO (2024) 'Epilepsy', Available at URL: <https://www.who.int/news-room/fact-sheets/detail/epilepsy> (Accessed: 14/5/24).

Young Epilepsy (2023) 'Key facts about epilepsy' Available at URL: <https://www.youngepilepsy.org.uk/what-we-do/health-research/information-about-epilepsy> (Accessed: 22/5/24).

Appendices

Appendix 1

https://www.google.com/search?q=louise+bourgeois&client=safari&sca_esv=31a3dd54a4fd3d08&sca_upv=1&rls=en&udm=2&biw=1324&bih=754&sxsrf=ADLYWIJybdS4HqwhhI_exjom-AKFrratQ%3A1716442959735&ei=T9dOZrrFLPOkhhIPk-G76As&oq=louise+bourgeois&gs_lp=Egxnd3Mtd2l6LXNlcnAiEGxvdWlzZSBib3VyZ2VvaXMqAggAMg0QABiABBixAxhDGIoFMgUQABiABDIKEAAYgAQYQxiKBTIKEAAYgAQYQxiKBTIKEAAYgAQYQxiKBTIKEAAYgAQYQxiKBTIFEAAAYgAQyBRAAGIAEMgoQABiABBhDGIoFMgUQABiABEj4DVAAWABwA3gAkAEAmAEAoAEAqgEAuAEByAEAmAIDoAIRmAMAIAYBkgcBM6AHAA&sclient=gws-wiz-serp

Appendix 2

“I suddenly felt that I didn’t have a clue where I was, ... and I sort of get [um], kind of a vision almost, kind of, almost hallucinates, and [um] the, the things I see are always really terrifying. And I feel very afraid and like I want someone to help me, and [um], just this really sinister feeling, and then, very suddenly my sort of insides turn the right way up again and I feel like I’m coming out of it.”

Mary, aged, 19 (p. 219, Ryan and Raïsaïnen, 2012)

Appendix 3

“R: cos your brain can only take so much. And I was worried that one day I would wake up and I wouldn’t be able to walk or, I would, or I might not wake up or, wake up as a you know. Mother: Cabbage.

R: A vegetable basically. And I wasn’t, wasn’t afraid of dying really, I was afraid of that because I always thought if I have a seizure and I die I don’t know about it, that’s it, but if I’m in a wheelchair or I don’t want my life ruined by it.”

Johnny, aged, 20 (p. 219, Ryan and Raïsaïnen, 2012)

Appendix 4

“it went from, on average to, every two weeks to every week and it can be anything from [em], half an hour, where I’ve woken up after one and gone into another, only happened twice though. From, if you like that, six days to two weeks [em] so after a week if I go for another week or two without the seizure I kind of develop more and more paranoia, depression, all that sort of thing that goes with it as to ‘come on, you know, just have the fit so I can get back to normal lifestyle”

Jono, aged, 22 (p. 220, Ryan and Raïsaïnen, 2012)

Appendix 5

“Actually you sort of go through a range of emotions. I don’t think it lasts for any longer than maybe 30 seconds itself, as well, but at first you sort of feel very frightened and you think, ‘Oh, what is happening?’ because it’s all visual. And then you sort of feel slightly calm and a bit surreal and then you almost think, well ok I’m accepting it now, I know what is going to happen. [. . .]”

Valerie, aged, 20 (p. 220, Ryan and Raïsaïnen, 2012)

Appendix 6

“I was frightened. I was anxious, I was worried. I’d had all the, all the. . . but then I was excited as well. I was looking forward to it as well. You know, thinking, ‘Oh God if, I’m finally not going to have this blooming rotten illness anymore.”

Mary, aged, 28 (p. 221, Ryan and Raïsaïnen, 2012)

Appendix 7

“I wish they’d never shown me some of the stuff that they showed me, yeah. And also I’d never seen myself have a fit before had I, and they showed me a video of myself having a fit, and

that upset me quite a bit. And I hadn't hadn't like cried in years, but when I saw that I was really crying. Yeah.”

Johnny, 20 (p. 222, Ryan and Raïsaïnen, 2012)

Appendix 8



E822 Multidisciplinary Dissertation: Education, Childhood and Youth

E822 Dissertation Ethical Agreement Form

Return this completed form by the TMA01 cut-off date in November, by emailing a scanned version which makes clear the handwritten signatures to email address: WELS-ECYS-Masters@open.ac.uk, marked in the subject line 'For the attention of the E822 module team'. If you need to change your decision from an SSI to an EP at a later date this should be only after discussion with your tutor. A new version of this form should be completed and returned as above.

Student details	Name: Ruby Hooper	PI number: G1349963
------------------------	-------------------	---------------------

Student declaration

I accept that the Open University is unable to offer liability insurance to cover any negative consequences of my actions in carrying out research as part of this dissertation module, which in particular relates to my decision to carry out the small-scale investigation format of this dissertation module.

Should I wish to carry out the small-scale investigation:

In order to explain the expectations of this module, I have shared the Letter to Setting Gatekeepers and Guidance for Setting Gatekeepers with the Setting Gatekeeper.

I agree to work with the Setting Gatekeeper and/or Supervisor to ensure that I adapt the processes and protocols supplied by the Open University to fulfil any legislative requirements and guidance relevant to that setting.

I understand that the setting will have expectations of me with respect to safeguarding practices related to interacting with participants who are aged under 18/vulnerable adults and the disclosure of criminal activities.

Should my participants be aged under 18/vulnerable adults, I have shared with the Setting Gatekeeper a copy of my Disclosure and Barring Service enhanced disclosure (DBS) certificate* (see page 3) (or equivalent for those outside the UK). If I do not have the stated certification, I have completed Annex 1 of this document and my Gatekeeper is happy that there will be safe arrangements for me to carry out data collection with participants aged under 18/vulnerable adults.

I commit to using both University and setting advice to support me in taking responsibility for completing my small-scale investigation safely for all involved, ensuring that the privacy, autonomy and dignity of individuals is preserved.

Please tick one of the boxes below:

1. I will be undertaking my data collection in a practice setting as part of a small-scale investigation (SSI) for my dissertation.	
2. I have decided not to complete data collection in a setting and will be conducting the extended literature review and proposal (EP) form of my dissertation.	X

Signed: Ruby Hooper

Date: 22/5/24

If you have ticked box 1, please complete the following section in conjunction with a leader who will act as the gatekeeper to the setting. This should be someone who can confirm you have permission to conduct data collection in your chosen setting, and who is either willing themselves or able to identify for you someone willing to supervise** your conduct while collecting data. (**See the Guidance for Setting Gatekeepers for further information about the role of a Setting Supervisor).

If you are not planning to conduct research directly in a research setting, and do not need to request support from the setting (and this has been agreed with your tutor), sign as the gatekeeper. In these cases you are also signing to say that you will let the leaders of the setting know about your plans for research as a courtesy and offer them a chance to comment before you start your research.

Gatekeeper details	Name:
	Position/role in setting:
Setting details	
Setting address: Postcode:	

Practice-setting gatekeeper declaration – I give permission for [the student/insert name] to carry out data collection as part of their masters’ multidisciplinary dissertation module E822, in [insert name of the setting]. I will act in the role of supervisor** or have delegated this role to someone within the setting to oversee the data collection tasks they will undertake (interview, observation, documentation and/or questionnaire). I have read the Open University E822 Letter to Setting Gatekeepers and Guidance for Setting Gatekeepers. The student and I have discussed the guidance provided and I agree that procedures and protocols will be followed which ensure the research is undertaken ethically in this setting. Please tick one of the statements below:

- [If relevant/delete if not relevant] I am satisfied that [student name] has the necessary disclosures (eg DBS) in place to work with participants under the age of 18/vulnerable adults.

- [Student name] does not have the necessary disclosures in place, but I have reviewed Annex 1 of this form and will ensure that they are supervised when collecting data with participants under the age of 18/vulnerable adults.
- [student name] will not be researching with participants under the age of 18/vulnerable adults.

Signed: _____

Date: _____

Please print name: _____

Please complete this form and return pp. 1–2 to the E822 Module team by the TMA01 cut-off date in November. No data collection should be made unless a signed form has been returned declaring the agreed arrangements for this to take place. We will keep this form for 2 years from the start of your study on E822 and then destroy it. If you need to change your decision from an SSI to an EP at a later date this should be only after discussion with your tutor. A new version of this form should be completed and returned to the email address on p1.

***The Disclosure and Barring Service disclosure certification (or equivalent in Scotland, Wales and Northern Ireland) must bear the same name as that given by you on p.1. Students in Scotland will also need to evidence that they meet the requirements of the Protection of Vulnerable Groups Scheme.** You must have a clear, enhanced DBS disclosure (or appropriate equivalent) which is current. It must be appropriate for the setting in which you intend to carry out your research and must be recent, i.e. within the last two years.

Annex 1: E822 Dissertation Ethical Agreement Self-Declaration

This form is an opportunity to self-declare and provide assurances that you do not pose a level of risk to others, in particular to those under the age of 18 and vulnerable adults, and should be completed if box 1 has been ticked on p.1 of this agreement for those unable to provide a clear DBS or national equivalent certificate. Annex 1 should be shared with the Setting Gatekeeper and should not be submitted in the documents returned to the University.

I confirm that (please tick the right-hand boxes as relevant to each statement):

I have no criminal convictions or conditional cautions considered to be unspent under the terms of the Rehabilitation of Offenders Act 1974***	
I have no spent cautions (reprimands or warnings) and convictions for serious violent and sexual offences or other offences of relevance for posts concerned with safeguarding children and vulnerable adults, nor any convictions resulting in a custodial sentence, whether or not suspended.	
To my knowledge there is no information held by the authorities that would be considered relevant to working with children	

and young people under the age of 18 or vulnerable adults.	
To my knowledge I am not on any barred lists of people not considered suitable for working with children and young people under the age of 18 or vulnerable adults.	

***The Rehabilitation of Offenders Act 1974 aims to give those with convictions or cautions the chance in certain circumstances to start afresh. Under the Act, eligible convictions or cautions become ‘spent’ after a specified period of time known as the ‘rehabilitation period’, the length of which varies depending on how the individual was dealt with. You can refer to the relevant extract from the Rehabilitation of Offenders Act 1974 explaining rehabilitation periods at: <http://researchbriefings.files.parliament.uk/documents/SN01841/SN01841.pdf> and criteria by which offences will be filtered from official Disclosure and Barring Service Checks, on which this form is based, at: <https://www.gov.uk/government/publications/filtering-rules-for-criminal-record-check-certificates/filtering-rules-for-dbs-certificates-criminal-record-checks>

The wording of this form has been guided by that taken from the Disclosure and Barring Service website, in particular from the Sample Policy for the Recruitment of Ex-Offenders <https://www.gov.uk/government/publications/dbs-sample-policy-on-the-recruitment-of-ex-offenders/sample-policy-on-the-recruitment-of-ex-offenders> and Checking Someone’s Criminal Record as an Employer <https://www.gov.uk/dbs-check-applicant-criminal-record>

Signed:

Date: