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**Transitions During Adolescence: A qualitative exploration of the  
developmental and healthcare transition experiences of adolescents with  
epilepsy.**

**And**

**Clinical Research Portfolio**

**Volume I**

(Volume II bound separately)

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*Submitted in partial fulfilment of the requirements for the degree of Doctorate in  
Clinical Psychology (DClinPsy)*

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## **Chapter One: Systematic Review**

### **Perceptions of Stigma in Adolescents with Epilepsy: A Systematic Review**

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*Prepared in accordance with the requirements for submission to Child: Care, Health and Development (See Appendix 1.1)*

## **Abstract**

**Background:** Research suggests that adolescents with epilepsy experience significant stigmatisation. This stigmatisation has been associated with peer rejection, educational underachievement and significant psychosocial difficulties. Factors including age, gender, seizure severity and age of onset have previously been reported to influence the extent of stigma perceived by adolescents with epilepsy. This review explored further the perceived stigma experiences of adolescents with epilepsy.

**Methods:** A systematic literature search was conducted using MEDLINE, Psychology and Behavioural Sciences Collection, PsychINFO, PsychARTICLES, CINAHL, the Cochrane Library and Science Direct to identify relevant studies. Articles were screened against *a priori* inclusion criteria. The quality of included studies was assessed.

**Results:** Seven studies met the inclusion criteria. Increasing age, male gender, less epilepsy knowledge, increased number of drugs taken, increased seizure severity, increased worry and negative perceptions of epilepsy were reported to significantly impact perceived stigma.

**Discussion:** Some significant findings in this review paralleled findings from the previous review, in particular, associations between increased age and epilepsy severity. Additional significant associations were reported, however variation in methodology meant only tentative comparisons could be made. Cultural variation needs to be considered when appraising these findings. Further research is needed in this area.

## Introduction

The currently recognised definition of epilepsy, developed by the International League Against Epilepsy is: *“a disease of the brain defined by any of the following conditions: (1) At least two unprovoked (or reflex) seizures occurring more than 24 hours apart; (2) one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years; (3) diagnosis of an epilepsy syndrome”* (Fisher et al., 2014, p. 475). It is reported to be the most common neurological condition in individuals under the age of 18 years in the UK (MacLeod & Appleton, 2007).

Adolescents with epilepsy are reported to experience a substantial amount of stigma due to their diagnosis (Jacoby et al., 2008). For example, Hirfanoglu et al. (2009) found that up to 40% of adolescents (N=533) with epilepsy reported feeling stigmatised by their peers. Stigma has had a number of definitions. Goffman (1963) described it as a status loss or discreditation caused by having a characteristic that is culturally defined as being different or undesirable. In relation to health conditions Weiss and Ramakrishna (2006) described stigma as *“a social process or related personal experience characterised by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgement about a person or group identified with a particular health problem”* (p.536). This latter definition makes a crucial change to the understanding of stigma as it includes not only direct experiences of adverse judgement, but also the anticipation of adverse judgement. Muhlbauer (2002) conceptualised three main forms of stigma: internalised, interpersonal, and institutional. Internalised stigma reflects the individual with the health condition's thoughts, feelings and concerns about being different. Interpersonal stigma is when an individual is treated differently and negatively within their interactions with others because of their health condition. Institutionalised stigma is understood as the indirect differential treatment within wider society of certain groups with particular health conditions, for example in the use of clinical terminology to describe them (“epileptic” rather than a person with epilepsy), or in exclusion from activities or insurance categories.



Adolescence is a turbulent period of drastic physical, social and emotional change during which identity and self-definition are developed (Devinsky et al., 1999) and independence and autonomy are fostered (Appleton & Neville, 1999; Erikson, 1968). Epilepsy can have a significant psychosocial impact on adolescents during this developmental stage. Adolescents with epilepsy are expected to incorporate additional knowledge and skills whilst also negotiating the same challenges as their peers (Sheth, 2002). Stigmatisation is one of the many factors that can influence their successful negotiation through this (Austin et al., 2014). Since the turn of the century, there has been an increased focus on understanding the impact of stigma on the development and life experiences of adolescents with epilepsy. This has included studies focussing on adolescents with epilepsy and adolescents within the general population in an attempt to understand the different forms of stigma described above (e.g. Austin et al., 2002). Studies have shown that adolescents with epilepsy who experience stigma are more vulnerable to developing psychological difficulties such as low self-esteem (Baker et al., 2005); symptoms of anxiety and depression (Adewuya & Ola, 2005); social adjustment problems (Baker et al., 2005), and higher rates of suicide (Zamani et al., 2012). Epilepsy related stigma has also been associated with peer rejection, school avoidance and academic underachievement (Buhs & Ladd, 2001). An Epilepsy Foundation Survey (N=19,441) found that a significant proportion of adolescents in the general population held negative perceptions of people with epilepsy and 75% thought teenagers with epilepsy would be more likely to be bullied (Austin et al., 2002). This highlights a significant example of institutionalised stigma, which has been associated with limited knowledge and less familiarity of epilepsy within this age group internationally (Ani et al., 2011; Rho et al., 2010; Hirfanoglu et al., 2009).

Two systematic reviews to date have explored the impact of stigma on adolescents with epilepsy. MacLeod and Austin (2003) extrapolated findings from six studies. The studies included in their review found significant positive correlations between perceived stigma and age and stigma and duration of epilepsy and a negative correlation between perceived stigma knowledge of epilepsy. They also found stigmatising perceptions towards epilepsy across adolescents in the general population. They concluded that more in-depth research was required to fully understand the experiences of stigma for adolescents with epilepsy. McEwan et al.

(2004) systematically reviewed the contribution of qualitative research in understanding the impact of epilepsy on the quality of life in children and adolescents. Only one study met inclusion criteria, however, from this and the process of excluding the remaining studies, they concluded that more emphasis needed to be placed on the views of those with epilepsy rather than gathering information from proxy reports from parents and teachers. There has been a significant increase in research being conducted in this area since these reviews were conducted, however no review was identified that looked specifically at quantitative research since 2003 exploring perceived stigma in adolescents with epilepsy.

### **Review Aim**

To systematically review perceived stigma in adolescents with epilepsy.

## **Method**

### **Selection Criteria**

To be included in this review, studies had to meet the following criteria:

- 1) Include adolescent participants (aged 10-19 in accordance with WHO definition, 2013);
- 2) Participants with epilepsy;
- 3) Direct measuring and reporting of stigma as perceived by adolescents;
- 4) Studies published in English peer reviewed journals between January 2002 and July 2014;
- 5) Quantitative methodology.

Studies were excluded if they met any of the following criteria:

- 1) Translation and/or validation of psychometric measures;
- 2) Proxy reporting of adolescent stigma;
- 3) Review papers;
- 4) Case studies;
- 5) Studies using qualitative methodology.

### **Search strategy**

A comprehensive search was conducted in July 2014 using the following databases: Science Direct, MEDLINE, CINAHL, PsychINFO, PsychARTICLES, Psychology and Behavioural Sciences Collection and the Cochrane Library. The search strategy included the following Medical Subject Headings (MeSH) headings or keywords: 1) *epilepsy or epilepsies*; *and* 2) *adolescent or adolescence or young person*; *and* 3) *stigma or quality of life or QOLIE-AD-48 or health related quality of life or HRQOL*; *and* 4) *measuring or measurement or instrument*. Key journals including *Seizure*, *Epilepsia*, *Epilepsy and Behavior*, and reference lists of identified papers were hand searched for additional references.

## **Quality Assessment**

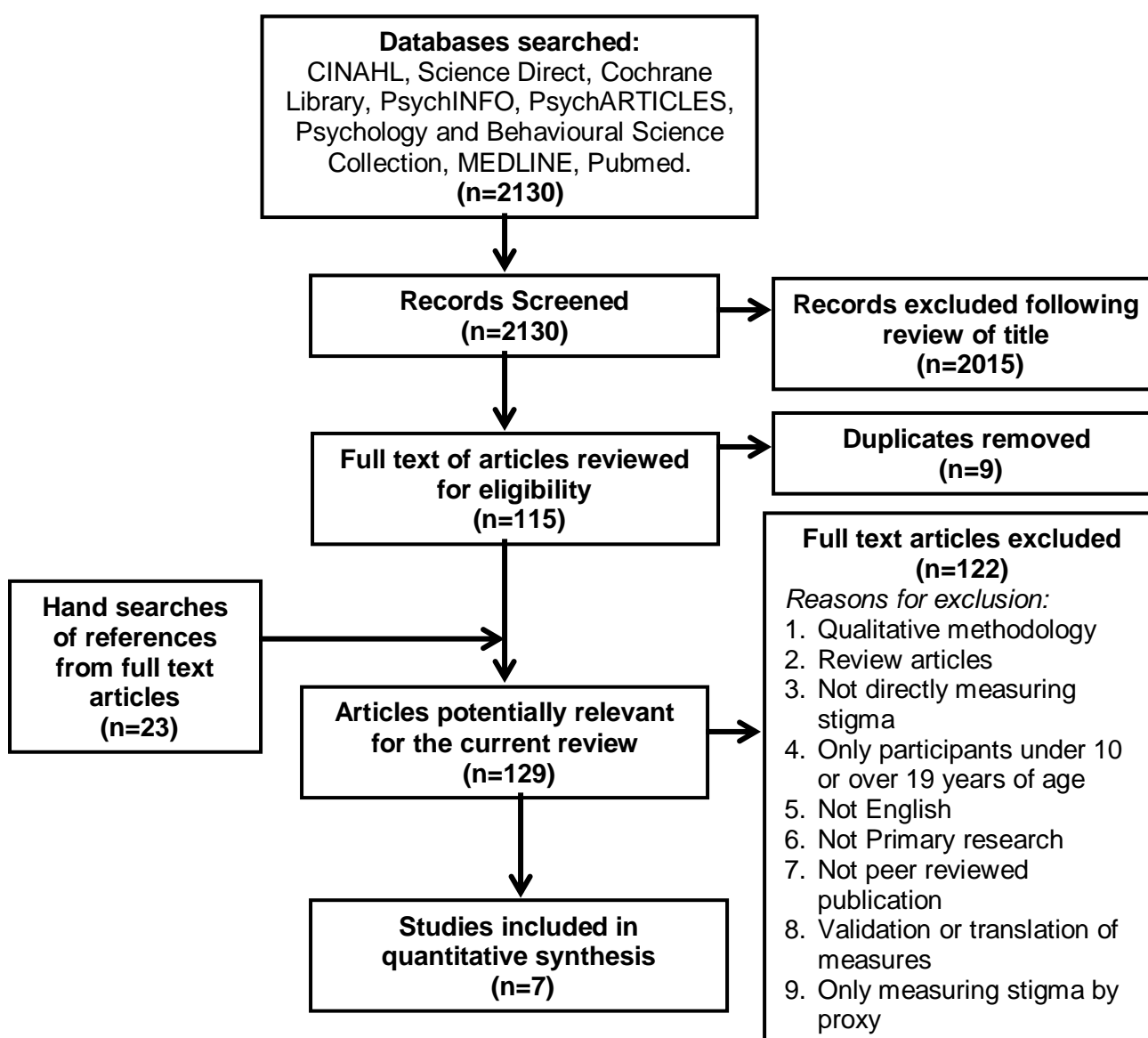
The quality of included studies was assessed using The Crowe Critical Appraisal Tool [CCAT] (Crowe & Sheppard, 2011). The most updated version [Version 1.4] (Crowe, 2013) contains 22 items in eight categories. The items are rated on a nominal scale as Present, Absent or Not Applicable and given a score out of five for each category, a total score and a total percentage (Appendix 1.2). An independent reviewer rated all included studies using the same quality rating scale. There was an 87% agreement between researchers. Any disagreements were resolved through discussions. The CCAT does not include qualitative descriptions of scores, however other critical appraisal tools state that >75% is considered good, >50% is considered acceptable and <50% is considered poor (e.g. Walsh & Downe, 2006). These descriptors will be considered in the Quality Review section below.

## Results

### Results of search strategy

The database search identified 2130 articles. 2015 were excluded on the basis of their title and nine duplicates were removed. Abstracts, full text and reference lists of the remaining 106 articles were reviewed using the full inclusion criteria. Hand searches of the reference lists generated a further 23 studies therefore 129 full texts were reviewed. This resulted in the exclusion of a further 122 studies. A total of seven studies met the full inclusion criteria measuring perceived stigma of adolescents with epilepsy. The study selection process is detailed in Figure 1.

Figure 1: Flow diagram of study selection process



## Overview of the articles

Of the seven studies identified for inclusion in this review, one surveyed the knowledge of, attitudes to and perceptions of epilepsy in children with epilepsy and their families and compared this to quality of life and stigmatisation (Hirfanoglu et al., 2009), five measured the concept of stigma as it is associated with overall health related quality of life [HRQOL] (Zamani et al., 2014; Zashikhina & Hagglof, 2014; Wu et al., 2010; Stevanovic, 2007; Benavente-Aguilar et al., 2004) and one measured the relationship between parental psychopathology and the concept of stigma as it associated with overall HRQOL in adolescents with epilepsy (Adewuya, 2006). Stigma in the context of health related quality of life of individual's with epilepsy is understood as *“the extent to which people with epilepsy are separated from society on the basis of the meanings that are attached to the term “epilepsy”*” (Reiss & Meinardi, 2002, p.s35). In the development of HRQOL scales for epilepsy, stigma related items refer specifically to the impact of social isolation, discrimination and the perceived impact of epilepsy on daily activities and life fulfilment (Ablon, 2002; Jacoby, 2002; Cramer et al., 1999). For the purpose of this review, statistics and findings relating to perceived stigma in adolescents with epilepsy were extracted from studies. Table 2 provides a detailed summary of the included studies.

## Quality Review

Table 1 provides a detailed summary of the scores obtained by each study including domain scores, total scores and total percentages. Using the qualitative descriptors detailed above, all studies were considered good. All studies scored four or five out of five for preliminaries (defined as abstract, title, aims and style), introduction, design and sampling other than Wu et al. (2010). This means that studies reported summaries of current knowledge, primary and secondary objectives and appropriate research design and sampling procedures. Three studies scored lower in the Ethical Matters category as they did not report enough items (Zamani et al., 2014; Zashikhina & Hagglof, 2014; Stevanovic, 2007). This category required studies to state participant ethics, including informed consent, privacy and confidentiality, and researcher ethics, including ethical approval, funding, conflicts of interest, subjectivities and relationships with participants. Two studies scored lower in the

discussion section as they did not report study limitations and future research prospects (Zashikhina & Hagglof, 2014; Hirfanoglu et al., 2009).

*Table 1: Quality Assessment Results*

Study	Country	CCAT Scores									
		Preliminaries	Introduction	Design	Sampling	Data Collection	Ethical Matters	Results	Discussion	Total	Total %
Adewuya (2006)	Nigeria	4/5	5/5	5/5	4/5	3/5	4/5	4/5	4/5	<b>33/40</b>	<b>83%</b>
Benavente-Aguilar et al. (2004)	Spain	4/5	4/5	4/5	5/5	4/5	5/5	4/5	4/5	<b>34/40</b>	<b>85%</b>
Hirfanoglu et al. (2009)	Turkey	5/5	4/5	5/5	4/5	4/5	4/5	4/5	3/5	<b>33/40</b>	<b>83%</b>
Stevanovic (2007)	Serbia	5/5	5/5	4/5	4/5	4/5	1/5	5/5	4/5	<b>32/40</b>	<b>80%</b>
Wu et al. (2010)	China	5/5	3/5	5/5	5/5	5/5	5/5	4/5	5/5	<b>37/40</b>	<b>92%</b>
Zamani et al. (2014)	Iran	5/5	5/5	4/5	5/5	4/5	3/5	4/5	5/5	<b>35/40</b>	<b>88%</b>
Zashikhina & Hagglof (2014)	Russia	5/5	5/5	5/5	4/5	3/4	2/5	4/5	3/5	<b>31/40</b>	<b>78%</b>

## Stigma Outcome Measures in Included Studies

*Quality of Life in Adolescents with Epilepsy Inventory [QOLIE-AD-48]*: This is a 48 item valid and reliable self-report measure of health related quality of life (HRQOL), specifically for adolescents with epilepsy (Cramer et al., 1999). It incorporates eight subscales: Health Perceptions, Epilepsy Impact, Memory/Concentration, Physical Functioning, Stigma, Social Support, School Functioning and Attitudes towards Epilepsy. Scores for each item are obtained from a Likert scale. Forty-two items have a 5 point Likert scale (1 for the worse and 5 for the best status) and 6 items have a 4 point Likert Scale (1 for the worse and 4 for the best status). Raw scores are translated into scores on a 0-100 response scale. The total score was determined by multiplying the mean by the relative weight for each domain (See Table 3 below). Higher scores indicate better HRQOL. For the purpose of this review, stigma scores and significant associations were extracted from studies. Lower perceived stigma is indicated in this measure by a higher score.

Table 3: Relative weight for each domain of the QOLIE-AD-48

Domain	Weight	Domain	Weight
1. Epilepsy Impact	0.31	5. Stigma	0.13
2. Memory/concentration	0.17	6. Social Support	0.02
3. Attitudes	0.09	7. School Behaviour	0.06
4. Physical Function	0.09	8. Health Perceptions	0.12

*Children's Questionnaire:* Hirfanoglu et al. (2009) used a 46 item questionnaire they developed to measure children's general knowledge and impact of epilepsy including attitude, perception, stigmatisation, social support, self-esteem, school and depression. The first ten questions collected demographic details including age, gender, duration of disease, anti-epileptic drugs, schooling, parental employment status and number of siblings. Of the remaining questions 12 items measured general knowledge on a 4 point Likert scale (1=yes, 2=no, 3=probably not, 4-I don't know) and 24 items measured impact on a 5 point Likert scale (1-nothing, 2-hardly any, 3-a few, 4-more often than not, 5-a lot/often). The scale is reported to have good content validity and internal consistency reliability ( $\alpha=0.92$ ).



Table 2: Summary of Included Studies

Study	Demographics*	Design	Measure*	Analysis	Stigma Related Findings
Adewuya (2006)	N=86 50 male, 36 female Mean Age: 14.5 ±2.1 yrs Age Range: 12-18 yrs Mean duration: 6.5±2.2 yrs Mean onset: 8.8±3.2 yrs	Cross Sectional	QOLIE-AD-48 (Yoruba translation) GHQ-30 <sup>^</sup> SRAS <sup>~</sup> SRDS <sup>+</sup>	Multi-variate regression analysis  Correlations	Mean stigma score: 65.99±11.31  Significant Associations: 1) Adolescent stigma & parental GHQ-30 score (r=0.305, P=0.01). Higher perceived stigma is associated with higher GHQ scores. 2) Adolescent stigma & parental SRDS score (r=0.584, P=0.01) Higher perceived stigma is associated with higher SRDS scores.
Benavente-Aguilar et al. (2004)	N=66 36 male, 30 female Mean age: 15 yrs Age range: 10-19 yrs Mean onset: 7.2 yrs Mean duration: 8.1 yrs	Cross Sectional	QUOLIE-AD-48 (Spanish version)  Veterans Administration Neurotoxicity Rating Scale	T-test ANOVA Socio demographic variables	Mean stigma score: 86±20.1  Significant differences: 1) Stigma scores in mild & moderate/severe epilepsy (P<0.01). Higher perceived stigma was reported by those with more severe epilepsy.
Hirfanoglu et al. (2006)	N=220 (children) 95 females, 125 males Mean age: 13.5±3.2 yrs Age range: 8-17 yrs Mean onset: not provided Mean duration: 4.43±3.96	Cross Sectional	Author developed scale	Descriptive Statistics  Correlations	41.2% reported feeling stigmatised by friends.  Significant Associations: 1) stigma & age (r=0.256, P=0.0001) – increasing age is associated with higher levels of perceived stigma. 2) Stigma & symptoms of depression (r=0.276, P=0.0001) – as symptoms of depression increase, perceived stigma increases 3) Stigma & negative perception (r=0.195, P=0.004) – as negative perception of epilepsy increases, perceived stigma increases. 4) Stigma & perceived lack of social support (r=0.266, P=0.000) – as perceived lack of social support increases, perceived stigma increases. 5) Stigma & knowledge (r=-0.180, P=0.008) – less knowledge is associated with higher perceived stigma. 6) Stigma & self-esteem (r=-0.150, P=0.026) – lower self-esteem is associated with higher perceived stigma.
Stevanovic (2007)	N=71 39 males, 32 females Mean age: 15.1±2.15yrs	Cross Sectional	QOLIE-AD-48 (Serbian Version)	Descriptive Statistics	Mean stigma score: 1) Total: 82.96±19.54 2) Males: 81.1±21.21, (95%Confidence Interval: 74.21-87.96)

	Age range: 11.5-18 yrs Mean onset: 5.16±3.85 yrs Mean duration: 11.5±5.12 yrs			Correlations  Regression Analysis	3) Females: 85.24±16.97 (95% Confidence Interval: 79.12-91.36).  Significant Associations: 1) Stigma & total HRQOL score ( $r=0.6$ , $P\leq 0.05$ ) 2) Stigma & health perception ( $r=0.25$ , $P\leq 0.05$ ) 3) Stigma & epilepsy impact ( $r=0.57$ , $P\leq 0.05$ ) 4) Stigma & memory/concentration ( $r=0.25$ , $P\leq 0.05$ ) 5) Stigma & physical functioning ( $r=0.28$ , $P\leq 0.05$ ) 6) Stigma & school behaviour ( $r=0.24$ , $P\leq 0.05$ ) 7) Stigma & attitudes towards epilepsy ( $r=0.42$ , $P\leq 0.05$ ). For the above stigma associations, a higher stigma score represents a better stigma quality of life score i.e. better quality of life or less perceived stigma. So each of the factors are significantly associated with better stigma related quality of life i.e. lower perceived stigma.  Predictors of stigma 1) Number of drugs taken ( $\beta=0.233$ , $P<0.001$ , $F$ value = 15.47, Variance = 31%) 2) Epilepsy concern ( $\beta=-0.01$ , $P=0.042$ )
Wu et al. (2010)	N=47 21 female, 26 male Mean Age: not provided Age range: 11-17 yrs Mean onset: 11.34±3.38 yrs Median duration: 2 yrs	Case control study	QOLIE-AD-48 (Chinese version)	T-tests  Step wise linear regression analysis	Mean stigma score: 62.9±26.4  Predictors of Stigma: 1) Duration in years ( $\beta=-0.395$ , $P=0.006$ ) AEDS ( $\beta=0.304$ , $P=0.031$ ) 2) Onset age ( $\beta=0.339$ , $P=0.035$ )
Zashikhina & Hagglof (2006)	<b>Epilepsy sample :</b> N=47 19 males, 28 females Mean age: 14.95 yrs Age range: 13-16 yrs Mean onset: not provided Mean duration: not provided	Cross Sectional	QOLIE-AD-48 (Russian translation)	Descriptive Statistics  Regression analysis	Mean stigma scores: 1) Total: 58.9±20.7 2) Males: 52.92±13.54 3) Females = 64.48±23.63;  Predictors of Stigma: 1) Gender ( $\beta=0.28$ , $t(47)=1.98$ , $P<0.05$ , $R^2=0.06$ ).
Zamani et al. (2014)	N=187 101 males, 86 females. Mean age: 14.28 ±2.54 yrs Age range: 11-17 yrs Mean onset: 7.28±3.4 yrs Mean duration: 7.01±3.14 yrs	Cross Sectional	QOLIE-AD-48 (Persian Version)	Descriptive Statistics  Correlations	Mean stigma score: 52.55±19.71  Significant correlations: 1) Stigma & age ( $r=-0.40$ , $P<0.001$ ) – as age increases stigma related quality of life decreases, i.e. perceived stigma increases 2) Stigma & number of drugs ( $r=-0.151$ , $P=0.041$ ) – as the

					<p>number of drugs taken increases, stigma related quality of life decreases, i.e. perceived stigma increases</p> <p>3) Stigma &amp; frequency of seizures (<math>r=-0.201</math>, <math>P=0.006</math>) – as the frequency of seizures increases, stigma related quality of life decreases i.e. perceived stigma increases.</p>
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\*Standard Deviations are provided where reported in studies.

#Translation refers to a validated translation, version refers to local translation provided specifically for the study including appropriate independent back translations

^General Health Questionnaire (Goldberg & Hiller, 1979)

~Zung's Self-Rating Anxiety Scale (Zung, 1971)

+Zung's Self-Rating Depression Scale (Zung, 1965)

## **Description of Studies and Key Stigma Related Findings**

Hirfanoglu et al. (2009) used their Children's Questionnaire to study associations between knowledge, quality of life and stigmatisation of Turkish children (8-17 years) with epilepsy (N=220) and their parents (N=313). Participants were recruited from a paediatric neurology department. Patients with intellectual impairment (defined as an IQ score <80 on WISC-R), vision or hearing impairments, a diagnosis of a progressive neurodegenerative disorder or who had participated in a pre-test, were excluded from the study. Forty one percent of children reported feeling stigmatised by their friends. Significant correlations were found between perceived stigma score and age ( $r=0.256$ ,  $P=0.0001$ ); knowledge ( $r=-0.187$ ,  $P=0.0008$ ); number of siblings ( $r=0.199$ ,  $P=0.003$ ); negative perception of epilepsy ( $r=0.195$ ,  $P=0.004$ ); perceived lack of support ( $r=0.266$ ,  $P=0.000$ ); and self-esteem ( $r=-0.150$ ,  $P=0.026$ ). They also reported increased perceived stigmatisation scores in children with at least one unemployed parent ( $P=0.015$ ). Authors acknowledge that, as this is the first study in Turkey to investigate this phenomenon, further, more comprehensive studies are required to validate their findings and to allow comparison with control groups.

Adewuya (2006) investigated the relationship between HRQOL and parental psychopathology in 86 adolescents with epilepsy (12-18 years). Participants were recruited from two specialist tertiary neuropsychiatry outpatient clinics and were required to have been on drug treatment for a least one year. Exclusion criteria included severe cognitive disabilities (defined as severe or profound learning disability) and being non-verbal. HRQOL was measured using a Yoruba translation of the QOLIE-AD-48. The mean score of perceived stigma in adolescents was 65.99 ( $\pm 11.31$ ). Significant correlations were found between adolescent stigma scores and parent GHQ-30 ( $r=0.305$ ,  $P=0.01$ ) and SRDS ( $r=0.584$ ,  $P=0.01$ ) scores. The author acknowledged the use of a hospital based sample, restricted age range and exclusion of individuals with learning disabilities as potential limitations of the study. A further difficulty is the lack of control group as parental psychopathology could also impact adolescents without epilepsy. Therefore it is not possible to definitively determine whether the difficulties experienced by these adolescents are related to their epilepsy or their parent's psychopathology. Parental psychopathology was mostly measured in mothers in the study (94.2%). Further exploration of fathers'

psychopathology and the use of a matched control group would perhaps allow these factors to be investigated in more depth.

Benavente-Aguilar et al., (2004) examined the HRQOL of a community sample of adolescents (10-19 years) with epilepsy (N=66). Participants were identified from hospital registers and were required to meet the following inclusion criteria: a diagnosis of active epilepsy (defined as at least one seizure in the last five years); illness duration of one year or more; not living in an institution and ability to read Spanish. Exclusion criteria included co-morbid psychiatric or other physical illness, deafness, blindness or patients who had undergone brain surgery in the previous year. This is the only study in the review that did not state cognitive impairment or learning disability as exclusion criteria. HRQOL was measured using the Spanish Version of the QOLIE-AD-48 (Benavente et al., 2002 [Spanish]). The mean stigma score was 86 ( $\pm 20.1$ ) overall, 90 ( $\pm 14.2$ ) in participants with mild epilepsy and 72.2 ( $\pm 27.2$ ) in participants with moderate to severe epilepsy. A significant difference was reported between stigma in mild versus moderate or severe epilepsy groups ( $P < 0.01$ ). This study attempted to capture the total population of young people with epilepsy in this province; however they acknowledge that those who do not access services will have been unintentionally excluded. The authors also acknowledged that associations found between increased severity and overall HRQOL (including stigma) may be confounded by the links between severity and increased exposure to neurotoxicity due to the subsequent increase in medications required by this sub-sample.

Stevanovic (2007) evaluated HRQOL of Serbian adolescents (11-18 years) with well controlled epilepsy (N=71). Participants were recruited from a Health Care institute and Neurology and Psychiatry clinic. To be included participants were required to have had active, uncomplicated epilepsy (defined as no seizures for more than one year) for more than five years. Participants with additional neurological or psychiatric disorders, major neuropsychological deficits or other chronic conditions, had undergone significant therapy or EEG changes, had been hospitalised or institutionalised for any reason or lived away from their parents and who had a failing grade or dropped out of school were excluded. HRQOL was measured using the Serbian Version of the QOLIE-AD-48 (Stevanovic et al., 2005). The mean stigma score was 82.96 ( $\pm 19.4$ ) overall, 81.1 ( $\pm 21.21$ ) for males and 85.24 ( $\pm 16.97$ ) for

females. Significant correlations were found between stigma and overall HRQOL score ( $r=0.6$ ,  $P\leq 0.05$ ); health perception ( $r=0.25$ ,  $P\leq 0.05$ ); epilepsy impact ( $r=0.57$ ,  $P\leq 0.05$ ); memory/concentration ( $r=0.25$ ,  $P\leq 0.05$ ); physical functioning ( $r=0.28$ ,  $P\leq 0.05$ ); school behaviour ( $r=0.24$ ,  $P\leq 0.05$ ); and attitude toward epilepsy ( $r=0.42$ ,  $P\leq 0.05$ ). Stigma was reported to be significantly predicted by the number of anti-epileptic drugs (AEDs) taken ( $\beta=0.233$ ,  $P<0.001$ ,  $F=15.47$ , Variance =31%) and the level of epilepsy concern ( $\beta=-0.01$ ,  $P=0.042$ ). The cross sectional design and absence of group comparisons are considered a potential limitation for generalisability by the authors. The specific inclusion and exclusion criteria are also considered a generalisability limitation. They also acknowledged that previous studies in well-controlled epilepsy have focused on quality of life rather than HRQOL therefore making comparisons difficult.

Wu et al. (2010) conducted a case control study of 47 pairs of Chinese adolescents (11-17 years) with epilepsy and matched normal controls to explore quality of life and related factors. Participants with epilepsy were recruited from a neurology outpatient clinic in Shanghai. They were required to be between 11 and 17 years of age, able to read Chinese, experienced active epilepsy within the previous six months and have an available parent who spoke and read Chinese. Individuals were excluded if they had undergone epilepsy surgery in the previous year, had additional neurological or psychiatric disorders, had major neuropsychological deficits or other conditions. Forty seven adolescents without epilepsy or any other chronic conditions were matched one-to-one to epilepsy cases by sex and age to within a year. HRQOL in adolescents with epilepsy was measured using the Chinese Version of the QOLIE-AD-48 (Wang et al., 2009). Quality of life in controls was measured using three domains unrelated to epilepsy (memory/concentration, physical functioning and social support). The mean stigma score in case participants was 62.9 ( $\pm 26.4$ ). Stigma were reported to be significantly predictable by duration of epilepsy ( $\beta=-0.395$ ,  $P=0.006$ ); number of AEDs taken ( $\beta=0.304$ ,  $P=0.031$ ); and onset age ( $\beta=0.339$ ,  $P=0.035$ ). The authors acknowledged that the economic level and availability of resources for participants in Shanghai may not be generalizable to rural China and therefore results may have a positive bias in terms of experiences of stigma. In addition they noted that due to their exclusion of surgical patients and

those with psychiatric co-morbidities, it is difficult to generalise the findings to patients with new onset or chronic epilepsy or to those with co-morbidities.

Zamani et al. (2014) conducted an analytical cross sectional study of the HRQOL in Iranian adolescents (11-17 years) with epilepsy (N=197). Participants were recruited from a Children's Hospital within a 14 month period. A diagnosis of epilepsy and attendance at the hospital are the only stated inclusion criteria in the study. HRQOL was measured using the Persian version of the QOLIE-AD-48 (Dashtbozorgi et al., 2010). The mean score of perceived stigma was 52.55 ( $\pm 19.71$ ). They reported that 65.8% of the participants never spoke to their friends or teachers about their epilepsy. Significant associations were found between stigma and age ( $r=-0.40$ ,  $P<0.0001$ ); number of drugs taken ( $r=-0.151$ ,  $P=0.041$ ); and frequency of seizures per year ( $r=-0.201$ ,  $P=0.006$ ). Age and seizure concern were found in this study to be a significant predictors of stigma ( $\beta=-0.286$ ,  $P=0.000$ ,  $F=7.003$  [age];  $\beta=0.213$ ,  $P=0.002$ ,  $F=7.003$  [seizure concern]). They compared stigma scores to previous studies using international translations of QOLIE-AD-48 and found lower scores in their sample than in previous studies suggestive of higher perceived stigma. The authors acknowledge the sample size as a limitation. The lack of reported exclusion criteria also makes it impossible to determine the homogeneity of the sample and make comparison with other studies difficult.

Zashikhina and Hagglof (2014) conducted a cross sectional survey to explore HRQOL in adolescents (13-16 years) with chronic illness in Northern Russia (N=173). Participants were recruited from child outpatient clinics and were required to have received their diagnosis at least one year prior to the study. Individuals were excluded if they had an additional diagnosis of "mental retardation", resided in an institution or had more than one chronic condition. The sample consisted of 47 adolescents with epilepsy, 50 with Type 1 Diabetes, 49 with asthma and their parents. HRQOL in adolescents with epilepsy (N=47) was measured using a Russian translation of the QOLIE-AD-48. The mean stigma score was 59.8 ( $\pm 20.7$ ) overall (N=47), 64.48 ( $\pm 23.63$ ) for females (N=29) and 52.92 ( $\pm 13.54$ ) for males (N=19). Gender was found to be a predictor of stigma in their sample ( $\beta=0.28$ ,  $t(47)=1.98$ ,  $P<0.05$ ,  $R^2=0.06$ ). Authors acknowledged that the cross sectional design and sample size were potential limitations. They also stated that the inability to make

comparisons between condition groups or with controls made the findings difficult to generalise.

## Perceived Stigma in Adolescents with Epilepsy

Significant correlations and predictive factors for stigma were reported across studies. Age, epilepsy severity and knowledge and support needs were directly correlated with perceived stigma. These will be considered in turn. Reported predictive factors will then be considered. Finally, additional significant findings will be considered.

### *Perceived Stigma:*

There was variation reported in average stigma scores across the studies indicative of varying levels of perceived stigma across samples and sample characteristics. Table 4 details the average stigma scores reported by studies using the QOLIE-AD-48 from highest (indicating higher HRQOL in this domain, that is lower perceived stigma) to lowest (indicating lower HRQOL and higher perceived stigma).

*Table 4: Average Perceived Stigma in Studies using QOLIE-AD-48*

Study	Country	Mean Stigma Score
Benavente-Aguilar et al. (2004)	Spain	86±20.1
Stevanovic (2007)	Serbia	82.96±19.54
Adewuya (2006)	Nigeria	65.99±11.31
Wu et al. (2010)	China	62.9±26.4
Zashikhina & Hagglof (2014)	Russia	58.9±20.7
Zamani et al. (2014)	Iran	52.55±19.71

The results suggest that adolescents with epilepsy in Spain and Serbia experience the least perceived stigma (indicated by a higher score) and those in Iran experience the most (indicated by lower score). The variation in scores needs to be considered carefully as the homogeneity of sample characteristics and the wide cultural variation in the studies make generalisability less robust.



### *Perceived Stigma and Age:*

Two studies (Zamani et al., 2014; Hirfanoglu et al., 2009) reported significant correlations between level of perceived stigma and the age of participants. Both studies reported that an increase in age was correlated with an increase in perceived stigma. Due to the scoring mechanisms or the outcome measures in each study this was described as an inverted correlation in Zamani et al.'s (2014) study (that is, as age increases stigma related quality of life decreases [ $r=-0.40$ ,  $P<0.001$ ]) and as a positive correlation in Hirfanoglu et al.'s (2009) study (that is, as age increases perceived stigma score increases [ $r=0.256$ ,  $P=0.0001$ ]). This was thought by the authors to be related to the increased importance of peer acceptance and social identity as participants progressed through adolescence.

### *Perceived Stigma and Epilepsy Severity:*

Two studies (Zamani et al., 2014; Benavente-Aguilar et al., 2004) reported significant correlations between stigma and epilepsy severity. Benavente-Aguilar et al. (2004) reported a positive correlation between increased perceptions of stigma and increased severity ( $P<0.01$ -full statistic not stated). Zamani et al. (2014) reported this as an inverse correlation between level of perceived stigma and increased seizure activity ( $r=-0.201$ ,  $P=0.006$ ). Neither study reported the specific diagnosis of epilepsy.

### *Significant Predictors of Perceived Stigma:*

Four studies used regression analysis to determine significant predictors of perceived stigma in adolescents with epilepsy. Five factors were determined: number of anti-epileptic drugs (Stevanovic, 2007 [ $\beta=0.233$ ,  $P=0.0001$ ,  $F=15.47$ , variance=31%]; Wu et al., 2010 [ $\beta=0.304$ ,  $P=0.031$ ]); epilepsy concern (Stevanovic, 2007 [ $\beta=-0.01$ ,  $P=0.042$ ]); duration of epilepsy (Wu et al., 2010 [ $\beta=-0.395$ ,  $P=0.006$ ]); gender (Zashikhina & Hagglof, 2014 [ $\beta=0.28$ ,  $t(47)=1.98$ ,  $P<0.05$ ,  $R^2=0.06$ ]); and onset age (Wu et al., 2010 [ $\beta=0.339$ ,  $P=0.035$ ]).

### *Additional Significant Findings:*

Hirfanoglu et al. (2009) reported significant correlations between higher levels of perceived stigma with higher negative perceptions of epilepsy ( $r=0.195$ ,  $P=0.004$ ),

lower reported self-esteem ( $r=-0.150$ ,  $P=0.026$ ) and symptoms of depression ( $r=0.276$ ,  $P=0.0001$ ). Suggesting that, in their sample, epilepsy had a significant impact on the internal experiences of adolescents. They also reported a significant negative correlation between higher stigma and less knowledge ( $r=-0.180$ ,  $P=0.008$ ) and a significant positive correlation between higher stigma and higher perceived lack of support ( $r=0.266$ ,  $P=0.000$ ). Adewuya (2006) reported significant positive correlations between increased perceived stigma in adolescents with epilepsy and parental psychopathology ( $r=0.305$ ,  $P=0.01$  [GHQ-30],  $r=0.584$ ,  $P=0.01$  [SRDS]), indicating that the mental health status of the wider system may be important to adolescents with epilepsy's perceptions of stigma. However, it is not clear from the latter study if or how stigma relating to parental psychopathology was accounted for. Zashikhina and Hagglof (2014) reported a significant difference between male ( $52.92\pm13.54$ ) and female ( $64.48\pm23.63$ ) participants perceived stigma scores, they reported that males perceived higher stigma (indicated by a lower score). The allocation of genders across the other variables in the studies is not stated, making it impossible to determine if and which additional factors were thought to influence this contrast in findings.

## **Discussion**

This review explored published research investigating perceived stigma in adolescents with epilepsy since MacLeod and Austin's (2003) review. Seven studies were identified, one looking at the impact of knowledge and perceptions of epilepsy on quality of life and perceived stigma (Hirfanoglu et al., 2009), five exploring stigma within overall HRQOL (Zamani et al., 2014; Zashikhina & Hagglof, 2014; Wu et al., 2010; Stevanovic, 2007; Benavente-Aguilar et al., 2004), and one looking specifically at the role of parental psychopathology within HRQOL of adolescents with epilepsy (Adewuya, 2006).

### *Perceived Stigma in Adolescents with Epilepsy:*

Research shows that stigma is an important factor in HRQOL of adolescents with epilepsy. Studies in this review add some further understanding to the factors that may contribute to the stigma experiences of the adolescents detailed in MacLeod and Austin's (2003) review.

The average perceived stigma of adolescents with epilepsy varied widely across studies in this review. This suggests that factors within each study need to be considered carefully before making generalisations. This was also found in MacLeod and Austin's review, with studies reporting lower than expected experiences of stigma suggestive of a better HRQOL than previous research would have suggested. In this review only one study implemented a methodology that allowed for direct comparison between adolescents with epilepsy and those within the general population (Wu et al., 2010). This meant that the external validity of the remaining studies is compromised and any comparisons between studies need to be considered with caution as they may not be a true reflection of the wider population's experiences. Benavente-Aguilar et al's (2004) study attempted to use a population sample which could counter balance this limitation, however they acknowledged that this province may not be a true representation of all Spanish culture. Similarly Wu et al. (2010) acknowledged that their sample was recruited from an affluent city in China and findings were likely to be significantly different if the study was conducted in rural China.

However, there were some interesting convergent and divergent factors significantly associated with perceived stigma across studies in this and the previous review by MacLeod and Austin (2003). These were considered (with caution) and allow for some insight into the factors that may impact these adolescents' experiences. Increased age was found to be an important factor in two studies in this review (Zamani et al., 2014; Hirfanoglu et al., 2009). Both studies excluded participants over the age of 17 years. Westbrook et al. (1992), in MacLeod and Austin's (2003) review, reported that perceived stigma was higher in 12-16 year olds than 17-20 year olds and concluded that younger subjects were more likely to feel stigmatised by their epilepsy. As Zamani et al. (2014) and Hirfanoglu et al. (2009) did not include older participants it is not possible to determine if a parallel change occurs after 17 years of age. It could be hypothesised from this information that progression into the period of adolescence may impact perceived stigma but this perhaps changes during the transition to adulthood. Further studies using extended age groups may assist with further exploration of this. Interestingly a more recent study (Austin et al., 2014), not included in either review, reported that younger age was associated with greater perceived stigma. Their sample included 9-14 year olds and posited that younger people have less knowledge and understanding about their epilepsy and experience more stigma due to this. Hirfanoglu et al. (2009) also found that less knowledge was associated with higher perceived stigma but in contrast found increasing age to be an important factor. It is possible that the variation in the age ranges and significance levels may indicate that perceived stigma and the impact of adolescence differs depending on the characteristics of the sample population. It may also be important to consider the sample sizes and the potential bias this may introduce to the findings. Further studies looking at specific ages or age ranges in the same parameters may help differentiate these differences.

As in the previous review by MacLeod and Austin (2003), significant differences across epilepsy severity were reported in the current review. More severe epilepsy was reported to be associated with higher perceived stigma across studies in both reviews. However, no studies separated the specific epilepsy diagnoses which may have a particular impact on individuals with more visual epilepsy than others. For example, there may be differences between adolescents with equally severe generalised tonic clonic seizures and absence seizures depending on their visibility

to others. Also adolescents who experience only nocturnal seizures may have different experiences than those who can experience seizures at any time of the day. This would be important to consider as it may impact others perceptions of the individual and in turn impact perceived stigma. What is also important to consider is that seizure severity as it increases, inherently impacts inclusion or exclusion from certain activities for adolescents. This could be considered within the realm of institutionalised stigma but also reflects the practicalities of this diagnosis for some individuals.

With each of the studies included in both this and the previous review it is important to consider the inherent difficulty in measuring perceived stigma in adolescents with epilepsy. Higher perceptions of stigmatisation may prevent adolescents from fully disclosing their experiences for fear of further stigmatisation. In addition, research shows that many adolescents with epilepsy strive to ensure that they experience as normal a life as possible (Elliott et al., 2005). This may mean that they perceive less stigma as they do not consider themselves to be different. Another important consideration discussed in the previous review is that of disclosure management. Research shows that a proportion of adolescents do not inform their friends about their condition. This would lead to a positive bias in findings related to perceived stigma. The studies in this review do not report on disclosures of adolescents' epilepsy. This would be important to consider as in MacLeod and Austin's (2003) review, incongruence between level of disclosure and perceived stigma were reported.

Similarly to the previous review the range of methodologies, aims and sample characteristics of the studies in this review do not allow for a coherent and consistent picture to be developed. Important similarities and differences across the studies allow some comparative considerations on factors such as gender, age, epilepsy severity and knowledge, however, as with the previous review, these comparisons require to be treated with extreme caution. What is clear is that there is still limited understanding of the experiences of these adolescents and further exploration using different methodologies may be beneficial. This would allow the variation in findings to be determined, which may indicate that this variation is in fact due to the cultural, social and developmental factors unique to each individual or may highlight that the

homogeneity of studies to date prevents more general hypotheses or assumptions to be made about the stigma experiences of adolescents with epilepsy.

#### *Cultural Variation:*

The studies were conducted in a range of countries and cultures which may impact on the comparability between findings. A number of studies referred specifically to this cultural consideration in their discussion. Benavente-Aguilar et al. (2004) attempted to gather a full population sample from a Spanish province. They posited that the better quality of life and reduced perception of stigma reported by their participants than in previous studies may be due to the nature of the lifestyle in this part of Spain. Wu et al. (2010) compared the rates of stigma in their participants to findings in western countries. They found that the average score was lower (indicating higher perceived stigma) than that of adolescents with active and well controlled epilepsy and suggested that there is considerable cultural variation between China and western countries. They made particular reference to research reporting the lower social value afforded to individuals with epilepsy within Chinese society and the subsequent social rejection and increased stigmatisation and discrimination they experience (Jacoby et al., 2008; Reidpath et al., 2005). Wu et al. also made reference to the differences between the epilepsy related knowledge and resources of the urban and rural communities of China and the generalisability implications of only having recruited participants from Shanghai. Zamani et al. (2014) found that attitudes towards epilepsy and social support were lower in their study than in previous studies and related this to the social and cultural standards in their country. Although not specifically referred to in the studies included in the review, it is important to consider not only the cultural variations in knowledge and attitudes relating to epilepsy, but also to the cultural variation in responses and attitudes towards some of the co-morbidities experienced by adolescents with epilepsy including cognitive impairments and mental health difficulties.

#### *External Validity:*

One study in this review recruited participants from a community sample (Benavente-Aguilar et al., 2004). The remaining studies recruited from specialised epilepsy and neurology clinics or paediatric departments. This potentially threatens the external validity of the studies as it introduces bias that reduces the

generalisability of the studies to wider populations. In addition, most of the studies excluded adolescents with additional chronic conditions (Zashikhina & Hagglof, 2014; Wu et al., 2010; Stevanovic, 2007); comorbid psychiatric illness (Wu et al., 2010; Stevanovic, 2007; Benavente-Aguilar et al., 2004); learning disabilities (Zashikhina & Hagglof, 2014; Hirfanoglu et al., 2009; Adewuya, 2006); and participants with abnormal neurological examinations or progressive brain disorder (Wu et al., 2010; Hirfanoglu et al., 2009; Stevanovic, 2007). It is important to consider the potential percentage of adolescents with epilepsy this excluded. For example, psychiatric co-morbidities are reported to be prevalent in 40-50% of adolescents with epilepsy (Pellock et al., 2004), neurodevelopmental co-morbidities are reported to be prevalent in up to 30.8% (Wagner et al., 2014), and learning disabilities are reported to be prevalent in potentially 20.7% (e.g. Sillanpaa, 2005). Although these rates may differ depending on samples and specific diagnosis, this further complicates the generalisability of findings. In addition, most studies reported small sample sizes which also threaten the external validity of studies. Many of the studies reported that theirs was the first to be conducted within their country and with this population (Zamani et al., 2014; Wu et al., 2010; Hirfanoglu et al., 2009; Adewuya, 2006; Benavente-Aguilar et al., 2004). Given the heterogeneity and size of the samples and the cross sectional design, further studies would need to be conducted using the same parameters to enable a matched comparison and to determine the validity of the finding within and between samples.

#### *Research Implications:*

MacLeod and Austin's (2003) review concluded that further research was required to understand the experiences of stigma in adolescents with epilepsy. They posited that the conflicted findings in the studies included in their review were suggestive of a lack of appropriate methodology in measuring or understanding this concept and the importance of more in-depth studies. This review similarly found variation across study findings however was able to make some comparisons as some studies had used the same psychometric measure. Although this has been important to do, it also highlights the need for further exploration of the factors that then account for these differences within the samples. Control group comparisons for each sample would allow for direct comparisons to be made between the differences in findings

and relate those to cultural and socioeconomic variations within populations and perhaps allow for more robust hypotheses of assumptions to be made.

### **Conclusion**

Findings from studies in this review demonstrate variation in the perceived stigma of adolescents with epilepsy. The limitations of the methodology used within the studies allows for only tentative comparisons to be made, however some discussion regarding the potential factors that impact the experiences of adolescents with epilepsy is possible. These are important considerations for exploration of the wider experiences of these adolescents at a time when there are significant social and medical transitions in their lives. The cultural variation in the included studies is particularly important to consider as this impacts the physical, social and emotional development of individuals, including the perceptions, beliefs and attitudes of the society in which they experience these developments. Further research would allow this to be explored in more depth.

### **Key Messages**

1. There is variation in the reported experiences of stigma for adolescents with epilepsy.
2. In this review, perceived stigma was reported to be significantly associated with increased age, male gender, increased number of drugs taken, increased seizure severity, increased worry, negative perceptions of epilepsy and lower knowledge of epilepsy among adolescents with epilepsy
3. Cultural variation in studies highlights the importance of wider systemic and societal implications for perceived stigma experiences of adolescents with epilepsy.
4. Methodological considerations, including homogeneity and sample sizes potentially impact the generalisability of the findings.
5. Further research using alternative methodology (for example control groups) to explore the factors that impact perceived stigma may provide more detail on the associations reported in these studies.



## References

- Ablon, J. (2002) The nature of stigma and medical conditions. *Epilepsy & Behavior*, **3**, 3-9
- Adewuya, A. O. (2006) Parental psychopathology and self-rated quality of life in adolescents with epilepsy in Nigeria. *Developmental Medicine & Child Neurology*, **48**, 600-603.
- Adewuya, A. O. & Ola, B. A. (2005) Prevalence and risk factors for anxiety and depressive disorders in Nigerian adolescents with epilepsy. *Epilepsy & Behavior*, **6**, 342-347.
- Ani, C., Ola, B. A. & Rotimer, C. (2011) School children's stigmatising attitude towards peers with epilepsy in Nigeria. *Vulnerable Children and Youth Studies*, **6**, 330-338.
- Appleton, R. E. & Neville, B. G. R. (1999) Teenagers with epilepsy. *Archives of Disease in Childhood*, **81**, 76–80.
- Austin, J. K., Perkins, S. M. & Dunn, D. W. (2014) A model for internalised stigma in children and adolescents with epilepsy. *Epilepsy & Behavior*, **36**, 74-79.
- Austin, J. K., Shafer, P. O. & Deering, J. B. (2002) Epilepsy familiarity, knowledge, and perceptions of stigma: report from a survey of adolescents in the general population. *Epilepsy & Behavior*, **3**, 368-375.
- Baker, G. A., Spector, S., McGrath, Y. & Soteriou, H. (2005) Impact of epilepsy in adolescence: A UK controlled study. *Epilepsy & Behavior*, **6**, 556-562.
- Benavente-Aguilar, I., Morales-Blancuez, C., Rubio, E. A. & Rey, J. M. (2004) Quality of life of adolescents suffering from epilepsy living in the community. *Journal of Paediatric Child Health*, **40**, 110-113.
- Benavente, I., Morales, C. & Rubio E. (2002) Adaptación transcultural del cuestionario de medida de calidad de vida (QOLIE-AD-48) en adolescents epilépticos. *Psiquis*, **23**, 226–37.
- Buhs, E. S., & Ladd, G. W. (2001) Peer rejection as an antecedent of young children's school adjustment: An examination of mediating processes. *Developmental Psychology*, **7**, 550–560.
- Cramer, J. A., Westbrook, L. E., Devinsky, O., Perrine, K., Glassman, M. B. & Camfield, C. (1999) Development of the Quality of Life in Epilepsy Inventory for Adolescents: The QUOLIE-AD-48. *Epilepsia*, **40**, 1114–21.

- Cramer, J. A., Smith, D. B., Mattson, R. H., Delgado-Escueta, A. V. & Collins, J. F. (1983) A method of quantification for the evaluation of antiepileptic drug therapy. *Neurology*, **33** (Suppl. 1), 26–37.
- Crowe, M. (2013) *Crowe Critical Appraisal Tool (CCAT) User Guide [Version 1.4]*. Creative Commons Attribution.
- Crowe, M., & Sheppard, L. (2011). A review of critical appraisal tools show they lack rigor: alternative tool structure is proposed. *Journal of Clinical Epidemiology*, **64**(1), 79–89.
- Dashtbozorgi, B., Majdinasab, N., Sabeti, Z., Alijani Ranani, H. & Latifi, S. M. (2010) The effect of progressive muscular relaxation on quality of life in adolescents with epilepsy. *Jundishapur Scientific Medical Journal*, **9**, 465–72.
- Devinsky, O., Westbrook, L., Cramer, J., Glassman, M., Perrine, K. & Camfield, C. (1999) Risk factors for poor health related quality of life in adolescents with epilepsy. *Epilepsia*, **40**, 1715-1720..
- Elliott, I. M., Lach, L. & Smith, M. L. (2005) I just want to be normal: a qualitative study exploring how children and adolescents view the impact of intractable epilepsy on their quality of life. *Epilepsy & Behaviour*, **7**, 664-678.
- Erikson, E. (1968) *Identity, Youth and Crisis*. Norton.
- Fisher, R. S., Acevedo, C., Arzimanoglu, A., Bogacz, A., Cross, H., Elger, C. E., Engel, J., Forsgren, L., French, J., Moshe, S. L., Perucca, E., Scheffer, I. E., Tomson, T., Watachcbe, M. & Wiebe, S. (2014) A pratical clinical definition of epilepsy. *Epilepsia*, **55**, 475–482,
- Goffman, E. (1963) *Stigma: notes on the management of spoiled identity*. Prentice-Hall, Inc.: Englewood Cliffs, N.J.
- Goldberg, D. & Hiller, V. F. (1979) A scaled version of the General Health Questionnaire. *Psychological Medicine*, **9**, 139-145.
- Hirfanoglu, T., Serdaroglu, A., Cansu, A., Soysal, A. S., Derle, E. & Gucuyener, K. (2009) Do knowledge of, perception of, and attitudes toward epilepsy affect the quality of life of Turkish children with epilepsy and their parents? *Epilepsy & Behavior*, **14**, 71-77.
- Jacoby, A., Wang, W., Vu, T.D., Wu, J., Snape, D., Aydemi, R. N., Parr, J., Reis, R., Begley, C., de Boer, H., Prilipko, L. & Baker, G. (2008) Meanings of epilepsy in its sociocultural context and implications for stigma: findings from ethnographic studies in local communities in China and Vietnam. *Epilepsy & Behavior*, **12**, 286-297.

- Jacoby, A. (2002) Stigma, epilepsy and quality of life. *Epilepsy & Behavior*, **3**, s10-20.
- MacLeod, S. & Appleton, R. E. (2007) Neurological disorders presenting mainly in adolescence. *Archives of Disease in Childhood*, **92**, 170-175.
- MacLeod, J. S. & Austin, J. K. (2003) Stigma in the lives of adolescents with epilepsy: a review of the literature. *Epilepsy & Behavior*, **4**, 112-117.
- McEwan, M. J., Espie, C. A. & Metcalfe, J. (2004) A systematic review of the contribution of qualitative research to the study of quality of life in children and adolescents with epilepsy. *Seizure*, **13**, 3-14.
- Muhlbauer, S. (2002) Experience of stigma by families with mentally ill members. *Journal of American Psychiatric Nurses Association*, **8**, 76-83.
- Pellock, J. M. (2004) Defining the problem: psychiatric and behavioural comorbidity in children and adolescents with epilepsy. *Epilepsy & Behavior*, **5(suppl 3)**, S3-S9.
- Reidpath, D. D., Chan, K. Y., Gifford, S. M. & Allotey, P. (2005) "He hath the French pox": stigma, social value and social exclusion. *Sociology of Health & Illness*, **27**, 468-489.
- Reis, R. & Meinardi, H. (2002) ILAE/WHO "Out of the Shadows Campaign" Stigma: does the flag identify the cargo? *Epilepsy & Behavior*, **3**, s33-37.
- Rho, Y. I., Lee, S. A., Yim, S. B., Chu, M., Park, H. M, Lee, G. H., Park, S. P. & Jung, D. S. (2010) Factors contributing to Korean adolescents' perceptions of stigma with respect to epilepsy. *Epilepsy & Behavior*, **19**, 627-30.
- Sheth, R. D. (2002) Adolescent Issues in Epilepsy. *Journal of Child Neurology*, **17**, 2523-2527.
- Sillanpää, M (2005) Epilepsy in Children: Prevalence, Disability, and Handicap *Epilepsia*, **33**, 444-449.
- Stevanovic, D. (2007) Health-related quality of life in adolescents with well-controlled epilepsy. *Epilepsy & Behavior*, **10**, 571-575.
- Stevanovic, D., Milandinovic-Lozanovic, D. & Sarenac, M. (2005) The Serbian QOLIE-AD-48: translation, cultural adaptation and preliminary psychometric evaluation. *Epilepsy & Behaviour*, **7**, 240-245.
- Wagner, J. L., Wilson, D. A., Smith, G., Malek, A. & Selassie, A. W. (2014) Neurodevelopmental and mental health comorbidities in children and adolescents with epilepsy and migraine: a response to identified research gaps.

- Walsh, D. & Downe, S. (2006). Appraising the quality of qualitative research. *Midwifery*, **22**, 108-119.
- Wang, M., Wu, L., Zheng, Y., Zhang, Q. & Li, C. (2009) The Chinese QOLIE-AD-48: translation, validity, and reliability. *Epilepsy & Behavior*, **14**, 476–80.
- Weiss, M. G. & Ramakrishna, J. (2006) Stigma interventions and research for international health. *Lancet*, **367(9509)**, 536-538.
- Westbrook, L. E., Bauman, L. J. & Shinnar, S. (1992) Applying stigma theory to epilepsy: a test of a conceptual model. *Journal of Paediatric Psychology*, **17**, 633-649.
- Wu, D., Ding, D., Wang, Y. & Hong, Z. (2010) Quality of life and related factors in Chinese adolescents with active epilepsy. *Epilepsy Research*, **90**, 16-20.
- Zashikhina, A. & Hagglof, B. (2014) Health-related quality of life in adolescents with chronic physical illness in northern Russia: a cross-sectional study. *Health and Quality of Life Outcomes*, **12**, 12-20.
- Zamani, G., Shiva, S., Mohammadi, M., Gharie, J. M. & Rezaei, N. (2014) A survey of quality of life in adolescents with epilepsy in Iran. *Epilepsy & Behavior*, **33**, 69-72.
- Zamani, G., Mehdizadeh, M. & Sadeghi, P. (2012) Attempt to suicide in young ages with epilepsy. *Iranian Journal of Pediatrics*, **22**, 404–407.
- Zung, W. W. K. (1971) A rating instrument for anxiety disorder. *Psychosomatics*, **12**, 371-379.
- Zung, W. W. K. (1965) A self-rating depression scale. *Archives of General Psychiatry*, **12**, 63-70.

## **Chapter Two: Major Research Project**

**Transitions During Adolescence: A qualitative exploration of the developmental and healthcare transition experiences of adolescents with epilepsy.**

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*Prepared in accordance with the requirements for submission to Child: Care, Health and Development (See Appendix 1.1)*

### **Plain English Summary**

**Background:** Epilepsy is the most common neurological condition of adolescence. Research shows that it can impact individuals' physical, emotional and social functioning during this critical period of development, when identity and sense of self are formed and independence and autonomy are key goals. Individuals whose childhood epilepsy will continue into adulthood, or who are diagnosed with epilepsy during adolescence, will require transition from child to adult oriented services. This process can be fraught with difficulties due to the fundamental differences between these services. This has received relatively little attention within epilepsy. Previous research highlighted the importance of involving adolescents with epilepsy in transition research in order to determine their specific needs.

**Methods:** This study explored the experiences of five adolescents with epilepsy currently attending a transition clinic using semi-structured interviews.

**Results:** It found that participants implemented a range of coping styles to manage being a teenager with epilepsy. Although different, these coping styles all appeared to fundamentally be strategies to allow them to feel safe and secure.

**Conclusions and Implications:** Variation in participants' knowledge and perceived knowledge needs regarding their condition and transition were highlighted. This requires further exploration to determine the factors both within the individual adolescents and within the systems around them that impact this process. It may also be important to ensure that adolescents are explicitly aware of the processes of transition and transfer as some inaccuracies were documented, which may impact longer term outcomes. Participants reported positive healthcare experiences in which they felt respected, heard and understood. Further research is required to explore how these findings relate to the wider population of adolescents with epilepsy.

## **Abstract**

**Background:** The most common neurological condition during adolescence is epilepsy, with 40-50% of those diagnosed requiring transition to adult orientated healthcare. The related transition of care is reported to be important for maximising both health and developmental outcomes. The scope of this study was to explore the health, social and developmental transition experiences of a number of adolescents with epilepsy.

**Methods:** Interpretative Phenomenological Analysis was used to explore the experiences of five adolescents (aged 14-17 years) currently attending an epilepsy transition clinic. Semi-structured interviews explored their experiences of being an adolescent with epilepsy.

**Results:** Three superordinate themes were identified: Coping Style, Differences and Healthcare Experiences. Each theme tracked the similarities and differences between participants' experiences using a number of subthemes. Participants' use of language was an important vehicle for more in-depth analysis of their narrative.

**Conclusion:** The health, social and developmental transition experiences of adolescents with epilepsy are influenced by the coping strategies they implement, their locus of control model and their level of engagement with their healthcare needs. These factors are influenced by internal and external circumstances that are important to consider when developing transitional care for this population. Further exploration of these internal and external factors and their influence is required.

## **Introduction**

The currently recognised definition of epilepsy, developed by the International League Against Epilepsy is: *“a disease of the brain defined by any of the following conditions: (1) At least two unprovoked (or reflex) seizures occurring more than 24 hours apart; (2) one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years; (3) diagnosis of an epilepsy syndrome. Epilepsy is considered to be resolved for individuals who either had an age dependent epilepsy syndrome but are now past the applicable age or who have remained seizure-free for the last 10 years and off anti-seizure medicines for at least the last 5 years”* (Fisher et al., 2014, p. 475). A seizure is defined as an episodic disturbance of movement, feeling, or consciousness caused by sudden synchronous, inappropriate, and excessive electrical discharges in the cerebral cortex (Berg et al., 2010). Seizures can be partial or generalised and the type of symptoms and seizures experienced by an individual depends on where the abnormal electrical activity takes place in the brain; the aetiology; their age; and their general health status (Marin, 2005). It is the most common neurological condition of adolescence (MacLeod & Appleton, 2007), impacting 0.45% of individuals under 18 years old in the UK (Joint Epilepsy Council of UK & Ireland, 2011).

Adolescence is a complex period of rapid developmental change related to physical, emotional and social development (Rettig & Athreya, 1991). During this period identity and sense of self are formed and consolidated (Austin & Huberty, 1993) and independence and autonomy are a key focus (Erikson, 1968). Adolescents with epilepsy face the same normative health issues and concerns as their peers during this period, however, they also face additional challenges as the physical, social and emotional consequences of their condition are superimposed on these dramatic changes (Sheth, 2002). Epilepsy is reported to negatively impact adolescent's psychological health (Turky et al., 2008), independence (Marin, 2005), and emotional adjustment (Elliott et al., 2005). These adolescents are also reported to be vulnerable to co-morbid difficulties including sleep disorders (Rodriguez, 2007) and cognitive and behavioural difficulties (Plioplys et al., 2007). In addition, whilst they strive for their independence in the same way as their peers, the reality is often one of continued dependence on family (Smith & Wallace, 2003). This can further



exacerbate a sense of difference that can impede the typical maturation process and the development of psychosocial independence (Asato et al., 2009).

Approximately 50-60% of childhood epilepsy syndromes remit prior to adolescence (Wheless & Kim, 2002), others begin or persist into this developmental stage (Camfield et al., 2012). Adolescents whose epilepsy persists into adulthood require transition to adult-oriented healthcare. Healthcare transition is defined as the *“purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems”* (Blum et al, 1993, p.570). The goal of transition is to optimise health and assist adolescents to acquire independent health care skills and prepare for an adult model of care (National Alliance to Advance Adolescent Health, 2014). Research into other health conditions, including diabetes, congenital heart disease and complex physical disabilities, highlights the importance of developmentally appropriate information, treatment adherence and the involvement of young people in the design of this transition (e.g. Dovey-Pearce et al., 2012; Clarizia et al., 2009). For example, Dovey-Pearce et al. (2012) conducted focus groups with adolescents (13-21 years) with complex physical health conditions to determine their experiences of transition and their ideas for improving transition services. They concluded that the inclusion of these young people was invaluable to understanding their specific needs at this time of significant change in their lives. Successful transition has been linked to optimal health and healthcare (Schwartz et al., 2011); the assumption of appropriate adult roles and functioning (American Academy of Paediatrics, 2002); and the maintenance of self-esteem and confidence (Smith & Wallace, 2003). Poor transition planning has been linked to harmful medical and psychological consequences including declines in adherence and health status (Dugueperoux et al., 2008). Consideration of the biomedical and psychosocial factors associated with specific conditions, are also reported to be crucial in transition planning as they may differ between conditions (Schwartz et al., 2011).

Despite consensus that a period of transition is required in which young people are ‘made ready’ to fulfil their expected roles and responsibilities within adult healthcare, there does not appear to be consensus regarding how service models should be implemented. There is significant variation across transition models implemented

across the UK including differences in: the age inclusion criteria (for example, Price et al. (2011) describe a diabetes transition service model that incorporates 16-25 year olds implemented in the North East of England. The west of Scotland epilepsy transition clinic in this study includes 14-17 year olds); the healthcare professionals involved (for example nurse or consultant led or configurations of paediatric and adult adult healthcare professionals); the format of sessions (clinic settings or, as in Ellingford's (2006) 'Wings Project' a "parents evening" approach in which young people visit various stations depending on their current information needs); and the timing of sessions.

Transition in epilepsy has received less attention relative to other chronic illnesses (Khan et al., 2013). Specific transition research has focused on the experiences of caregivers (e.g. Schultz, 2013; Davies et al., 2011) and the views of healthcare providers (e.g. Iyer & Appleton, 2013). Schultz (2013) and Davies et al. (2011) used qualitative methodology to explore the transition experiences of parents of adolescents with epilepsy. Schultz (2013) developed the Journey of Advocacy Theory using a grounded theory approach with parents of adolescents with epilepsy and cognitive impairments. This highlighted the importance of a comprehensive, co-ordinated transition plan that incorporates the interrelationship between adolescents, their parents and their environment. Davies et al. (2011) included parents of adolescents with epilepsy within the wider exploration of the parents of adolescents with chronic neurological conditions and intellectual impairments. They concluded that parents felt a sense of abandonment during the transition process due to the lack of co-ordination between services and the lack of appropriate sources of support. Parental resourcefulness was highlighted as a key factor in ensuring the success of transition processes. Iyer and Appleton (2013) conducted a survey of all the UK transition clinics for young people with epilepsy based within tertiary paediatric epilepsy services. Fifteen centres completed a survey enquiring about the nature of the clinic (including time, frequency, referral criteria, waiting lists and staffing) and the information and support provided to young people and their families. They discuss the challenges of developing and maintaining an appropriate transition service for this population, as seen by the healthcare providers, and the current lack

of integration of these processes into clinical services. They conclude that further work is required to improve both services and outcomes for adolescents with epilepsy during transition to adult health services. Research has also focused on the development of transition models, incorporating knowledge from other health conditions (Khan et al., 2013; Patel, 2013; Camfield et al., 2012; Jurasek et al., 2010). They have emphasised the importance of viewing transition as a structured, dynamic and developmentally appropriate process that meets the individual needs of adolescents with epilepsy. They also agree that transition should include paediatric and adult healthcare professionals in a collaborative clinic model (Iyer & Appleton, 2013; Camfield et al., 2012; Jurasek et al., 2010; Smith et al., 2002). Studies have also measured the perceived impact of epilepsy during adolescence and associated it with styles of psychological adjustment (Baker et al., 2005); quality of life (Hirfanoglu et al., 2009); medical adherence (Asato et al., 2009); and knowledge (Lewis et al., 2010; Kongsaktrakul et al., 2006; Bell et al., 2002). These studies support the reported need for accurate and timely information and the on-going monitoring of social functioning within this population to support independence, autonomy and successful transition to both adulthood and adult healthcare services. However, few studies have directly reported the views and experiences of young people embarking on this process (Ellingford, 2006; Reeve & Lincoln, 2002). Adolescents with epilepsy are documented as a group who often have particular needs that are not well addressed by traditional paediatric and adult services (SIGN, 2005). Thus making well managed transition a key focus for epilepsy services. Baker et al. (2005) stated that adolescents with epilepsy should be provided with the specialist services they require and talking to them would be the only efficient way of determining their needs. In line with this, Khan et al. (2013) recommended that exploratory research focusing on these adolescents' experiences across different stages of transition, would be beneficial for designing transitional care that meets their needs. In addition Camfield (2013) recommended that more comprehensive descriptive data (both medical and social) is required to support adolescents with epilepsy through this period. Giving these young people the opportunity to describe their understanding and experiences of transition and the concurrent impact on their development may allow for a better understanding of their needs (physical, social and emotional) and how healthcare services can meet these needs.

The aim of this study was to explore the current experiences of adolescents with epilepsies embarking on transitions, using a qualitative approach. These transitions include, but are not exclusive to, healthcare transition experiences and the developmental transitions that occur at this stage of life.

## **Methods**

### **Design:**

The use of a qualitative approach was determined as the most appropriate method to undertake this exploration as it allows participants to identify and prioritise factors that are important to them and provide insight into the meaning of their experiences (Kerr et al., 2011). Interpretative Phenomenological Analysis (IPA) was the qualitative design used. IPA involves a two-stage process as the researcher explores lived experiences to examine how young people make sense of their personal and social world and tries to understand what the world is like from their perspective. This is referred to as the “double hermeneutic” (Smith & Osborn, 2003, p.51). Within this approach, it is recognised that the researcher’s own beliefs and assumptions will influence how they interpret a participant’s account. This is the fundamental dynamic and interpretative process of IPA. It has been widely used in health and illness research (Brocki & Wearden, 2006) and to explore issues of life transitions (Smith et al., 2009). In accordance with IPA methodology, purposive sampling was used. This refers to a pre-defined group of individuals who, through their experiences, may provide insight into the phenomena under study (Smith et al., 2009). IPA emphasises the use of small sample sizes to allow researchers to explore participant’s narratives in more depth. Between four and six interviews are reported to be appropriate for professional doctorates, allowing the researcher to sufficiently analyse and reflect on their interpretation of the data (Smith & Osborn, 2003).

### **Recruitment:**

The Paediatric Epilepsy Service from which participants were recruited currently employs a transition pathway that incorporates attendance at a ‘teen’ clinic between the ages of 14-17 years. Prior to this, patients with epilepsy are seen within the paediatric clinic and following this they either return to the care of their General Practitioner (GP) or are transferred to an adult service in an external health-board, depending on their epilepsy status at the time of transfer. Fifty six potential participants were identified by Epilepsy Clinic staff as meeting the inclusion criteria for the study (Table 1). Young people with a learning disability were excluded for the purpose of sample homogeneity. All potential participants were sent Research Packs including an Invitation Letter, Information Sheet, Response Form and

Freepost envelope for replying to the researcher (Appendix 2.1.1). Participants who indicated their agreement to take part in the research were contacted by the researcher to arrange an interview. The researcher did not have access to participant information until they completed the Response form.

*Table 1: Inclusion and Exclusion Criteria*

Inclusion Criteria	Exclusion Criteria
<ol style="list-style-type: none"> <li>1. Aged 14-17 years</li> <li>2. Confirmed diagnosis of epilepsy</li> <li>3. Currently attending Paediatric Epilepsy Clinic</li> <li>4. Under the care of Consultant Paediatrician with special interest in Epilepsy</li> </ol>	<ol style="list-style-type: none"> <li>1. Additional diagnosis of a learning disability</li> </ol>

### Participants:

Five participants took part in the study, three females and two males aged between 14 and 17 years. Table 2 provides a summary of the participants. Gender appropriate pseudonyms have been provided to preserve the anonymity of participants.

*Table 2: Summary of Participants*

	Participant				
	Claire	Amy	Tom	Rebecca	Chris
<b>Age</b>	16	15	16	16	14
<b>Epilepsy Type</b>	Ring Chromosome 20	Generalised Tonic Clonic Seizures	[unknown by participant]*	[unknown by participant]*	Benign Rolandic Epilepsy
<b>Age of onset</b>	10 years	10 years	5 years	[unknown by participant]*	10 years
<b>Additional difficulties</b>	Memory impairments	Diabetes	Not reported <sup>#</sup>	Not reported <sup>#</sup>	Not reported <sup>#</sup>

\*indicates information the participant was unable to recall. <sup>#</sup> indicates information not revealed by participants

### Procedure:

Data were collected between April and July 2014 through individual semi-structured interviews with the researcher (Appendix 2.1.5). Interviews were conducted in a private interview room within the Paediatric Epilepsy Clinic premises and lasted 30-

45 minutes. Written informed consent was obtained from participants and parents (if the participant was under 16 years) at the beginning of each interview (Appendix 2.1.2).

Interviews were digitally recorded and downloaded onto an encrypted laptop then erased from the recording device. Interviews were transcribed verbatim by the researcher. Transcripts were anonymised during this process to ensure participants were not identifiable from their account; this included the removal of references to people and places. Pseudonyms were also assigned. Two transcripts were reviewed by the researcher's academic supervisor to enhance reliability.

### **Data Analysis:**

Analysis was conducted in accordance with IPA methodology (Smith et al., 2009). The first stage involved reading the transcript several times. The second stage involved making descriptive, linguistic and conceptual notes of interest. The third stage involved the exploration of emerging themes which were then examined and clustered together according to conceptual similarities in stage four. A table of themes and subthemes was then developed. In keeping with the idiographic approach, each transcript was thoroughly analysed on an individual basis, patterns across transcripts were then explored. Finally a list of superordinate themes were developed, these formed the basis of the narrative account. An example of coding is provided in Appendix 2.2.

### **Reflexivity:**

Reflexivity is a key feature of IPA, illuminating the researcher's perspective and making clear that interpretations are made in light of this (Smith & Osborn, 2003). Care was taken during the analysis to reflect on the influence the researchers own experiences and beliefs may have on the interpretations of the participants narratives. The researcher had previous experience of conducting research on transition with young people with complex physical disabilities. This made her aware of the wide range of implications this process can have on young people and the emotional distress and uncertainty this can evoke. It also made her aware of the frustrations that can be experienced by young people, their families and healthcare professionals during this process. The researcher spoke to clinicians in the field to gain awareness of some of the unique issues facing participants. In addition, during

the analytic process, the researcher discussed themes with her supervisors and other professionals with experience of using this methodological approach to ensure she was not influenced by her own conceptions.

**Ethical Approval:**

Approval for the study was received from NHS Ayrshire and Arran Psychological Services Clinical Governance Research and Strategy Group in January 2014, the University of Glasgow in February 2014, and the West of Scotland Research Ethics Committee (Appendix 2.3) and NHS Ayrshire and Arran Research and Development in April 2014 (Appendix 2.4).



## **Results**

### **Setting the scene**

The aim of the study was to develop an understanding of the experiences of adolescents with epilepsy at this developmental stage during which a number of transitions occur, including healthcare transition. During analysis it became clear that understanding these young people's experiences lays the foundation for building a transition process that incorporates their needs, whilst also acknowledging the ongoing developmental transitions at this stage in their lives. Three superordinate themes emerged from the analysis: *Coping Style*, *Differences* and *Healthcare Experiences*. Table 3 details the emergent themes.

*Table 3: Emergent Themes*

<b>Superordinate Theme</b>	<b>Sub-themes</b>
<b>1. Coping Style</b>	<b>a.</b> Striving for Normalcy <b>b.</b> Feeling Safe <b>c.</b> Minimising the Impact <b>d.</b> External Locus of Control
<b>2. Differences</b>	<b>a.</b> Identity Changes <b>b.</b> Peer Comparisons <b>c.</b> Others Responses
<b>3. Healthcare Experiences</b>	<b>a.</b> Clinic Experiences <b>b.</b> Transition Experiences <b>c.</b> Transition Knowledge and Expectations

Quotations from participants are represented in Italics. Quotations from the researcher are in regular script. Key emotional expressions are presented in parentheses (e.g. laugh). Additional information added in to quotes to increase understanding is presented in square brackets.

### **1. Coping Style**

This emerged from the convergent and divergent ways participants described how they cope with their epilepsy. It is made up of four subthemes: *Striving for Normalcy*, *Feeling Safe*, *Minimising the Impact* and *External Locus of Control*. The interpretation of these themes is emphasised in the language used to convey experiences and strategies for coping.

a. Striving for Normalcy

Participants emphasised the importance of attempting to experience a sense of normalcy in their lives. Fifteen year old Amy described her efforts to ensure she has “normal” teenage experiences, including negotiations within her social life:

*“...I haven’t actually told them [sports coach] I’ve been off the tablets...because they wouldn’t let me row...I told my mum not to tell them (Laugh)...because I haven’t had one in such a...or in a while, and the last one was in bed and it’s normally in bed”*

(Amy, page 3, line 85-94)

Both Amy and Christopher explicitly talked about the elements of their life that are not impacted by their epilepsy and allow them to function alongside their peers.

*“...has it at any point stopped you doing the things that you want to do?”*

*“No”*

(Christopher, page 7, line 235).

Despite this, there appeared to be some incongruence between this idea of attempting to experience a degree of normalcy and both participants descriptions of the ways in which they cope with other elements of their epilepsy. For example Amy talked about her determination to stay overnight with friends and to challenge what she perceives to be her parents over protectiveness at one point in the interview, however she later states that she doesn’t go anywhere without her family as this ensures her sense of safety:

*“...they are reluctant to let me do some stuff – like sleep over at my friend’s house maybe”*

*“So does that happen now?”*

*“(laugh) yeah, it still happens but I go anyway (laugh)”.*

(Amy, page 4, line 114-116).

*“I don’t really go anywhere without my family...”*

(Amy, page 13, line 435).

This desire for a normal life could be a reflection of how different young people with epilepsy feel. It may emphasise how hard they are working to protect themselves from being different at a developmental stage where integration and similarities are essential for social acceptance.

b. Feeling Safe

This theme relates to the strategies that participants described using to maintain a sense of safety and certainty. This is understandable given the unpredictable nature of epilepsy and the changes and transitions that occur both within certain types of epilepsy during adolescence, and within the wider context of this developmental stage. This theme includes strategies such as ensuring they have adequate knowledge of their epilepsy; ensuring those around them are equipped to support them; knowing who to contact in a crisis; and planning for specific events in the future.

Throughout her interview Amy emphasised the importance of being understood by others, especially those close to her. This appeared to be important to her sense of identity and in allowing her to explore the world safe in the knowledge that others around her are able to meet both her medical and identity needs.

*“Well, my friends have medical conditions too (laugh)...so they understand”*

(Amy, page 2, line 64).

*“My family know a lot about it so it’s not really impacted me in that way when I’m at home I feel safe. When I’m out and about I’m normally with people that know everything about it...and I have a card in my purse if anything happens...”*

(Amy, page 10, line 510-512).

Tom and Amy emphasised the importance of having adequate knowledge of their epilepsy, triggers, and medication to feel safe and to share with others to enable them to support them:

*“... I like to know what I can and can’t do so that I don’t get myself in danger”*

(Amy, page 3, line 108).

*“..if I've says to them [friends] what the things to look out for so that if they ever see me fixating on a target then they know that's me maybe starting to have a seizure... they could turn the lights down and put me in a dark room”*

(Tom, page 3, line 60-61).

Tom appeared to value the importance of having strategies in place for potential future scenarios in order to feel prepared. He was talking specifically about the impact that medication changes may have and how he accesses support with this:

*“...I was like: if I feel anything will I just come back to you and get my dose upped again? and he [consultant] was like...yeah come back and we'll see what we can do”*

(Tom, page 5, line 108).

### c. Minimising the Impact

Three participants projected a sense that they were minimising the impact their epilepsy has on their lives, their development, and their participation in healthcare and social transitions. Each stated their epilepsy doesn't affect them:

*“...because it's not such a big thing in my life...”*

(Amy, page 10, line 315)

*“..I've only had one seizure as a teenager...that was the only time that really it impacted my life.”*

(Tom, page 3, line 52)

*“...it's not really impacting me that much.”*

(Christopher, page 7, line 234)

Christopher refers to his epilepsy as annoying throughout his narrative generally and in relation to specific tasks:

*“...you miss out on stuff at school...because you have to go to a clinic...so it’s quite annoying...”*

(Christopher, page 2, line 76).

There are a number of potential interpretations of participants’ minimisation. Firstly that they are using this as a way to reduce distress and prevent themselves being overwhelmed by their experiences. Secondly, to project to others that they are no different from their peers and therefore do not need to be treated differently or have restrictions imposed upon them. Finally, it could be a reflection of the volume of their epilepsy within their complex difficulties and life experiences. This latter interpretation may be particularly relevant for Amy who also has diabetes, and Tom whose epilepsy is one of a number of challenges he currently or previously faced including being placed in care and experiencing significant bullying.

One of the key vehicles of this interpretation of minimisation is the language that the participants used. There was repeated use of matter of fact statements and dismissive tones that could be interpreted as a mockery of others over-protectiveness. It was the use of language that triggered the researcher’s deeper interpretation. Subtle changes in participants’ language position indicated shifts from topics that appear to be safe to discuss in relation to their experiences and those that require more distance. This is highlighted in Amy’s shift between using the first person position, when relating practical and factual information, to the second person when discussing the potential emotional impact or need for support with this:

*“...I tried off the medication before I had a seizure and I got put back on it”.*

(Amy, page 7, line 224).

*“...in the clinic you do have the psychologist and you have the doctors and I think if you needed to see the psychologist they would...refer you to her or him”.*

(Amy, page 7, line 228)

This is paralleled across participants’ accounts within each of the themes suggestive of a difficulty engaging with their experiences at an emotional level. This may be a

reflection of a defence strategy or a lack of integrated emotional narrative because of an appropriate medical focus during their early experiences and perhaps a minimal focus on the development of social and emotional well-being. It is also evident in the change between a coherent and less coherent narrative in Christopher's account when he shifts between talking about his experiences and thinking about what it might be like for other teenagers with epilepsy. When recounting his own experiences and thoughts he tended to have some difficulties expressing himself. However when asked about his approach to his epilepsy in relation to other teenagers he succinctly stated:

*"I really just think it depends on what type of epilepsy you have and how frequent it is because if it's very frequent or if it could happen at any time you might be more anxious and you might be more prone to think about it more."*

(Christopher, page 9, line 288).

#### d. External Locus of Control

Several participants emphasised their reliance on external factors for enabling them to manage their epilepsy both on an emotional and practical level. For example, Claire identified her medication as the reason for her increased ability to attend school:

*"...how come you can tell [epilepsy triggers and onset] now?"*

*"...something to do with my meds improving"*

(Claire, page 7, line 257-258).

Participants spoke about having limited responsibility for elements of their epilepsy care, relying on others to be gatekeepers for information. For Christopher this appeared to be related to him not needing to have lots of information because he prefers not to think about it:

*"Are you somebody that does lots of research about the kind of epilepsy you have?"*

*"No (laugh)"*

*"So, in your family who knows the most about it?"*

*"My mother.....well she just knows what the doctors told her...and also my gran knows a bit because my mother told my gran..."*

(Christopher, page 8, line 259-263).

Christopher's tone and use of laughter indicates a slight mockery of the idea that he may want to have knowledge of his condition. This could be interpreted as a defence of his position that his epilepsy isn't a big deal. Similarly, Claire appears to rely on others to take responsibility for information holding and sharing. This is echoed in her description of clinic appointments when she highlights that it is her parents who speak to the clinician and she conveys a sense of being a passive observer:

*"So mum and dad do most of the talking, what do they talk about?"*

*"I think it's to do with like my mainly maybe my meds"*

*"...and so do you listen in to their chatting"*

*"I think so"*

*"... and do you ever talk to the doctor by yourself?"*

*"Not really".*

(Claire, page 5, line 187-191).

Claire reported experiencing short term memory difficulties at times; this may be a reflection of this difficulty. It may also be due to additional factors enhancing this passive role, such as the expectations of others on her ability to participate, or concerns around protecting her from the full impact of her diagnosis. This is also in contrast to Amy and Tom who strive to have as active a role as possible in their healthcare.

*"I try to take charge of as much as I can obviously I get some help here and there...I have tried to take charge as soon as I could..."*

(Amy, page 3, line 110-112).

## **2. Differences**

This emerged from comparisons participants made between themselves and their peers. It is made up of three subthemes: *Identity Changes*, *Peer Comparisons* and *Others Responses*.

a. Identity Changes

Amy, Claire and Christopher reported noticing a change in themselves following the onset of their epilepsy or as a result of other factors directly relating to this. Amy discussed her change in identity within her family:

*“I was the healthy one in my family (laugh)”*

(Amy, page 14, line 448).

Claire described noticing a change in temperament, although she also makes reference to the transition from primary to secondary school as a potential trigger for this change. She had also, however, mentioned having a reduced timetable at school and noted a loss of friendships and it may be, therefore, that there was some impact of these factors:

*“I think it was either since I was getting into secondary or because of epilepsy I’m not quite sure I’ve become more shy”.*

(Claire, page 4, line 134).

Christopher talked about feeling as though his epilepsy status had led to an acceleration of his development. He described himself as transitioning from someone who was *“tantrumish”* (page 4, line 114) to *“more grown up about things”* (page 4, line 130) because of his epilepsy.

b. Peer Comparisons

Some participants spoke directly about how different they felt from their peers, others spoke more generally about their lives, which highlighted crucial differences in their experiences of adolescence. For example, Rebecca stated:

*“... sometimes I just think that my epilepsy makes me really strange...it makes me feel different from other people”*

(Rebecca, page 3, line 90-93).

Claire spoke about not being able to attend school full time and being unable to participate in Physical Education when she did attend:



*“...well I don’t go to PE...Instead of everyone else cos if I get out of breath that it can cause me to have an absence”*

(Claire, page 7, line 240).

Rebecca talked about her anxieties about becoming more independent, highlighting her dependence on others and the overwhelming impact her epilepsy has on her daily functioning and her thoughts about the future:

*“Is there anything in particular you’re worried about getting older and having epilepsy?”*

*“I don’t want to be living on my own...I think I might find it hard to deal with if I was living on my own”*

(Rebecca, page 2, line 63-64).

Social media currently plays an important role for adolescents. Rebecca’s description of being unable to have a photograph taken in fear of triggering a seizure highlights another factor that influences her feelings of difference from her peers:

*“...does that ever stop you doing things?”*

*“Yeah.”*

*“What kind of things?”*

*“I mean...actually sometimes...I don’t know...stop someone taking a photo and stuff like that”.*

(Rebecca, page 2, line 58-62).

### c. Others Responses

Participants reflected on being treated differently by others because of their epilepsy. This appeared to be prevalent in two ways, firstly being treated differently pre and post diagnosis and secondly being treated differently to peers because of their epilepsy. Claire reflected on a change in her friendships following her diagnosis, this appeared to be related to a lack of understanding that they and she had at the time, but also in part due to the practical implications of her diagnosis leading to her missing a significant amount of school:

*“...when I first started having the big seizures I kind of like lost some of my friends by having it, at the start...because of my illness so I didn’t really get to see them that much...”*

(Claire, page 2, line 60-64).

Tom talked about his epilepsy being a reason for his peers to bully him, highlighting that this made him appear vulnerable and different to others:

*“..if people know then it can be quite embarrassing because you get bullied sometimes...like young people sometimes slag you because they don't understand what its...what's really happening...they just see it as a target to bully people.”*

(Tom, page 2, line 32).

Amy felt that school teachers treated her differently from her peers and linked this to their concern about her safety:

*“In the school people treat me like...you’re wrapped in bubble wrap, or something...The teachers act as if you’re a bit special... they don’t send you out the class and stuff like that.”*

(Amy, page 2, line 52-54).

### **3. Healthcare Experiences**

This is made up of three subthemes: *Clinic Experiences*, *Transition Experiences*, and *Transition Knowledge and Expectations*.

#### **a. Clinic Experiences**

Participants talked about the importance of the relationship they had with the healthcare professionals in shaping their clinic experiences. A particularly prominent topic was the communication style of the clinicians, allowing the participants to feel respected, heard and understood. Tom spoke about the confidence this gave him:

*"It's probably the way he [the clinician] is with me as well, because I'm assured that he's going to be nice to me and that also gives me the confidence to know that I can go in and be myself with him and he'll be fine with me".*

(Tom, page 4, line 92).

In Amy's account this was highlighted in her confidence and ability to independently contact the clinicians out-with the clinic to receive information or support:

*"...if you didn't have a clinic appointment for ages how else would you manage...if you were worried?"*

*"I would probably text her [consultant] because I have their numbers"*

(Amy, page 8, line 265-266).

For some participants the familiarity of clinic seemed to provide a sense of security. This appeared to be linked to an increased duration and frequency of attendance since their diagnosis. Claire and Tom spoke of their familiarity and positive perception of their clinic experiences:

*"I kind of like coming here [clinic] since I used to come here a lot when my epilepsy was kind of bad"*

(Claire, page 5, line 170).

*"I know this sounds crazy but actually I look forward to coming here for my appointments"*

(Tom, page 6, line 130).

For Tom this was described within the context of escaping from more difficult and potentially uncertain environments. In contrast, Christopher portrayed his clinic experiences as an annoyance that meant he missed important learning at school:

*"It's just you miss out on...precious time when you have to learn stuff...because you have to go to a clinic."*

(Christopher, page 3, line 76).

Tom and Claire described collaborative clinic experiences. For Tom, this could be interpreted as arising from a mutual respect and understanding that he has experienced as he has transitioned from a young child to an adolescent. Whereas for Claire, this was interpreted as the only moment in her account that she appeared to indicate any active role in her healthcare or in the determination of her future:

*"We've taken another med down like for now and we're just seeing what it's...like really"*

(Claire, page 2, line 46).

A final element of clinic experiences appears to be shaped by the practical factors related to who attends and participates in appointments. There was variation in participants' styles of recounting and perception of this part of their experience but all were accompanied into appointments. Christopher and Amy described this as being determined by their parents' desire to attend clinic rather than their wanting support,

*"My mother or my gran or my father goes with me"*

*"And who out of you guys does the most talking?"*

*"...usually my mother"*

(Christopher, page 6, line 193-195).

*"...have you had appointments when you've gone in by yourself with the doctor"*

*"Not really my mum is always there".*

(Amy, page 5, line 161-162).

For Tom this clearly created a tension between his desire to be independent and the duty of care of his current guardians.

*"...it can be quite embarrassing at times [being accompanied into appointments] because it's almost as if you're getting treated like a baby sometimes...it's just, it's quite frustrating."*

(Tom, page 5, line 112).

## b. Transition Experiences

Due to their ages, participants were at different stage of the transition process. Their accounts highlight these differences and give some insight into their preparedness for transfer to adult services. For example, Amy appeared to have an understanding of the rationale and process of transition:

*“...because I’m in the transition period everyone tells me things about this stuff...[doctor] sent me out a letter saying I was of a certain age and I needed to talk about these things...it was weird because I’d never thought about any of these things before...”*

(Amy, page 10, line 322-324).

Claire on the other hand does not appear to have experienced any difference in her clinic experiences. This could be a reflection of her co-morbid difficulties and her overall experience of being a teenager with epilepsy, as well as the expectations and approaches of those around her. It is interesting to note that Claire and Amy are the same age.

One element of change that was recognised by all the participants was the way in which they were spoken to in clinic sessions from the age of 14. Christopher is the youngest participant, having recently turned 14 and therefore become eligible for the transition/teen clinic:

*“...well I think it’s in the way doctors’ talk to you”*

*“Can you tell me a bit more about that?”*

*“Some doctors when you’re a bit younger they talk down to you a bit but as you grow older they start to talk to you more maturely...”*

(Christopher, page 5, line 154-158)

Tom is the oldest participant and is making his transfer to adult services imminently. He also reflects on the change he noticed in the communication style of the clinicians during the transition period.

*“...small things like some of even the language he uses as well...just describing the condition...”*

(Tom, page 7, line 138).

Amy also makes reference to the change in the communication style of clinicians' but also in whom they direct this conversation to:

*"They treat you not like a child anymore I guess...like you can understand these things; they talk to you more than they talk to my mum"*

(Amy, page 9, line 302-304)

Amy was the only participant who spoke explicitly about transition. She reflected on her feelings about the more personal topics covered during transition such as family planning, alcohol consumption and thinking about future life choices. She described these as awkward conversations that she perhaps would have had a few years later with her mother rather than at this age with a healthcare professional. However, she highlights an important element of her transition experiences in relation to her diabetes that is not necessarily evident for her epilepsy due to the nature of the service and her epilepsy status:

*"Well I'm glad they have the [diabetes] transition clinic because it has some of the adult doctors as well, you get to know them"*

(Amy, page 9, line 298).

This is important to consider as it marks a significant difference in the practicalities of transition and transfer.

### c. Transition Knowledge and Expectations

There was a variety of knowledge and expectations within participants' accounts in relation to the future of their healthcare. In addition, variance was noted in the emphasis placed on elements of change within that process. Tom talked about the concerns for him being around adapting to change and being in a waiting room with adults and peers who he perceives as having the potential to judge him:

*“...it will be really difficult for me to adapt to this change probably...I think it will be a big leap because you’re going from sitting in the reception with small children to sitting in with adults and it’ll be a totally different atmosphere...the way adults treat you in the reception might be different, like the way they look at you...”*

(Tom, page 9, line 198).

He also talked about the role of the healthcare professionals in making this transition and transfer a success for him:

*“...it depends on what my new doctor will be like...if I’ll get on well with them or if they will be similar to [Consultant]...”*

(Tom, page 10, line 206).

Several participants appeared to portray a ‘matter-of-fact’ perception of adult services, that they would be treated like an adult and that they were aware of the expectations of independence and autonomy:

*“I’d have to go in myself and all that because I’m required to because I’m 16 and that”*

*“what would that be like?”*

*“it would be fine, it’d just be instead of me with my mother it’d just be myself”*

(Christopher, page 7, line 226-229).

It is important to note that Christopher has a form of epilepsy that, although still prevalent, is expected to remit by this time he turns 17. It may therefore not be necessary for him to transfer to adult services. This could be impacting his attitude towards the experience; alternatively it may be linked to the early discussion around his avoidance of thinking about his epilepsy as it leads to anxiety.

An interesting element of this theme is participants’ knowledge of what will happen when they reach the point of transfer from paediatric to adult services. One of the key differences for these adolescents is the pathway following discharge from paediatric services. Their care is transferred to their General Practitioner (GP) if their

epilepsy is considered stable and to an adult service within an external Health Board if it is considered unstable. This causes understandable concern for healthcare professionals, who are aware of the importance of seamless transition. Despite this, the participants' accounts reflect a limited or incorrect knowledge of these processes. For example Rebecca reports not knowing what will happen to her healthcare when she is older and Claire is unable to remember exactly what has been spoken about:

“do you know much about that [healthcare as get older]?”

*“no not really”*

(Rebecca, page 2, line 75-76).

*“I think if I remember correctly I might be going somewhere else”*

“do you know where that could be?”

*“I can't remember”*

(Claire, page 9, line 309-312).

Tom on the other hand appeared to be confident in his knowledge about accessing adult services within the same hospital as his paediatric clinic; however the researcher is aware that this is not an accurate description of what will occur:

*“I have been transferred to the adult clinic which is downstairs I think...”*

(Tom, page 8, line 166).



## **Discussion**

The aim of this study was to explore the experiences of adolescents with epilepsy during an identified period of transition. The complexity of this developmental stage was prominent throughout their narratives, highlighting the importance of understanding the range of factors that influence adolescents with epilepsy's experiences as they transition into adulthood and to adult services.

Three superordinate themes were identified: Coping Style, Differences and Healthcare Experiences. In general there seemed to be high concordance between participants; however, some sub-themes were more pertinent for some participants than others.

*Coping Styles:* The first theme explored how participants cope with their epilepsy during adolescence. Initial analysis highlighted a contrast between those who appeared to have a positive coping style and internal locus of control and those with a more external locus of control who perceived their epilepsy to be overwhelming. However, more in-depth analysis, with particular consideration of the nuances of participant's language, led to the interpretation of different coping strategies, ranging from avoidance and minimisation to striving to obtain a sense of normalcy. Each of these was interpreted to have a protective foundation or function. Previous qualitative research emphasises the value adolescents with epilepsy place on their desire to be normal (Elliott et al., 2005). This was emphasised by participants both literally and in their description of the ways in which they negotiate the tasks of adolescence linked with social independence, identity development and academic progress. In concordance with research pertaining to information needs, this theme highlighted variance in both the level of knowledge these young people have and their perceived information needs (Lewis et al., 2010). Some adolescents voiced a desire to have as much information and knowledge as possible, whereas others required others to gate-keep this for them. This further links to research emphasising the key role caregivers often have for adolescents with epilepsy managing transitions (Schultz, 2013; Davies et al., 2011). Schultz (2013) and Davies et al.'s (2011) qualitative studies into parents perceptions of transition both highlighted the importance of parents experiences and their advocacy role in transition. Although these two studies included parents of adolescents with additional cognitive

impairments, the findings from the current study suggest that the parental role may also be important for adolescents with epilepsy and without cognitive impairments. Taking the information needs and desire to be normal together, these findings could demonstrate further the links found by Baker et al. (2005). They used a matched control design to investigate the psychological and social impact of epilepsy on adolescents and measured self-esteem, social adjustment, depression and obsession. They suggested that one reason adolescents may not possess a high level of knowledge about their condition is their desire not to acknowledge its existence for fear of being stigmatised. Interestingly, the pattern of incongruence in this sense of normality that these adolescents are striving for and the safety behaviours they implement, parallels findings by Austin et al. (2004) in relation to stigma and epilepsy. In their study developing instruments for measuring stigma in adolescents and their parents they found that adolescents with epilepsy did not have high perceived levels of stigma, however then discovered that the majority of participants had not disclosed their condition to their peers. Taken on face value this finding would have misrepresented adolescents' experiences, highlighting the important role of qualitative research in this area but also recognising the complexity of the experience of being an adolescent with epilepsy. Transition research in other conditions is moving towards the development of specific tools to measure when an adolescent is ready to transition from paediatric to adult services (e.g. Sawicki et al., 2011). The findings from this study, however begs the question of the validity of such a measure within this population without first fully understanding the context of epilepsy in adolescence.

Securing a sense of safety and certainty was a prominent feature in participants' narratives. At times this was explicitly shared and at other times it was through deeper interpretation that links were made between behaviours and the motivations behind them. Developmental psychology and attachment theory highlight the importance of a sense of safety and security as fundamental to a person's ability to then explore the world and develop a sense of identity (Bowlby 1969). For these young people the uncertainty and unpredictability of their condition adds a layer of complexity to this process, leading to their use of additional strategies to maintain a sense of safety. For some participants this was portrayed in their reliance on proximity to family and understanding friends. This mirrors previous findings of the

tension between continued dependence on family members and desire for independence during this stage of development (Smith & Wallace, 2003). For others this was emphasised in their lack of information sharing with their peers. This is in line with previous research into stigmatisation of adolescents with epilepsy that has described epilepsy as a hidden disorder (Austin et al., 2002) which adolescents do not talk to their peers or teachers about (Zamani et al., 2014). It could be important for young people, families and healthcare professionals to have an awareness of these coping strategies and the function they serve. This may maximise opportunities to develop appropriate strategies that match these needs and meet the expectations of adult services.

*Differences:* The second theme explored participants' experiences of themselves in relation to other adolescents. Adolescence is a stage of development where individuals desire to be accepted and be the same as their peers is paramount (Marin, 2005). Research emphasises the importance of this for the development of identity and for maturation processes. These participants highlighted a number of key spheres in which they experience themselves as different from their peers. Friendships become increasingly important during adolescence, however for many of the participants, friendships were impacted by their epilepsy, either at the time of diagnosis or due to the practical implications of their condition. This mirrors previous research pertaining to the ways in which epilepsy can impede psychosocial development during adolescence. Asato et al. (2009) conducted a cross-sectional survey to explore the experiences and perceptions of adolescents with epilepsy and their parents. They found that adolescents reported lower overall quality of life and compromised social functioning compared with other chronic conditions including asthma, diabetes and rheumatoid arthritis. Fear of difference is another reason adolescents reportedly do not disclose their epilepsy to others (Baker et al., 2008). This is repeatedly evident in this sample. Participants also spoke about differences in themselves in this period, including accelerated maturation processes and changes in temperament. There is no evidence to suggest that a participant's diagnosis is the cause of these changes. All maturation timing and processes are considerably individualised for all young people and adolescence can be linked to a decrease in socialisation, however, the importance here is the link that these young people make between these experiences and their epilepsy. This is important to consider within

transition processes as it highlights that these young people may make links between experiences and epilepsy that emphasise to them their differences from others. Finding a way to normalise these experiences, without minimising the importance they hold for that individual, may reduce this overwhelming sense of difference these adolescents with epilepsy currently experience.

*Healthcare Experiences:* This theme explored participants' experiences of healthcare. Due to the nature of their condition and the age of onset, most participants have spent a significant amount of time attending healthcare services. For many participants the longevity of their attendance resulted in a familiarity that perhaps could be interpreted as adding to the sense of security they are striving for. Alternatively it could be interpreted as a way of incorporating the unusual significance of health services into their narrative during a period when they are exploring and developing their identity. The majority portrayed the clinic as a positive experience allowing them to understand their epilepsy, map their medical progress and feel respected, heard and understood. This is in direct contrast to previous research by McNellis et al. (2007) who conducted focus groups to explore the concerns and needs of adolescents with epilepsy and their parents. They found that adolescents with epilepsy felt ignored by healthcare professionals. In relation to this, the contrast between those who appreciated their clinic experiences as a way to development and maintain their self-esteem and confidence and those within the sample who found this role more difficult, mirrors debate in previous research about adolescents' confidence to participate fully in their healthcare (Beresford & Sloper, 2003; Smith & Wallace, 2003). There was wide variation in participants' knowledge and expectations of transition. One of the many reasons transition services were introduced was to bridge the perceived 'chasm' between paediatric and adult services (van Staa et al., 2011). The participants' accounts provide an interesting insight into the differences that are prominent for them, the confusion that is evident from the contradictions within some of their accounts, and the uncertainty highlighted by their incorrect expectations of what will happen when they transition to adult services. Although only one participant explicitly acknowledged their participation in a transition process, the majority of participants identified changes within their healthcare experiences which match the transition protocol implemented by the service, including the content and style of consultations. The variation in transition

knowledge may reflect the different ages of the participants within the study and their context at the time of interview, however there was a high degree of concordance relating to expectations of adult services. These were particularly focused on being treated like an adult and attending appointments independently, which mirrors what is written about the expectations of individuals attending adult services (Schwartz et al., 2011; American Academy of Paediatrics, 2002).

As discussed previously, one of the key differences for these young people regarding transition is the pathway following discharge from paediatric services. The positive experiences some of these young people have described could imply that those involved are succeeding in providing an appropriate and seamless service experience for these young people and that perhaps it is not necessary for participants to be explicitly aware that they are in a period of transition. On the other hand, many participants had limited or inaccurate knowledge of the future of their healthcare, perhaps suggesting that the wide chasm between paediatric and adult services is not being entirely bridged by this approach.

Although there was concordance across some elements of the analysis, it is important to consider the differences in some of these young people's experiences and trajectories in terms of their epilepsy. They all experience different severities of impact on their daily functioning, for example, at the time of interview Rebecca was experiencing a transition within her epilepsy status that was causing her significant distress and uncertainty, leading to the impression that she currently lives moment to moment with limited resources to consider the future. Claire portrays herself as someone with a particularly passive role in her healthcare at present which will be expected to change within the next two years when she is transferred to adult services. For Tom it appeared important to him that others perceive him to be someone who has significant knowledge and understanding of his epilepsy to allow him to negotiate further independence and autonomy and perhaps in the process there has been some misunderstanding or miscommunication. Again this highlights an important consideration when thinking about transition timing, how is it possible to determine a single age point when young people with epilepsy will be "ready" to transfer to adult services fully equipped to meet the expectations of that service and to take on the responsibilities for their healthcare? The contrast between Amy and Claire in the *Transition Experience* subtheme fuels this debate further. They are both

16 and, under current legislation, will transfer to adult services within the next year. However there is a stark difference between their knowledge, skills and experiences that adds to current research emphasising that transition readiness, as a concept, is more complex than a chronological age (Stinson et al., 2014; Gilleland et al., 2012).

It is also important to consider the factors that impact the differences in participants' accounts and knowledge around transition and transfer. The differences in their epilepsy diagnosis and severity have been mentioned, however there are systemic factors that are important to consider in terms of the expectations of those around them, the roles that others have played and also the narrative the young person and their system have about their diagnosis and its impact. Further exploration into the attitudes, perceptions and expectations of the wider systems around these young people may allow this to be determined.

**Study Limitations:** The variation in specific epilepsy diagnosis within the sample is a potential limitation. This is due to the possibility that the onset of adolescence may impact epilepsy syndromes differently with some remitting at this time and others becoming more pronounced due to hormonal changes. In addition, this diagnosis determines the anti-epileptic drugs (AEDs) administered to adolescents. Although participants were asked about any AED side effects, this was not explored in significant detail, which may be an important factor in their experiences. It could be suggested that the sample size is a potential limitation of the study. However, IPA is committed to the analysis of small numbers to provide the opportunity for more in-depth analysis. In addition, it includes a level of interpretation from the researcher, suggesting that different researchers may interpret elements within narratives differently. The reflexivity statement is aimed at providing the context within which the researcher makes these interpretations. An additional potential limitation is that the author is an IPA novice. Steps were taken to ensure the quality of the analysis however this should still be considered a potential limitation.

**Clinical Implications:** The unique circumstances of the current service design make clinical implications more difficult to determine. What is clear is that adolescents with epilepsy value being heard and understood by healthcare professionals and, at present, do not appear to find the transition process overwhelming. Despite this, the

information needs and transition knowledge of these adolescents may need addressed to prevent misconceptions of their future healthcare disrupting their positive experiences. This study has highlighted that there are similarities and differences in adolescents' needs and preparedness for transition. Understanding the specific needs of individuals both medically and socially will be an important aspect of ensuring that their needs are met as they progress through this process. Given the important role that caregivers play in many of the narratives in this study, it is also important to ensure their level of preparedness matches that of the adolescent to ensure maximum outcomes in the long term.

**Further Research:** Looking at coping styles across age groups or specific epilepsy diagnoses may provide further insight into their function for young people and enable transition plans and processes to be adapted to this. This could also be an important factor in measuring transition readiness. It may also be important to explore the attitudes, perceptions and expectations of the wider systems around these young people to determine the impact they have on their experiences. Also, this study provided a snapshot of the experiences of adolescents at a particular stage in the transition process. Studying a cohort of participants from pre-transition, through the transition service, to adult services would allow for a longitudinal experiential narrative to be explored. This would allow longer term outcomes of transition models in epilepsy to be determined. This may be particularly important for adolescents within services that are not able to provide collaborate paediatric and adult transition services at this time.

## **Conclusions**

Young people's experiences of being a teenager with epilepsy are influenced by the coping strategies they implement, their current locus of control model and the extent to which they engage with the circumstances of their healthcare needs. Some of the findings here are in accordance with previous findings related to the transition experiences and needs of young people with chronic health conditions; however there are also elements of difference. For example, in parallel to previous research, these young people were found to have differing knowledge and information needs, both in terms of their epilepsy and transition processes (Lewis et al., 2010). In

contrast these needs appear to be not only related to their developmental circumstances (Dovey-Pearce et al., 2012), but also the roles and responsibilities they are afforded by the system around them and the unique circumstances of the service pathway. Transition is a dynamic process within a dynamic process of development. These young people are being expected to negotiate an extra ordinate amount of change during a period when they have little control over other changes that are occurring, and many of them are burdened with additional difficulties relating to their epilepsy. Given that this is the case it seems counterintuitive to impose uniformity on what is expected from them at certain ages. This study highlights that there are multiple component parts to this process for adolescents with epilepsy including coping style, knowledge, expectations and support needs and that further exploration of these is required to develop an in-depth inventory of the elements that healthcare professionals need to consider in their search for a successful epilepsy transition model. What is clear is that the approach being implemented at present is successful in many ways, including maintaining both a medical and psychosocial focus; however it may not be entirely bridging the gap between paediatric and adult services for some young people.

### **Key Messages**

1. Three themes emerged from this qualitative exploration of the experiences of adolescents with epilepsy: Coping Style, Differences and Healthcare Experiences.
2. The main findings are that adolescents with epilepsy's experiences are influenced by the coping strategies they implement, their locus of control model and their level of engagement with their healthcare needs.
3. Further exploration of their experiences is required to determine factors that influence their readiness or preparedness for transition to adult oriented services.
4. Transition knowledge is varied. It may be beneficial to ensure that all adolescents and caregivers have the same information and knowledge about the transition processes to maximise positive long term outcomes.



## References

- American Academy of Pediatrics (2002) A consensus statement on healthcare transitions for young adults with special healthcare needs. *Pediatrics*, **110**, 1304-1306.
- Asato, M. R., Manjunath, R., Sheth, R. D., Phelpes, S. J., Wheless, J. W., Hovinga, C. A., Pina-Garza, J. E., Haskins, L. S., & Zingaro, W. M. (2009) Adolescent and Caregiver experiences with epilepsy. *Journal of Child Neurology*, **24**, 562-571.
- Austin, J. K., MacLeod, J., Dunn, D. W., Shen, J. & Perkins, S. M. (2004) Measuring stigma in children with epilepsy and their parents: instrument development and testing. *Epilepsy & Behavior*, **5**, 472-482.
- Austin, J. K., Shafer, P. O., & Deering, J. B. (2002) Epilepsy familiarity, knowledge, and perceptions of stigma: report from a survey of adolescents in the general population. *Epilepsy & Behaviour*, **3**, 368-375.
- Austin, J. K. & Huberty, T. J. (1993) Development of the Child Attitude Toward Illness Scale. *Journal of Paediatric Psychology*, **18**, 467-480.
- Baker, G. A., Hargis, E., Hsih, M. M., Mounfield, H., Arzimanoglou, A., Glauser, T., Pellock, J. & Lund, S. (2008) Perceived impact of epilepsy in teenagers and young adults: An international survey. *Epilepsy & Behavior*, **12**, 395-401.
- Baker, G. A., Spector, S., McGrath, Y. & Soteriou, H. (2005) Impact of epilepsy in adolescence: A UK controlled study. *Epilepsy & Behavior*, **6**, 556-562.
- Bell, G. S., Nashef, L., Kendall, S., Solomon, J., Poole, K., Johnson, A. L., Moran, N. F., McCarthy, M., McCormick, D., Shorvan, S. D. & Sander, J. W. (2002) Information recalled by women taking anti-epileptic drugs for epilepsy: a questionnaire study. *Epilepsy Research*, **52**, 139-146.
- Beresford, B. & Sloper, P. (2003) A causal model of self-care behaviour for adolescents with epilepsy. *Journal of Adolescent Health*, **33**, 172-179.
- Berg, A. T., Berkovic, S. F., Brodie, M. J., Buchhalter, J., Cross, J. H., van Emde Boas, W., Engel, J., French, J., Glauser, T. A., Mathern, G. W., Moshe, S. L., Nordli, D., Plouin, P. & Scheffer, I. E. (2010) Revised terminology and concepts for organization of seizures and epilepsies: Report of the ILAE Commission on Classification and Terminology, 2005–2009, *Epilepsia*, **51**, 676–685.
- Blum, R., Garell, D., Hodgman, C., Jorissen, T. W., Okinow, N. A., Orr, D. P. & Slap, G. (1993) Transition from child-centred to adult health-care systems for

adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, **14**, 570–576.

Bowlby J. (1969). *Attachment. Attachment and Loss: Vol. 1. Loss*. Basic Books: New York.

Brocki, J. M. & Wearden, A. J. (2006) Critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, **21**, 87-108.

Camfield, P. (2013) Help youths with epilepsy to become competent and happy adults: Transition care. *Seizure*, **22**, 414-415.

Camfield, P., Camfield, C. & Pohlmann-Eden, B. (2012) Transition from paediatric to adult epilepsy care: a difficult process marked by medical and social crisis. *Epilepsy Currents*, **12**, s13-s21.

Clarizia, N. A., Chahal, N., Manhiot, C., Kilburn, J., Redington, A. N., & McCrindle, B. W. (2009) Transition to adult health care for adolescents and young adults with congenital heart disease: Perspectives of the patient, parent and health care provider. *Canadian Journal of Cardiology*, **25**, e317-e322.

Davies, H., Rennick, J. & Majnemer, A. (2011) Transition from paediatric to adult health care for young adults with neurological disorders: parental perspectives. *Canadian Journal of Neuroscience Nursing*, **33**, 32-39.

Dovey-Pearce, G., Price, C., Wood, H., Scott, T., Cookson, J. & Corbett, S. (2012) Young people (13-21) with disabilities in transition: An exploratory, qualitative study of the developmental experiences and health care needs. *Educational and Child Psychology*, **29**, 86-100.

Dugueperoux, I., Tamalet, A., Sermet-Gaudelus, I., Le Bourgeois, M., Gerardin, M., Desmazes-Dufeu, N. & Hubert, D. (2008) Clinical changes of patients with cystic fibrosis during transition from pediatric to adult care. *The Journal of Adolescent Health*, **43**, 459–465.

Ellingford, C. (2006) Refocusing transition [short report]. *Paediatric Nursing*, **18**, 37.

Elliott, I. M., Lach, L. & Smith, M. L. (2005) I just want to be normal: a qualitative study exploring how children and adolescents view the impact of intractable epilepsy on their quality of life. *Epilepsy & Behaviour*, **7**, 664-678.

Erikson, E. (1968) *Identity, Youth and Crisis*. Norton: New York.

- Fisher, R. S., Acevedo, C., Arzimanoglu, A., Bogacz, A., Cross, H., Elger, C. E., Engel, J., Forsgren, L., French, J., Moshe, S. L., Perucca, E., Scheffer, I. E., Tomson, T., Watachcbe, M. & Wiebe, S. (2014) A practical clinical definition of epilepsy. *Epilepsia*, **55**, 475–482.
- Gilleland, J., Amaral, S., Mee, L., & Blount, R. (2012) Getting Ready to Leave: Transition Readiness in Adolescent Kidney Transplant Recipients. *Journal of Pediatric Psychology*, **37**, 85-96.
- Hirfanoglu, T., Serdaroglu, A., Cansu, A., Soysal, A., Dele, E. & Gucuyener, K. (2009) Do knowledge of, perception of, and attitudes towards epilepsy affect the quality of life of Turkish children with Epilepsy and their parents? *Epilepsy and Behaviour*, **14**, 71-77.
- Iyer, A. & Appleton, R. (2013) Transitional services for adolescents with epilepsy in the UK: a survey. *Seizure*, **22**, 433-437.
- Joint Epilepsy Council of UK & Ireland (2011) *Epilepsy prevalence, incidence and other statistics*. JEC: Leeds. Accessed online at: [http://www.epilepsyscotland.org.uk/pdf/Joint\\_Epilepsy\\_Council\\_Prevalence\\_and\\_Incidence\\_September\\_11\\_\(3\).pdf](http://www.epilepsyscotland.org.uk/pdf/Joint_Epilepsy_Council_Prevalence_and_Incidence_September_11_(3).pdf) on 11<sup>th</sup> July 2014.
- Jurasek, L., Ray, L., & Quigley, D. (2010) Development and Implementation of an Adolescent Epilepsy Transition Clinic. *Journal of Neuroscience Nursing*, **42**, 181-189.
- Kerr, C., Nixon, A. & Angalakuditi, M. (2011) The impact of epilepsy on children and adult patients' lives: Development of a conceptual model from qualitative literature. *Seizure*, **20**, 764-774.
- Khan, A., Baheerathan, A., Hussain, N. & Whitehouse, W. (2013) Transition of children with epilepsies to adultcare. *Acta Paediatrica*, **102**, 216-221.
- Kongsaktrakul, C., Suchaxaya, P., Kantawang, S., Schepp, K., Visudtibhan, A. & Chinvarun, Y. (2006) A causal model of self-care behaviour for adolescents with epilepsy. *Thai Journal of Nursing Research*, 264-275.
- Lewis, S. A., Noyes, J. & Mackereth, S. (2010) Knowledge and information needs of young people with epilepsy and their parents: Mixed-method systematic review. *BMC Pediatrics*, **10**, 103-120.
- Macleod, S. & Appleton, R. E. (2007) Neurological disorders presenting mainly in adolescence. *Archives of Disease in Childhood*, **92**, 170–5.

- Marin, S. (2005) The impact of epilepsy on the adolescent. *The American Journal of Maternal/Child Nursing*, **30**, 321-326.
- McNellis, A., Buelow, J., Myers, J. & Johnson, E. (2007) Concerns and needs of children with epilepsy and their parents. *Clinical Nurse Specialist*, **21**, 195-202.
- National Alliance to Advance Adolescent Health (2014) *Six Core Elements of Healthcare Transition [Version 2.0]*. Got Transition: Washington DC.
- Patel, A. (2013) Lost in transition? A practice tool for finding your way to adulthood. *Epilepsy Currents*, **13**, 186-187.
- Plioplys, S., Dunn, D. W. & Caplan, R. (2007) 10-year research update review: psychiatric problems in children with epilepsy. *Journal of the American Academy of Child & Adolescent Psychiatry*, **46**, 1389-1402.
- Price C, Corbett S, Lewis-Barned N, Oliver L, Dovey-Pearce G, (2011) Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes. *Child: Care Health & Development*, **37**, 852-860.
- Reeve, D. K., & Lincoln, N. B. (2002) Coping with the challenge of transition in older adolescents with epilepsy. *Seizure*, **11**, 33-39.
- Rettig, P. & Athreya, B. (1991) Adolescents with chronic disease. *Arthritis Care and Research*, **4**, 174-180.
- Rodriguez, A. J. (2007) Pediatric sleep and epilepsy. *Current Neurology & Neuroscience Reports*, **7**, 342-347.
- Sawicki, G., Lukens-Bull, K., Yin, X., Demars, N, Huang, I., Livingood, W., Reiss, J. & Wood, D. (2011) Measuring the Transition Readiness of Youth with Special Healthcare Needs: Validation of the TRAQ—Transition Readiness Assessment Questionnaire. *Journal of Paediatric Psychology*, **36**, 160-171.
- Schultz, R. J. (2013) Parental experiences transitioning their adolescent with epilepsy and cognitive impairments to adult health care. *Journal of Pediatric Health Care*, **27**, 359-366.
- Schwartz, L. A., Tuchman, L. K., Hobbie, W. L., & Ginsberg, J. P. (2011) A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child: care, health and development*, **37**, 883–895.
- Scottish Intercollegiate Guideline Network (2005) *81: Diagnosis and Management of*

*Epilepsies in Children and Young People. A National Clinical Guideline.* SIGN: Edinburgh.

Sheth, R. D. (2002) Adolescent Issues in Epilepsy. *Journal of Child Neurology*, **17**, 2523-2527.

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

Smith J. A. & Osborn, M. (2003) Interpretative Phenomenological Analysis. In: Smith, J. A (eds) *Qualitative Psychology: A Practical Guide to Research Methods*. London: SAGE Publications, 51–80.

Smith, P. E. M., Myson, V. & Gibbon, F. (2002) A teenager epilepsy clinic: observational study. *European Journal of Neurology*, **9**, 373-376.

Smith, P. E. & Wallace, S. J. (2003) Taking over epilepsy from the paediatric neurologist. *Journal of Neurology, Neurosurgery & Psychiatry*, **74**, Supplement 1, i37-i41.

Stinson, J., Kohut, S. A., Spiegel, L., White, M., Gill, N., Colbourne, G., Sigurdson, S., Duffy, K. W., Tucker, L., Stringer, E., Hazel, B., Hochman, J., Reiss, J. & Kaufman, M. (2014) A systematic review of transition readiness and transfer satisfaction measures for adolescents with chronic illness. *International Journal of Adolescent Medicine & Health*, **26**, 159-174.

Turky, A., Beavis, J. M., Thapar, A. K. & Kerr, M. P. (2008) Psychopathology in children and adolescents with epilepsy: an investigation of predictive variables. *Epilepsy & Behavior*, **12**, 136-144.

Van Staa, A. L., Jedeloo, S., van Meeteren, J. & Latour, J. M. (2011) Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child: care, health and development*, **37**, 821-832.

Wheless, J. W. & Kim, H. L. (2002) Adolescent Seizures and Epilepsy Syndromes. *Epilepsia*, **43**(Suppl. 3), 33–52.

Zamani, G., Shiva, S., Mohammadi, M., Gharie, J. M. & Rezaei, N. (2014) A survey of quality of life in adolescents with epilepsy in Iran. *Epilepsy & Behavior*, **33**, 69-72.

## **Chapter Three: Advanced Clinical Practice I – Reflective Critical Account**

### **Reformulating Formulation**

#### **Abstract**

I have chosen to focus on the development of my formulation skills in this reflective account using Driscoll's (1994 & 2000) What? Model of Structured Reflection and Burch's (1970s) Conscious Competence Model. Formulation is a core skill in Clinical Psychology. The expected progression of these skills is documented in the DCP (2011) Good Practice Guidelines and the Intended Learning Outcomes (ILO's) for doctoral trainees. These expectations are paralleled in the experiences detailed in my account. I have also incorporated the four criteria of reflective functioning.

The main themes in my reflection pertain to the development and changes in my formulation skills from simple and structured approaches to more complex and fluid approaches and the importance of reflective practice and utilisation of timely clinical supervision to this learning. I have also drawn parallels between the processes of formulation and my journey through training, both being key dynamic learning processes that will continue throughout qualified practice.

## **Chapter Four: Advanced Clinical Practice II – Reflective Critical Account**

### **Reflecting on the Systems of Psychological Provision**

#### **Abstract**

I have chosen to reflect on the Management competency and the ways in which a number of key experiences in first and third year have allowed me to develop an awareness of how the provision of psychological systems, services and resources are managed. I have used Gibb's (1988) Reflective Cycle to structure both the individual experiences and the wider learning that I have considered important within this reflection. Gibb's model provides a structure with sufficient flexibility to allow it to be adaptable to clinical and research experiences, which is why it has been useful for me during this process of reflection. I have included Burch's (1970) Conscious Competence Learning Model/Matrix in the reflective review section as, for me, this model fits the majority of learning experiences and key developments that I have reflected on throughout my training. I also think it maps well onto the competency development framework for the University, the HCPC and the expectations of qualified clinical psychologists within the NHS. The main theme in my reflection is that of the parallels between the development of my skills, knowledge and confidence and my ability to consider the wider context of my learning experiences within the culture of a changing provision of psychological services. In particular the ways in which I have come to understand, appreciate and consciously participate in the implementation of processes aimed at supporting the efficiency and efficacy of service provision and the many factors that impact these processes.

## **Appendices**

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## Appendix 1.1: Child: Care, Health and Development Author Guidelines\*

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### Content of Author Guidelines\*:

1. General
2. Ethical Guidelines,
3. Submission of Manuscripts,
4. Manuscript Types Accepted,
5. Manuscript Format and Structure,
6. After Acceptance

\*For the purpose of this volume, only sections 1, 2, 4 and 5 have been included.

### 1. GENERAL

*Child: Care, Health and Development* is an international, peer-reviewed journal which publishes papers dealing with all aspects of the health and development of children and young people. We aim to attract quantitative and qualitative research papers relevant to people from all disciplines working in child health. We welcome studies which examine the effects of social and environmental factors on health and development as well as those dealing with clinical issues, the organization of services and health policy. We particularly encourage the submission of studies related to those who are disadvantaged by physical, developmental, emotional and social problems. The journal also aims to collate important research findings and to provide a forum for discussion of global child health issues.

Please read the instructions below carefully for details on the submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication in *Child: Care, Health and Development*. Authors are encouraged to visit Wiley-Blackwell Author Services for further information on the preparation and submission of articles and figures.

### 2. ETHICAL GUIDELINES

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#### 2.1. Authorship and Acknowledgements

Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the Journal. ALL named authors must have made an active contribution to the conception

and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

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The following checklist should be used to check the manuscript before submission. Articles are accepted for publication at the discretion of the Editor. A manuscript reporting original research should ideally be between 2000 and 3000 words. In the case of complex qualitative research reports, or systematic reviews, the editors may in some circumstances be prepared to extend the word limit to 5000 words. The manuscript should consist of the sections listed below.

**Title Page:** The title page should give both a descriptive title and short title. The title should be concise and give a brief indication of what is in the paper. Authors are required to detail in full: qualifications, current job title, institution and full contact details. Also a word count for the article and keywords should be given on the title page.

To allow double-blinded review, please submit (upload) your main manuscript and title page as separate files as explained in section 3.4.

**Abstract:** Structured abstracts, not more than 300 words, including background, methods, results and conclusions are preferred

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### Main Text

Generally, all papers should be divided into the following sections and appear in this order: Abstract (structured abstracts, not more than 300 words, including background, methods, results and conclusions are preferred); Introduction; Methods; Results; Discussion;

Acknowledgements (these should be brief and must include references to sources of financial and logistical support); References; Tables; Figures.

### **Key Messages**

From 2007 onwards a key messages box should be provided with each manuscript. This should include up to 5 messages on key points of practice, policy or research. This also applies to articles solicited for themed issues.

### **5.3. References**

References cited in the text should list the authors names followed by the date of their publication, unless there are three or more authors when only the first author's name is quoted followed by et al. References listed at the end of the paper should include **all** authors' names and initials, and should be listed in alphabetical order with the title of the article or book, and the title of the Journal given in full as shown:

Havermans, T. & Eiser, C. (1994) Siblings of a child with cancer. *Child: care, health and development*, **20**, 309-322.

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**Figures and Tables:** Always include a citation in the text for each figure and table. Artwork should be submitted online in electronic form. Detailed information on our digital illustration standards is available below. Any abbreviations used in figures and tables should be defined in a footnote.

## Appendix 1.2: Crowe & Sheppard's (2011) Critical Appraisal Tool

### Crowe Critical Appraisal Tool (CCAT) Form (v1.4)

Reference

Reviewer

This form must be used in conjunction with the CCAT User Guide (v1.4); otherwise validity and reliability may be severely compromised.

Citation	
	Year

Research design (add if not listed)	
<input type="checkbox"/> Not research	Article   Editorial   Report   Opinion   Guideline   Pamphlet   ...
<input type="checkbox"/> Historical	...
<input type="checkbox"/> Qualitative	Narrative   Phenomenology   Ethnography   Grounded theory   Narrative case study   ...
<input type="checkbox"/> Descriptive, Exploratory, Observational	A. Cross-sectional   Longitudinal   Retrospective   Prospective   Correlational   Predictive   ... B. Cohort   Case-control   Survey   Developmental   Normative   Case study   ...
Experimental	<input type="checkbox"/> True experiment Pre-test/post-test control group   Solomon four-group   Post-test only control group   Randomised two-factor   Placebo controlled trial   ...
	<input type="checkbox"/> Quasi-experiment Post-test only   Non-equivalent control group   Counter balanced (cross-over)   Multiple time series   Separate sample pre-test post-test [no Control] [Control]   ...
	<input type="checkbox"/> Single system One-shot experimental (case study)   Simple time series   One group pre-test/post-test   Interactive   Multiple baseline   Within subjects (Equivalent time, repeated measures, multiple treatment)   ...
<input type="checkbox"/> Mixed Methods	Action research   Sequential   Concurrent   Transformative   ...
<input type="checkbox"/> Synthesis	Systematic review   Critical review   Thematic synthesis   Meta-ethnography   Narrative synthesis   ...
<input type="checkbox"/> Other	...

Variables and analysis		
Intervention(s), Treatment(s), Exposure(s)	Outcome(s), Output(s), Predictor(s), Measure(s)	Data analysis method(s)

Sampling						
Total size	Group 1	Group 2	Group 3	Group 4	Control	
Population, sample, setting						

Data collection (add if not listed)	
Audit/Review	a) Primary   Secondary   ... b) Authoritative   Partisan   Antagonist   ... c) Literature   Systematic   ...
Observation	a) Participant   Non-participant   ... b) Structured   Semi-structured   Unstructured   ... c) Covert   Candid   ...
Interview	a) Formal   Informal   ... b) Structured   Semi-structured   Unstructured   ... c) One-on-one   Group   Multiple   Self-administered   ...
Testing	a) Standardised   Norm-ref   Criterion-ref   Ipsative   ... b) Objective   Subjective   ... c) One-on-one   Group   Self-administered   ...

Scores				
Preliminaries	Design	Data Collection	Results	Total [/40]
Introduction	Sampling	Ethical Matters	Discussion	Total [%]

General notes



Appraise research on the merits of the research design used, not against other research designs.

Category Item	Item descriptors [ <input type="checkbox"/> Present; <input type="checkbox"/> Absent; <input type="checkbox"/> Not applicable ]	Description [Important information for each item]	Score [0–5]
<b>1. Preliminaries</b>			
Title	1. Includes study aims <input type="checkbox"/> and design <input type="checkbox"/>		
Abstract (assess last)	1. Key information <input type="checkbox"/> 2. Balanced <input type="checkbox"/> and informative <input type="checkbox"/>		
Text (assess last)	1. Sufficient detail others could reproduce <input type="checkbox"/> 2. Clear/concise writing <input type="checkbox"/> ; table(s) <input type="checkbox"/> ; diagram(s) <input type="checkbox"/> ; figure(s) <input type="checkbox"/>		
Preliminaries [/5]			
<b>2. Introduction</b>			
Background	1. Summary of current knowledge <input type="checkbox"/> 2. Specific problem(s) addressed <input type="checkbox"/> and reason(s) for addressing <input type="checkbox"/>		
Objective	1. Primary objective(s), hypothesis(es), or aim(s) <input type="checkbox"/> 2. Secondary question(s) <input type="checkbox"/>		
Is it worth continuing?			Introduction [/5]
<b>3. Design</b>			
Research design	1. Research design(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of research design(s) <input type="checkbox"/>		
Intervention, Treatment, Exposure	1. Intervention(s)/treatment(s)/exposure(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Precise details of the intervention(s)/treatment(s)/exposure(s) <input type="checkbox"/> for each group <input type="checkbox"/> 3. Intervention(s)/treatment(s)/exposure(s) valid <input type="checkbox"/> and reliable <input type="checkbox"/>		
Outcome, Output, Predictor, Measure	1. Outcome(s)/output(s)/predictor(s)/measure(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Clearly define outcome(s)/output(s)/predictor(s)/measure(s) <input type="checkbox"/> 3. Outcome(s)/output(s)/predictor(s)/measure(s) valid <input type="checkbox"/> and reliable <input type="checkbox"/>		
Bias, etc	1. Potential bias <input type="checkbox"/> ; confounding variables <input type="checkbox"/> ; effect modifiers <input type="checkbox"/> ; interactions <input type="checkbox"/> 2. Sequence generation <input type="checkbox"/> ; group allocation <input type="checkbox"/> ; group balance <input type="checkbox"/> ; and by whom <input type="checkbox"/> 3. Equivalent treatment of participants/cases/groups <input type="checkbox"/>		
Is it worth continuing?			Design [/5]
<b>4. Sampling</b>			
Sampling method	1. Sampling method(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of sampling method <input type="checkbox"/>		
Sample size	1. Sample size <input type="checkbox"/> ; how chosen <input type="checkbox"/> ; and why <input type="checkbox"/> 2. Suitability of sample size <input type="checkbox"/>		
Sampling protocol	1. Target/actual/sample population(s): description <input type="checkbox"/> and suitability <input type="checkbox"/> 2. Participants/cases/groups: inclusion <input type="checkbox"/> and exclusion <input type="checkbox"/> criteria 3. Recruitment of participants/cases/groups <input type="checkbox"/>		
Is it worth continuing?			Sampling [/5]
<b>5. Data collection</b>			
Collection method	1. Collection method(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of collection method(s) <input type="checkbox"/>		
Collection protocol	1. Include date(s) <input type="checkbox"/> ; location(s) <input type="checkbox"/> ; setting(s) <input type="checkbox"/> ; personnel <input type="checkbox"/> ; materials <input type="checkbox"/> ; processes <input type="checkbox"/> 2. Method(s) to ensure/enhance quality of measurement/instrumentation <input type="checkbox"/> 3. Manage non-participation <input type="checkbox"/> ; withdrawal <input type="checkbox"/> ; incomplete/lost data <input type="checkbox"/>		
Is it worth continuing?			Data collection [/5]
<b>6. Ethical matters</b>			
Participant ethics	1. Informed consent <input type="checkbox"/> ; equity <input type="checkbox"/> 2. Privacy <input type="checkbox"/> ; confidentiality/anonymity <input type="checkbox"/>		
Researcher ethics	1. Ethical approval <input type="checkbox"/> ; funding <input type="checkbox"/> ; conflict(s) of interest <input type="checkbox"/> 2. Subjectivities <input type="checkbox"/> ; relationship(s) with participants/cases <input type="checkbox"/>		
Is it worth continuing?			Ethical matters [/5]
<b>7. Results</b>			
Analysis, Integration, Interpretation method	1. A.I.I. method(s) for primary outcome(s)/output(s)/predictor(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Additional A.I.I. methods (e.g. subgroup analysis) chosen <input type="checkbox"/> and why <input type="checkbox"/> 3. Suitability of analysis/integration/interpretation method(s) <input type="checkbox"/>		
Essential analysis	1. Flow of participants/cases/groups through each stage of research <input type="checkbox"/> 2. Demographic and other characteristics of participants/cases/groups <input type="checkbox"/> 3. Analyse raw data <input type="checkbox"/> ; response rate <input type="checkbox"/> ; non-participation/withdrawal/incomplete/lost data <input type="checkbox"/>		
Outcome, Output, Predictor analysis	1. Summary of results <input type="checkbox"/> and precision <input type="checkbox"/> for each outcome/output/predictor/measure 2. Consideration of benefits/harms <input type="checkbox"/> ; unexpected results <input type="checkbox"/> ; problems/failures <input type="checkbox"/> 3. Description of outlying data (e.g. diverse cases, adverse effects, minor themes) <input type="checkbox"/>		
Results [/5]			
<b>8. Discussion</b>			
Interpretation	1. Interpretation of results in the context of current evidence <input type="checkbox"/> and objectives <input type="checkbox"/> 2. Draw inferences consistent with the strength of the data <input type="checkbox"/> 3. Consideration of alternative explanations for observed results <input type="checkbox"/> 4. Account for bias <input type="checkbox"/> ; confounding/effect modifiers/interactions/imprecision <input type="checkbox"/>		
Generalisation	1. Consideration of overall practical usefulness of the study <input type="checkbox"/> 2. Description of generalisability (external validity) of the study <input type="checkbox"/>		
Concluding remarks	1. Highlight study's particular strengths <input type="checkbox"/> 2. Suggest steps that may improve future results (e.g. limitations) <input type="checkbox"/> 3. Suggest further studies <input type="checkbox"/>		
Discussion [/5]			
<b>9. Total</b>			
Total score	1. Add all scores for categories 1–8		
Total [/40]			

## Appendix 2.1: Major Research Project Proposal

### Title

A Qualitative Exploration of the Transition Experiences of Adolescents with Epilepsy

### Abstract

**Background:** Adolescence requires young people to negotiate through many transitions as they move into adult life. When chronic illness is superimposed on typical adolescence, challenges associated with these transitions are exaggerated. Approximately 90% of young people with chronic health conditions require transition of their care at this stage between paediatric and adult services. Research indicates well managed transition benefits young people in a range of ways, including long term health outcomes; debate continues regarding the needs and expectations of patients, parents and service providers across populations, locations and health conditions. There is limited research specifically considering transition for young people with epilepsy.

**Aim:** This research aims to explore the understanding and experiences of young people with epilepsy who are moving through healthcare transitions. Transitions at this time include moving from child to teenage clinics as well as preparing to move to adult services for management of their epilepsy.

**Methods:** Interpretative Phenomenological Analysis will extract themes from semi-structured interviews conducted with young people with epilepsy aged 14-17 years.

**Applications:** If healthcare professionals have a better understanding of the experiences of young people with epilepsy as they move through transitions, services could be sensitively targeted to the needs of the population, thereby improving both transition experiences and long term health outcomes.

### Introduction

#### Adolescence and Transition

Adolescence is a period of rapid change related to physical and emotional development, educational choices, career choices, and evolving family and peer relations (Rettig & Athreya, 1991). Adolescents with chronic health conditions share the same normative health issues and concerns as their peers, including sexuality,



mood changes, mental health, substance use, and choice between health-promoting or health-damaging behaviours (Rosen, 1994). When chronic illness is superimposed on typical adolescence the difficulty of navigating transitions to adult life is exaggerated, including the transition to specialised adult healthcare services (Jurasek, Ray & Quigley, 2010).

The increased life expectancy of young people with chronic health conditions means approximately 90% will require transition to adult-oriented care for life long disease management and surveillance (Blum, 1995). Research shows that well-managed healthcare transition allows young people to optimise their health and their ability to manage their disease; assume adult roles and functioning (American Academy of Paediatrics, 2002); and receive developmentally and medically optimal care (Schwartz, Tuchman, Hobbie & Ginsberg, 2011). Poor transition planning, on the other hand, may result in harmful medical and psychological consequences including declines in adherence and health status and increased rates of hospitalisation (Dugueperoux et al., 2008).

Research in healthcare transition for young people with specific long term health conditions has progressed researchers and healthcare professionals understanding of the needs and experiences of these young people as they move through transitions in adolescence (e.g. Price et al., 2011; Clarizia et al., 2009; McDonagh, 2007). Common themes and condition specific differences in experiences have been repeatedly highlighted. Common themes have included the importance of developmentally appropriate information presented at an appropriate time; treatment adherence; and the importance involving young people in decisions about transition services (e.g. Dovey-Pearce et al., 2012). Condition specific differences include aspects pertaining to biomedical factors (e.g. Westwood et al., 1999); and the psychosocial impact of specific conditions on adolescent development (e.g. Schwartz et al., 2011). This knowledge has been used to begin developing readiness measures to improve transition services (for example Gilleland et al., 2012; Schwartz et al., 2011).

## Transition in Epilepsy

Epilepsy is one of the most common chronic neurological conditions of childhood (Scottish Intercollegiate Guideline Network, 2005). There is limited literature pertaining to transition of young people with epilepsy from paediatric to adult healthcare services. Qualitative studies demonstrated the different information needs of these young people that, if gauged incorrectly, can lead to misconceptions and communication barriers to the transition process (e.g. Lewis et al., 2010). In addition the studies reported the important role of parents and caregivers in this process (Schultz, 2012; Davies et al., 2011). Quantitative studies have measured a range of factors that may impact outcomes including: styles of psychological adjustment/functioning (Baker et al., 2005; Reeve & Lincoln, 2002); quality of life (Asato et al., 2009; Hirfanoglu et al., 2009); medical adherence (Asato et al., 2009); and knowledge (Hirfanoglu et al., 2009; Kongsaktrakul et al., 2009; Baker et al., 2005; Bell et al., 2002). These studies demonstrated the importance of accurate and timely information and on-going monitoring of social functioning/outcomes in supporting independence, autonomy and successful transition to both adulthood and adult healthcare services. Lewis et al.'s (2010) systematic review of the information needs of young people with epilepsy concluded that current models for facilitating information and self-care around transition are neither effective or efficient. They reported that young people are critical of healthcare professionals practice. However, there are few evidenced interventions for these professionals to draw on and this needs to be addressed. Additional reviews acknowledge the stark difference between paediatric and adult services and highlight the importance of developmentally appropriate information during transition processes (e.g. Camfield & Camfield 2013; Kosoff et al., 2013). There is consensus across each of the current practice examples that transition should be a structured, dynamic, developmentally appropriate and gradual process that optimises outcomes for young people and is continuously monitored to ensure it is fit for purpose (Iyer & Appleton, 2013; Khan et al., 2013; Patel, 2013; Camfield et al., 2012; McRandall et al., 2012; Jurasek et al., 2010; Smith et al., 2002). There is no coherent published analysis of these current practice examples. Patel (2013) and Khan et al. (2013) acknowledge the lack of coherent evidence regarding 'best practice' in relation to transition for young people with epilepsies. They provide potential recommendations to begin addressing this.

Patel describes the American Epilepsy Societies' transition tool, a flexible framework that allows for a gradual process of transition. However, the developmental process of the tool is unclear and its implantation and analysis is not available. Khan et al. recommend the formulation of a transition pathway that considers all the factors known to affect transitional care for this population. However, they conclude that in order to determine the support needs and perspective of this population, additional exploratory research focusing on patient's experiences across different stages of transition is required.

### Current Proposal

Adolescence is a complex period of rapid developmental change. Young people with epilepsies are required to incorporate additional knowledge, skills and expectations during this period, which arguably adds additional pressure. It is clear that there is no consensus regarding the most beneficial way to support these young people through transitions, particularly healthcare transitions. The literature provides a patchy picture of the factors that affect positive outcomes or constitute successful healthcare transition. In addition, there appears to be limited consideration of the views and perspectives of the young people undergoing this process. Giving these young people the opportunity to describe their understanding and experiences of transition and the concurrent impact on their perceptions of their development and progression may allow for a better understanding of their needs (physical, social and emotional) and how best healthcare services can meet these needs.

### Aim

To explore the understanding and experiences of young people with epilepsy who are moving through healthcare transitions. Their transitions at this time in their lives include moving from child to teenage clinics as well as preparing to move to adult services for management of their epilepsy.

### Plan of Investigation

#### ***Participants:***

The NHS Ayrshire and Arran Paediatric Epilepsy Service employ a transition pathway that incorporates 'teen' sessions from the age of 14 years old. There are

currently 54 young people with epilepsy, aged between 14 and 17 years, attending the Service. Epilepsy specific clinics occur once per month and individuals who meet the inclusion criteria will be invited to participate. Recruitment will take place over a four month period from a sample of convenience of appointments made during this time by the Epilepsy Team. In accordance with IPA sample size guidelines for doctoral research 4-6 participants will be interviewed (Smith et al., 2003). Following initial analysis of this data, the researcher will make an informed decision regarding whether or not data saturation has been reached. Further participants will then be recruited should this be required.

### ***Inclusion and Exclusion Criteria:***

#### **Inclusion:**

- Confirmed diagnosis of epilepsy demonstrated by accessing the NHS Ayrshire and Arran Paediatric Epilepsy Service;
- Under the care of Consultant Paediatricians with a specialist interest in epilepsy who are implementing the service transition pathway;
- Eligible for inclusion in transition clinics (aged 14+ years);
- Scheduled to attend an annual epilepsy clinic appointment within the four month recruitment period.

#### **Exclusion:**

- Not suitable to approach, according to the Consultant Paediatrician;
- No diagnosis of epilepsy;
- Young people with a diagnosed learning disability (these young people's care is situated within a specialist learning disability service);

### ***Recruitment Procedures:***

Invitations to participate in a short semi-structured interview will be sent to young people who meet the inclusion criteria (Appendix 2.1.1). This will include an Information Sheet (outlining the aims of the study and the nature of their potential involvement); Participant Response Form (indicating if they would like to take part in the research and, if so, consent to be contacted by the researcher and details of how they would prefer to be contacted); and a Freepost return envelope. Potential

participants will be asked to indicate their decision to participate and consent to be contacted by the researcher to arrange an interview. When contacted by the researcher participants will be given the choice of attending an interview immediately prior to or following their epilepsy clinic appointment or at an alternative time that is more suitable. Participants will be offered the option of an interview prior to or following their clinic appointment as the Paediatric Epilepsy Service is an area wide service therefore patients may be travelling a significant distance to attend and it is not feasible to reimburse travel for the purposes of this research. In addition, participants aged 14-16 years will be informed that parental consent will be required in addition to their own consent and that this will be collected at the beginning of the interview by the Chief Investigator. On attendance at the interview, appropriate consent will be collected by the Chief Investigator (Appendix 2.1.2). Interviews will not be conducted without completion of appropriate consent forms. If participants aged 14-16 years attend independently and do not have the appropriate parental consent form either verbal consent will be sought from parents (by telephone with the young person's consent) or an alternative interview date will be scheduled to allow parental consent to be confirmed in writing.

The Epilepsy Nurse Specialist (ENS) will ask potential participants who have not responded by the time of their epilepsy clinic appointment if they received the information. If they have received it and decided not to participate, they will not be contacted again regarding this. If they did not receive the information, the ENS specialist will provide them with the research pack and the remainder of the above process will follow on as previously detailed.

### ***Design:***

This study will use Interpretative Phenomenological Analysis (IPA). IPA explores lived experiences to examine how people make sense of their personal and social world and tries to understand what the world is like from their perspective. IPA is reported to be particularly suitable for research focusing on the uniqueness of experiences and how these are made meaningful (Shaw, 2001). It has been widely used in health and illness research (Brocki & Wearden, 2006) and to explore issues of life transitions (Smith et al., 2009). In accordance with IPA methodology,

purposive sampling will be used. Analysis will focus on content and systematic analysis of a text to identify themes and categories (Frost, 2011).

**Individual Interviews:** Research highlights benefits and drawbacks of both individual interviews and focus groups as qualitative data collection methods (Appendix 2.1.3). Published healthcare transition research has employed both methods to explore a range of factors in transition (Appendix 2.1.4). This study will use individual interviews because they allow for more in-depth exploration of the topic and are reported to be more appropriate for sensitive topics or rare respondent types. Transition clinics incorporate discussions about sensitive topics such as relationship and family planning advice and sudden unexplained death in epilepsy (SUDEP), at a time when, developmentally, young people are transitioning into adulthood and developing their identity and independence.

***Recruitment process:***

1. Ethical approval will be sought from IRAS
2. Research and development paperwork will be completed and submitted for local area approval.
3. Invitations to participate will be sent to young people meeting the inclusion criteria (Appendix 2.1.1). This will include:
  - a. An Information Sheet outlining the aims of the study and the nature of their potential involvement;
  - b. A Participant Response Form indicating if they would like to take part in the research and, if so, consent to be contacted by the researcher and details of how they would prefer to be contacted.
  - c. A Freepost return envelope to send their response to the researcher.
4. Potential participants who have not replied by the date and time of their clinic appointment and who have not received their research pack, will be provided this at their appointment.
5. On receipt of the Participant Response Form, the researcher will contact the participant to discuss the study further and arrange an interview.
  - a. Participants aged 14-16 years will be informed that they will need parental consent in addition to their consent in order to take part.

6. The Chief Investigator will obtain appropriate written consent at the time of interview
  - a. For participants aged 14-16 years this will include young person and parental consent (Appendix 2.1.2)
  - b. For participants aged 16+ years this will include young person consent only (Appendix 2.1.2).
7. Semi-structured interview will be completed (Appendix 2.1.5). This will be recorded using a digital audio recording device.
8. Interviews will be uploaded onto a encrypted, password protected laptop and deleted from the digital audio recording device.
9. Interviews will be transcribed verbatim within a week following the interview. Following this transcription the audio recording will be deleted. Data will be anonymised during transcription.
10. Transcripts will be analysed according to IPA methodology:
  - a. Read transcript;
  - b. Look for emerging themes;
  - c. Examine emerging themes and cluster them together according to conceptual similarities;
  - d. Table of themes produced showing the structure of themes and subthemes.
11. Once all transcripts analysed a table of themes will be constructed. This provides basis for writing up narrative account.
12. The academic supervisor will review two transcripts with a view to enhance the reliability of the findings.
13. Findings will be written up in accordance with course recommendations.

### ***Data analysis:***

Transcripts will be analysed according to IPA methodology. This incorporates four main stages:

1. Read transcript;
2. Look for emerging themes;
3. Examine emerging themes and cluster them together according to conceptual similarities;

4. Table of themes produced showing the structure of themes and subthemes.

### ***Justification of sample size:***

IPA methodology is primarily concerned with collecting a detailed account of individual's experiences, therefore they usually benefit from an 'intensive focus on a small number of participants' (Frost, 2011: 49). Smith and Eatough (2006) add that "smaller sample sizes allow the researcher to explore the participants narratives in more depth, allowing for a greater understanding of their experiences, rather than producing a 'superficial qualitative analysis'" (p.327). Smith & Osborne (2003) suggest around 5-6 (p.54) participants are sufficient in IPA. They also stated that sample size is dependent on factors including richness of individual accounts, commitment to level of analysis and the constraints a researcher is working under. Turpin, Barley, Beail, Scaife, Slade, Smith, & Walsh (1997) state that for the purpose of conducting a Doctorate in Clinical Psychology thesis, a sample size of eight is feasible and appropriate and Smith & Osborn (2003) state that four to six participants are sufficient for the elaboration of meaningful points without becoming overwhelmed by the quantity of data. Taking all this into consideration and given the time constraints of the research project will aim to recruit and interview four to six young people. An informed decision about data saturation will be made following primary analysis and further participants will be recruited and interviewed should this be necessary.

### ***Settings and equipment:***

Interviews will take place in the same department as the epilepsy clinic. See Appendix 2.1.6 for detail regarding equipment.

### **Health and Safety Issues**

See Appendix 2.1.7.

### **Ethical Issues**

The potential sample includes children and young people (less than 16 years) therefore consent both from the young person and their parents will be obtained in accordance with The Declaration of Helsinki (World Medical Association 1964 &



2008) principles for conducting research with children; The National Children's Bureau Guidelines for Research with Children (NCB, 1993); the Legal Age of Capacity (Scotland) Act (1991); and The British Psychological Society (2010) Code of Human Ethics Research (see Appendix 9). Participants in the present study will have access to additional support from a Clinical Psychologist as required. As with all research involving participants within a service making changes, it will be important to keep in mind the possible implications of any research findings on the service following analysis. The use of the Paediatric Epilepsy Nurse Specialist to provide the young people with information on the research may lead to young people feeling obliged to participate in the research. In order to reduce the impact of this, the Paediatric Epilepsy Nurse Specialist will be asked to emphasise that their role is to provide the information and they have no further part in the research process; that the information provided in the interview will be used for research analysis and not in their clinic appointments or impact their current care; that all information in the research will be anonymised; and that they are in no way obligated to take part in the research.

### **Financial Issues**

See Appendix 2.1.6.

### **Proposed Timetable**

15 <sup>th</sup> April 2013	<ul style="list-style-type: none"> <li>• Submit MRP proposal to University.</li> </ul>
May - October 2013	<ul style="list-style-type: none"> <li>• Systematic Review reading</li> <li>• Amendments to Proposal as required</li> </ul>
November 2013	<ul style="list-style-type: none"> <li>• Resubmit proposal</li> <li>• Systematic Review reading</li> </ul>
December 2013	<ul style="list-style-type: none"> <li>• Amendments to proposal</li> <li>• Submit proposal to clinical governance</li> <li>• Complete ethics form</li> </ul>
January-February 2014	<ul style="list-style-type: none"> <li>• Resubmit proposal</li> <li>• Submit to R&amp;D for review</li> <li>• Submit to ethics</li> <li>• Plan systematic review</li> </ul>
March-May 2014	<ul style="list-style-type: none"> <li>• Recruitment &amp; initial analysis</li> <li>• Complete systematic review</li> </ul>
May-July 2014	<ul style="list-style-type: none"> <li>• Analysis</li> <li>• Write up</li> </ul>
July 2014	<ul style="list-style-type: none"> <li>• Submit Thesis to University.</li> </ul>

## **Practical Applications**

If healthcare professionals have a better understanding of the experiences of young people with epilepsy as they move through transitions during their adolescence, it is hoped that services could be targeted to the needs of the population, thereby improving the experience of transition and in turn improving their long term health outcomes.

## **References**

- American Academy of Pediatrics (2002) A consensus statement on healthcare transitions for young adults with special healthcare needs. *Pediatrics*, 110(6): 1304-1306.
- Asato, M. R., Manjunath, R., Sheth, R. D., Phelps, S. J., Wheless, J. W., Hovinga, C. A., Pina-Garza, J. E., Haskins, L. S., & Zingaro, W. M. (2009) Adolescent and Caregiver experiences with epilepsy. *Journal of Child Neurology*, 24(5): 562-571.
- Baker, G., Spector, S., McGrath, Y., & Soteriou, H. (2005) Impact of epilepsy in adolescence: A UK controlled study. *Epilepsy and Behaviour*, 6: 556-562.
- Bell, G. S., Nashef, L., Kendall, S., Solomon, J., Poole, K., Johnson, A. L., Moran, N. F., McCarthy, M., McCormick, D., Shorvan, S. D. & Sander, J. W. (2002) Information recalled by women taking anti-epileptic drugs for epilepsy: a questionnaire study. *Epilepsy Research*, 52: 139-146.
- Blum, R.W. (1995) Transition to adult health care: setting the stage. *Journal of Adolescent Health*, 17: 3–5.
- British Psychological Society (2010) *Code of Human Ethics Research*. BPS: Leicester.
- Brocki, J. M. & Wearden, A. J. (2006) Critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, 21(1): 87-108.
- Camfield, P. & Camfield, C. (2013) Help youth with epilepsy to become competent and happy adults: transition care. *Seizure*, 22: 414-415.
- Camfield, P., Camfield, C. & Pohlmann-Eden, B. (2012) Transition from paediatric to adult epilepsy care: a difficult process marked by medical and social crisis. *Epilepsy Currents*, 12(4): s13-s21.

- Clarizia, N. A., Chahal, N., Manhiot, C., Kilburn, J., Redington, A. N., & McCrindle, B. W. (2009) Transition to adult health care for adolescents and young adults with congenital heart disease: Perspectives of the patient, parent and health care provider. *Canadian Journal of Cardiology* 25(9): e317-e322.
- Davies, H., Rennick, J. & Majnemer, A. (2011) Transition from paediatric to adult health care for young adults with neurological disorders: parental perspectives. *Canadian Journal of Neuroscience Nursing*, 33(2) 32-39.
- Dugueperoux, I., Tamalet, A., Sermet-Gaudelus, I., Le Bourgeois, M., Gerardin, M., Desmazes-Dufeu, N. & Hubert, D. (2008) Clinical changes of patients with cystic fibrosis during transition from pediatric to adult care. *The Journal of Adolescent Health*, 43: 459–465.
- Frost, N. (2011) *Qualitative Research Methods in Psychology: Combining Core Approaches*. McCraw-Hill: Open University Press.
- Gilleland, J., Amaral, S., Mee, L., & Blount, R. (2012) Getting Ready to Leave: Transition Readiness in Adolescent Kidney Transplant Recipients. *Journal of Pediatric Psychology* 37(1): 85-96.
- Great Britain. *Legal Age of Capacity (Scotland) Act (1991)*. London: The Stationary Office.
- Hirfanoglu, T., Serdaroglu, A., Cansu, A., Soysal, A., Dele, E. & Gucuyener, K. (2009) Do knowledge of, perception of, and attitudes towards epilepsy affect the quality of life of Turkish children with Epilepsy and their parents? *Epilepsy and Behaviour*, 14: 71-77.
- Iyer, A. & Appleton, R. (2013) Transitional services for adolescents with epilepsy in the UK: a survey. *Seizure*, 22: 433-437.
- Jurasek, L., Ray, L., & Quigley, D. (2010) Development and Implementation of an Adolescent Epilepsy Transition Clinic. *Journal of Neuroscience Nursing* 42(4): 181-189.
- Khan, A., Baheerathan, A., Hussain, N. & Whitehouse, W. (2013) Transition of children with epilepsies to adultcare. *Acta Paediatrica*, 102(3): 216-221.
- Kongsaktrakul, C., Suchaxaya, P., Kantawang, S., Schepp, K., Visudtibhan, A. & Chinvarun, Y. (2006) A causal model of self-care behaviour for adolescents with epilepsy. *The Journal of Nursing Research*, 264-275.
- Kosoff, E. H., Henry, B. J. & Cervenka, M. C. (2013) Transitioning paediatric patients

- receiving ketogenic diets for epilepsy into adulthood. *Seizure*, 22: 487-489.
- Lewis, S. A., Noyes, J. & Mackereth, S. (2010) Knowledge and information needs of young people with epilepsy and their parents: Mixed-method systematic review. *BMC Pediatrics*, 10: 103-120.
- McDonagh, J. E. (2007) Transition of Care from Paediatric and Adult Rheumatology. *Archives of Disease in Childhood*, 92(9): 802-807.
- McRandell, M., Arthur, A. & Whitehouse, W. P. (2012) Letter to the editor: Young person's epilepsy clinic. *Child, care health and development*, 38(4): 604.
- National Children's Bureau (1993) *Guidelines of Research with Children*. London: NCB.
- Patel, A. (2013) Lost in transition? A practice tool for finding your way to adulthood. *Epilepsy Currents*, 13(4): 186-187.
- Price, C., Corbett, S., Lewis-Barnard, N., Morgan, J., Oliver, E., & Dovey-Pearce, G. (2011) Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes. *Child: care, health and development* 37(6): 852-860.
- Rettig, P. & Athreya, B. (1991) Adolescents with chronic disease. *Arthritis Care and Research*, 4(4): 174-180.
- Reeve, D. K., & Lincoln, N. B. (2002) Coping with the challenge of transition in older adolescents with epilepsy. *Seizure*, 11: 33-39.
- Rosen, D. (1994) Transition from paediatric to adult-oriented healthcare for adolescents with chronic illness or disability. *Adolescent Medicine*, 5(2): 241-248.
- Ryan, J. L., Ramsey, R. R., Fedele, D. A., Wagner, J. L., Smith, G. & Chaney, J. M. (2012) Exploration of age and sex differences in depressive symptoms and illness attitudes for youth with epilepsy and juvenile rheumatic disease. *Journal of Child Neurology*, 27(8): 1004-1010.
- Schultz, R. J. (2013) Parental experiences transitioning their adolescent with epilepsy and cognitive impairments to adult health care. *Journal of Pediatric Health Care*, 27(5): 359-366.
- Schwartz, L. A., Tuchman, L. K., Hobbie, W. L., & Ginsberg, J. P. (2011) A social-ecological model of readiness for transition to adult-oriented care for adolescents

- and young adults with chronic health conditions. *Child: care, health and development*, 37 (6): 883–895.
- Scottish Intercollegiate Guideline Network (2005) *81: Diagnosis and Management of Epilepsies in Children and Young People. A National Clinical Guideline*. SIGN: Edinburgh.
- Shaw, R. L. (2001) Why use interpretative phenomenological analysis in health psychology? *Health Psychology Update*, 10(4): 48-54.
- Sheth, R. D. (2002) Adolescent Issues in Epilepsy. *Journal of Child Neurology*, 17(2): S23-S27
- Smith, J. A., Flowers, P., & Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method & Practice*. London: Sage.
- Smith, J. A. & Eatough, V. (2006) Interpretative Phenomenological Analysis. In G. M. Bakewell, S. Hammond, C. Fife-Shaw & J. A. Smith (eds) *Research Methods in Psychology* (pp.322-340) (3<sup>rd</sup> edition). Sage Publications.
- Smith, J. A. & Osborne, M. (2003) in J. A. Smith (eds) *Qualitative Psychology*. London: Sage.
- Smith, J. A., Jarman, M. & Osborne, M. (1999) Doing Interpretative Phenomenological Analysis. In M. Murray & K. Chamberlain (eds) *Qualitative Health Psychology Theories and Methods* (pp.218-240). London: Sage Publications Ltd.
- Smith, P. E. M., Myson, V. & Gibbon, F. (2002) A teenager epilepsy clinic: observational study. *European Journal of Neurology*, 9(4): 373-376.
- Westwood, A., Henley, L., & Willcox, P. (1999) Transition from paediatric to adult care for persons with cystic fibrosis: Patient and parent perspectives. *Journal of Paediatrics and Child Health*, 35: 442-445.
- World Medical Association (2008) *Declaration of Helsinki*. 59<sup>th</sup> General Assembly, Seoul.
- World Medical Association (1996) *Declaration of Helsinki*, 48th WMA General Assembly, Somerset West, Republic of South Africa.

## Appendix 2.1.1: Invitation Letter and Research Pack



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### INVITATION LETTER

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Paediatric Epilepsy Service  
Crosshouse Hospital  
Crosshouse, Kilmarnock  
KA2 0BE  
Telephone: 01294 323072

Dear [patient name]

I am writing to let you know about a research study that is taking place at the Paediatric Epilepsy Service at Crosshouse Hospital. The researchers name is Jen Cookson and she is a Trainee Clinical Psychologist with the University of Glasgow. As part of her Doctorate in Clinical Psychology she is conducting a research project in partnership with The Paediatric Epilepsy Clinic.

She is really interested in finding out more about what it is like for young people with a diagnosis of epilepsy and how it impacts their daily life and their experiences. The information sheet below provides information about the study in more detail.

Thank you for taking the time to read this invitation.

If you would like more information please contact the researcher. Details on how to do this are provided at the end of the information sheet.

Yours sincerely

Dr. Christine Findlay

**Consultant Paediatrician**

Paediatric Epilepsy Service  
Crosshouse Hospital  
Kilmarnock  
KA2 0BE

Telephone: 01294 323072

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## PARTICIPANT INFORMATION SHEET

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**Title of Project:** Exploration of transition experiences of adolescents with Epilepsy

**Name of Primary Researcher:** Jen Cookson (Trainee Clinical Psychologist).

**Contact Details for the Primary Researcher, Research Supervisor and Independent Contact for the Project can be found at the end of the Information Sheet.**

I would like to ask you to take a few minutes of your time to read over this information sheet. My name is Jen Cookson and I am a Trainee Clinical Psychologist with the University of Glasgow. As part of my Doctorate in Clinical Psychology I am conducting a research project in partnership with The Epilepsy Clinic at Crosshouse Hospital.

I am contacting you to ask if you would like to take part in a research study. This leaflet is designed to give you all of the information that you need to decide if you want to take part. If you have any questions about the research or want to talk to me about it, you can contact me (my phone number and address are at the bottom of this leaflet).

### What is the study about?

We know that there is a lot of research about teenager's experiences of having a health condition, (for example, research that looks at their experience of going to clinic/hospital appointments and about having to make decisions about their health. This research has helped people understand what having a health condition is like for teenagers and knowing this can help make services better suited to what teenagers need. There is, however, not very much research on how teenagers with epilepsy feel as they move from child services to adult services and what this experience feels like and this is why this research is being carried out. The researcher wants to find out what it is like to be a teenager with epilepsy going to clinic appointments and making health decisions.

### How is the research being monitored?

The research has been given a favourable opinion by [insert REC] research Ethics Committee, the University of Glasgow Mental Health and Wellbeing department and NHS Ayrshire and Arran Research and Development Department. The progress of this research is being monitored by the trainee's clinical and academic supervisors.

### What will my involvement be?

The researcher is asking to talk to you about your experiences of being a teenager with epilepsy and your experiences of coming to clinic appointments. If you choose to take part, you will be asked to fill in the *Participant Response Form* (included in this pack) and send it back to the researcher in the Freepost envelope. If you are under 16 years old, your parents will also need to say it is ok for you to take part. If you choose to take part, the researcher will arrange to meet with you at Crosshouse hospital where you attend the epilepsy clinic. The interview will take place within the vicinity of the epilepsy clinic and will take 30-45

minutes. The researcher will ask for your permission to record the interview to allow for analysis. All interviews will be anonymised when the researcher transcribes them so your details will be taken out. Any direct quotes from your interview will also be anonymised. You can choose to have the interview before or after your epilepsy clinic appointment, or at another time that is better for you.

#### Do I have to take part?

- No, you do not have to take part in the research.
- Your choice to take part or not will not impact your medical care.
- You can change your mind about taking part at any time and do not have to tell the researcher why.

#### What will happen with the information?

After the interview, the researcher will compare what you say to others who have taken part. This will be written up as part of the University research project and marked. The information you give the researcher will be anonymised, this means that no-one will know which answers were yours.

#### Confidentiality

The purpose of the interview is to find out about your experiences and this is what the questions are designed to guide the discussion about. However, it is important to say that if you disclose something during the interview that concerns the interviewer, they have a duty of care to talk to your epilepsy care team about this. They will not do this without speaking to you about it first. Other than for this reason, the discussions during the interview will be anonymised so others will not be able to determine which of the answers were yours.

#### Additional information

The interviewer has a number of predetermined questions to ask you. These are designed to guide discussion about your experiences. If the process of the interview becomes upsetting for you in any way it will be stopped. There is additional support available from the Clinical Psychologist within the Paediatric Epilepsy Team should this be required.

#### Complaints Procedure

If you decide to take part in the study and become unhappy with anything during this process, you are entitled to make an official complaint using the NHS Ayrshire and Arran Complaints Procedure by contacting the Complaints team on the details below:

PO Box 13, Eglinton House, Ailsa Hospital,  
Dalmellington Road,  
Ayr  
KA6 6AB  
Telephone: 01292 513620 **please note:** your call may be recorded  
Fax 01292 513665  
Email: [complaintsteam@aapct.scot.nhs.uk](mailto:complaintsteam@aapct.scot.nhs.uk)

#### If I want to take part, would do I do next?



1. Read all the information.
2. Talk to your parents about the information.
3. Decide if you want to take part.
4. Fill in the *Participant Response Form* – including your name and how you would like the researcher to contact you.
5. Send the form back to the researcher in the envelope provided. As this is a Freepost address you don't need to put a stamp on it.
6. When they receive the form, the researcher will contact you to arrange an interview.
7. When you come to the interview the researcher will ask you to fill in a *Consent Form* which says that you have decided to take part. If you are 14 or 15 years old your parents will also need to fill in a *Parental Consent Form*. If you are 16 years or older your parents do not need to do this.

If you have any questions about the information please contact the researcher on the details given below. Thank you for taking the time to read this information leaflet and for any further participation that you may have.

**Jen Cookson**  
**Trainee Clinical Psychologist**

**Contact Details:**

***Researcher:***

Jen Cookson, Trainee Clinical Psychologist  
 Mental Health and Wellbeing  
 Admin Building, Gartnavel Royal Hospital  
 1055 Great Western Road  
 Glasgow, G12 0XH  
 Tel: 0141 201 0803  
[j.cookson.1@research.gla.ac.uk](mailto:j.cookson.1@research.gla.ac.uk)

***Project Supervisor:***

Dr Nicola Scott, Clinical Psychologist  
 Medical Paediatric Psychology Service  
 Ward 1B, Crosshouse Hospital  
 Crosshouse, Kilmarnock  
 KA2 0BB  
 Tel: 01294 323072  
[nicola.scott@aapct.scot.nhs.uk](mailto:nicola.scott@aapct.scot.nhs.uk)

***Independent Contact:***

Dr. Sharon Mulhern, Consultant Clinical Psychologist  
 2<sup>nd</sup> Floor, Horseshoe Building,  
 Ayrshire Central Hospital, Irvine  
 KA12 8SS.  
 Tel: 01294 274191  
[Sharon.mulhern@aapct.scot.nhs.uk](mailto:Sharon.mulhern@aapct.scot.nhs.uk)

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**PARTICIPANT RESPONSE FORM**

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**Title of Study:** Exploration of transition experiences of adolescents with Epilepsy

**Name of Primary Researcher:** Jen Cookson (Trainee Clinical Psychologist).

*Please tick:*

I have read the *Participant Information Sheet* and I would like to find out  
more about the study.

☐

If you are aged 14 or 15 years old: my parents are happy for me to  
Find out more about the study.

☐

I am happy to be contacted by telephone to talk about the study and  
arrange an interview.

☐

It is ok for the researcher (Jen Cookson) to leave a message if I don't  
answer the phone.

☐

**Name (please print in block capitals):**

**Name of parent:**

**Telephone number:**

**Date and time of my next Epilepsy**

**Clinic Appointment:**

## Appendix 2.1.2: Consent Forms



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### CONSENT FORM FOR PARTICIPANTS

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Title of Project: Exploration of transition experiences of adolescents with Epilepsy

Name of Researcher: Jen Cookson (Trainee Clinical Psychologist).

Please initial all boxes

- |   |                          |
|---|--------------------------|
| 1. I confirm that I have read and understand the information sheet dated January 2014 (version 5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.  | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.  | <input type="checkbox"/> |
| 3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from NHS Ayrshire and Arran from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. | <input type="checkbox"/> |
| 4. I understand that this research is part of a University course.  | <input type="checkbox"/> |
| 5. I understand that this will be written up as part of a research project and that my name will not be on it.  | <input type="checkbox"/> |
| 6. For people aged 14-16 years old – I know that my parents also need to to me taking part.   | <input type="checkbox"/> |
| 7. I agree to take part in the above study.   | <input type="checkbox"/> |
| 8. I agree to the interview being recorded and I understand that the transcript will be anonymised.   | <input type="checkbox"/> |
| 9. I agree for anonymised quotes to be used.  | <input type="checkbox"/> |

---

Name of Participant

---

Date

---

Signature

---

Name of Person  
taking consent.

---

Date

---

Signature

---

**PARENTAL CONSENT FORM**

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Title of Project: Exploration of transition experiences of adolescents with Epilepsy

Name of Researcher: Jen Cookson (Trainee Clinical Psychologist).

Please initial all boxes

- |   |                          |
|---|--------------------------|
| 1. I confirm that I have read and understand the information sheet dated January 2014 (version 5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.  | <input type="checkbox"/> |
| 2. I understand that my child's participation is voluntary and that they are free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.  | <input type="checkbox"/> |
| 3. I understand that relevant sections of my child's medical notes and data collected during the study, may be looked at by individuals from NHS Ayrshire and Arran from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my child's records. | <input type="checkbox"/> |
| 4. I understand that this research is part of a University course.  | <input type="checkbox"/> |
| 5. I understand that this will be written up as part of a research project and that my child's name will not be on it.  | <input type="checkbox"/> |
| 6. I agree to my child taking part in the above study.  | <input type="checkbox"/> |
| 7. I agree to my child's interview being recorded and I understand that the transcript will be anonymised.  | <input type="checkbox"/> |
| 8. I agree for anonymised quotes to be included in the study write up.  | <input type="checkbox"/> |

_____	_____	_____
Name of Parent	Date	Signature

_____	_____	_____
Name of Person taking consent.	Date	Signature

### Appendix 2.1.3: Individual Interviews vs. Focus Groups

	<b><u>Focus Groups</u></b>	<b><u>Individual Interviews</u></b>
<b><u>Advantages</u></b> (Azzara, 2010; Straus, 2010)	<ul style="list-style-type: none"> <li>• Runs on group dynamics;</li> <li>• Gets more done in a shorter period of time;</li> <li>• Better simulates real-world dynamics;</li> <li>• Provides an overview of topics;</li> <li>• Explores consensus/debate within a sample;</li> <li>• Understands commonalities and differences within segments of a sample;</li> <li>• Allows for point-counterpoint discussion and resolution;</li> <li>• Draws out latent issues;</li> <li>• Avoids rapport and transference effects.</li> </ul>	<ul style="list-style-type: none"> <li>• Allow for more in-depth exploration of topics;</li> <li>• Allows participants more time to have their input;</li> <li>• Easier to do with sensitive topics or rare respondent types;</li> <li>• Requires less skill to conduct effectively;</li> <li>• Understands differences within target segments of a sample;</li> <li>• Allows for exploration of sensitive, embarrassing, controversial or personal topics;</li> <li>• Allows for collection of views and experiences without the group influence factors;</li> <li>• Better for working with small populations or if deep layers of information from probing is required</li> </ul>
<b><u>When to use interviews or focus groups:</u></b> (Frechtling & Sharp, 1997)	<ul style="list-style-type: none"> <li>• When interaction of respondents may stimulate a richer response;</li> <li>• When group/peer pressure will be valuable in challenging thinking and illuminating conflicting responses;</li> <li>• When the subject matter is not so sensitive that respondents will temper responses or withhold information;</li> <li>• When the topic is such that most respondents can say all that is relevant or all they know within 10 minutes;</li> <li>• When the volume of issues isn't extensive;</li> <li>• When strings of behaviour are not relevant;</li> <li>• When an acceptable number of target respondents can be assembled in 1 location.</li> </ul>	<ul style="list-style-type: none"> <li>• When group interaction is likely to be limited or non-productive;</li> <li>• When group/peer pressure would inhibit responses and cloud the meaning of results;</li> <li>• When the subject matter is so sensitive that respondents would be unwilling to talk openly in a group;</li> <li>• When the topic is such that greater depth of response per individual is desirable, as with complex subject matters and very knowledgeable respondents;</li> <li>• When it is necessary to understand how attitudes and behaviours link together on an individual basis;</li> <li>• When respondents are dispersed or not easily assembled for other reasons.</li> </ul>
<b><u>Best Practice Guidelines for Qualitative Research with Children</u></b> (London School of Economics, 2012)	<ul style="list-style-type: none"> <li>• Best when you want to consider not only the child's accounts of reality but also the way they negotiate these accounts with others, therefore showing divergence and convergence between their views.</li> </ul>	<ul style="list-style-type: none"> <li>• Best when you are interested in individual information regarding several topics of interest that can be obtained through an informal conversation alone with the child informant.</li> </ul>

## Appendix 2.1.4: Healthcare Transition Research Topics

<b><u>Healthcare Transition Research Topics using Focus Groups (not titles)</u></b>	<b><u>Healthcare Transition Research Topics using Individual Interviews (not titles)</u></b>
<ul style="list-style-type: none"><li>• Reiss et al. (2005) Comparisons between young people, parents and providers experiences of transition;</li><li>• Dovey-Pearce et al. (2012) Giving young people the opportunity to choose their participation method.</li><li>• Huang et al (2011) allowing young people to meet with others having similar experiences.</li><li>• Kingsnorth et al. (2011) to capitalise on group dynamics and explore a range of parent participant experiences.</li><li>• Kelly (2011) to facilitate discussion between paediatric and adult healthcare professionals.</li></ul>	<ul style="list-style-type: none"><li>• Soanes &amp; Timmons (2004) attitudes of young people with chronic illness transitioning to adult healthcare.</li><li>• Clarizia et al. (2009) perspectives of patients with congenital heart disease, parents and healthcare providers.</li><li>• Price et al. (2011) analysis of transition pathway in diabetes.</li><li>• Van Staa et al. (2011) young adults, parents and providers experiences and recommendations for improving transitional care.</li></ul>

## Appendix 2.1.5: Interview Schedule



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### INTERVIEW SCHEDULE

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**Title of Project:** Exploration of transition experiences of adolescents with Epilepsy

**Name of Primary Researcher:** Jen Cookson (Trainee Clinical Psychologist).

Hello, my name is Jen Cookson; I am a trainee clinical psychologist. Thank you for saying yes to coming to talk to me today. I am really interested in finding out what it is like for teenagers who have epilepsy and go to clinics. I have some questions that I would like to ask you about your experiences and that should take about half an hour/45 minutes. It said in the information sheet that I would like to record what we talk about so that I can write it up later, is that still ok with you? No-one else will listen to the recording and all information about who you are will be taken out.

Before we start, I need to find about a bit about you:

- How old are you?
- Do you know what kind of epilepsy you have?
- Are you prescribed anti-epileptic medication? If so, do you experience any side effects?
- How old were you when you found out you have epilepsy?

Thank you for that. The next few questions are about your experiences of having epilepsy and attending clinics and your thoughts about the future:

1. What is it like being a teenager with epilepsy?
  - a. How does it make you think/feel
  - b. Does this impact you at home/school/with friends
  - c. Has this changed in any way as you have gotten older
2. I'm interested to hear about the kind of changes/differences you have noticed in your life as you have gotten older.
  - a. Has having epilepsy impacted this?
3. I'm wondering if there is anything about getting older and having epilepsy that you are particularly worried about?
  - a. Do you have specific worries about becoming an adult with epilepsy?
  - b. Any specific concerns around changes to your healthcare as you get older?
  - c. Is there anything or anyone that you think could help with these worries?
4. I'm wondering if you could tell me about your experiences of coming to the epilepsy clinic?
  - a. How think/feel about it
  - b. What is it like coming to talk about your epilepsy & what it means for you?

- c. Are there helpful or unhelpful things about coming to attending an epilepsy clinic?
- 5. What is your experience of having/attending different clinics as you get older?
  - a. Has there been anything different happening in clinic that you have noticed?
  - b. Different time/place/location/support/topics
  - c. How does it make you think/feel about having epilepsy?

Thank you for talking to me today.



## Appendix 2.1.6: Equipment and Finances

### RESEARCH EQUIPMENT, CONSUMABLES AND EXPENSES

Trainee .....1103942.....

Year of Course .....2nd.....

Intake Year...2011.....

Please complete the list below to the best of your ability

Item	Details and Amount Required	Cost or Specify if to Request to Borrow from Department
Stationary		Subtotal:
Postage	Postage for letters inviting participation (x58 max)	58x0.69 = £40.02
	Freepost for returned forms- maximum 58.	58x0.69 = £40.02
		Subtotal: £80.04 (maximum)
Photocopying and Laser Printing ( <b>includes cost of white paper</b> )	B&W print original x7 sheets Photocopy x323 sheets	0.05x7 = £0.35 0.05x323 = £16.15 Subtotal: £16.85
Equipment and Software	Installation of NVivo 10 University laptop	£30 Request to borrow Subtotal: £30
Measures	N/A	Subtotal:
Miscellaneous		Subtotal:
<b>Total</b>		<b>£126.54</b>

For any request over £200, please provide further justification for all items that contribute to a high total cost estimate:

Trainee Signature.....

Date.....

Supervisor's Signature .....

Date .....

## Appendix 2.1.7: Health and Safety Form

WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW

DOCTORATE IN CLINICAL PSYCHOLOGY

HEALTH AND SAFETY FOR RESEARCHERS

1. Title of Project	Exploring transition during adolescence: Experiences of Young People with Epilepsy.
2. Trainee	Jen Cookson
3. University Supervisor	Dr. Alison Jackson
4. Other Supervisor(s)	Dr. Nicola Scott
5. Local Lead Clinician	Dr. Nicola Scott
6. Participants: (age, group or sub-group, pre- or post-treatment, etc)	Young people aged 14-17 years diagnosed with epilepsy attending epilepsy clinic.  This participant sample are not normally associated with dangerous or unpredictable behaviour.
7. Procedures to be applied (eg, questionnaire, interview, etc)	Semi-structured interviews will be conducted with a minimum of 6 young people. These will be recorded, transcribed verbatim, anonymised and analysed in accordance with IPA qualitative methodology procedures.
8. Setting (where will procedures be carried out?)  i) General	Interviews will be conducted at Crosshouse hospital Epilepsy clinic in a small office or clinic room as available.  This is a setting that participants routinely attend and there are procedures in place to minimise risk to staff. These are thought to be adequate in the context of the proposed study.
ii) Are home visits involved	No

<p>9. Potential Risk Factors Identified</p> <p>(see chart)</p>	<p>This study includes young people under 16 years of age therefore needs to consider issues pertaining to consent, capacity to consent and parental consent. There is no single law that defines the age of a child across the UK. The UN Convention on the Rights of the Child, ratified by the UK government in 1991, states that a child “means every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier.” (Article 1, <u>Convention on the Rights of the Child</u>, 1989). In the UK, specific age limits are set out in relevant laws or government guidance. There are, however, differences between the UK nations. For example the Legal Age of Capacity (Scotland) Act (1991) states that Young people aged 16 and above are presumed to be competent to give consent [for medical procedures or treatment] until proven otherwise. It continues: Young people under the age of 16 can also give legally binding consent to any surgical, medical or dental procedure or treatment as long as they are believed by the medical practitioner to be competent. The Medical Research Council states that in the absence of law dealing specifically with research, the principles of Scottish law relating to consent procedures and treatment might reasonably be applied to research. At the same time, the threshold for understanding will vary according to the complexity of the research being undertaken. The Studies not governed by the Medicines for Human Use (Clinical Trials) Regulations 2004 legislation states that UK law is untested with regard to the legal age of consent to take part in research (as opposed to treatment). It is possible to apply the principle of Gillick competence for research in the UK. This can be summarised that children who are felt to be competent to understand the research proposal and thus make decisions can give consent on their own behalf. It is unwise to use this for children younger than ten years of age. (NHS National Patient Safety Strategy [2011] <i>Information sheets &amp; consent forms: guidance for research and researchers</i>. National Research Ethics Service.). The British Psychological Society (2010) Code of Human Ethics Research states: “In accordance with the <i>Code of Ethics and Conduct</i>, researchers should ensure that every person from whom data are gathered for the purposes of research consents freely to the process on the basis of adequate information. They should be able, during the data gathering phase, freely to withdraw or modify their consent and to ask for the destruction of all or part of the data that they have contributed. For children under 16 years of age and for other persons where capacity to consent may be impaired the additional</p>
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	<p>consent of parents or those with legal responsibility for the individual should normally also be sought.” (p.16).</p> <p>The Declaration of Helsinki (World Medical Association 1964, amended most recently 2008) documents the principles for conducting research applicable to all human subjects. The section referring specifically to research with children states: “when the subject is a minor, permission from the responsible relative replaces that of the participant in accordance with national legislation. Whenever the minor child is in fact able to give consent, the minor’s consent must be obtained in addition to the consent of the minor’s legal guardian.” (WMA 1996, paragraph 1.9, 11). The guidelines are clear that the consent of the child should be sought in addition to that of the responsible adult. In addition the researcher will be asking young people to participate in research at a time when they are already experiencing the pressure of transitioning to adult healthcare, especially those with a recent diagnosis. The National Children’s Bureau Guidelines for Research with Children (NCB, 1993) state that researchers need to consider the impact of research on children, especially where the participant has been discussing painful or difficult experiences, and advice that the research has information regarding local sources of support should this be required. Participants in the present study will have access to additional support from a Clinical Psychologist should it be required.</p> <p>The young people taking part in the research all have a diagnosis of epilepsy, therefore there is a risk that they will experience a seizure during the interview time. As the interviews are taking place in proximity to the epilepsy clinic and epilepsy trained professionals, this is not thought to present a significant risk beyond that which the young people already experiences with this diagnosis.</p> <p>It is possible that young people may become upset or distressed during the interview process. Procedures for this are detailed below.</p>
<p>. 10. Actions to minimise risk (refer to 9)</p>	<p>In accordance with the Declaration of Helsinki and the NCB Best Practice Guidelines parental consent will be sought for all participants aged 14-16 in addition to their consent to participate. All participants will be provided with an information sheet detailing their involvement and their right to withdraw their consent at any time in the research process. This will be reviewed with each participant at the beginning of the interview.</p>

	<p>All participants will have access to Clinical Psychology should this become appropriate for them during the research process. The interviews are taking place in proximity to the epilepsy clinic and epilepsy trained professionals, this is not thought to present a significant risk beyond that which the young people already experiences with this diagnosis. In addition the young person's parents will be within close proximity.</p> <p>The epilepsy nurse specialist will highlight any participants with epilepsy that is not well controlled to allow appropriate risk to be assessed.</p> <p>If young people become distressed or upset during the interview process they will be offered a break; reminded they can withdraw at any time; and, as stated above, clinical psychology are available to them should this be indicated. In addition, sources of additional support will be highlighted to them.</p>
--	---

Participants	
Yes	No
This participant sample is not normally associated with dangerous or unpredictable behaviour	This participant sample is associated with impulsive, irrational or unpredictable behaviour, and/or has poor emotional control

Procedures	
Yes	No
The procedures in the study are same/similar to those used by clinical psychologists with these participants and are not normally associated with production of significant distress.	These are novel procedures, are not used with this group and by their nature might produce anger, irritability or distress.

Settings	
Yes	No
These are clinical or University research settings, or other institutional settings, that participants routinely attend (eg, a school). They have procedures in place to minimise risk to staff and these are thought to be adequate in the context of the proposed study.	A private or other setting where there are not health and safety procedures that are relevant to research or clinical work proceeding without risk

## Appendix 2.2: Coding Example

Middle column: transcript with line numbers

Left hand column: initial themes

Right hand column coding key:

Blue = descriptive

Purple = language

Black = conceptual

<p>I know my ep. I feel in control</p> <p>taking charge motivation/determinedness</p> <p>matter of fact.</p> <p>Others are protective</p> <p>determination/motivation Trying to be as normal as poss.</p>	<p>yourself and your medical conditions and how they impact you then?</p> <p>108. <u>Yeah erm i like to know what i can and cant do so that well i dont do them and dont get myself in danger</u></p> <p>109. Ok and is that something you kinda feel in charge of or do other people take charge of that for you?</p> <p>110. <u>I try to take charge of as much as i can obviously i get some help here and there</u> <i>inevitableness.</i></p> <p>111. And has that always been the case or is that a new thing</p> <p>112. <u>Well since i wasn't diagnosed when i was really young i have tried to take charge as soon as i could</u> <i>sense of urgency + determination</i></p> <p>113. Uh-huh ok. And are there times when you think its ok to do stuff or are thinking yeah its alright and other people kinda of come in and go no no no you can't do that?</p> <p>114. Erm, <i>others.</i> <u>they are reluctant to let me do some stuff – like sleep over at my friends house maybe.</u></p> <p>115. So does that happen now? Are you still able to do that?</p> <p>116. <i>(laugh)</i> <u>yeah, it still happens but i go anyway (laugh)</u></p> <p>117. (laugh) and who who's <u>who's the reluctant party in that?</u></p> <p>118. <u>My mum</u></p> <p>119. Ok and is that always been the case?</p> <p>120. Yeah</p> <p>121. Yeah ok. So whats that like for you guys in your relationship if your wanting to do things and be in control of things and shes a</p>	<p>having knowledge of boundaries + limitations</p> <p>↳ This is in contrast to the earlier stuff about not telling raring that off meds.</p> <p>Awareness + control</p> <p>Acknowledgement of help @ times</p> <p>Independence &amp; sense of control</p> <p>appropriate age + stage of understanding + control</p> <p>↳ sounds like an inevitable natural process of indep/autonomy in line with what's expected during adol but also in healthcare expectations.</p> <p>Others reluctance or idea of what is ok to do.</p> <p>↳ This is more risky than raring cos happen determination/motivation @ night.</p> <p>Protective role of parent</p> <p>↳ this doesn't match idea of @ keeping secret from raring about off meds</p> <p>↳ is this a day/night time diff + is an actual measure of risk?</p>
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8

## Appendix 2.3: WoSREC Approval Letter

**WoSRES**  
**West of Scotland Research Ethics Service**



**West of Scotland REC 3**

Ground Floor – The Tennent Institute  
Western Infirmary  
38 Church Street  
Glasgow G11 6NT  
[www.nhsggc.org.uk](http://www.nhsggc.org.uk)

Mrs Jen Cookson  
Trainee Clinical Psychologist  
Mental Health & Wellbeing  
University of Glasgow  
Admin Building - Gartnavel Royal Hospital  
1055 Great Western Road  
Glasgow  
G12 0XH

Date	1 April 2014
Your Ref	
Our Ref	
Direct line	0141 211 2123
Fax	0141 211 1847
E-mail	Liz.Jamieson@ggc.scot.nhs.uk

Dear Mrs Cookson

<b>Study title:</b>	<b>A Qualitative exploration of the transition experiences of Adolescents with Epilepsy.</b>
<b>REC reference:</b>	<b>14/WS/0051</b>
<b>IRAS project ID:</b>	<b>137928</b>

Thank you for your recent email responding to the Committee's request for further information on the above research and submitting revised documentation.

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

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Mrs Liz Jamieson, [Liz.Jamieson@ggc.scot.nhs.uk](mailto:Liz.Jamieson@ggc.scot.nhs.uk).

### Confirmation of ethical opinion

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

### Ethical review of research sites

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



## Conditions of the favourable opinion

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

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

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

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

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

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

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

## Registration of Clinical Trials

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

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

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

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

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

## Approved documents

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

Document	Version	Date
Interview Schedules/Topic Guides	6 - App 7	07 March 2014
Investigator CV		31 January 2014
Letter of invitation to participant	6 - App 2	07 March 2014



Other: Supervisor's CV		31 January 2014
Other: App 1 - Plain English Summary	4	04 November 2013
Other: App 5 - Focus Groups vs Interviews	3	04 November 2013
Other: App 6 - Healthcare Transition	3	04 November 2013
Other: App 8 - Settings & Equipment	1	17 March 2013
Other: App 9 - Health & Safety	3	04 November 2013
Other: Proceed to Ethics Form	1	04 February 2014
Other: Summary CV for Field Supervisor N Scott	1	31 January 2014
Participant Consent Form: Parent	6	07 March 2014
Participant Consent Form: Young Person	6	07 March 2014
Participant Information Sheet: Appendix 2	6	07 March 2014
<i>Participant Response Form: Appendix 2</i>	6	<i>07 March 2014</i>
Protocol	9	31 January 2014
REC application		11 February 2014
Response to Request for Further Information	Email	

### Statement of compliance

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

### After ethical review

#### Reporting requirements

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

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

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

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

<b>14/WS/0051</b>	<b>Please quote this number on all correspondence</b>
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>  
With the Committee's best wishes for the success of this project.

Yours sincerely

A handwritten signature in black ink, reading "Liz Jamieson". The signature is written in a cursive, flowing style.

**Liz Jamieson**  
**Committee Co-ordinator**  
**On behalf of Dr Adam Burnel, Chair**

## Appendix 2.4: NHS Ayrshire & Arran Research & Development Approval Letter



Research & Development  
58 Lister Street  
University Hospital Crosshouse  
Kilmarnock  
KA2 0BB

Mrs Jennifer Cookson  
Trainee Clinical Psychologist  
Mental Health & Wellbeing  
University of Glasgow  
Admin Building – Gartnavel Royal Hospital  
1055 Great Western Road, Glasgow  
G12 0XH

Date 2 April 2014  
Your Ref  
Our Ref AG/KLB/AMK 2014AA011  
Enquiries to Karen Bell  
Extension 25850  
Direct line 01563 825850  
Fax 01563 825806  
Email [Karen.bell@aaaht.scot.nhs.uk](mailto:Karen.bell@aaaht.scot.nhs.uk)

Dear Mrs Cookson

### ***A Qualitative Exploration of the Transition Experiences of Adolescents with Epilepsy***

I confirm that NHS Ayrshire and Arran have reviewed the undernoted documents and grant R&D Management approval for the above study.

#### **Approved documents:**

Document	Version	Date
IRAS R&D Form	3.5	11 February 2014
IRAS SSI	3.5	11 February 2014
Protocol	9.0	31 January 2014
App1 – Plain English Summary	4.0	4 November 2013
App2 – Participant Information Sheet	6.0	7 March 2014
App2 – Participant Response Form	6.0	7 March 2014
App2 – Participant Invitation Letter	6.0	7 March 2014
App3 – Participant Consent Form: Young Person	6.0	7 March 2014
App4 – Participant Consent Form: Parent	6.0	7 March 2014
App5 – Focus Groups vs Interviews	3.0	4 November 2013
App6 – healthcare	3.0	4 November 2013

Transition		
App7 - Interview Schedule	6.0	7 March 2014
App8 – Settings & Equipment	1.0	17 March 2013
App9 – Health & Safety	3.0	4 November 2013
Proceed to Ethics Form	1.0	4 February 2014

The terms of approval state that the investigator authorised to undertake this study within NHS Ayrshire & Arran is: -

- Jennifer Cookson, NHS Ayrshire & Arran

With additional investigator: -

- Dr Nicola Scott, NHS Ayrshire & Arran

The sponsors for this study are NHS Ayrshire & Arran.

This approval letter is valid until 2 March 2015.

**Regular reports of the study require to be submitted. Your first report should be submitted to Dr K Bell, Research & Development Manager in 12 months time and subsequently at yearly intervals until the work is completed.**

Please note that as a requirement of this type of study your name, designation, work address, work telephone number, work e-mail address, work related qualifications and whole time equivalent will be held on the Scottish National Research Database so that NHS R&D staff in Scotland can access this information for purposes related to project management and report monitoring.

In addition approval is granted subject to the following conditions: -

- All research activity must comply with the standards detailed in the Research Governance Framework for Health and Community Care [www.cso.scot.nhs.uk/publications/ResGov/Framework/RGFEdTwo.pdf](http://www.cso.scot.nhs.uk/publications/ResGov/Framework/RGFEdTwo.pdf) and appropriate statutory legislation. It is your responsibility to ensure that you are familiar with these, however please do not hesitate to seek further advice if you are unsure.
- You are required to comply with Good Clinical Practice (ICH-GCP guidelines may be found at [www.ich.org/LOB/media/MEDIA482.pdf](http://www.ich.org/LOB/media/MEDIA482.pdf)), Ethics Guidelines, Health & Safety Act 1999 and Data Protection Act 1998.
- If any amendments are to be made to the study protocol and or the Research Team the Researcher must seek Ethical and Management Approval for the changes before they can be implemented.
- The Researcher and NHS Ayrshire and Arran must permit and assist with any monitoring, auditing or inspection of the project by the relevant authorities.
- The NHS Ayrshire and Arran Complaints Department should be informed if any complaints arise regarding the project and the R&D Department must be copied into this correspondence.

- The outcome and lessons learnt from complaints must be communicated to funders, sponsors and other partners associated with the project.
- As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collated in line with NHS Scotland IT Security Policies, until the destruction of these data. Under no circumstances should personal data be stored on any unencrypted removable media e.g. laptop, USB or mobile device (for further information and guidance please contact the Information Governance Team based at Ailsa Hospital 01292 513693 or 513694).

If I can be of any further assistance please do not hesitate to contact me. On behalf of the department, I wish you every success with the project.

Yours sincerely



**Dr Alison Graham**  
**Medical Director**

c.c. Libby Prentice, NHS Ayrshire & Arran  
Lesley Douglas, Finance, Ailsa Hospital  
Information Governance, Ailsa Hospital  
Dr Alison Jackson, University of Glasgow  
Dr Nicola Scott, NHS Ayrshire & Arran  
Dr Christine Findlay, NHS Ayrshire & Arran  
Joanne Pascual, NHS Ayrshire & Arran