National Institute for Health and Care Excellence

FINAL

Epilepsies in children, young people and adults: diagnosis and management

[20] Evidence review: Transition from paediatric to adult epilepsy services

NICE guideline NG217

Evidence reviews underpinning recommendations 11.2.1 to 11.2.6 in the NICE guideline

April 2022

FINAL

Developed by the National Guideline Centre

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Content

1 Transition from paediatric to adult epilepsy services

1.1 Review question

How should the transition from children's and young people's services to adults' epilepsy services be managed?

1.1.1 Introduction

The NICE guideline “Transition from children’s to adults’ services for young people using health or social care services” sets out generic guidance covering the period before, during and after a young person moves from children’s to adults’ services. Young people with epilepsy face additional important challenges that may include uncertainty of prognosis; stigma; risk of injury or death owing, for example, to SUDEP; mental health co-morbidities; side effects of anti-seizure medications and in young women there may be additional risks of medications on the unborn child during pregnancy. Transition planning forms an important part of young people’s epilepsy service design and delivery of care when moving into adult services. This chapter examines the available evidence related to the specific needs of young people with epilepsy in planning and preparing for transition.

1.1.2 Summary of the protocol

For full details see the review protocol in Appendix A.

Table 1: PICO characteristics of review question

Objective	The aim of the review is to identify factors that will help prepare a young person to transition between child and adult epilepsy services. When changing, the young person will be expected to become more involved in decision making on the medical issues affecting them. This review will identify information that is needed to aid the transition.
Population and setting	Inclusion: children and young people with epilepsy, their families and carers 3 groups for access to service strata • People with drug-resistant epilepsies • People with learning disabilities (access to service-strata) • People with otherwise well-controlled epilepsy
Context	Adolescence is a period of rapid change, both physical and psychosocial, for any young person. Transition can be a difficult time and should be a planned process of addressing the medical and associated comorbid conditions from paediatric to adult care. Significant apprehension may arise as a young person and their family move from a service where they have built therapeutic alliances to an unknown adult service. Both paediatric and adult epilepsy teams need to be motivated to provide a successful and safe transition for these patients.
Review strategy	Synthesis of qualitative research. Results will be presented in a narrative table format. The quality of the evidence will be assessed by a GRADE CerQual approach for each review finding.

1.1.3 Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods specific to this review question are described in the review protocol in appendix A and the methods document.

Declarations of interest were recorded according to NICE's conflicts of interest policy.

1.1.4 Qualitative evidence

1.1.4.1 Included studies

We searched for qualitative studies exploring young people's, parents or carer's perceptions of their experiences of transitioning from paediatric to adult epilepsy services.

Two qualitative studies were included in the review; [34,62] one study focussed on people with epilepsy and the other on people with epilepsy and cognitive impairments. The findings were extracted as narratively synthesised information into broad overarching themes, summarised in Table 2 below. Key findings from these studies are summarised in the clinical evidence summary below (Table 3). See also the study selection flow chart in Figure 1, study evidence tables in Appendix D, and excluded studies listed in Appendix E.

1.1.4.2 Excluded studies

Excluded studies can be found in Table 6 in Appendix E.

1.1.5 Summary of studies included in the qualitative evidence

Table 2: Summary of studies included in the evidence review

Study	Design	Population	Research aim	Comments
Lewis 2013[34]	Semi – structured Interviews or focus groups with two-stage analytical approach: thematic analysis and pattern matching UK n=58 (n=30 young people and n=28 parents of young people who participated)	Young people aged between 13–19 years with epilepsy. Parents of young people with epilepsy who met the inclusion criteria were also invited to participate.	To explore the views of young people with epilepsy (and their parents) about their experience of communication, information and knowledge exchange in two epilepsy services.	
Schultz 2013[62]	Semi-structured Interviews using grounded theory methods, using coding and constant comparison analysis USA n=7	Parents or guardians of adolescents 18 years or older with epilepsy and severe to profound cognitive impairments	To explicate processes that parents of adolescents with epilepsy and cognitive impairments undergo as they help their adolescent transition from paediatric to adult health care	

See Appendix D for full qualitative evidence tables.

1.1.6 Summary of the qualitative evidence

Table 3: Review findings

Main findings	Population	Statement of finding
Clarity	Young people aged between 13–19 years with epilepsy and their parents.	Young people perceived that when healthcare professionals used medical jargon, they were keeping information about their epilepsy from them. Most girls (aged 13-<18 years) had yet to receive information, or could not remember receiving information about contraception and pregnancy.
Communication barriers	Young people aged between 13–19 years with epilepsy and their parents.	Young people not knowing what questions to ask healthcare professionals about their epilepsy, what they needed to know about their own epilepsy, and parents being unable to seek information with their child present.
Information	- Young people aged between 13–19 years with epilepsy and their parents. - Parents or guardians of adolescents 18 years or older with epilepsy and severe to profound cognitive impairments	Continuity of information encompassed the importance of young people remembering facts through repeating information at staged clinical intervals and the negative impact that lack of continuity of information had on the behaviours of parents and lives of young people. Parents expressed difficulty in locating information and understanding the ‘ins and outs’ of it.
Disengaging from healthcare	Young people aged between 13–19 years with epilepsy and their parents.	Disengaging with healthcare professionals and services was linked with young people and parents’ first experience with healthcare professionals in the hand-over clinic.
Ongoing engagement with healthcare professionals	Young people aged between 13–19 years with epilepsy and their parents.	On-going and beneficial engagement was helped by befriending and continuity of care.
Negative stigma	Young people aged between 13–19 years with epilepsy and their parents.	Stigma originating from peers had a significant impact on the behaviour of young women and men, which may reinforce negative feelings about continued engagement with services.
Turmoil	Parents or guardians of adolescents 18 years or older with epilepsy and severe to profound cognitive impairments	Experienced by all parents. They experienced feelings of fear, rejection or uncertainty.
Parents as advocates	Parents or guardians of adolescents 18 years or older with epilepsy and severe to profound cognitive impairments	Experienced by all parents. They assumed the role of protector and information gatherer.
Waiting	Parents or guardians of adolescents 18 years or older with epilepsy and severe to profound cognitive impairments	Discontinuity between agencies resulted in waiting for answers before being able to move forward.
Transition sparked by crisis	Parents or guardians of adolescents 18 years or older with epilepsy and severe to profound cognitive impairments	Transitioning is not planned and is usually a result of a health issue.

See Appendix D for full details of qualitative evidence.

1.1.6.1 Narrative summary of review findings

Review finding 1: Clarity
Young people perceived that when healthcare professionals used medical jargon, they were keeping information about their epilepsy from them, with one stating, "The Doctors were just, “I don’t know, I don’t know”. They just didn’t want to say too much sort of thing." When imparting a diagnosis of epilepsy, the issue of lack of clarity tended to cause confusion, stress and anxiety. Another stated they ‘didn’t know what was going on for ages.’ Girls aged 16–17 years who had not yet received reproductive health information thought that the ideal age to start discussing gender-specific issues was 14 years of age. The majority of girls (aged >18-19 years) had received some information at various clinic appointments in children’s and adult services but could not be specific about what they were told. A number of the girls remembered being told by the nurse not to become pregnant whilst taking their medication due to the risk of congenital malformations. All the girls worried about starving their baby of oxygen during a seizure and about harming their baby should they fall. They did not know if they could give birth ‘naturally’.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 2: Communication barriers
Young people stated not knowing what questions to ask healthcare professionals about their epilepsy, what they needed to know about their own epilepsy, and parents felt unable to seek information with their child present. Some young people were afraid of receiving some epilepsy information, developed an inability to adjust, and were in fear of being alone in case something bad happened. One stated, “I didn’t want to speak to anyone about it at all [epilepsy] and I was just really upset all of the time”. Parents found it difficult to ask questions and were frequently unable to seek information with their child present. For example, one parent could not ask questions as she was afraid that the information might be frightening to both of them. One common concern was the risk of fatal accidents and sudden death due to seizures. Some parents were too afraid to ask about the risks associated with seizures; however, young people appeared less worried about this in comparison to parents. Shutting down communication with their parents occurred when young people took ownership of their epilepsy in an overly self-protecting way and only talked about epilepsy with their parents and peers when they had to.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 3: Information
The continuity of information encompassed the importance of young people remembering facts through repeating information at staged clinical intervals and the negative impact that lack of continuity of information had on the behaviours of parents and lives of young people. One stated, “I need something told to me three times before I take it in...perhaps be told something and then read it, go through it, you know”. Children and young people wanted verbal information given by healthcare professionals to be backed up with written materials. They were more interested in the format, presentation and relevance of information rather than the type of information, such as information in leaflets and books versus DVDs and web resources. Repeating information at times annoyed some young people, however, the

majority benefited from this approach of repetition of information as it strengthened recall and understanding, enabling ability to self-care.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 4: Disengaging from healthcare

Disengaging with healthcare professionals and services was linked with young people and parents' first experience with healthcare professionals in the hand-over clinic. Once in adult services young people felt forgotten by adult healthcare professionals due to infrequent clinic visits, which were fewer than when following the children's epilepsy care pathway. Parents felt that healthcare professionals in the handover clinic lacked facilitative skills when communicating with their children. The outcome was that some young people disengaged with healthcare professionals and subsequently the adult clinic, as they refused to attend.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 5: Ongoing engagement with healthcare professionals

On-going and beneficial engagement was helped by befriending and continuity of care. Young people who entered the teenager clinic at an early age (14–15 years) and were befriended/supported by a multi-disciplinary team that included the children's epilepsy nurse appeared more confident and able to communicate. This confidence continued when engaging with adult services, with one stating, “I felt a bit shy at first moving … because I have been with that doctor for years and I was used to him, moving on was a bit scary”. Young people who saw the same healthcare professional, who was responsive to their needs, at frequently staged intervals, developed a positive rapport. Even when older, many young people said being able to bring parents into the clinic room helped. They felt that if they forgot or did not understand what had been said, then at least they could turn to their parent for the information. Including parents during consultations seemed to improve family functioning, and young people could see that this alleviated their parents' stress and worry.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Review finding 6: Negative stigma

The stigma of having epilepsy originating from peers had a significant impact on the behaviour of girls and boys, which may reinforce negative feelings about continued engagement with services. An inability to cope with stigma, especially for girls, originated from being stigmatised by peers at school and work. One participant mentioned, “Someone came up to me the other day and they said, ‘do you remember that time when you had a fit', and I said ‘no' ‘well we call it a funky chicken' and I said ‘why?' (she mimicked flapping her arms to demonstrate what the other person did)...I didn't like going to school if I had one so I would stay at home for about a week afterwards…Because I was scared what people would say”. Young people were more inclined to stay engaged with epilepsy services if they could experience some tangible benefits from continued attendance.

Explanation of quality assessment: the study had no or very minor concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

1.1.6.2 Narrative summary of review findings from those with learning disabilities

Review finding 1: Turmoil

Turmoil was experienced by all parents. They experienced feelings of fear, rejection or uncertainty. One participant stated that "changes are scary. And especially when it has to do with health - living or dying. To me, it's very frightening." Parents also felt uncertainty regarding where they could receive healthcare or the source of insurance coverage. Another participant said, “there are a lot of unknowns… there’s too many of them – just to leave them hanging”.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations and the relationship between the researcher and participants not being adequately considered.

Review finding 2: Parents as advocates

This was experienced by all parents. They assumed the role of protector and information gatherer, with one participant mentioning, "you have to be very diligent in the way that you cover yourself in terms of if you really don't want that service". Parents took charge of locating and sustaining essential health care services. As an information gatherer they needed to identify resources whilst understanding the differences in eligibility requirements and delivery of services for various agencies.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations and the relationship between the researcher and participants’ not being adequately considered.

Review finding 3: Information

Parents expressed difficulty in locating information and understanding the ‘ins and outs’ of it. One parent mentioned the difficulty in locating information and understanding it. They stated it is a “...huge web of trying to figure out how it all works", and parents found support groups the most helpful source. Along with support groups ‘just networking with parents’ was also claimed to be a valuable source.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations and the relationship between the researcher and participants not being adequately considered.

Review finding 4: Waiting

Because of participants experiencing discontinuity between agencies, they were confined to a state of 'captive waiting' for answers before being able to move forward. This captivity generated feelings of uncertainty and a fear of loss of services. Waiting on lists to acquire new services was not new to many of the families. Furthermore, parents often did not have the choice of coverage; they were at the mercy of the 'system' to determine when and where they were going to receive services.

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations and the relationship between the researcher and participants' not being adequately considered.

Review finding 5: Transition sparked by crisis

Participants explained how transition is not planned and is usually a result of a health issue. It was mentioned how there is no preparation, and they are just transferred to the adult system. One participant stated, "…nothing was planned or nothing. It was like this is an emergency, so now we've got to fix it".

Explanation of quality assessment: the study had moderate concerns of methodological limitations in the contributing studies; no or very minor concerns regarding coherence, relevance or adequacy with nothing to lower our confidence. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations and the relationship between the researcher and participants' not being adequately considered.

1.1.7 Qualitative evidence summary

Table 4: Summary of evidence

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Clarity					
1 study Lewis 2013[34]	A combination of interviews and focus groups	Young people perceived that when healthcare professionals used medical jargon, they were keeping information about their epilepsy from them.	Limitations	No or very minor limitations	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Communication barriers					
1 study Lewis 2013[34]	A combination of interviews and focus groups	Young people not knowing what questions to ask healthcare professionals about their epilepsy, what they needed to know about their own epilepsy, and parents being unable to seek information with their child present.	Limitations	No or very minor limitations	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Information					
1 study Lewis 2013[34]	A combination of interviews and focus groups	Continuity of information encompassed the importance of young people remembering facts through repeating information at staged clinical intervals and the negative impact that lack of continuity of information had on the behaviours of parents and lives of young people.	Limitations	No or very minor limitations	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Disengaging from healthcare					
1 study Lewis 2013[34]	A combination of interviews and focus groups	Disengaging with healthcare professionals and services was linked with young people and parents' first experience with healthcare professionals in the hand-over clinic.	Limitations	No or very minor limitations	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Ongoing engagement with healthcare professionals					
1 study Lewis 2013[34]	A combination of interviews and focus groups	On-going and beneficial engagement was helped by befriending and continuity of care.	Limitations	No or very minor limitations	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No concerns	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Negative stigma					

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
1 study Lewis 2013[34]	A combination of interviews and focus groups	Stigma originating from peers had a significant impact on the behaviour of girls and boys, which may reinforce negative feelings about continued engagement with services.	Limitations	No or very minor limitations	HIGH
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	No concerns	

Those with learning disabilities

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Findings**	**Criteria**	**Rating**	**Overall assessment of confidence**
Turmoil					
1 study Schultz 2013[62]	Individual interviews	Experienced by all parents. They experienced feelings of fear, rejection or uncertainty.	Limitations	Moderate limitations[1]	LOW
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[2]	

[1] *downgraded for lack of information on; participant/researcher relationship and ethical considerations*
[2] *downgraded for small sample size, n=7*

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Parents as advocates					
1 study Schultz 2013[62]	Individual interviews	Experienced by all parents. They assumed the role of protector and information gatherer.	Limitations	Moderate limitations[1]	LOW
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[2]	

[1] downgraded for lack of information on; participant/researcher relationship and ethical considerations
[2] downgraded for small sample size, n=7

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Information					
1 study Schultz 2013[62]	A combination of interviews and focus groups	Parents expressed difficulty in locating information and understanding the 'ins and outs' of it.	Limitations	Moderate limitations[1]	LOW
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[2]	

[1] downgraded for lack of information on; participant/researcher relationship and ethical considerations
[2] downgraded for small sample size, n=7

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Waiting					
1 study Schultz 2013[62]	Individual interviews	Discontinuity between agencies resulted in waiting for answers before being able to move forward.	Limitations	Moderate limitations[1]	LOW
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[2]	

[1] *downgraded for lack of information on; participant/researcher relationship and ethical considerations*
[2] *downgraded for small sample size, n=7*

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	Design	Findings	Criteria	Rating	Overall assessment of confidence
Transition sparked by crisis					
1 study Schultz 2013[62]	Individual interviews	Transitioning is not planned and is usually a result of health issue or change in insurance.	Limitations	Moderate limitations[1]	LOW
			Coherence	No or very minor concerns	
			Relevance	No or very minor concerns	
			Adequacy	Moderate concerns[2]	

[1] *downgraded for lack of information on; participant/researcher relationship and ethical considerations*
[2] *downgraded for small sample size, n=7*

1.1.8 Economic evidence

The committee agreed that health economic studies would not be relevant to this review question, and so were not sought.

1.1.9 The committee's discussion and interpretation of the evidence

1.1.9.1 The quality of the evidence

High-quality evidence was found for the themes of clarity, communication barriers, disengaging from healthcare, ongoing engagement with healthcare professionals and negative stigma.

Low-quality evidence was found for the themes of information giving, turmoil, parents as advocates, waiting, and transition sparked by a crisis.

The committee noted one small study was from the US and that configuration of services would be quite different to UK practice. However, the committee agreed the description of the concerns reported by parents of young people with learning disabilities were common and still applicable.

1.1.9.2 Findings identified in the evidence synthesis

Clarity, communication, and lack of information were identified as important aspects of the evidence that concerned information giving during transition from children to adult epilepsy services. Young people reported a lack of clarity caused by the use of medical jargon, and this led to a perception that health professions were withholding information. Young women expressed concern that they were not provided information on contraception or pregnancy and the associated risks of epilepsy in pregnancy. There is a risk that unclear information provided to young women might result in their abruptly stopping medication without understanding the consequences if they were to become pregnant. The importance of providing clear and balanced information to young people about their medication and any associated risks was acknowledged by the committee.

Barriers to communication expressed by young people included not knowing what to ask or being afraid to ask about risks associated with epilepsy such as SUDEP. Young people considered information about their plan for transition could be facilitated by health professionals repeating information at staged intervals to ensure their management plan and the support that is to be provided is understood and agreed. Parents of young people with epilepsy reported difficulty discussing epilepsy in front of their children. The committee acknowledged that both parents and young people could feel inhibited in discussing sensitive issues in front of each other and agreed health professionals should provide the opportunity for joint and individual meetings with parents and the young person to facilitate open discussion.

The committee noted the evidence highlighted the importance of providing information without jargon and in an accessible format which should be repeated at different time points over the transition period. The evidence reported children and young people valued having verbal information given by healthcare professionals backed up with written materials. The committee decided to make a recommendation that information should be provided on the individual's management plan for transition in a format that meets the young person's needs using language they understand. The committee also recommended that this may require regularly revisiting the individualised management plan over a period of time to ensure the young person fully understands their care plan and the support to be provided.

The themes of engagement and disengagement with healthcare professionals and services were also identified from the evidence. The committee acknowledged that transition could be a distressing time for both children and adults. The evidence found that young people who engaged with a multidisciplinary team (MDT) felt more confident and able to communicate their views*.* Health care professionals befriending the young person also facilitated engagement with services and continuity of care. The evidence also described how young people disengaged with services and healthcare professionals due to negative experiences when attending ‘hand-over’ appointments and at subsequent clinic visits. Less frequent or delayed clinic appointments in adult services than had occurred in children’s services resulted in young people feeling forgotten about or were interpreted as being unsupportive. The committee agreed that encouraging discussion of the expectations of service provision between the young person and their new adult epilepsy team can be helpful to establish the person’s needs and what the service is able to provide. Making sure young people are aware of the importance of attending appointments was discussed, and the committee agreed adult services should not automatically discharge young people who miss appointments during the transition, although they were aware this does happen occasionally.

The committee discussed the value of having a management plan developed by the epilepsy multidisciplinary teams who can then facilitate the transition rather than transition occurring in crisis (for example, by a sixteen-year-old attending the accident and emergency department and meeting the adult care team for the first time in this context). It was considered essential that planning should occur with both paediatric services and the adult MDT working together. Other external agencies may also need to be included as part of the MDT such as social care services and school nurses. Descriptions of barriers to a smooth transition were noted by the committee, who acknowledged the importance of clear communication channels and sharing of information between multi-professional epilepsy teams, young people and their parents or carers. The committee also noted that a young person’s transition is bespoke to that person and should be recognised as such by the paediatric and adult MDT. The committee discussed how the severity of a young person’s epilepsy may change over time, and planning for transition should include a review of the diagnosis and medical management of the person with epilepsy. The committee discussed that there could be a lack of certainty around the diagnosis of epilepsy, for example, that dissociative seizures may look similar to epileptic seizures indicating the necessity of the clinician to review the original diagnosis. The committee agreed this opportunity for review should not be missed and recommended this should involve both paediatric and adult MDT.

The evidence showed stigma of having epilepsy originating from peers had a significant impact on the behaviour of young people, which may reinforce negative feelings about continued engagement with services. Stigma can have a significant impact on young people’s everyday activities and school attainment. Participation in social activities can also be adversely curtailed because of seizure activity or the young person avoiding social events due to embarrassment or negative self-image. The committee acknowledged the importance of encouraging young people to discuss their experiences and providing support during consultations on transition.

The themes arising from the evidence on young people with learning disabilities were turmoil, parents as advocates, information, waiting, and transition as a result of a crisis. Parents of young people with learning disabilities expressed feelings of fear, rejection or uncertainty around their child’s transition from paediatric to adult services. Parents assumed the role of protector and information gatherer and described difficulty in finding information and understanding the implications of the changes in service provision for their child. The committee noted that parents and carers should be empowered to have the confidence to speak up and advocate for the young person, and health professionals need to be mindful of how intimidating the system can be. Parents observed discontinuity between agencies involved with transition of care, who often acted as a barrier to successful transfer due to lack of coordination between teams, leading to delays in moving plans forward. It was noted that transitioning was often not planned and would occur as a consequence of a crisis. The committee acknowledged the significant anxiety that some parents or carers can experience as the young person prepares to transfer to the adult service, and how important it is to make time to include parents and carers in the planning stage and explain the process fully.

The committee considered the themes described by parents and carers of young people with learning disabilities and observed that these often overlapped with the themes described in the other study of young people who didn’t have a learning disability. The committee agreed this demonstrated the generalisability of the findings across the studies and were applicable to all young people, their parents and carers during transition, although difficulties can be particularly marked in young people with complex needs.

The committee agreed that people with learning disabilities may have very complex needs, and transition to adult services could require more planning, need longer appointments and involve many other specialities, including professionals from a learning disabilities MDT, CAMHS and special needs schools. The committee noted that transition of young people with learning disabilities could occur considerably later than other young people with epilepsy, even up to the age of 24 years, and this was often because of the multiple agencies required to organise an optimal package of care and the different age cut-offs used in services for young people with learning disabilities. The committee acknowledged some young people with complex health and social care needs, such as treatment-resistant epilepsies may require additional management support or input from multiple agencies to provide appropriate packages of care. The committee decided to make a consensus recommendation based on their experience that planning transition for these young people should start earlier, although agreed it would be inappropriate to specify a timeframe as this would be dependent on individual circumstances and needs.

The committee made recommendations based on the themes found in the evidence review, but they also identified issues from their experience that they considered important to include in discussions as part of transition. These were topics often raised by the young person during preparations for transfer. The committee decided to make a consensus recommendation that highlighted these key concerns, or questions, that are commonly raised. These include adherence to medication, the effects epilepsy and medication may have on cognition and behaviour, and other work and education-related issues such as advice on how to access benefits or special arrangements that may be required for taking exams. Young people often described disturbance of sleep patterns, and the committee noted the importance of discussing attending social activities safely, such as parties or staying overnight at other people's houses, and ensuring the young person is aware of the need to adhere to a healthy sleep regime. Other common concerns raised include being able to participate in activities such as sports or driving and being aware of triggers such as flashing lights that can induce a seizure. Many young people want to discuss preparing for independent living with someone outside of their family and turn to the MDT for advice and guidance. The committee agreed it was important to discuss potential co-morbidities of epilepsy, especially impaired memory and low mood. The committee also acknowledged social aspects of epilepsy such as decisions on when or if to disclose epilepsy status and the emotional health and psychological wellbeing of the young person as issues of stigma and cognitive consequences of the person's epilepsy can have a negative impact on mental health.

1.1.9.3 Cost-effectiveness and resource use

Cost-effectiveness evidence was not sought as this was a qualitative review. The recommendations generally provide guidance regarding the content of information and support specific to people transitioning from child to adult epilepsy services in line with the general principles of provision of information already established in the existing NICE Transition from Children's to Adults' Services Guideline and so the recommendations concerning the information and support provided to young people with epilepsy transitioning were not considered to have a substantial resource impact over and above this.

The committee noted that transition for children to adult epilepsy services should be individually tailored to the young person and acknowledged it is current best practice to plan earlier transition for people who have complex or additional social care needs but for a small proportion of people, this does not happen. It was discussed that although planning transition earlier will result in additional costs for the NHS at the pre-transition phase, these will likely be offset by cost savings observed in the form of better health care received in adult services.

Reviewing the diagnosis and management plan of a young person with epilepsy during transition to adult services is generally current practice at epilepsy centres, but the level of review and involvement of both paediatric and adult multidisciplinary teams can vary from centre to centre, especially for people with more complex epilepsy. The committee stressed the importance of an ‘in-depth’ review of a person’s epilepsy as this may be an ideal time and opportunity for a full holistic review to be conducted. The committee noted that taking the time to review the young person’s epilepsy has the potential to lead to substantial health gains if it means people subsequently receive better-tailored health care plans. A review of a young person’s epilepsy will generally consist of; communication between both the children’s and adult epilepsy teams, an initial meeting with the adult epilepsy services team, and any tests a person may receive as a result of these. The need for tests will be individualised to a person’s epilepsy and will only be conducted if the clinician believes young people may benefit from long-term health gains. The committee noted that around 20%-30% of young people might undergo additional testing when transitioning from children to adults’ services, with most of these tests being outpatient appointments. It is important to have early discussions about the potential need for inpatient tests at the time of transition or in the future to reduce anxiety and allow preparatory hospital/ward visits. As reviewing a person’s epilepsy is generally current practice at epilepsy centres, this is unlikely to have a substantial resource impact. At epilepsy centres where the level of reviewing is less than stated in the recommendation, there may be a small resource impact, but these additional costs have the potential to be offset by health gains achieved by optimal diagnosis and individualised management.

1.1.10 Other factors the committee took into account

The committee acknowledged the Ready Steady Go programme for transition to adult services developed by Southampton Children’s Hospital, now widely adopted within epilepsy healthcare services. The committee considered the recommendations in the NICE guideline Transition from children to adult services to be applicable and provided guidance on the general principles for planning and organising the transfer of young people to an adult epilepsy service. A cross-reference to the guideline was made.

1.1.11 Recommendations supported by this evidence review

This evidence review supports recommendations 11.2.1 – 11.2.6 in the NICE guideline.

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Appendices

Appendix A Review protocols

A.1 Review protocol for transition to care from children's and young people's services to adults' services

ID	Field	Content
1.	Review title	How should the transition from children's and young people's services to adults' epilepsy services be managed?
2.	Review question	How should the transition from children's and young people's services to adults' epilepsy services be managed?
3.	Objective	The aim of the review is to identify factors that will help prepare a young person to transition between services. When changing the young person will be expected to become more involved in decision making on the medical issues affecting them. The review will identify information that is needed to aid in the transition.
4.	Searches	The following databases (from inception) will be searched: • Embase • MEDLINE • PsycINFO • CINAHL Searches will be restricted by: • English language studies • Human studies

		Other searches: - Inclusion lists of systematic reviews The searches may be re-run 6 weeks before the final committee meeting and further studies retrieved for inclusion if relevant. The full search strategies will be published in the final review.
5.	Condition or domain being studied	Children and young people with epilepsy transitioning from children's and young people's services to adult services
6.	Population	Inclusion: children and young people with epilepsy, their families and carers 3 groups for access to service strata • People with drug resistant epilepsies • People with learning disability (access to service- strata) • People with otherwise well-controlled-controlled epilepsy Exclusion: New-born babies (under 28 days) with acute symptomatic seizures
7.	Intervention/Exposure/Test	Views, opinions and experiences in relation to information, education or support that will help prepare a young person to transition between services.
8.	Comparator/Reference standard/Confounding factors	Not applicable
9.	Types of study to be included	Qualitative studies using any appropriate methodology (e.g., semi-structured interviews or focus groups with ethnography or grounded theory-based analysis) and systematic reviews of qualitative studies will be considered for inclusion. Qualitative studies for transition of care will provide the personal experiences of people with epilepsy and their carers and this will feed into the recommendations.

10.	Other exclusion criteria	• Non-English language studies. • Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias • Studies conducted in non-OECD countries
11.	Context	Adolescence is a period of rapid change, both physical and psychosocial for any young person. Transition can be a difficult time and should be a planned process of addressing the medical and associated comorbid conditions from paediatric to adult care. Significant apprehension may arise as a young person and their family move from a service where they have built therapeutic alliances to an unknown adult service. Both the paediatric and adult epilepsy teams need to be motivated to provide a successful and safe transition for these patients.
12.	Primary outcomes (critical outcomes)	Themes will be derived from the evidence identified for this review and may include driving, teratogenicity of certain anti-epileptic medications, interaction of anti-epileptic medications with contraception, effect of alcohol/recreational drugs on seizures, psychosocial aspects of epilepsy as people move out of the parental home e.g., to work, to University, independence. Memory, stigma, mental heath
13.	Secondary outcomes (important outcomes)	Not applicable.
14.	Data extraction (selection and coding)	EndNote will be used for reference management, sifting, citations and bibliographies. All references identified by the searches and from other sources will be screened for inclusion. 10% of the abstracts will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third independent reviewer. The full text of potentially eligible studies will be retrieved and will be assessed in line with the criteria outlined above. A standardised form will be used to extract data from studies (see Developing NICE guidelines: the manual section 6.4) https://www.nice.org.uk/process/pmg20/chapter/reviewing-research-evidence#reviewing-research-evidence Once saturation is considered to have been reached (all the themes are already covered in the data extraction) data from other included papers will not be extracted or critically appraised, but the paper will still be read to check for any additional themes and will be noted in the included studies. The point at which data extraction is reached will be noted within the review.

15.	Risk of bias (quality) assessment	The methodological quality of each study will be assessed using the CASP qualitative checklist and the GRADE CERQual approach used to provide overall risk of bias at outcome level 10% of all evidence reviews are quality assured by a senior research fellow. This includes checking: • papers were included /excluded appropriately • a sample of the data extractions • correct methods are used to synthesise data • a sample of the risk of bias assessments Disagreements between the review authors over the risk of bias in particular studies will be resolved by discussion, with involvement	
16.	Strategy for data synthesis	• CERQual will be used to synthesise data from qualitative studies. The synthesis of qualitative data will follow a thematic analysis approach. Information will be synthesised into main review findings. Results will be presented in a detailed narrative and in table format with summary statements of main review findings. If suggested by the evidence, themes may be reported separately for patients, families and carers.	
17.	Analysis of sub-groups	None.	
18.	Type and method of review	☐	Intervention
		☐	Diagnostic
		☐	Prognostic
		☒	Qualitative
		☐	Epidemiologic
		☐	Service Delivery
		☐	Other (please specify)

19.	Language	English		
20.	Country	England		
23.	Stage of review at time of this submission	Review stage	Started	Completed
		Preliminary searches	☐	☑
		Piloting of the study selection process	☐	☑
		Formal screening of search results against eligibility criteria	☐	☑
		Data extraction	☐	☑
		Risk of bias (quality) assessment	☐	☑
		Data analysis	☐	☑
24.	Named contact	5a. Named contact Angela Cooper National Guideline Centre Angela.cooper@rcplondon.ac.uk 5b Named contact e-mail epilepsies@nice.org.uk 5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and the National Guideline Centre		

25.	Review team members	From the National Guideline Centre: Gill Ritchie, Guideline Lead Angela Cooper, Senior Research Fellow Rafina Yarde, Systematic reviewer Margaret Constanti, Senior Health economist Joseph Runicles, Information specialist
26.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Centre which receives funding from NICE.
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of [Developing NICE guidelines: the manual](). Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10112/documents
29.	Other registration details	
30.	Reference/URL for published protocol	
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts

		• issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
32.	Keywords		
33.	Details of existing review of same topic by same authors		
34.	Current review status	☒	Ongoing
		☒	Completed but not published
		☐	Completed and published
		☐	Completed, published and being updated
		☐	Discontinued
35.	Additional information		
36.	Details of final publication	www.nice.org.uk	

Appendix B Literature search strategies

This literature search strategy was used for the following reviews:

- What information and support is needed by people, parents or carers in relation to epilepsy, and when should this be provided?
- How should the transition from children's and young people's services to adults' epilepsy services be managed?

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual.[46]

For more information, please see the Methodology review published as part of the accompanying documents for this guideline.

B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL, Current Nursing and Allied Health Literature (EBSCO) and PsycINFO (ProQuest). Search filters were applied to the search where appropriate.

Table 5: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	1946 – 30 December 2019	Qualitative studies Exclusions
Embase (OVID)	1974 – 30 December 2019	Qualitative studies Exclusions
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 30 December 2019	
PsycINFO (ProQuest)	Inception – 30 December 2019	

Medline (Ovid) search terms

1.	exp epilepsy/
2.	seizures/
3.	exp status epilepticus/
4.	seizures, febrile/
5.	(dravet syndrome or epilep* or continuous spike wave or slow sleep or landau kleffner syndrome or lennox gastaut syndrome or infant* spasm* or seizure* or west syndrome).ti,ab.
6.	or/1-5
7.	letter/
8.	editorial/
9.	news/
10.	exp historical article/
11.	Anecdotes as Topic/
12.	comment/
13.	case report/

14.	(letter or comment*).ti.
15.	or/7-14
16.	randomized controlled trial/ or random*.ti,ab.
17.	15 not 16
18.	animals/ not humans/
19.	exp Animals, Laboratory/
20.	exp Animal Experimentation/
21.	exp Models, Animal/
22.	exp Rodentia/
23.	(rat or rats or mouse or mice).ti.
24.	or/17-23
25.	6 not 24
26.	limit 25 to English language
27.	"patient acceptance of health care"/ or exp patient satisfaction/ or consumer health information/ or needs assessment/
28.	Patient Education as Topic/ or exp patients/ or exp family/ or caregivers/ or patient preference/
29.	((information* or advice or advising or advised or support*) adj3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*)).ti,ab.
30.	(information* adj2 support*).ti,ab.
31.	((client* or patient* or user* or carer* or consumer* or customer* or parent* or famil* or spouse*) adj2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion* or preference* or focus group*)).ti,ab.
32.	or/27-30
33.	"Continuity of Patient Care"/
34.	Patient Transfer/
35.	Patient Care Planning/
36.	"Delivery of Health Care, Integrated"/
37.	shared care.ti,ab.
38.	shared service*.ti,ab.
39.	((healthcare or care or service*) adj3 integrat*).ti,ab.
40.	transition*.ti.
41.	(transfer? or transferred or transferral or transferring).ti.
42.	(transition* adj10 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department? or patient?)).ab.
43.	((transfer? or transferred or transferral or transferring) adj10 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department? or patient?)).ab.
44.	(transition* and (adult? adj3 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department?))).ab.
45.	((transfer? or transferred or transferral or transferring) and (adult? adj3 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department?))).ab.
46.	(transfer? or transferred or transferal or transferring or transition).ab. and (adult?.ti. or (adult focused or adult oriented).ti,ab.)
47.	(continuity adj3 (care or health care or healthcare or treatment? or therapy or therapies or patient? or "doctor-patient" or nurse patient)).ti,ab.
48.	or/33-47

49.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
50.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
51.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
52.	or/49-51
53.	26 and 52 and (32 or 48)

Embase (Ovid) search terms

1.	exp epilepsy/
2.	seizure/
3.	epileptic state/
4.	febrile convulsion/
5.	(dravet syndrome or epilep* or continuous spike wave or slow sleep or landau kleffner syndrome or lennox gastaut syndrome or infant* spasm* or seizure* or west syndrome).ti,ab.
6.	or/1-5
7.	letter.pt. or letter/
8.	note.pt.
9.	editorial.pt.
10.	case report/ or case study/
11.	(letter or comment*).ti.
12.	or/7-11
13.	randomized controlled trial/ or random*.ti,ab.
14.	12 not 13
15.	animal/ not human/
16.	nonhuman/
17.	exp Animal Experiment/
18.	exp Experimental Animal/
19.	animal model/
20.	exp Rodent/
21.	(rat or rats or mouse or mice).ti.
22.	or/14-21
23.	6 not 22
24.	limit 23 to English language
25.	patient attitude/ or patient preference/ or patient satisfaction/ or consumer attitude/ or needs assessment/
26.	patient information/ or consumer health information/ or patients/ or family/ or caregivers/
27.	((information* or advice or advising or advised or support*) adj3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*)).ti,ab.
28.	(information* adj2 support*).ti,ab.
29.	((client* or patient* or user* or carer* or consumer* or customer* or parent* or famil* or spouse*) adj2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion* or preference* or focus group*)).ti,ab.
30.	patient education/

31.	or/25-30
32.	*patient care/
33.	*patient transport/
34.	patient care planning/
35.	integrated health care system/
36.	shared care.ti,ab.
37.	shared service*.ti,ab.
38.	((healthcare or care or service*) adj3 integrat*).ti,ab.
39.	transition*.ti.
40.	(transfer? or transferred or transferral or transferring).ti.
41.	(transition* adj10 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department? or patient?)).ab.
42.	((transfer? or transferred or transferral or transferring) adj10 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department? or patient?)).ab.
43.	(transition* and (adult? adj3 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department?))).ab.
44.	((transfer? or transferred or transferral or transferring) and (adult? adj3 (care or service? or center? or centre? or clinic? or facility or facilities or unit? or department?))).ab.
45.	(transfer? or transferred or transferal or transferring or transition).ab. and (adult?.ti. or (adult focused or adult oriented).ti,ab.)
46.	(continuity adj3 (care or health care or healthcare or treatment? or therapy or therapies or patient? or "doctor-patient" or nurse patient)).ti,ab.
47.	or/32-46
48.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
49.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
50.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
51.	or/48-50
52.	24 and 51 and (31 or 47)

CINAHL (EBSCO) search terms

S1.	(MM "Seizures")
S2.	(MH "Status Epilepticus+")
S3.	(MH "Epilepsy+")
S4.	(MH "Convulsions, Febrile")
S5.	(dravet syndrome or epilep* or continuous spike wave or slow sleep or landau kleffner syndrome or lennox gastaut syndrome or infant* spasm* or seizure* or west syndrome)
S6.	S1 OR S2 OR S3 OR S4 OR S5
S7.	(MH "Consumer Satisfaction+") OR (MH "Patient Education") OR (MH "Health Education")
S8.	((information* or advice or advising or advised or support*) n3 (patient* or need* or requirement* or assess* or seek* or access* or disseminat*))
S9.	(information* n2 support*)

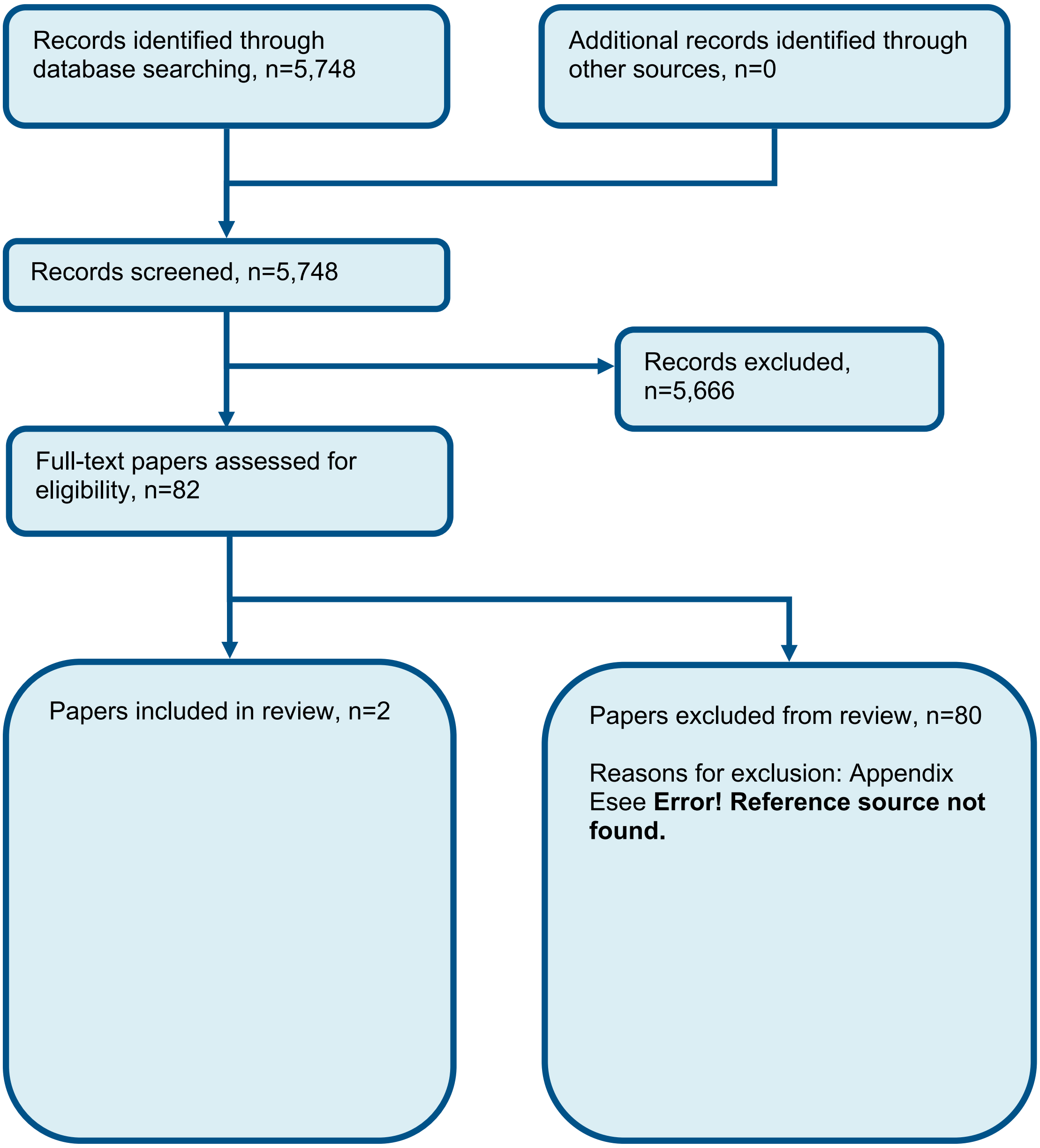
S10.	((client* or patient* or user* or carer* or consumer* or customer*) n2 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact* or inform* or experience or experiences or opinion*))
S11.	S7 OR S8 OR S9 OR S10
S12.	(MH "Qualitative Studies+")
S13.	(MH "Qualitative Validity+")
S14.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
S15.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
S16.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* n3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*)
S17.	S12 OR S13 OR S14 OR S15 OR S16
S18.	S6 AND S11 AND S17

PsycINFO (ProQuest) search terms

1.	(MJMAINSUBJECT.EXACT.EXPLODE("Epilepsy") OR MAINSUBJECT.EXACT("Seizures") OR MAINSUBJECT.EXACT("Status Epilepticus") OR TI,AB(dravet syndrome OR epilep* OR continuous spike wave or slow sleep OR landau kleffner syndrome OR lennox gastaut syndrome OR infant* spasm* OR seizure* OR west syndrome)) AND (SU.EXACT("Client Education") OR SU.EXACT.EXPLODE("Client Attitudes") OR TI,AB((information* OR advice OR advising OR advised OR support*) NEAR/3 (patient* OR need* OR requirement* OR assess* OR seek* OR access* OR disseminat*)) OR TI,AB(information* NEAR/2 support*) OR TI,AB((client* OR patient* OR user* OR carer* OR consumer* OR customer*) NEAR/2 (attitud* OR priorit* OR perception* OR preferen* OR expectation* OR choice* OR perspective* OR view* OR satisfact* OR inform* OR experience OR experiences OR opinion*))) AND ((su.exact.explode("qualitative methods") OR su.exact("narratives") OR su.exact.explode("questionnaires") OR su.exact.explode("interviews") OR su.exact.explode("health care services") OR ti,ab(qualitative OR interview* OR focus group* OR theme* OR questionnaire* OR survey*) OR ti,ab(metasynthes* OR meta-synthes* OR metasummar* OR meta-summar* OR metastud* OR meta-stud* OR metathem* OR meta-them* OR ethno* OR emic OR etic OR phenomenolog* OR grounded theory OR constant compar* OR (thematic* NEAR/3 analys*) OR theoretical-sampl* OR purposive-sampl* OR hermeneutic* OR heidegger* OR husserl* OR colaizzi* OR van kaam* OR van manen* OR giorgi* OR glaser* OR strauss* OR ricoeur* OR spiegelberg* OR merleau*)))Limits applied

Appendix C Qualitative evidence study selection

Figure 1: Flow chart of qualitative study selection for the review of transition to care from children's and young people's services to adult services



Appendix D Qualitative evidence

Study	Lewis 2013[34]
Aim	To explore the views of young people with epilepsy (and their parents) about their experience of communication, information and knowledge exchange in two epilepsy services, during transition from children's' to adult epilepsy services.
Population	All young people aged between 13–19 years with epilepsy attending the children's, transitional teenager, handover and adult epilepsy clinics were identified in each Case. The qualitative unit of analysis was children's and adult epilepsy services in two District General Hospitals (Case 1 and Case 2) and two embedded units of analysis were young people and their parents within each Case. Young people were included if they had a diagnosis of epilepsy and who had reported experience of a seizure in the past 12 months. Young people with severe learning disabilities (and their parents) were not included in this study as they were considered a different group with specific information and communication needs. Parents of young people with epilepsy who met the inclusion criteria were also invited to participate, n=58.
Setting	Children's and adult epilepsy services in two District General Hospitals. UK.
Study design	A qualitative comparative embedded case study.
Methods and analysis	Semi-structured focus groups and interviews with a two-stage analytical approach was guided by the theoretical framework and propositions. First, thematic analysis using the Framework approach was used to explore experiences of young people with epilepsy and their parents attending epilepsy services. Second, pattern matching using theory-based evaluation was applied to test the theoretical framework and propositions and better understand which models of service delivery worked during transition to adult services, for whom, and in what contexts.
Findings	Clarity: Young people perceived that when healthcare professionals used medical jargon, they were keeping information about their epilepsy from them. Most girls (aged 13-<18 years) had yet to receive information, or could not remember receiving information, about contraception and pregnancy.

Study	**Lewis 2013[34]**
	Communication barriers: Young people not knowing what questions to ask healthcare professionals about their epilepsy, what they needed to know about their own epilepsy, and parents being unable to seek information with their child present.
	Information: Continuity of information encompassed the importance of young people remembering facts through repeating information at staged clinical intervals, and the negative impact that lack of continuity of information had on the behaviours of parents and lives of young people.
	Disengaging from healthcare: Disengaging with healthcare professionals and services was linked with young people and parents' first experience with healthcare professionals in the hand-over clinic.
	Ongoing engagement with healthcare professionals: On-going and beneficial engagement was helped by befriending and continuity of care.
	Negative stigma: Stigma originating from peers had a significant impact on the behaviour of girls and boys, which may reinforce negative feelings about continued engagement with services.
Limitations and applicability of evidence	The study had minor methodological limitations providing valuable research and findings. There was a judgement of high confidence in this finding due to no concerns regarding the applicability of this finding to the overarching question.

Study	**Schultz 2013[62]**
Aim	To explicate processes that parents of adolescents with epilepsy and cognitive impairments undergo as they help their adolescents to transition from paediatric to adult health care. Because parents are the healthcare agents for their adolescents with cognitive impairments and epilepsy, an improved understanding of the processes that these parents experience as they help their adolescents transition from paediatric to adult healthcare is needed to develop effective, individualised transition plans.
Population	Participants were parents or guardians (mothers, fathers or both) of adolescents 18 years or older with epilepsy and severe to profound cognitive impairments who had transitioned to an adult provider more than 1 year ago but less than 5 years ago and spoke English. n=7

Study	Schultz 2013[62]
Setting	Participant’s home, USA
Study design	Qualitative interview study
Methods and analysis	Semi-structured individual interviews with grounded theory methodology. Individual interviews were conducted from June through September 2009 using open-ended semi-structured questions. All interviews were conducted in the participant’s home, audio-taped, transcribed verbatim, and reviewed to ensure accuracy. Data collection and analysis occurred concurrently according to the tenets of grounded theory methodology using coding and constant comparison analysis. Open coding was done to identify conceptual labels that described participants’ experiences.
Themes with findings	Turmoil: Experienced by all parents. They experienced feelings of fear, rejection or uncertainty.
	Parents as advocates: Experienced by all parents. They assumed the role of protector and information gatherer.
	Information: Continuity of information encompassed the importance of young people remembering facts through repeating information at staged clinical intervals and the negative impact that lack of continuity of information had on the behaviours of parents and lives of young people.
	Waiting: Discontinuity between agencies resulted in waiting for answers before being able to move forward.
	Transition sparked by crisis: Transitioning is not planned and is usually a result of a health issue or change in insurance.
Limitations and applicability of evidence	The study had moderate methodological limitations providing valuable research and findings. There was a judgement of moderate confidence in this finding due to concerns regarding the ethical considerations and the relationship between the researcher and participants’ being adequately considered. There were no concerns regarding the applicability of the evidence.

Appendix E Excluded studies

E.1 Clinical studies

Table 6: Studies excluded from the qualitative review

Reference	Reason for exclusion
Abubakar 2015[1]	Incorrect population, included those without epilepsy.
Alkhamra 2012[2]	Incorrect study design, questionnaire.
Amjad 2016[3]	Included in information review, no information on transition.
Andrade 2017[4]	Incorrect study design, recommendations.
Aytch 2001[5]	Incorrect population, included those without epilepsy.
Baca 2018[6]	Incorrect study design, not qualitative.
Baird 2003[7]	Quantitative study with some themes reported, doesn’t mention quantitative analysis.
Benson 2015[8]	Included in information review, no information on transition.
Benson 2016[10]	Included in information review, no information on transition.
Benson 2017[9]	Included in information review, no information on transition.
Blank 2014[11]	Incorrect study objectives, addressing why elderly patients don't regularly attend clinic.
Burke 2018[12]	Systematic review, references individually assessed, not all looked at epilepsy, those that did have already been ordered.
Butau 1993[13]	Incorrect study design: close ended questions, no clear themes identified.
Camfield 2017[14]	Incorrect study design, conference proceedings.
Canvin 2006[15]	Incorrect objective; asking opinions on joining an epilepsy trial.
Chen 2010[16]	Included in information review, no information on transition.
Chew 2018[17]	Included in information review, no information on transition.
Chiu 2014[18]	Included in information review, no information on transition.
Chong 2016[19]	Systematic review: not all qualitative studies, already have the ones that are.
Collard 2019[20]	Systematic review, not all studies qualitative, ordered relevant ones.
Eklund, 2003[21]	Included in information review; no information on transition.
Elliot, 2005[22]	Included in information review, no information on transition.
Gauffin 2015[23]	Included in information review, no information on transition.

Reference	Reason for exclusion
Geerlings 2015[24]	Systematic review: not all qualitative studies, already have the ones that are.
Hames, 2009[25]	Incorrect study design, written accounts.
Harden 2015[27]	Included in information review, no information on transition.
Harden 2016[26]	Systematic review, not all studies qualitative, ordered relevant ones.
Heath 2016[28]	Incorrect study objective, about surgery.
Hightower, 2002[29]	Included in information review, no information on transition.
Joung 2019[30]	Included in information review; no information on transition.
Kaddumukasa 2019[31]	Included in information review, no information on transition.
Kampra 2017[32]	Included in information review, no information on transition.
Kuchenbuch 2013[33]	Incorrect study design, questionnaire.
Louik, 2017[35]	Incorrect study design, questionnaire.
MacLeod, 2009[36]	Included in information review, no information on transition.
Mc Govern 2018[37]	Incorrect study design, actual transition programme.
McAuley, 2012[38]	Incorrect study objective.
McEwan, 2004[39]	Included in information review, no information on transition.
McNelis 2007[40]	Included in information review, no information on transition.
Mengoni 2016[41]	Included in information review, no information on transition.
Miller, 2014[42]	Incorrect population, providers e.g., neurologists and doctors.
Moffat, 2009[43]	Included in information review, no information on transition.
Mu 2008[44]	Included in information review, no information on transition.
Nashef, 1998[45]	Incorrect population and study design, not all SUDEP, not qualitative data analysis.
Ninnoni 2019[47]	Included in information review, no information on transition.
Nisbet, 2017[48]	Incorrect population, neurologists and doctors.
O'Toole 2016[49]	Included in information review, no information on transition.
Pashley, 2009[50]	Included in information review, no information on transition.
Prinjha 2005[51]	Included in information review, no information on transition.
Prinjha, 2005[51]	Duplicate.
Ramachandran Nair, 2016[54]	Incorrect study comparisons.

Reference	Reason for exclusion
Ramachandrannair, 2013[53]	Included in information review, no information on transition.
RamachandranNair, 2016[52]	Included in information review, no information on transition.
Ridsdale, 2012[55]	Incorrect study objective.
Roberts, 2011[56]	Included in information review, no information on transition.
Ronen, 1999[57]	Included in information review, no information on transition.
Rushe, 2011[58]	Unavailable.
Saburi 2006[59]	Incorrect study design, survey
Sample 2006[60]	Included in information review, no information on transition.
Scheffer 2014[61]	Incorrect study design, not qualitative study.
Shih 2018[63]	Incorrect study objective, discussing people considering surgery.
Smith 2014[64]	Included in information review, no information on transition.
Snape 2009[65]	Included in information review, no information on transition.
Sonecha 2015[66]	Incorrect study objective.
Swarztrauber 2003[67]	Incorrect study objective, more about surgery.
Tanaka 2018[68]	Incorrect study population, people with mental health issues.
Thompson 2013[70]	Incorrect study design, online survey.
Thompson, 2008[69]	Included in information review, no information on transition.
Tonberg 2015[71]	Included in information review, no information on transition.
Van Naarden Braun 2006[72]	Incorrect study design, cross sectional study.
Varley, 2011[73]	Included in information review, no information on transition.
Wagner, 2009[74]	Included in information review, no information on transition.
Wallace 1999[75]	Included in information review, no information on transition.
Watkins 2006[76]	Incorrect study design, not qualitative.
Webster 2016[77]	Included in information review, no information on transition.
Weckesser 2013[78]	Systematic review, not all papers looking at epilepsy, relevant ones ordered/we have.
Westin 2018[79]	Included in information review, no information on transition.
Widnes 2012[80]	Included in information review; no information on transition
Wilde 1996[81]	Included in information review, no information on transition.
Wo 2018[82]	Included in information review, no information on transition.