

INTRODUCTION

Epilepsy is estimated to affect 3.26 per 1,000 children between the ages 0-14 in the UK (1) and 20-40% of these children also have a learning disability (LD) (2). Approximately 50% of children with early-onset epilepsy achieve long-term remission into adulthood with appropriate anti-epileptic medication (3).

Recent evidence has also shown that a third of transitioned paediatric patients to adult services obtained an improvement in seizure control (4). Factors associated with this improvement included transitioning at a younger age, one-to-one nursing appointments before transition and the ability to try newly licensed anti-epileptic medication (3, 4).

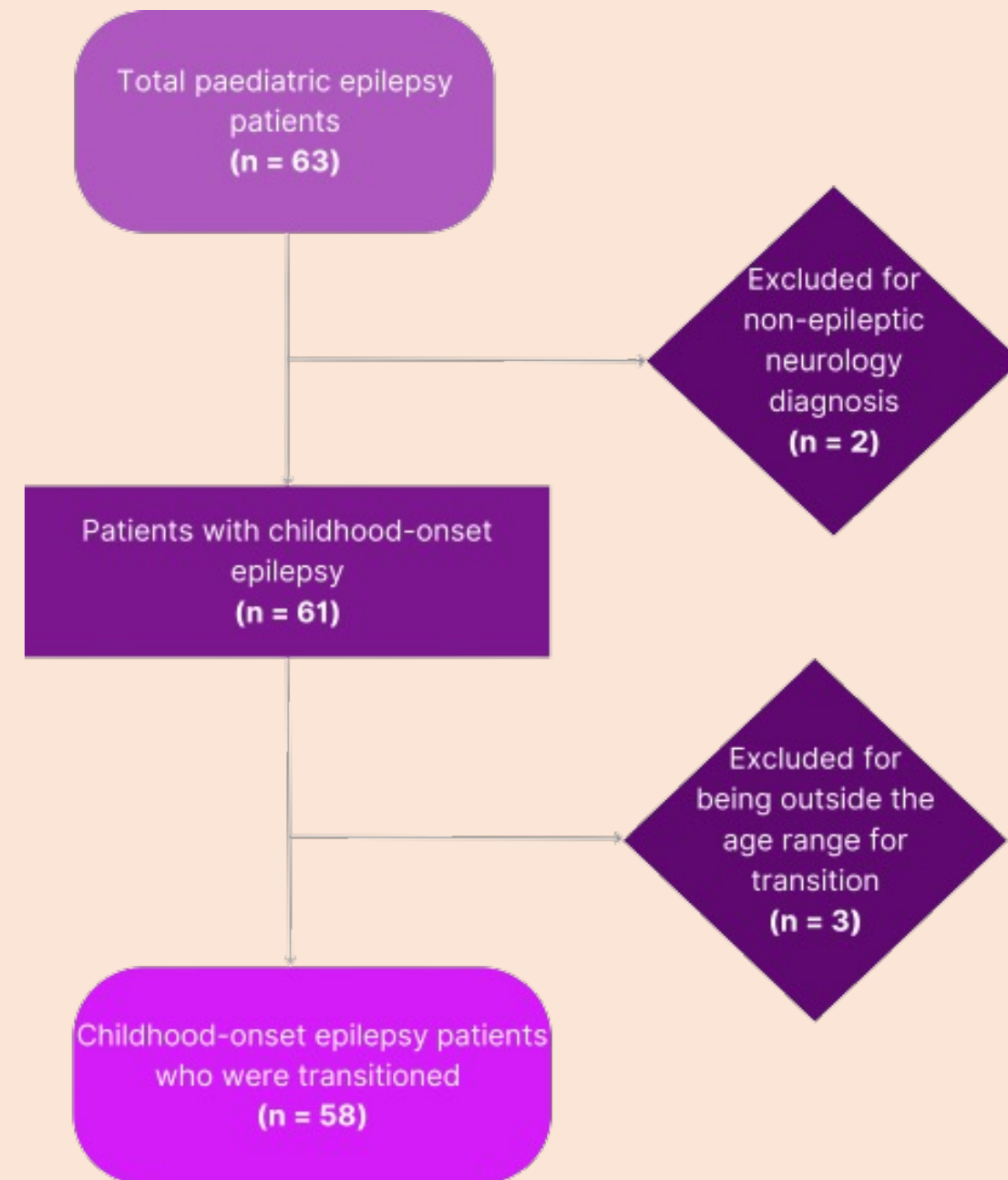
‘Transition from children’s to adult’s services’ NICE (QS140) provides a detailed outline on planning a transition (5). Whilst newer guidance ‘Epilepsies in children, young people and adults’ NICE (NG217) is epilepsy specific and adds further information on what a transition should entail, which members of the MDT should be involved and includes encouraging the young person to have more active participation in their transition (6).

AIMS

- To assess compliance with NICE guidelines (QS140 and NG217) on transition of paediatric epilepsy patients to adult Epilepsy service in Atkinson Morley Regional Neuroscience Centre.
- To assess whether the number of patients with a ‘Named’/‘Transition Worker’ has increased since the previous audit 5 years ago (2017).
- To improve the continuity of care for paediatric patients with Epilepsy.

METHODS

- Retrospectively evaluated electronic patient notes from iClip and EPR who were transitioned in the Epilepsy Transition Clinics (ETCs) at the Atkinson Morley Regional Neuroscience Centre St George's University Hospitals NHS Foundation Trust, between December 2017 and June 2023.
- Only patients booked into the ETC were included, those who were discharged prior to clinic were not.
- A total of 6 parameters were used to identify compliance with NICE guidance. This included: age at first mention of transition, what was discussed before, during and after transition, key stakeholders involved and whether the patient had a learning disability.



RESULTS

A total of 58 patients were identified, with an average age of 16 years old at time of transition. Most paediatric patients had a learning LD (figure 2) and of those only 20% were actively included in their transition.

Transition

- Planned early (before the age of 14) in 13% of LD cases and only 8% in non-LD.
- Only 29% had an Epilepsy CNS appointment before ETC to discuss transition, with even fewer (5%) having a paediatric to adult CNS referral. However, all patients had a paediatric consultant to adult consultant referral.
- All patients had a ‘Named Consultant’ to facilitate the transition.
- A high proportion of ETCs (71% and 87%, non-LD and LD respectively) had documentation of joint review of management plan and diagnosis from paediatric and adult teams, as well as, being reviewed in the MDT clinic.

Documentation

- The transition clinic proforma used to detail the young person’s epilepsy history was uploaded to iClip or EPR for 86% of patients.
- Information was discussed in an accessible format (86%). However, for 54% of patients and their parents/carers there was no evidence on electronic notes confirming that they were given the service leaflets on the transition to adult services process.

- Most patients without a LD (71%) were encouraged to build independence following their move into adult services, compared to only 23% of LD young people.
- In most cases transitions were tailored to each young person (93%).
- The ‘*Managing Transition, a Structured Interview*’ checklist was only completed in 4% of overall cases (figure 1).

Follow-up

- Seventy-four percent of patients had an annual review of their epilepsy. However, it is important to note some patients are not yet at the stage for an annual review.

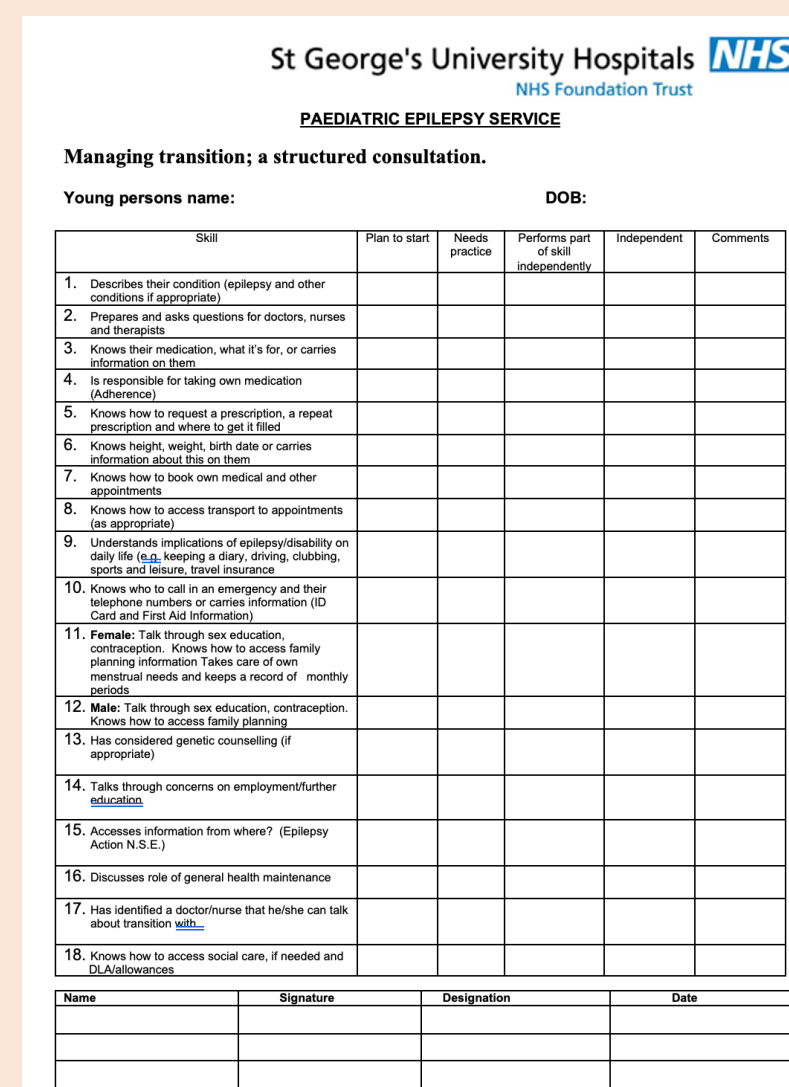


Figure 1. ‘Managing Transition, a Structured Interview’ checklist

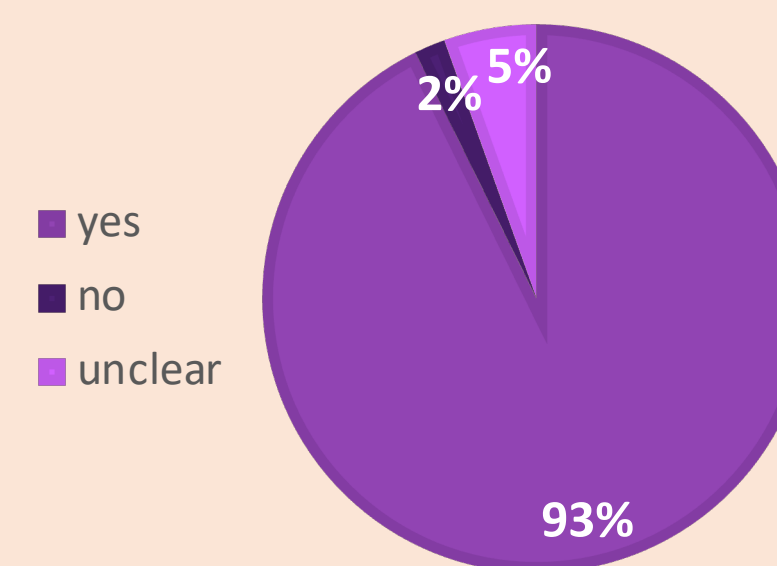


Figure 3. Pie chart indicating whether transitions were tailored for each young person

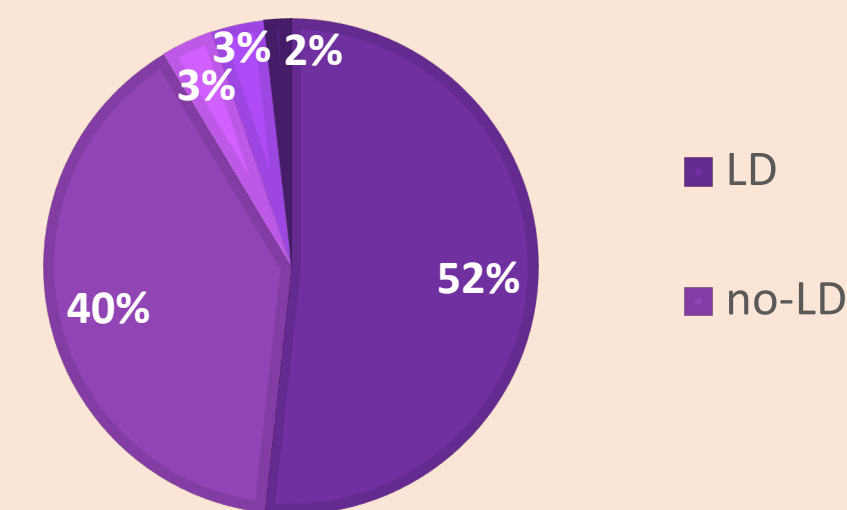


Figure 2. Pie chart showing the proportion of paediatric epilepsy patients with LD, non-LD, autism spectrum disorder (ASD), non-verbal and those where it was not clearly documented if the patient had any additional confirmed comorbidities.

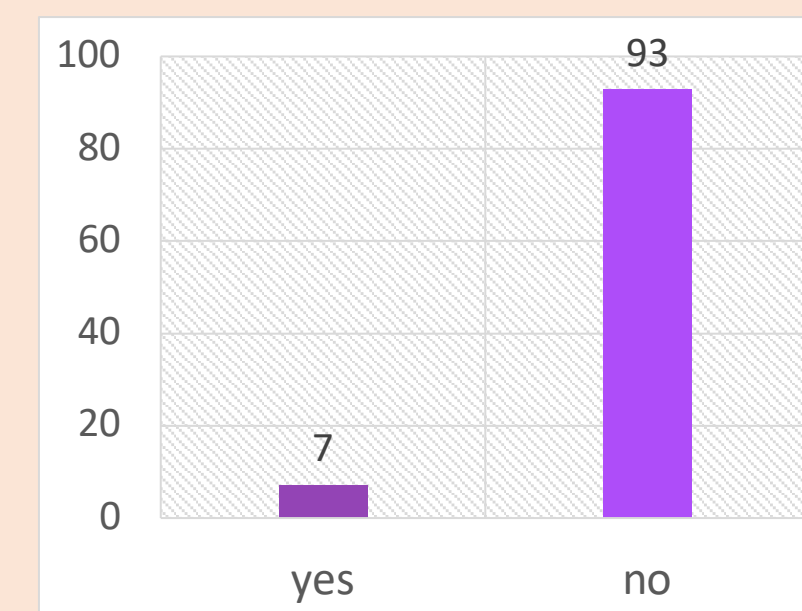


Figure 4. Bar graph highlighting the percentage of cases using the ‘Managing Transition, a Structured Interview’ checklist

DISCUSSION

Overall, evidence suggests that improvements still need to be made to meet national guidance.

- Despite the number of patients with a ‘Named Consultant’ at 100%, there is still very little evidence that patients are receiving a specific ‘Transition Worker’ which was indicated from patients in a previous audit as potentially useful.

- NICE 217 recommends appointments with an Epilepsy CNS to facilitate transition but results show that the service is falling well below the standard.

- Whilst there is good record keeping of the transition referral proforma, there was little evidence of what was discussed in the ETCs being readily available.

- ETCs should also include discussion of topics such as activities of daily living and epilepsy care as an adult. The limited use of either checklist meant it was difficult to determine how much the young person or parent/carer, especially for those with a LD, understood about what changes to their care as an adult.

- Transition planning was also started later than the guidance advises (13/14 years old) and in some cases, it was difficult to ascertain when transition planning was started but this is likely due to only using electronic records for data collection.

- Guidance also suggests that YP should be involved in their transition. More non-LD epilepsy patients were promoted to improve their independence, compared to those with a LD. However, it is understood that severe LD patients may struggle with total independence in their adult life, effort should be made to involve all patients wherever possible.

- At ETCs, information packs were given out, it appears they were not specifically tailored, instead providing generic information on topics such as driving. Which may not be suitable for each young person.

- Lastly, another identified issue was the information packs are only available in English, which raises obvious concerns for patients and their carers for whom English is a second language.

- There are some limitations to this audit. Only electronic patient keeping records were included, therefore excluding information that may be kept in paper format. In addition, patients’ views on transition were not obtained.

CONCLUSION

To improve ETCs and the care provided to patients, the following should be considered:

- ✓ Specific Transition Worker – who would work with the young person before, during and after transition to streamline transition and identify concerns.
- ✓ A pre-uploaded checklist for ETCs on iClip – allowing for faster use and increased documentation.
- ✓ Start transition earlier – this could allow for better preparedness before transition.
- ✓ Tailoring transition for those with LDs – involving them where possible in their transition and inviting social care services (if applicable) and more consistent participation of adult LD service to ETCs.
- ✓ Information packs for the adult epilepsy service handed at ETC in different languages.
- ✓ To continue to involve patients in their transition.

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