

Understanding the experiences of young people with epilepsy from communities that experience marginalisation

Scoping Review



Ann Hagell
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Introduction

Epilepsies are one of the most common significant long-term neurological conditions of childhood. Young people growing up in areas of deprivation, with co-occurring conditions or belonging to communities more likely to experience marginalisation (such as those from ethnic minority groups) may find it particularly difficult to access support. They may need targeted help to ensure they get the care they need.

This project was funded by the Royal College of Paediatrics and Child Health (RCPCH) through the Epilepsy12 National Clinical Audit. It aimed to improve understanding of the experiences of groups of children, young people and families more likely to experience marginalisation, specifically in relation to epilepsy care and management and to make recommendations for practice improvements. The aim was to improve communication with young people in these situations, and achieve better care and outcomes for them.

The focus was particularly on children and young people with epilepsy from Black and minority ethnic communities, those living in deprived areas, and also those with co-occurring neuro diverse conditions and/or learning disabilities. These groups have been identified to align with the children and young people's Core20PLUS5 health inequalities approach from NHS England as well as filling gaps in knowledge about the needs of specific groups. It is acknowledged that there are likely to be other communities experiencing marginalisation not represented within this project.

The importance of engaging directly with the young people themselves to hear their perspectives lies in evidence that this can help to make services more responsive and appropriate. Without talking with young people we may get this wrong. In one illustration, a study demonstrated a lack of fidelity between intervention programme theories and what children and young people found difficult with medication self-management and managing the effects of epilepsy. As the authors concluded, this revealed an urgent need for more innovative and individually tailored interventions to address specific challenges to epilepsy self-management as identified by children and young people themselves (Lewis et al, systematic review 2015).

A separate report from AYPH presents the findings of engagement with young people themselves, undertaken in partnership with the Race Equality Foundation, Young Epilepsy and RCPCH &Us. As background to that work we undertook this scoping review, to assess the extent of existing evidence on this issue.

In summary, our interest here is on previous work that has also sought to engage specifically with these groups of young people (rather than all young people with epilepsy) in order to improve access and outcomes. As will become obvious, we found very little indeed that achieved this.

Methods

We undertook a brief scoping of existing evidence focusing on the views of children, young people and their families on their epilepsy care and their preferences for communication with a specific emphasis on groups more likely to experience marginalisation. We undertook a series of online searches for relevant research studies, sought input from all project delivery partners and issued a call for evidence.

Epilepsy in children and young people

Epilepsies are one of the most common significant long-term neurological conditions of childhood, affecting over 100,000 children and young people in the UK. Recent estimates suggest that, in the UK, the estimated overall point prevalence for epilepsy is approximately 9 per 1000 persons (Wrigglesworth et al, 2023). Specifically, in relation to under 18s, epilepsy affects perhaps 1% of young people and is associated with neurocognitive and psychosocial comorbidities, increased risk of mortality, and poor health-related outcomes (Wagner et al, 2023). Epilepsy Action has separately estimated that there will be an average of two children with epilepsy in every primary school and nine in every secondary school (Epilepsy Action, 2023).

The condition incorporates dozens of different kinds of seizure types and causes and can be difficult to diagnose. NICE's guideline on the diagnosis and management of epilepsies estimates that in 5–30% of people diagnosed with epilepsy the diagnosis is incorrect (NICE 2022). The Joint Epilepsy Council (2011) reported that up to 40% of children referred to tertiary epilepsy clinics did not have epilepsy.

Overlap between deprivation and communities experiencing marginalisation

Against this background there is growing evidence both of overlap of epilepsy with deprivation in terms of diagnosis (and thus possible cause), but also of an association in terms of poorer access to health services and poorer health outcomes after diagnosis. It is the latter, access and health outcomes, that is of interest here.

The suggestion of an overlap with deprivation has been around for several decades (eg, Szaflarski, 2014). A 2000 study identified positive correlations between epilepsy, social deprivation and prevalence, and also inpatient admissions. Difficulties were increased by overlap with mental health problems and learning disability (Morgan et al, 2000). Similarly, Camfield et al (2016) followed 421 children with new onset epilepsy diagnosed in Nova Scotia, Canada between 1977 and 1985. Parental income, education and home ownership were noted at the time of epilepsy onset, and patients were followed for an average of 26 years. Economically deprived children had significantly more adverse social outcomes, including failure to graduate from high school, unemployment, personal poverty, inadvertent pregnancy, and psychiatric diagnoses. A 2018 report by Public Health England also found that people with epilepsy were three times more likely to die from their condition if they live in a deprived area. Seizures more often occur in children and adolescents who are socially or economically disadvantaged and have comorbid conditions, according to data published by the USA's Centre for Disease Control (Cui, 2015).

However, these data rarely relate directly to our age group of interest (children and young people), and recent studies are still concluding that health disparities in children and youth with epilepsy have been understudied (Wagner et al 2023), and that *“a suggestion of a relationship between deprivation and epilepsy [...] needs further investigation”* (Wrigglesworth et al, 2023). It is unclear from the existing research what exactly the specific structural and access barriers are that may be preventing young people with epilepsy in more deprived areas from having the same health outcomes as their peers in less deprived areas. Indeed, in the literature, inclusion and exclusion in relation to children with epilepsy often refers to their school experiences (eg, Johnson et al, 2021), not to their healthcare experiences.

Previous accounts of young people's perspectives

The issue with existing research on young people's perspectives on living with epilepsy and epilepsy services is two-fold. The first is that the samples are general, not specific to the groups we are interested in, and the second is that this work tends to be formal qualitative research, not engagement work. Overall, as Epilepsy Research UK has noted (2021), public patient involvement (PPI) programmes involving people with epilepsy have been extremely limited. Part of the problem (endemic in work on engagement work with young people in general) is that the projects that do exist are often not formally written up or published, existing perhaps only in the memories of people involved.

As a result, the number of available descriptions of patient and public involvement studies with young people with epilepsy - undertaken to improve service design and delivery - are limited. Where they exist, they tend to focus on living with epilepsy as a young person in day-to-day life, coping with epilepsy treatment and school, and transition from children's services to adult services.

There are examples of specific PPI groups set up around research projects and innovative projects, such as the MICE Study Patient and Public Involvement (PPI) Group, which consists of parents rather than young people, exploring whether treating mental health problems in children with epilepsy affects certain outcomes, such as education, health and parents' mental health. Another research example is the PPI set up around the Castle Sleep-E clinical trial, where children and young people with childhood centrotemporal spikes epilepsy and their parents/carers inform the research process (Castle Sleep-E 2022). The CHOICE study undertook a Delphi consensus-building process with children and young people to rate the importance of different outcomes in centrotemporal spikes epilepsy, which identified 39 outcomes across 10 domains that contributed toward a core outcome set for use in epilepsy research (Cruddington et al, 2019). However, these projects are not about improving or targeting services, but informing the scope of research studies.

Direct engagement around the experience of services is undertaken around the RCPCCH Epilepsy12 project, including use of a Patient Reported Experience Measure (PREM) questionnaire and through the volunteering of the [Epilepsy12 Youth Advocates](#) or through clinic chats with children and young people (eg, Healthcare Quality Improvement Partnership, 2018). However, there are very few other documented examples of what might be thought of as classic youth engagement in relation to access to services.

Young people's views are encapsulated in surveys about living with epilepsy (eg, Young Epilepsy, 2021) and particularly in research on transition from paediatric to adult services (eg, Colver et al 2019; Colver et al 2020; Lewis et al, 2013). Stigma has been a longstanding theme in research on their experiences (eg, MacLeod et al, 2003, Mayor et al, 2022), as has family support (eg, Chew et al, 2018; Epilepsy Research UK, 2020) and the need for better

information (eg, Lewis et al, 2010). Healthtalk also has a number of resources such as films of young people talking about their views of epilepsy services (Healthtalk, 2016). These are not all, strictly speaking, engagement or participation work, but provides some suggestions about what is important.

Themes emerging from these sources include:

- The importance of feeling listened to, and the likelihood that this was more often the case in paediatric care rather than after the transition to adult services.
- The role of good communication skills in talking to young people including building trust and respecting confidentiality.
- The need to talk about how epilepsy might impact on a range of life issues, including exams and driving.
- Experience of stigma and bullying, and its impact on self-esteem and confidence.
- The need to acknowledge and tackle the impact on mental health.
- The role of adequate levels of direct contact with people who could help them to manage the condition; the extent to which help with self-management could be improved.
- Problems of balancing medical appointments with everyday life.
- The preference for longer clinic appointments than those usually available, to allow more discussion.

While these messages are not specific to young people from communities more likely to experience marginalisation, they are likely to be exacerbated for these groups.

Results of the call for evidence

As part of the scoping review, we issued a call for evidence for case studies of engagement work or innovative projects seeking to learn directly from young people. We asked to hear from any services, commissioners, researchers or others who had examples of child and/or young people engagement that would help us to understand the barriers some young people with epilepsy may experience when accessing the services they need. We emphasised that we were particularly interested in children, young people and families from groups experiencing marginalisation, such as those from minority ethnic communities, living in deprived areas, with learning disabilities or neuro-diverse needs. We explained that the aim was to understand how epilepsy management and care, as well as communication with families, could be improved.

We only had five formal responses to our call for evidence. Further searching and consultation with our networks highlighted some other examples of work with young epilepsy patients on issues such as improving the service offer, but again not always projects that specifically tackled the issues faced by young people in more marginalised situations and communities. As with the existing evidence on young people’s perspectives, the examples tend to relate to young people with epilepsy in general, not specific groups.

Examples of these kinds of projects are presented in Figure 1.

Figure 1: Responses to call for evidence and further searching

Project	Description
NSS network for Children with Exceptional Healthcare Needs, National Services Scotland	A national network to support equity of health services for children with complex disabilities that often include epilepsy and additional needs. Creates educational material and information for families, carers and practitioners to support the aims of the network in collaboration with support groups and professional education organisations. Includes an Experts by Experience Group.
Epilepsy12 youth advocate programme, RCPCH & Us	Participation work with children and young people with epilepsy (Down et al, 2019)
Integrated mental health pilot project, Cambridge university Hospitals	Project to ensure inclusion of all children, young peoples and families with epilepsy from all social backgrounds including those who may be vulnerable to mental health problems due to comorbidities such as intellectual disability and autistic spectrum disorder and those who have been poorly reached by help and treatment in the past. Unclear if patient participation/engagement work is part of the programme.

<p>Patients Know Best project, Luton CCG and Luton and Dunstable Hospital</p>	<p>Empowering patients about their epilepsy control, digital access to medications and changes, improving communication with professionals. A two-year pilot delivering targeted service to the population of children with epilepsy in Luton CCG. Not specifically targeted to young people from marginalised communities; extent of direct participation or engagement work with young people unclear? https://www.hsj.co.uk/the-hsj-awards/hsj-awards-2022-using-data-to-connect-services-award/7033629.article</p>
<p>Youth Voice Network & NHS CYP Transformation Programme</p>	<p>Programme to ensure the voices of CYP with epilepsy influenced recommendations and standards set out in a national bundle of care. Activities & Engagement: CYP on Oversight Group, CYP in working groups focused on four key areas, CYP Session to review the final bundle of care. CYP Co-producing resources within the bundle of care. Delivered by Young Epilepsy and NHS England.</p>

Conclusions

Overall, the primary finding of our scoping exercise was that there is very little evidence on the voice of children and young people with epilepsy from deprived or marginalised communities in the UK being used to inform service development and delivery. This may mostly be because the work has not been done, but it may also arise from a lack of documentation and formal evidencing of engagement work that has been undertaken but not written up or published.

What we do know from existing evidence is that these groups of young people are more likely to struggle to access the services they need and more likely to have poorer health outcomes. Patient and public involvement work with young people with epilepsy is growing, and several – but not many - examples exist where young people are being directly engaged. Where this is the case, the messages emerging are similar to those from projects involving young people with other long-term conditions such as diabetes or severe obesity. This includes the importance of understanding, reduced feelings of stigma, improved staff training on working with young people. There may be particular and specific issues with epilepsy in relation to heterogeneity of the disease types and the high comorbidity with learning disability and neurodiversity, and more is needed to understand the implications for access to services from the young people’s perspectives. Overall, we need more direct evidence in order to address the questions set for this scoping review.

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For more information

For more information about the project and the analyses summarised here, email info@ayph.org.uk

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