

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

Themes from engagement work



Nick Morgan & Emma Rigby
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About the report design

A co-production workshop was held with young people to inform the design of this report. The icons focus on areas that young people prioritised in the session including the importance of information, family and peer support, the importance of the hospital environment for young people with epilepsy and finally the need for reassurance.

Executive summary

Epilepsy is one of the most common significant long-term neurological conditions of childhood and affects over 100,000 children and young people in the UK¹. Epilepsy is also one of the five clinical areas of focus in the NHS England 'Core20PLUS5'² approach to reducing health inequalities for children and young people.

The aim of this project was to hear about the experiences of managing epilepsy care from children, young people, and families from groups which may be more likely to face marginalisation. Our focus was particularly on children and young people with epilepsy from Black and minority ethnic communities, those living in deprived areas, and those with a co-occurring neuro diverse condition and/or a learning disability. These groups were identified both 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.

Findings from our [associated scoping review](#) of relevant literature highlighted that there is little published evidence from youth engagement projects on the voice of children and young people diagnosed with epilepsy, especially from communities that experienced marginalisation.

We spoke to 48 children and young people from a wide range of ages, geographical locations and a number of different communities. Their feedback highlighted ways to help engage them better in managing their epilepsy and take agency in their health care.

These included:

- **Reducing stigma and raising awareness about epilepsy:** Some young people told us that in their culture or religion epilepsy was not taken seriously. A better understanding of epilepsy in different cultures and religions would help young people feel safer.
- **Accessible tools to support young people and families to manage their complex condition:** Epilepsy is a far more complex condition than people realise. Technology needs to be simple and multiple options also need to be available to overcome barriers such as language and cost.
- **Providing young people with agency:** As well as support from parents and carers, young people with epilepsy also need opportunities for peer support and group work, particularly as they grow older, so that they can manage their own health.
- **Tailoring communication for young people:** communication styles and approaches should meet young people's needs and ensuring translation services are available is vital.
- **Managing an uncertain future –** Many of the older young people we spoke to had concerns about managing their transition into adulthood. This was especially prevalent in those who had other competing needs such as a learning disability or cultural barriers.

1 The incidence and prevalence of epilepsy in the United Kingdom 2013–2018: A retrospective cohort study of UK primary care data – Seizure – European Journal of Epilepsy (seizure-journal.com)

2 NHS England (2022) Core20PLUS5 Infographic – Children and young people

Introduction & context

This project was funded by the Royal College of Paediatrics and Child Health (RCPCH) through the Epilepsy12 Audit.

Its aim was to hear from children, young people, and families from groups that may be more likely to face marginalisation about their experiences of managing their epilepsy care and to make recommendations for practice improvements. The intention was to inform efforts to improve communication with young people and support better care and improved health outcomes, particularly for these groups facing additional barriers.

The project was led by the [Association for Young People's Health \(AYPH\)](#), working closely with the [Race Equality Foundation](#), [Young Epilepsy](#), and [RCPCH &Us](#). The project included a scoping review and participation work with young people diagnosed with epilepsy and their families.

Our partnership enabled us to reach young people and their families from groups whose voices may be missing from mainstream conversations about health and inequalities. Our focus was to hear from young people from Black and minority ethnic communities, those living in deprived areas and those with co-occurring neurodiverse conditions or learning disabilities. These groups were identified to align with the NHS England's children and young people's Core20PLUS5 health inequalities approach as well as filling gaps in knowledge about the needs of specific groups.

Methodology

The organisations involved in the project collaborated to create an appropriate methodology and questions for the engagement sessions and interviews.

Our aim was to create a methodology that would enable as broad a range of young people and families more likely to be affected by marginalisation to have their voices heard as possible. The methodology was agreed with the project oversight group established with clinical and RCPCH Epilepsy12 leads and reviewed by three young experts by experience from Young Epilepsy. This ensured an approach that was as sensitive as possible to young people's needs and informed by their experience. For example, we included guidance for facilitators on how potentially triggering some of the questions may be, particularly around Sudden Deaths in Epilepsy (SUDEP) and media stories on the possible complications surrounding pregnancy for those with epilepsy.

Engagement workshops, clinic chats (discussions arranged while attending clinic appointments) and one-to-one interviews were structured around agreed questions (listed in the box). However, the methodology allowed for flexibility in its delivery so that staff leading the sessions could make them as engaging, sensitive and safe as possible and enable young people, who may not usually engage with or be able to access this type of process, to participate. For example, Young Epilepsy staff made specific adaptations in order to run a session for young people with significant learning difficulties and RCPCH &Us staff adapted the materials to be more engaging for younger children. Each conversation was run by a facilitator with expertise in directly working with children, young people, and families from their communities/areas of focus. We were also very fortunate to have amongst our team a dual language speaker, who was able to engage in Punjabi with families and young people who spoke this as a first language. This made a significant difference to engagement in the clinic chats.

Workshops and interviews took place in-person and remotely via video calls. RCPCH &Us ran their engagement sessions in epilepsy clinics in a range of geographical locations across the UK. Transcriptions or notes were made of each of the clinic chats, group sessions, and interviews. These have been systematically analysed to extract the main themes, drawing on a simplified grounded theory method, allowing ideas and concepts to appear directly from the data. This included two members of the team separately scanning the transcripts and identifying the key themes. The themes from the sessions were then sense-checked with all the organisations and workers who undertook the engagement to ensure they reflect the conversations they had and the themes that arose in them.

Questions from the engagement methodology

1. **What** can stop children and young people from receiving effective help in managing epilepsy in their lives?
2. **Where** do you think children and young people would like to get more support from, to manage their epilepsy?
3. **Who** are the people who can best support care – what is their role (teacher, GP, youth worker) AND what skills do they have that help you?
4. **What** are the methods/ways children and young people currently use to support and look after their epilepsy?
5. **What** do you think is the most effective way to communicate with children and young people like you to support better epilepsy care?
6. **What methods** of communication are the best for you? Staff, teachers, social media, AND which social media?
7. **What** are your biggest concerns about managing your epilepsy in the long-term?
8. **What one thing** do young people say they would like to change for the next generation of children and young people who have epilepsy?
9. **Anything else** that emerged but which did not fit the framework?

Who took part?

In total, we engaged with 48 young people from all four nations of the UK. Just over half (29) of the young people identified as White British with the remaining coming from a range of ethnic backgrounds including Black, Black British, Pakistani, Bangladeshi and Mixed ethnicity. Whilst our focus was on young people, we spoke to a wide range of children and young people with the oldest being 25 years and the youngest being the family of an 11-month-old. Many younger children (we spoke to 10 children under 11 years) were supported by their parents or carers and were generally seen during the clinic chats run by RCPCH &Us. We spoke to 29 young men and 19 young women. We met with young people who identified as LGBTQ+ and young people with a diagnosis of various neurodiverse conditions. One of our sessions was run at a residential school for young people with significant learning disabilities and epilepsy.

Our aim was to speak to as diverse a group of young people as possible according to our criteria. Each project partner had a specific focus to work with their established networks. The Race Equality Foundation focused on reaching young people from ethnic minorities with epilepsy, Young Epilepsy focused on engaging with young people from across their services with a range of experience of neuro diversity and learning disability and RCPCH &Us focused on running clinic chats in areas with higher levels of deprivation and significant Black and ethnic minority populations. AYPH also contacted nationwide epilepsy organisations, such as Epilepsy Action and Epilepsy UK and other contacts from our networks, to identify young people.

Attempting to target young people with a specific experience of a health condition from a community or group more likely to experience exclusion is challenging. Significant work was undertaken by all partners to identify young people and families to work with in ways that did not increase stigmatisation or discomfort. The range of children and young people we spoke to has ensured that we have a rich set of feedback.



What young people told us

The children, young people and parents who took part shared a range of thoughts, ideas, and challenges on how those more likely to face marginalisation experience their epilepsy care. Here we have summarised some of the main themes from the engagement sessions, clinic chats and interviews.

A lack of understanding and awareness of epilepsy

Young people and parents told us their experiences had been very varied in relation to community-based information and awareness about their epilepsy, which could affect how they interacted with services. This lack of awareness was compounded by stigma about epilepsy from people more broadly, including sometimes health professionals, and the young people's own families.

I don't tell all the family because with the whole stigma and stuff.

YOUNG PERSON

Older young people and parents particularly referenced the fact that there is little awareness in the general public about epilepsy, including what to do if you are worried, which may prevent young people getting early help. Thus, as one parent suggested, this could make it difficult to support the young person;

[Other] Parents not understanding the health condition, [it's] very hard to explain to others as her condition can vary. [There's] Mixed / different symptoms. Parents / school not always sure due to condition does not speak so can't say how she is feeling.

PARENT

In addition, some young people also suggested that they felt there may be a lack of knowledge amongst professionals of the complexity and variety of types of epilepsy in everyone, which could lead to disengagement from families and young people.

It's really hard to get support as not [had] enough education, missed out on trips as no one to go with him, [there's a] lack of awareness and support for children and young people and families.

PARENT

Many conversations focused on young people's experiences in schools, where they wished their peers and teachers had better education and awareness of epilepsy. There were some splendid examples of specialist nurses going into schools with the young person's permission to do some training with a group of teachers, but this was rarely the case. Although this is beyond the reach of some clinical teams, understanding the context can help to build trust with young people.

Our participation staff reflected that there were some specific challenges in relation to information and awareness in different cultures. There were different levels of stigma about epilepsy in different cultures highlighted in the conversations and interactions they had. For example, some of the words used in epilepsy care do not have a direct translation in different languages and this, together with the use of jargon, can lead to increased stigma and fear in different religious and community cultures. As one young person shared;

But the wider community – I was speaking last week or when I was with the teams call and I was speaking about how the society was like they're uneducated, ... they won't care about the condition. They would just come up with some rubbish, like some of them say you're possessed with the devil if you've got epilepsy, and so I don't tell the wider community.

YOUNG PERSON

When reflecting on what they would like to change for other young people, those involved spoke about the need for age appropriate, relevant and correct information that was shared more effectively. The importance of staff who can speak community languages was also highlighted by the project team's experience of delivering the work with the assistance of a multiple-language speaker.

Getting the right information [is important]. If I've got the right information sooner than later, then maybe I would have lowered expectations, maybe I wouldn't have gone disappointed.

YOUNG PERSON

The challenges of managing a complex condition

Epilepsy is a complex condition, which can be challenging to manage and can be unpredictable. As one young person said;

I was lucky in terms of my seizures and the pattern, but a large part is that it is so random. I can go four years, I had a burst of them, then four years and nothing happened – didn't change my routine or get into a situation and then boom another one happens, it's a very random condition.

YOUNG PERSON

It was important to young people that managing their epilepsy was, as much as possible, an unintrusive part of their lives. This meant getting more support in schools, universities, the community and at home. Some young people talked about how helpful some youth workers or mental health professionals were for their epilepsy, helping

I think what would prevent getting good health care is not having a care plan at school or college and others not understanding what you go through

YOUNG PERSON

them navigate and manage triggers, especially if seizures were caused by certain activities or by anxiety, or other mental health needs. Again, understanding this broad context of young people's experiences in the community is important for engaging with them in health services;

Having a routine and keeping track were also mentioned a lot in our conversations as being beneficial to young people's epilepsy. This included, for example, having reminders to take medication at the same time each day, tracking seizures to try and notice patterns and ensuring they got to bed at a regular time. Making plans if they knew they might be having a later night than normal was also important.

It is worth noting that for young people living, for example, in areas of high deprivation, living in cramped accommodation or with parents stressed by other pressures, keeping routines and tracking may be particularly difficult.

Many young people, particularly in the older age range, mentioned the use of phone apps and websites to help them monitor these elements of their lives. As well as tracking, young people found these spaces useful for finding out further information about epilepsy and how best to manage it.

The usefulness of an all-purpose phone app was talked about a lot. As one young person shared, "I keep a track of the seizures I have by using apps". It was clear that some do exist, but there was definitely a sense that the young people had to do a lot of research about these themselves and would prefer to be simply recommended an NHS, youth friendly, purpose built app, that had everything they needed in one place and they knew they could rely on the information.

I wasn't used to taking medication as a xx-year-old, so remembering it's taken on time and keeping on track of that was really difficult

YOUNG PERSON

I have never used epilepsy apps to help manage my epilepsy, I just use google drive, – I would say when I had one [seizure] and where I was.

YOUNG PERSON

I used to share them with my neurologist because they would always ask when was your first and last seizure, this helped when I was changing medications because it helped see what was working.


YOUNG PERSON

A few young people also talked about how this could be a two-way app, that their clinical team could have access to, and they could talk about in appointments. Again, access to the kind of support needed to find and use these kinds of apps may be more challenging for those in some of the communities we spoke to, where access to devices may be more limited.



How parents, carers, peers and communities are involved in care and support

Many young people we spoke to highlighted the support they got from their parent/carers. Family support was important in supporting young people to learn about their condition, manage their medication, recognise their triggers and manage at school.




Yeah. In fact, my parents are very supportive. And they understand my situation. Sometimes I'm in my room, and I get very upset. 'Oh my god, like, why? Why do I have seizures?' That's what sometimes I feel like, but then my parents be like, 'No don't worry, don't stress. Some people don't have the ability what you have.' So they do support me and this is very nice of them, basically.

YOUNG PERSON

Faith and faith organisations were also highlighted by some young people as being important for them in terms of support.


The importance of connecting in person with peers came up several times, as well as online forums and communities. The need for more group and peer to peer opportunities was highlighted by some young people, including both online and in person peer support groups. In general, this is a finding common to the adolescent and early adult age group, for whom peers are particularly important.

Participation staff reflected on the fact that sometimes there could be an over-reliance on families and parents by the health system because of the complexity of the condition and that there was a need to focus on building young people's agency. In some cases, diagnosis could lead to young people losing a sense of 'self' and seeming younger and less able to be independent. The sessions with young people with learning disabilities and neuro diverse conditions highlighted that young people often felt invisible as professionals communicated straight away and only with their parents, when in fact – with skill and support – the young people may have been very able to communicate their own needs too. As one said,



My faith has really, really helped me.

YOUNG PERSON



I get a lot of support from epilepsy Facebook groups – they're great because they give that support that no one else can because they all have epilepsy, so they can empathise like no one else can.

YOUNG PERSON



They speak to my parents rather than me even though I understand.

YOUNG PERSON


During the group workshops, there was a definite sense of comradeship amongst the young people, which in turn enabled them to be better engaged and more open about their experiences. Even in one-to-one interviews, many young people referenced a positive experience when they had done something with a group, or even just meeting someone else around their age with epilepsy.

However, some young people faced barriers to peer to peer and group work. One young person had difficulties engaging due to cultural beliefs in the family and another spoke of things seeming 'behind' where he lived, after engaging with young people from other areas of the UK. Understanding the importance of peer support, and enabling this within the health service context, may be particularly important for some young people from more marginalised communities.

Effective communication

Several young people we spoke to shared experiences of not being heard and suggested that communication could be unpredictable and unreliable. Some notable examples of effective communication were also shared, for example, a young person being able to phone, or 'WhatsApp' their nurse for advice. Overall young people highlighted the need for clear, structured communication with them and within healthcare teams.

For families where English is not spoken there were clear additional barriers to communication. In addition, the management of much of the care using technology could be a barrier with a lack of resources adding to inequalities – for example if families did not have a smart phone.



Friend group support is the most important because I feel like when I was a kid I didn't really care much about doctors or like even the school staff or anything helping me out.

YOUNG PERSON

What would be good, would be meeting up with people. Not just sitting down and talking but going for a walk or something with other young people with epilepsy.

YOUNG PERSON



I ask the doctor questions.

It's best when the doctor uses simple words that are easy to understand.

YOUNG PERSON



It would need to have words and pictures to help me understand.

YOUNG PERSON


...like I said the best way to communicate with me is face to face, [my] neurologist breaks things down for me explains everything really clearly he takes something complex makes it easy to understand.

YOUNG PERSON

Young people spoke about the importance of communication that was tailored to their specific needs.


Different young people have different preferences in terms of mode of communication, including face to face discussions, one to one sessions, online videos, texts, phone calls etc. but the importance of communicating regularly with the same person was highlighted, such as with a key worker for example. And overall, respect in communication was central.

Social media and YouTube were mentioned, with videos and animations being key ways to engage young people. Young people mentioned that it would be great to see information about epilepsy mixed in with other things they were interested in, again adding to the 'normalising' of epilepsy:



it's important for staff to have good communication techniques when speaking to young people – they need to be very open, and kind get down to their level and talk with respect.

YOUNG PERSON




I like following good social media accounts on Instagram, Facebook and TikTok. There's lots of young people that put information out there but there's also people training to become nurses and neurologists.

YOUNG PERSON

Age appropriateness came up quite a lot throughout our conversations. We heard experiences of age-inappropriate material being given and how this contributes to cutting off engagement from a young person. For example, having two types of information – one for the under 5's and then one for all other young people of all the remaining ages was not felt to be sufficient.

Although this is not specific to young people from communities experiencing marginalisation, ensuring the information they get is in a form that speaks directly to them is a key way of ensuring they can be engaged despite other barriers.



When I got info I was 12 at the children's hospital, and they gave you all the information, but I was 12 getting a book for a 5-year-old so you are getting all the adult stuff and all the children's stuff but nothing for teenagers.

YOUNG PERSON

Managing an uncertain future

Adolescents said that they would like to also be given more information on a regular basis about their future with epilepsy. Several young people talked about how they were worried about living on their own or being able to drive and that understanding this earlier in their life, and setting realistic expectations, would be helpful to managing it as they got closer to those times in their lives. This is both a practical and an emotional issue:

I don't know, I'm just worried, like, obviously, it's gonna be forever with me in my life. And I'll just have to be very positive and be like, there are other people who are going through more problems. So it's not just me and like, thinking positive. Yeah.

YOUNG PERSON

Young people shared lots of thoughts about their future, from having children, to driving, to fears of Sudden Unexpected Death in Epilepsy, to living alone and coping with stress. Although young people mostly talked quite positively about how they manage their epilepsy, it did not deter from the fact that they did not know what the future held for them, which caused great anxiety.

To me the biggest worry is just about living on my own. I'm obviously with my girlfriend now but if we split up or something happened, I'd have to live with my mum and dad until they're really old and then I'll be out by myself. I won't be able to live on my own with this I am having to get Ubers and it takes away your independence.

YOUNG PERSON

Young people facing barriers to accessing regular support services because of their life situation, such as those living in some of the communities we spoke to, may find it particularly hard to get this kind of support and advice from those around them at the time they need it.



Other themes and reflections

In addition to the themes identified above, some other specific issues were raised. For example, challenges in relation to diagnosis were raised by some young people who reported there had seemed to be a reluctance to diagnose.

Epilepsy may be particularly hard to diagnose, especially in situations where there are co-occurring and complicated conditions existing at the same time. However, finding ways to support young people through this process is important if they are to establish trusting relationships with services that will be critical to their longer-term management of the condition after diagnosis.

Finally, it was clear when having these conversations and discerning the themes that adaptations to ways of working or ways of communication with young people should be co-produced with young people for them to be truly relevant to young people and their peers. Through the engagement work conducted, everyone involved offered ways and means of improving their service. Incorporating young people's perspectives into service development undoubtedly makes the offer more age and situation appropriate.

It took so long for them to diagnose me with epilepsy – I was having all of the symptoms and for ages they diagnosed me with anxiety migraines. It wasn't until [!] actually had a seizure in front of them that they believed me and that she apologised to my parents.

YOUNG PERSON



Conclusion

Epilepsy is a complex condition that young people need considerable support to manage. For certain groups of young people this is made more challenging because of language barriers, a lack of understanding from their communities and schools, fear and stigma or because of the other health conditions and social challenges that they must manage alongside their epilepsy.

Many of the things young people highlighted are also highlighted in general principles for youth friendly services, such as the NICE guidelines for babies, children and young people's experience of healthcare³, and the newly revised You're Welcome criteria for youth friendly health care⁴. These both stress the importance of youth friendly communication and clear processes for transition as young people get older. However, due to the complexity of epilepsy there is an amplification of these issues for young people and the provision of information, technology and tools tailored specifically to their needs relevant for the communities they come from is vital to getting care and support right.

Furthermore, a focus on supporting young people's agency and rights as they grow older is particularly important. This can be done together with families, but – particularly for adolescents – enabling and supporting engagement with peers in a similar situation may be especially important. For example, the work of young representatives and advocates working with Young Epilepsy and other charities could support more effective engagement with young people moving forward.

4 NICE (2021) *Babies, children and young people's experiences of healthcare* NICE guideline NG204

5 OHID (2023) *'You're Welcome': Establishing youth-friendly health and care services*

Recommendations from young people

The young people we spoke to suggested how the epilepsy care offered to them could be improved to help reduce access barriers to services and they explained what they saw as ideal changes for services in the coming years. These included:

1

Improve the range of information for different ages, young people from different communities and with different needs.

Information needs to be created specifically with young people in mind and co-designed with young people to ensure it meets young people's needs. It should be in a range of formats to provide choice and help accessibility.

"I think videos are the best way to communicate, when people are talking to me, I find it quite hard to take in, so a video is a better way to get that information across" "I really like some of the animated videos that Young Epilepsy have made"

YOUNG PERSON

2

Increase opportunities for young people with epilepsy to work with their peers and help co-produce solutions.

An increased range of ways for young people to be involved in improving the care and the information they receive is vital to improving care. This must include opportunities for young people with neuro diverse conditions and or learning disabilities.

Focusing on building relationships with voluntary, community and faith organisations in the area who can support engagement work with groups that health services will not be able to easily reach is really important.

"Other young people with epilepsy can be really supportive it's really important that young people with epilepsy have the chance to meet with each other and support each other"

YOUNG PERSON

3

Introduce stigma busting and awareness training in communities and schools.

Community groups, teachers, schools, colleges and universities need to be more aware about epilepsy to reduce stigma and help young people not feel singled out. Training with community groups and in schools and colleges, as well as epilepsy peer advocates speaking out, should help 'normalise' epilepsy and help young people feel more comfortable talking about it with their peers.

"I get a lot of stigma from the ... community and it does annoy me a lot, out of 100 people in that community I would only tell 20 people about my epilepsy."

YOUNG PERSON

4

Increase availability of accessible and simple technology.

Staff need to be aware of the barriers some young people and families face to accessing technology and provide support and a range of options to enable families to manage epilepsy well. Staff training on how health inequalities impact young people specifically would help build awareness of the kinds of issues young people face when accessing technology and services more generally. Lessons from other areas focusing on poverty proofing services would also be useful.

"On the phone [it] goes in one ear and out the other, [maybe better] a letter that explains everything so you can look at it again and take everything in."

YOUNG PERSON

About the organisations undertaking this work

The Association for Young People's Health

AYPH is the leading independent voice for young people's health in the UK. To find out more about our work visit ayph.org.uk.



The Race Equality Foundation

The Race Equality Foundation seeks to explore discrimination and disadvantages and use that knowledge to help overcome barriers and promote race equality in health, housing, and social care.



RCPCH &Us

RCPCH &Us is the voice of children, young people, parents, and carers for the Royal College of Paediatrics and Child Health, created to actively seek and share their views to influence and shape policy and practice.



Young Epilepsy

Young Epilepsy is a charity that campaigns for children's rights. They deliver health services and research that improves diagnosis and treatments. They also support children and young people with epilepsy providing information, advice and practical help. Young Epilepsy runs the youth voice network which is a community network that engages in participation and co-production activities.

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