Epilepsy Care at the transition from child to adult services

Engagement report

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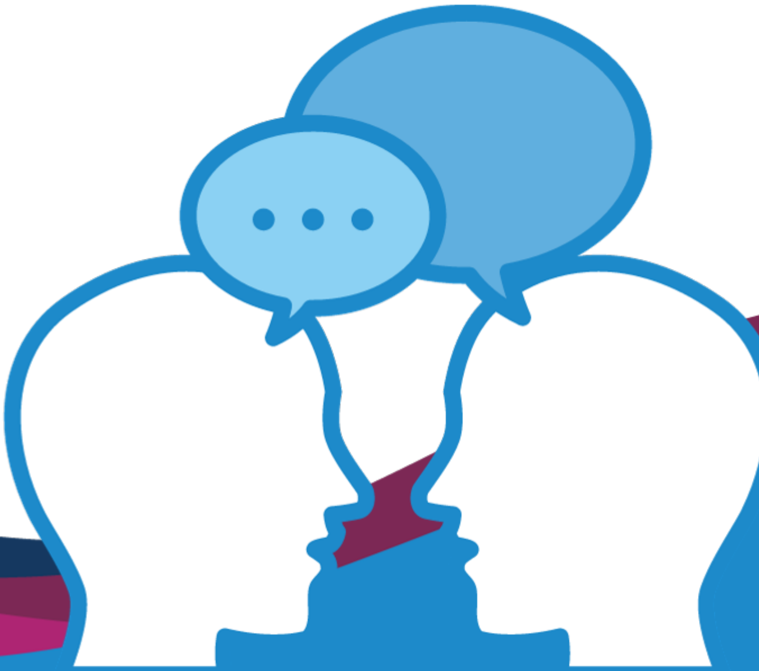
NHS Lancashire and South Cumbria ICB
communications and engagement team
lscicb.communications@nhs.net



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Acknowledgements

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Introduction

Epilepsy is among the most prevalent long-term conditions affecting children and young people in the UK. Historically, however, epilepsy services have not consistently received the level of input, attention or resources that this may indicate. NHS England 2022 formally recognised Paediatric epilepsy as a priority clinical area within the CYP Core20PLUS5 framework, bringing a significant national focus to epilepsy care for children and young people in England.

In 2023, NHS England published a national bundle of care outlining the expected standards for four key priorities of epilepsy care for children and young people, aligning closely with NICE guidance. One of the primary focus areas within this framework is the transition from paediatric to adult epilepsy services.

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Preparing for transition should begin at the latest when a young person is aged 13 or 14, although this depends upon the age a young person is when they are diagnosed. If after age 14, preparing for transition should begin immediately. This indicates the importance of transition, as young people can be preparing to transfer for up to four years or more.

Young person transition (to adult services) * clinics are already provided across much of Lancashire and South Cumbria by Paediatric Epilepsy Specialist Nurses. These usually take place about once a month, where between 4 and 8 patients will be seen by the Epilepsy Specialist Nurses. The frequency of clinic visits for young people in transition, according to the bundle of care, should be tailored to their individual needs. Each clinic provided the opportunity to engage a new group of young people.

* Throughout the report the term transition clinic is used to refer to young person transition to adult services clinics.

Executive summary

Over a six-month period, young people with epilepsy and their parents or carers currently attending epilepsy transition clinics were asked to provide their feedback, thoughts and concerns about the transition to adult epilepsy services. Although many expressed an interest in getting involved, only 16 people completed the detailed survey. Over a third (37.5%) of these were the young epilepsy patients themselves.

The feedback received identified that the paediatric epilepsy services was a good or excellent service which helped control or stabilise seizures, was professional and informative, where patients and families could speak to someone and have concerns addressed promptly. They helped young people feel they could accomplish things, despite their epilepsy.

Both young people and their parents had worries or fears about the transfer to adult epilepsy services that included if they would be seen regularly, having no-one to call, or having no support or help going forward, either directly or via advocates. Concerns were also about a lack of appointments, long waiting times and a lack of consistency of staff. Perhaps most important of all, young people had concerns about having to be independent, make their own appointments, to live with their epilepsy as an adult, when they may not feel ready for it.

Feedback on the type of information that was important to them at transition clinics included information about independent living and access to health and health professionals, followed by obtaining and accessing support, safety and employment opportunities.

The feedback also indicated that, ideally, transition clinics should be in the afternoon or evening, in hospital or in the community, and face-to-face. Appointments would ideally be made by text or post. However, this would not necessarily suit all, and some flexibility of arrangements ought to be considered.

Respondents were asked to consider the information they would like to receive prior to and after transition clinics. Before clinics the feedback was relatively standard and included the date, time and location of appointments, how long they will last, who they will see, their purpose, contact details and appointment reminders. After clinics the information requested was more variable and included contact details of professional staff (for help and support), what ongoing support was available, including information about support groups, information on seizure control and medication and a recap on what was discussed.

Lastly, feedback was requested about what would be useful prior to the move to adult clinics and having contact details for professional staff was mentioned again in this context. Other useful information included the difference between paediatric and adult clinics, what would be expected, how to book appointments, where they will go and whether parents could still attend.

Some recommendations were made, requesting both paediatric and adult epilepsy services ensure the worries and concerns expressed in this report are addressed and that the information identified is made available where this is not already in place.

What have we been talking to people about and why?

NHS Lancashire and South Cumbria Integrated Care Board (LSC ICB) wanted to understand the experiences and needs of young people aged 14 and above, and their parents or carers, so that any improvements to the transition of care could be identified and implemented. This in turn, would help the ICB meet the bundle of care introduced by NHS England.

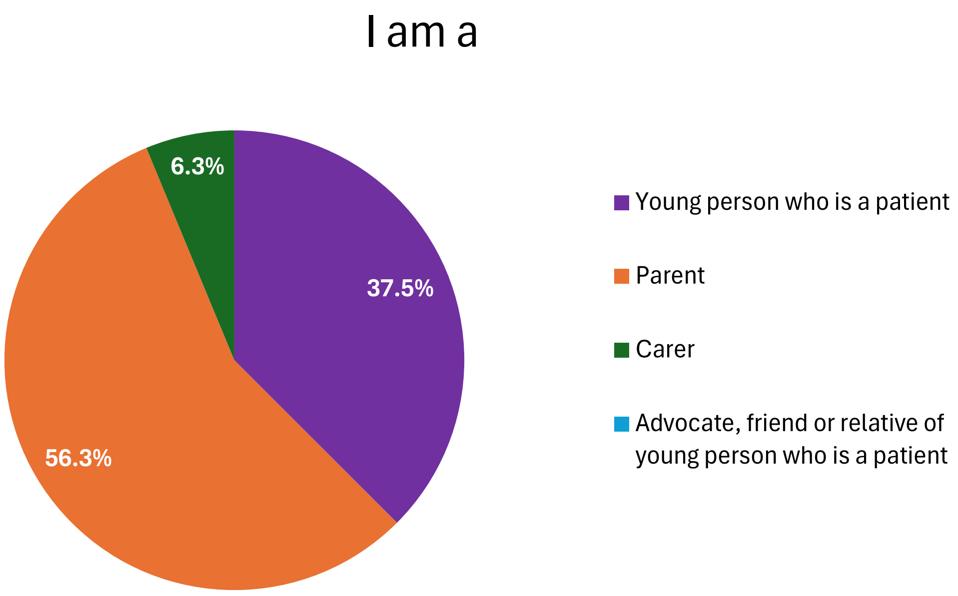
It is important to listen to young people, and their parents and carers, if the transition clinics are to be as valuable as possible to the people living with this condition and their families. The primary method of engagement was through existing epilepsy transition clinics, which involved liaising with the Epilepsy Transition Nurses, each provider Trust and children and young people service commissioners at the ICB. All participants were given a detailed survey to complete.

The feedback from the patient engagement exercise will be used to support the development of the transition clinics, ensuring as far as possible that they meet the needs of young people with epilepsy and provide the level of service that parents and carers would wish to see.

Who have we heard from?

The number of young people with epilepsy going through transition is comparatively small. 60 young patients were seen by the Lead Paediatric Epilepsy Nurse of the ICB and/or the Engagement Officer during a sixth month period, from December 2024 to May 2025, with at least one of their parents/carers. Over 90% of these indicated they were willing to participate in the engagement process and were provided with the materials to do so. Unfortunately, this willingness to participate did not often materialise into full participation and completion of the survey.

Despite additional prompts and reminders, only 16 individuals completed the survey. While this number may initially seem modest, it represents approximately 13.4% of the overall cohort approached—including parents and carers—which aligns with typical response rates for surveys of this nature. Notably, 37.5% of respondents were young people with epilepsy, as detailed below.



How did we speak to people?

A targeted approach was undertaken, reaching out to young people with epilepsy, and their parents or carers, through the epilepsy transition clinics already taking place across the region. In this way, it would be possible to gather the thoughts and ideas of those currently going through the process, at whichever stage they were experiencing.

Prior to the engagement a detailed survey was developed, building on the Youth Experiences in Epilepsy Care | 2021 Findings | Report, together with information for parents/carers and patients. This included an Easy Read leaflet, developed by the

ICBs Communications and Engagement Team, which explained why the engagement was being undertaken and what it hoped to achieve.

The Roald Dahl Epilepsy Specialist Nurses (ESN) working within each Provider Trust were approached for their agreement to participate in the co-production exercise. Once attendance at the transition clinics was agreed, the ESN's asked each young person and parent/carer attending the clinic whether they agreed to see the ICB's representatives (the Lead Paediatric Roald Dahl Epilepsy Specialist Nurse and/or one of the engagement team) following their appointment. As mentioned above, over 90% agreed to do so.

Most discussions with young people and their parents were conducted face-to-face, although a few were over the telephone or by Teams, depending on how the family had chosen to attend the transition clinic. At these discussions the reason for the engagement was explained and the materials (information, Easy Read and survey) shared.

Due to family commitments, other appointments, and the time already given to attend the clinics, families were not expected to complete the survey or enter in-depth conversations during the face-to-face discussion. Where families indicated they were willing to participate, further consent was needed from both young people and their parents, so that all the materials could be sent to them electronically. This would provide families with a range of options on how to complete the survey - online, via QR code or a paper copy. It would also give them more time to consider their responses.

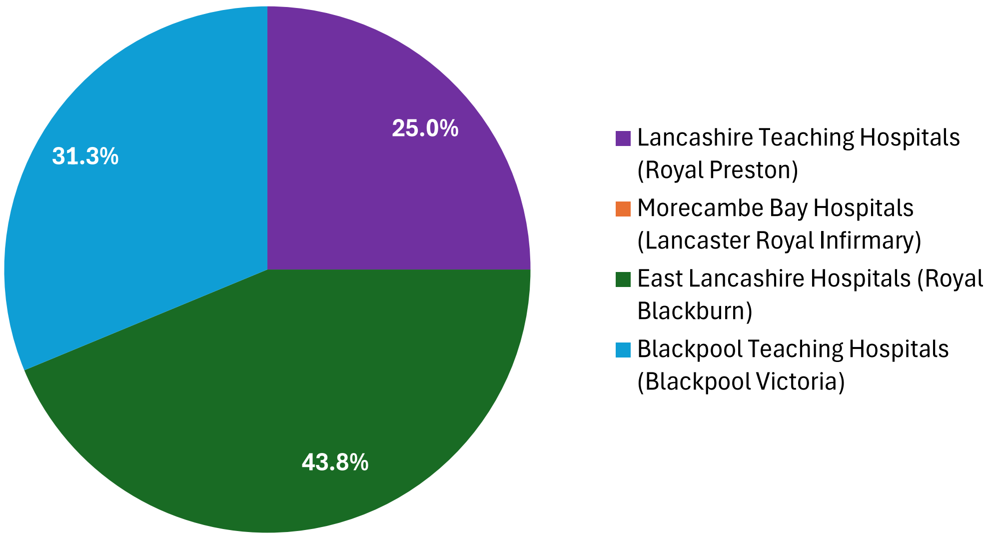
It was made clear to young people with epilepsy that they could submit their responses alone or involve their parents or carers. The choice was theirs. Parents and carers were also asked to complete the survey separately.

The targeted engagement did not provide the level of response it was hoped for. As a result, the exercise was promoted more widely through GP Practices in May, requesting them to reach out to epilepsy patients on their lists within the age bracket identified. It is unclear whether this generated any additional responses, as face-to-face clinics continued during this period.

What did we hear?

In order to effectively analyse feedback from the survey, responses to qualitative questions, where respondents are given a free text box to say what they wish, may be grouped into themes. Direct quotes from respondents are used to help illustrate themes and demonstrate the thoughts of real people engaging with these services. Percentages are rounded to the nearest whole number.

Which epilepsy service do you use?

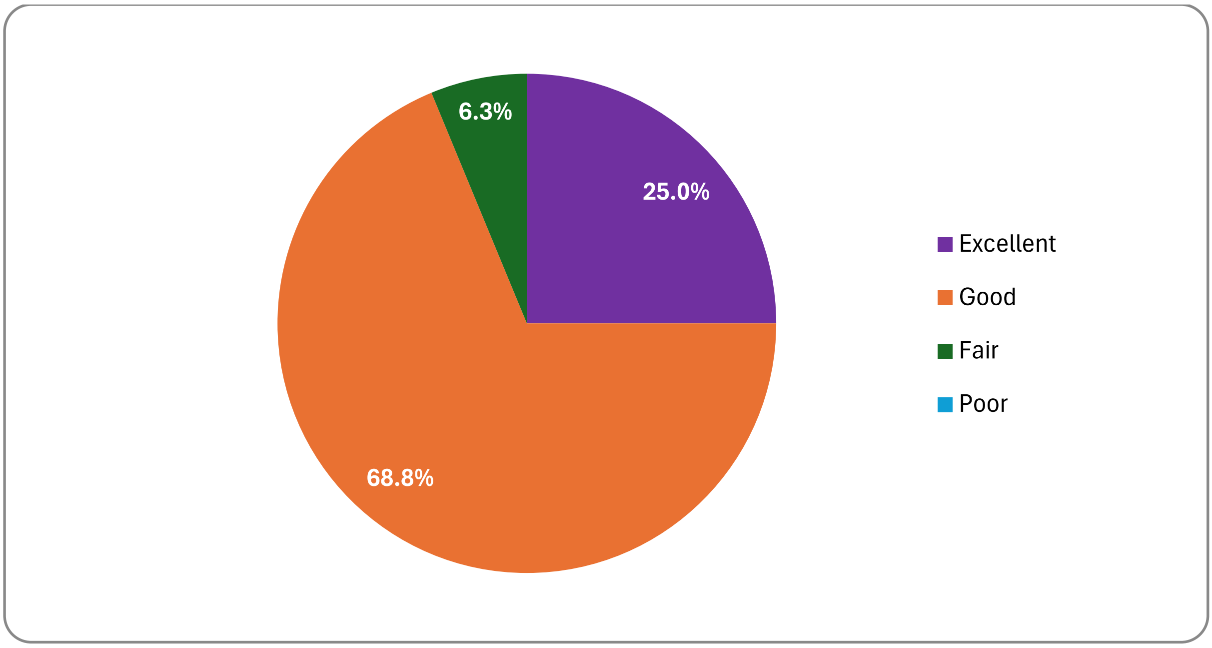


There was a reasonable spread of responses from across the hospital Trusts in which the children and young people’s epilepsy service is provided. Close to a half of the respondents used the service at East Lancashire Hospitals.

There were no responses from anyone attending Morecambe Bay Hospitals, although it should be noted that the Epilepsy Specialist Nurse is a relatively new post at the Trust. The nurse will be working to introduce transition (to adult services) clinics. This may be reflected in the current lack of responses.

How has your epilepsy care been so far?

The chart below indicates that almost all respondents, whether young people or their parents, were almost universal in saying the epilepsy care provided was excellent or good. It cannot be said that this truly reflects the service as a whole, due to the relatively small number of respondents, but it can be taken as a strong indication that this is the case. There is an argument that those approached who choose not to respond would have done so if they were unhappy or had concerns, but this remains conjecture and is not proven. Nevertheless, it is reasonable to consider that the paediatric epilepsy services are providing a valued service.



Respondents were asked to give their reasons for the answers they gave above, and all but one did so.

A few themes that could be identified within the responses given, but there were also several different elements to the reasons the service was considered a good one by most respondents. The reasons given were:

- Seizures – a third of respondents referred to seizures, with most feeling these were under control, had improved or stabilised – “I’ve not had a seizure in 5 years”
- Medication – a quarter of respondents mentioned the medication, half of whom mentioned it positively, and half negatively:
  “I explain symptoms to epilepsy team and the team reassure and most of the time change the dose of medications.”
  “The only problem I had was not being informed about side effects from my previous medication.”
- It was a professional and informative service
  “Brilliant consultant who listens and advises with care and sensitivity.”
- Able to speak to someone if needed
- Concerns were acted on promptly and efficiently
- Appointments were regular.
- It was a friendly service
- Gave advice on what can or can’t be done (by the epilepsy patients)
- Try their best to understand and support children.

The main difference between the parent feedback and that of the young people with epilepsy was that the young people themselves tended to focus more on what they could accomplish or achieve as a result of the support from the epilepsy service, as the quotes below indicate.

“I have had many opportunities to show what I can do despite having epilepsy!”

"The team…give me information to help me. They give me advice on what I can or can't do."

A few of those with a positive experience referred to some issues that were not as good. These were:

- Letters between epilepsy team and GP being received can make repeat prescriptions hard
- There are not enough nurses, "please help them as it isn't fair."

What are your worries or fears about the move from children to adult epilepsy services?

Respondents were asked what their worries or fears were around the move to adult services. Everyone gave feedback to this question, and although a quarter said they had no worries, the remaining three quarters gave a wide range of concerns about the transfer to adult epilepsy services. These included:

- Want the transfer to be smooth and not stressful
- They might not have anyone to call if they have a seizure
- Hope they receive the same level of care and attention
- Concern about having to be independent and arrange their own appointments
- Making sure there is someone in adult services who understands those with special needs/poor understanding of learning disability
- That no-one will advocate for them
- That there will be no-one to help in adult service – it will be just a phone call rather than seeing a doctor
- There won't be a consistency of staff
- That they will be just a "statistical number accessing a service"
- That they won't be seen regularly/there will be a lack of appointments and long waiting times
- Waiting in an adult setting waiting areas

Several of the concerns expressed above relate to the potential lack of support available or 'allowed' in adult services, whether that be the support from family members, or from within the service itself. For some respondents, there seems to be an expectation that people will go from having support as needed on one day, then not having that support available the next. There was also concern expressed for young people with additional needs or conditions, including where "my son struggles with changes." To allay these concerns, adult epilepsy services would need to be sensitive to the needs of the young people transferring from paediatric services.

What information do you need to feel happy about the transition from children to adult epilepsy care?

Respondents were asked what information they needed to feel happy about the transition to adult care. Nine categories of information were offered. All respondents answered this question.

			Response Percent	Response Total
1	Safety		81.25%	13
2	Independent living		43.75%	7
3	Education opportunities		31.25%	5
4	Employment opportunities		31.25%	5
5	Access to health and health care professionals		68.75%	11
6	Drugs and alcohol		6.25%	1
7	Sex and contraception		18.75%	3
8	Driving		25.00%	4
9	Obtaining and accessing support		56.25%	9

Safety (81%) and access to health and health care professionals (69%) were to the two areas of information that most respondents chose. Obtaining and accessing support was the next highest, and these were the only categories chosen by more than half of respondents. Independent living was the fourth highest on the list, with a little under half of respondents choosing this category. These four top categories of information correspond to some degree with the concerns expressed in the previous question.

Further analysis identified that the young people responding considered independent living and access to health and health professionals the two highest categories of information, followed by obtaining and accessing support, safety and employment opportunities.

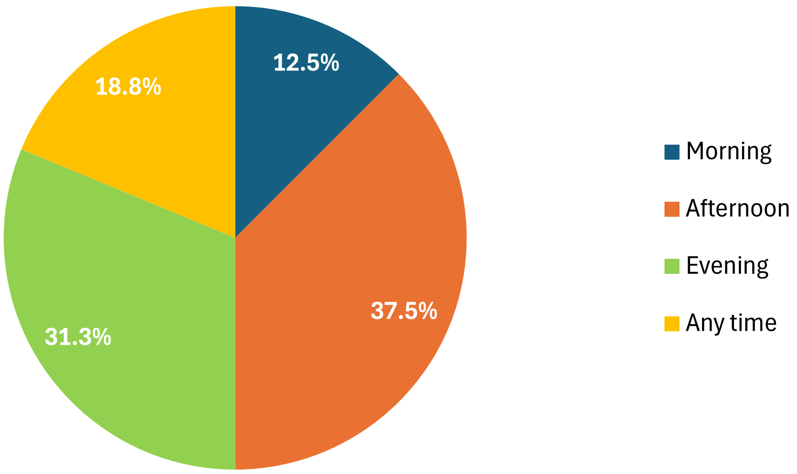
Respondents were then asked whether there was any information they thought would be helpful that had not been mentioned. Most respondents answered no, skipped the question or reiterated one of the categories already mentioned (safety, accessing support/having someone to talk to).

There were however, a few additional points of note. One young person was concerned with what happens when they end up going to hospital, which maybe another reflection of the idea that, once an adult, they are on their own. They would like more information about this to support the transfer to adult services.

There was a plea for people to be given a greater understanding of epilepsy so that they do not make inappropriate judgments and would know, for example, not to disturb an epilepsy dog.

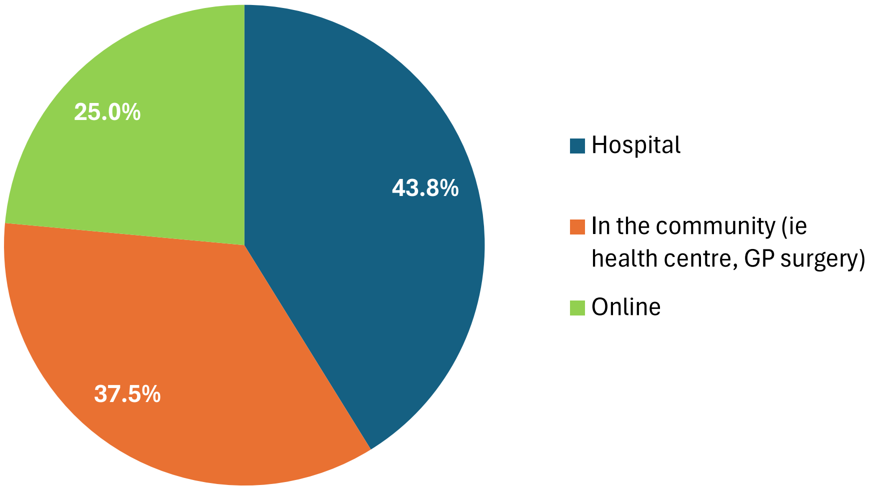
A parent of a young person with epilepsy and severe learning difficulties who had recently been through transition, although grateful for the “only transition he’s actually had to any adult service”, did have a few concerns. It was felt it would be really beneficial to have dedicated clinic time which involved the learning disability team, and this did not happen. It was also felt that the adult team, although involved, “had no idea how to speak to my son,” and were uncomfortable with dealing with someone with learning difficulties. Ultimately, it was felt the transition was not tailored to the needs of the young person.

What time would be best for an epilepsy clinic for young people at the transition of child and adult services?



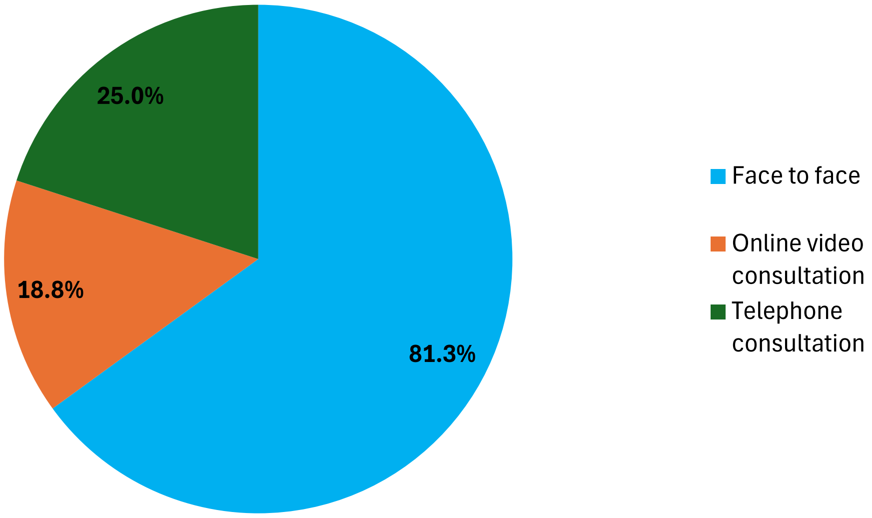
When asked what time would be best for an epilepsy clinic for young people at the transition to adult services, respondents chose all the times available, although ‘afternoon’ was the most common (%). The young people who responded were split between ‘anytime’ and ‘evening’, whereas most of the parents/carers responding went for the afternoon slot.

Where would you like the clinics to be held?



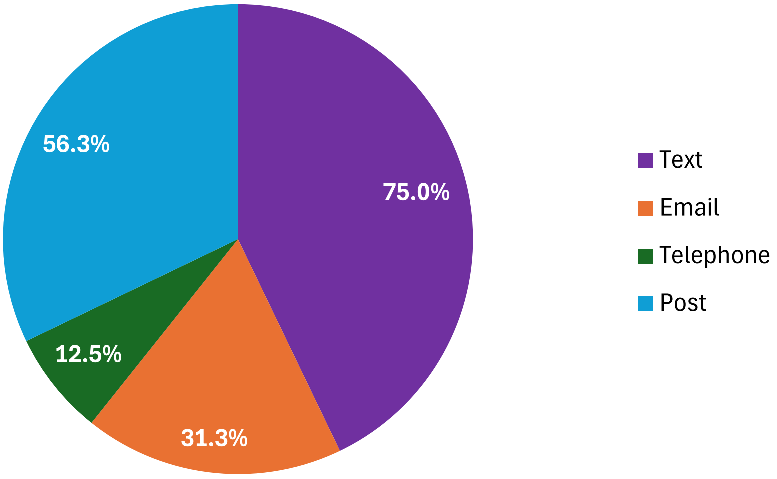
When asked where they would like clinics to be held, more respondents (overall) chose the hospital setting, with the fewest choosing online. For the young people who responded, the community setting was the most popular and online the least popular. Respondents could choose more than one option, but only two did so.

How would you like the clinics to be run?



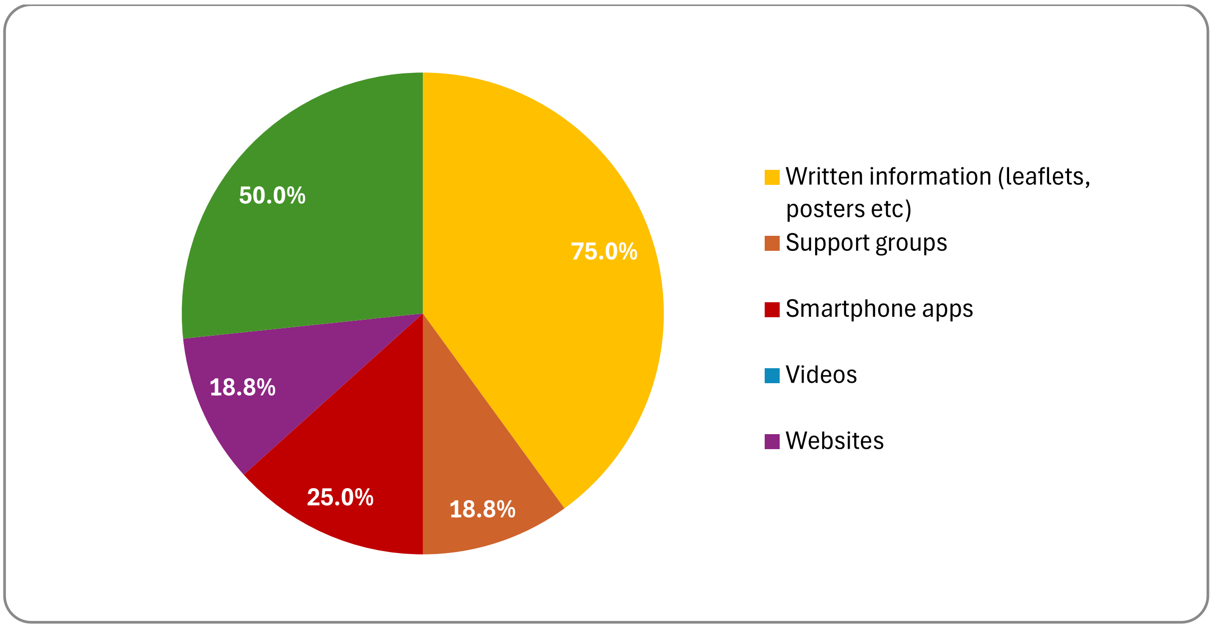
When responding to how they would like the clinics to be run, face-to-face clinics were by far the most popular answer, with 81% of respondents choosing this option. Online video consultation was the least popular overall. All but one of the young people responding went for face-to-face clinics with no young people choosing the online video consultation option. Again, respondents could choose more than one option but only a few did so.

How would you like to be informed of your appointment?



As with the previous few questions, respondents could choose more than one option about how they would like to be informed of their appointments. Unlike previously, over half of respondents did choose more than one option. Three quarters of respondents choose text as a method of being informed of their appointment, and over half of these also choose post as an option. Overall, telephone was the least popular method of informing people about their appointments. Of the respondents who did not choose the most popular text option, all but one chose post or telephone as their preferred method. This suggests that text or post are the preferred methods for most people.

How do you prefer to receive health and related information?



Respondents could choose how many options they wished. Written forms of information (leaflets, posters etc.) was the method of receiving health and related information that most respondents opted for. Verbal information was the next most popular, and these two were significantly higher than the other options.

For the young people responding written or verbal were equally popular, closely followed by smart phone apps. No young people chose videos as an option, and only one chose websites.

Although not conclusive, these responses indicate that there is still a demand for written information and that health professionals providing information verbally is also welcomed in an increasingly digital world.

What information would you need before you attend the clinic?

37.5% of respondents did not answer this question and much of the feedback came from the young people responding. The issues raised in relation to what information would be needed before attending the clinic is summarised below:

- The date, time and location of the appointment
- What will be discussed at the appointment/it's purpose/what to expect
- Who will be seen at the appointment
- Will the patient/parents be involved in any decisions that are made
- How those running the appointment can be contacted
- How long the appointment will last
- Appointment reminders
- Disabled access

Some of these had practical value - "date and time so I can give college the letter", and some were concerned with personal feelings - "what to expect, to reduce anxiety".

After the clinic, what information or support might be helpful or important to you?

75% of respondents gave their feedback about what information or support might be helpful or important following the transition clinic. In general, although there were a few points mentioned by several respondents, the feedback identified a broad range of requests/ideas in response to this question. These included:

- Having the names and contacts of health professionals/someone to contact when help needed
- What the next steps would be/ongoing support and information
- Information about any support groups available
- How to control seizures
- Information about medication
- A recap of what was discussed
- Support with deputyship

In addition, there was a plea to speak to service users with special needs in a different way, slowly, ensuring this is face-to-face, so that they have a better chance of understanding what is being discussed or what they are being told.

The young people responding were particularly concerned about the next steps, having ongoing support or information about support groups and having a contact.

What do you need to know, or find useful before you move from children to adult epilepsy services?

62.5% of respondents provided feedback to this question, although a few of these felt there was nothing to add. The main points raised by the other respondents are as follows:

- Contact details for someone in adult epilepsy services
- What the differences are between children and young people's epilepsy services and adult epilepsy services
- How to book an appointment

- Whether parents can still go with the young person/patient
- Who the new consultant/nurses will be
- What is expected
- Where they will go (location) in future
- Information about satellite clinics

These responses indicate a need for reassurance, especially by the young people themselves, about having a professional within adult epilepsy services who can be easily contacted. They would like to know that “someone is there to pick up the phone to speak to,” if they need help or have any concerns, or have any “issues surrounding epilepsy such as the epilepsy becomes uncontrolled.” The young people were also the respondents who wanted to know the differences between adult and paediatric epilepsy services, and who the consultant and nurses would be and how to book an appointment. In some respects, these are relatively basic requirements, but they can be overlooked.

Insights we have gained from this process

The focus on young people currently going through the transition clinics across Lancashire did not yield the level of feedback/number of responses expected. The limited responses received provided some rich information and was in percentage terms of the cohort originally approached, statistically relevant, but still feels uncomfortably low. Any further engagement with this cohort of patients will need to consider a different approach or focus on a wider range of potential respondents from the outset.

Conclusion and recommendations

On the evidence of the engagement undertaken for this report, the paediatric epilepsy transition service would appear to be well received by both the young people they serve and their parents and carers. The transfer to adult epilepsy services clearly holds some concerns for families and both paediatric and adult epilepsy services have a role to play in ensuring patient and family needs and concerns are fully addressed.

It is recommended that the worries and concerns identified in this report are shared with both services and, where these are not appropriately addressed, agreement reached on who and how this should be done, both in terms of the information made available to families and in the service being delivered. This includes:

- Informing people of the level of support available in adult epilepsy services
- Having named individuals and contact numbers for patients or families to call
- Identifying and explaining the appointment schedule and staffing arrangements in adult epilepsy services, including who the new consultant/nurses will be and how to book an appointment
- Clarity about the differences between paediatric and adult epilepsy services

- Sensitive to the needs of young people transferring to adult epilepsy services and understanding where continuing parental support or involvement may be needed
- Making additional considerations about ongoing care for complex patients as they reach adulthood
- Consider additional linked support within adult epilepsy services, including Youth Workers
- Request or require adult epilepsy services to include a review of transition support for new arrivals into adult epilepsy care
- What will be expected going forward.

It is also recommended that the information identified by young people and their parents as useful to them at the transition clinic, either before or after, is provided where this is not already the case. This includes:

- Full details of appointments and their purpose
- Appointment reminders
- Contact information
- Information about the control of seizures and medication, where appropriate
- Next steps and what ongoing support is available
- A recap of what was discussed
- Provide information as printed/written resources as a preference.

It is recognised that access to an adult epilepsy specialist within the transition clinics will help to achieve some of the young people's expectations.

Next steps

This report will be shared with the Epilepsy Clinical Network. In addition, comments made will be fed back to the relevant service providers to support the improvement of existing services and to help providers understand what is currently working well and identify what could be improved for future patients.