NHS
Lancashire and
South Cumbria
Integrated Care Board

Feedback Fortnight Pilot

Analysis report

April 2025

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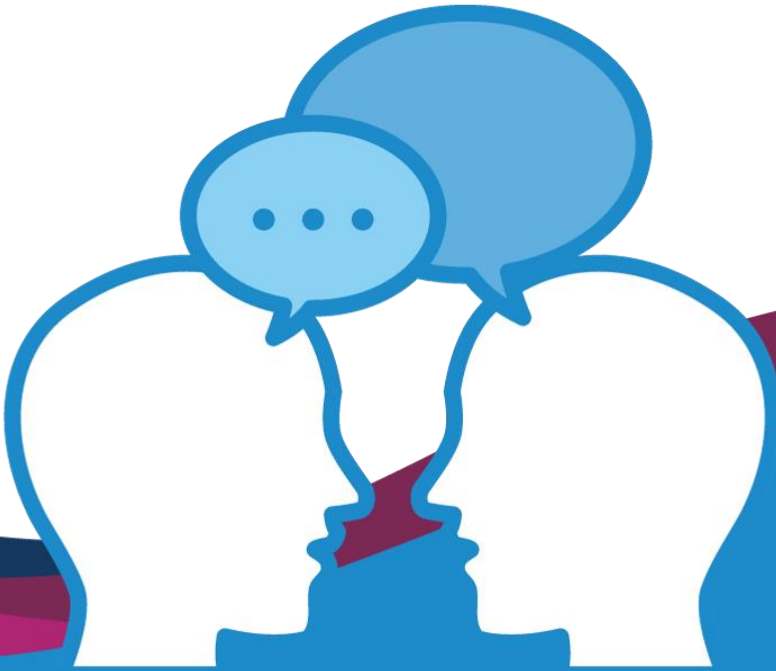


Contents

Acknowledgements

The ICB would like to extend their heartfelt gratitude to all the staff, providers, and service users who took part in the Feedback Fortnight roadshow event. Your dedication and active participation were instrumental in making this pilot initiative a success.

To Rossendale Youth Council, thank you for your time, effort and innovative design of the QR poster, video and questionnaire used for Feedback Fortnight. Your creative input has been invaluable. See Appendix 4 for poster and Appendix 5 link to the video.

To our staff, thank you for your unwavering commitment and hard work in organising and executing the event. Your efforts in engaging with participants were truly commendable.

To our providers, your collaboration and support were invaluable. Your willingness to gather and share feedback has provided us with critical insights that will help us improve our services and better meet the needs of our community.

To our service users, thank you for taking the time to share your thoughts and experiences. Your feedback is essential in helping us understand what we are doing well and where we can make improvements. Your voices are at the heart of our efforts to enhance our services.

Together, we have made significant strides in understanding and addressing the needs of our community. I look forward to continuing this journey with all of you and building on the valuable lessons we have learned.

Thank you once again for your dedication and support.

Introduction

NHS Lancashire and South Cumbria Integrated Care Board (ICB), Children, Young People team is constantly working to improve local services. A key element of improving local services is to hear from local communities about their views and experiences of children and young people's services. Not all services routinely collect or share feedback on their services; therefore, it was felt that a 'Feedback Fortnight' pilot may provide valuable user experience and help form a baseline for future engagement and insight.

Feedback Fortnight is a method of providing a 'real-time' snapshot over a short period of time, ensuring that the perspectives of children and young people, parents, and carers, (including those who share the protected characteristics within the Equality Act 2010 or live in underserved communities), are considered.

We gathered this feedback via questionnaires, one aimed at children and young people, and one aimed at parents/ carers. Where appropriate, the questions were phrased differently to help children and young people as young as 8 years old to respond.

A Feedback Fortnight information pack was circulated to ICB Providers, along with other organisations who engage with children and young people, to encourage the people they work with to complete the questionnaires. The ICB also completed a roadshow of events across Lancashire & South Cumbria, to support children, families and carers to complete the questionnaire. Additionally, the questionnaires were promoted across ICB social media platforms. (please see Appendix 8 for the exhaustive list)

Executive summary

The responses we have received have highlighted positive and negative feedback relating to services within Lancashire and South Cumbria. This feedback provides valuable insights into the experiences and needs of service users across Lancashire and South Cumbria and although feedback has been predominantly positive, it has highlighted common themes which should be addressed when considering future service delivery.

Notably respondents from each locality within Lancashire and South Cumbria gave examples of excellent service. There were also respondents from each locality who gave examples of poor service, relating to both access to services and delivery of services.

Access to Services: Service users provided detailed feedback on their experiences accessing healthcare services. Participants noted challenges related to waiting times for appointments across a range of services; this was a concern for both autism and ADHD assessments (and was replicated in all localities). Comments also included the clarity and usefulness of the information provided, and the overall ease of accessing services. Many participants highlighted the need for more timely and efficient service delivery, (reduced waiting times) and the need to improve the overall accessibility of healthcare services.

Satisfaction Levels: The feedback also revealed satisfaction levels with the care received. Participants highlighted areas of excellence, such as the professionalism and compassion of healthcare staff, as well as areas needing improvement. Some common themes for improvement included the need for better communication between different departments, across healthcare providers and between healthcare providers and patients; further highlighting the importance of personalised care to address individual needs.

The largest single area of concern was access to autism and ADHD support. Parents and carers noted that even when assessments had been made, there was a variation in the scope and quality of support provided. Concern was expressed regarding children and young people with neurodivergent needs being triaged by staff with a lack of knowledge or awareness of children living with autism. This also applied to children with learning difficulties and/or mental health issues.

Service Improvements: Based on the feedback gathered, a number of suggestions were made for improving healthcare services. These included enhancing communication channels to ensure clear and timely information is provided to children, families and carers, implementing measures to reduce waiting times and increasing the availability of services in community venues. Feedback also highlighted the need for better support for children with specific needs, such as autism and sensory processing issues and a need for stronger continuity in care. The importance of continuous engagement and feedback was emphasised to ensure that the needs of children and young people are met effectively.

Overall, the insights gained from Feedback Fortnight 2025 highlight the importance of actively involving children, families and carers in the evaluation and improvement of healthcare services. By addressing the identified areas for improvement, healthcare providers can enhance service delivery and better meet the needs of their communities. By engaging with our local communities, we can ensure that the voices of children and young people are effectively heard and acted upon in future projects.

Participants appreciated the opportunity to provide feedback in a structured and meaningful way. The overall sentiment was that the Feedback Fortnight provided a valuable platform to share experiences and contribute to the improvement of healthcare services in Lancashire and South Cumbria.

Purpose

The purpose of Feedback Fortnight is to ensure the active participation of children, young people, families, and carers in decisions regarding their health and well-being, to gather their feedback and insights to improve services and programs of work.

The original concept for this project was presented at the system wide Operational Leadership Group (CYP) for approval. From there a task & finish group was established, which met on a regular basis to share ideas and move the project forward. Meetings were arranged with all local authority Family Hub Managers, who were asked to book sessions over the two week period on the times/dates when they had suitable footfall. We also contacted the Youth Service to ask Youth Workers to promote the project at their sessions with Children & Young People.

A ‘Health Bus’ was booked for the two weeks in March (to encourage people to attend), this team were able to support one of the community sessions.

What have we been talking to people about and why?

NHS Lancashire and South Cumbria Integrated Care Board (ICB), Children &Young People team wanted to gather insight and information on the full range of services currently provided to the children and families of Lancashire and South Cumbia. These services include, GP services, Speech and Language, Bladder and Bowel, SEND (Special Educational Needs and Disability) Asthma, autism and ADHD, hospital services, dentists, and over ten other services.

Children, young people and parents/carers have been asked to share their experiences and thoughts as to how we can improve services.

The feedback from this patient engagement exercise will be used to inform future planning and delivery of services for children and young people.

Overview of events

Feedback Fortnight was held from the 3rd to the 14th of March 2025. The event included a series of roadshow events across Lancashire and South Cumbria, held in Family Hubs for face-to-face engagement and online ‘Teams’ evening events. The roadshow aimed to gather feedback from children, young people, and parents/carers regarding the care received

from NHS services within the region. (Please see appendices 8 & 9).
Events also took place in our local hospitals, supported by ICB staff carrying this out or the hospital teams.

Who have we heard from?

During Feedback Fortnight we have spoken to and received feedback from children, young people, parents and carers attending family hubs, clinics and hospital services, schools, and other service venues. In total we collected 583 responses (439 for parents and carers, 144 for CYP). Responses came from across Lancashire and South Cumbria, including Rossendale, Burnley, Pendle, Ribble Valley, Blackburn with Darwen, Hyndburn, South Ribble, Chorley district, Preston, West Lancashire, Fylde and Wyre, Blackpool, Lancaster district, Barrow in Furness, and Westmorland and Furness.

How did we speak to people?

Two separate online questionnaires were developed to gather the views of children and young people and parents/carers. The children and young people questionnaire was co-produced with The Youth Council, in the Rossendale area. The Parent/Carer questionnaire was circulated to parent/carer forums for feedback prior to finalisation. In addition to co-producing the questionnaire, The Youth Council also developed a poster with an embedded QR code and a promotional video for Feedback Fortnight. To show thanks for their involvement we attended a youth council meeting and presented certificates for their portfolios for all their hard work and involvement, (please see Appendix 7).

As well as being able to access the questionnaires online, paper copies were available for people to complete.

The questionnaire went live on Monday 3rd March and was shared with the following people/organisations who were asked to try and promote uptake through their networks and channels. An information pack was circulated to these organisations which included an information presentation about Feedback Fortnight as well as posters and questionnaires which were available to print.

- East Lancashire Hospital Trust
- Blackpool Teaching Hospitals
- Lancashire Teaching Hospital
- Lancashire County Council
- Lancashire and South Cumbria Foundation Trust
- ICB Place Leads
- Barnardos
- Child Action North West

- Blackburn with Darwen Council
- Blackpool Council
- Westmorland and Furness Council
- Blackburn Rovers Foundation Trust
- Burnley Football Club Foundation
- Preston North End
- Home Start
- Twinkle House
- Spring North
- Carers Link
- Parent Carer Forum
- Nightsafe
- HCRG
- We are With You
- Derian House
- Brian House
- Jigsaw
- UCLAN
- Onside Youth Zones
- Lancashire Mind
- Healthier Fleetwood
- Contact
- NHS England
- Youth Futures Team at Lancashire County Council

Members of the ICB's Children and Young people's team and the ICB's engagement team attended over 38 face-to-face engagement opportunities at community venues across Lancashire and South Cumbria as well as hosting 3 MS Teams evening sessions across the fortnight deemed the 'Feedback Fortnight Roadshow'. We attended:

- Chai Centre, Burnley
- Haslingden Community Link and Family Hub
- Central Family Hub, Blackpool
- Shadsworth Family Hub, Blackburn
- Little Harwood Family Hub, Blackburn
- Burnley General Hospital
- Royal Blackburn Teaching Hospital
- Fylde Family Hub
- Clitheroe Family Hub
- North Family Hub, Blackpool
- Livesey Family Hub, Blackburn
- Darwen Family Hub
- Ribbleton Family Hub, Preston
- South Family Hub, Blackpool
- Lune Children's Centre, Lancaster
- Wensley Fold Family Hub, Blackburn
- Longridge Family Hub

- Higher Croft Children’s Centre, Blackburn
- Nicholas CofE Primary School, Rossendale
- Skelmersdale Family Hub
- West Paddock Family Hub, Leyland
- The Park Family Hub, Accrington
- Greenland’s Family Hub, Blackpool
- Barrow in Furness Family Hub
- Whitworth Library
- Great Harwood Family Hub
- Rawtenstall Family Hub

Please see Appendix 8 and Appendix 9 for Feedback Fortnight Roadshow posters which contain further details of the roadshow.

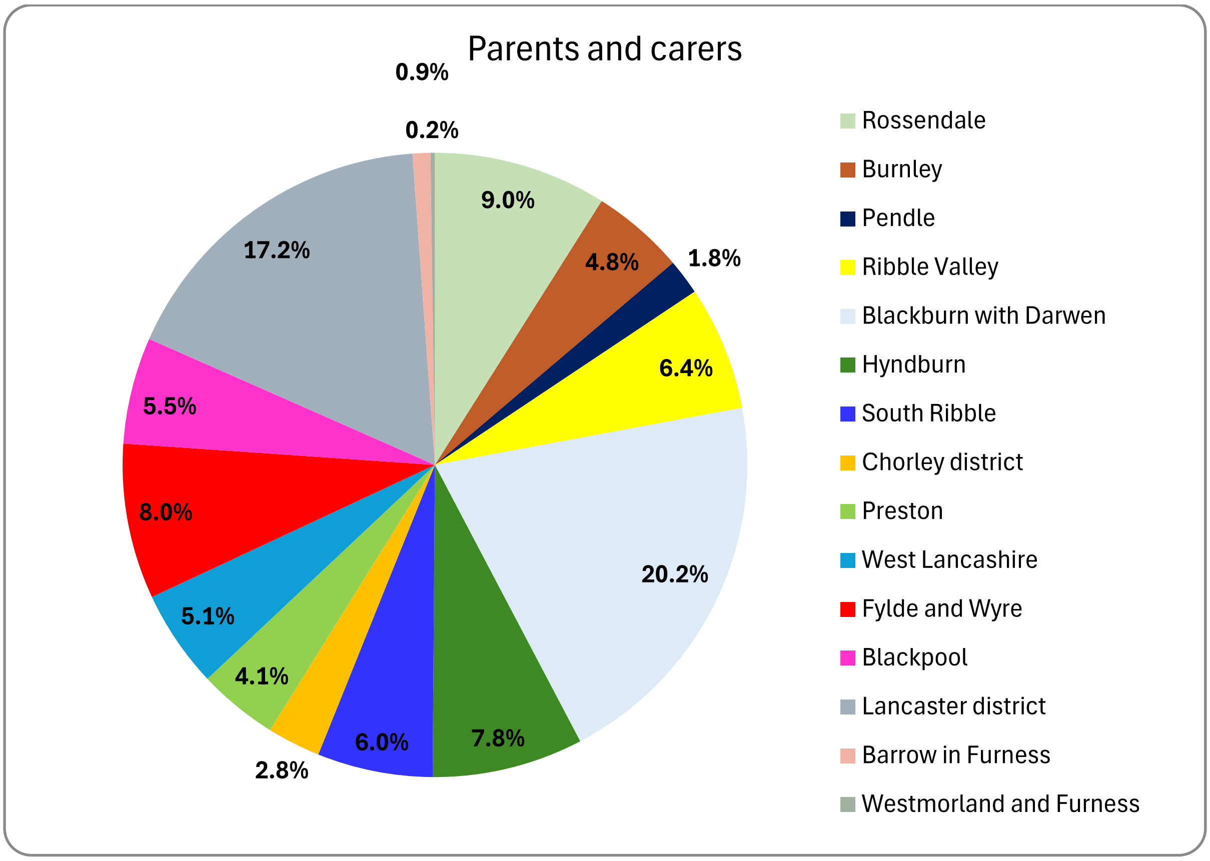
To allow a deeper insight into the responses to qualitative questions, respondents were given a free text box to allow them to speak freely. (Please see Appendices 1 & 2 for a summary of the questionnaire responses).

In addition to the Feedback Fortnight Roadshow, the questionnaires and promotional video were posted across different social media platforms. The video produced by Rossendale Youth Council achieved over 1000 views on Facebook. The Director for Children and Young people, Vanessa Wilson, appeared on That’s TV Lancashire prior to Feedback Fortnight to encourage children and young people and parents/carers to share their thoughts by completing the questionnaire on their local NHS children’s services.

What did we hear?

A summary of the feedback received during the engagement is below. Where the surveys asked the same or comparable questions, the feedback may be combined to give a full picture if it is appropriate to do so. To effectively analyse feedback given in both surveys, responses to qualitative questions, where respondents are given a free text box to say what they wish, have been 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 area of Lancashire and South Cumbria do you live in?



439 parents or carers completed the survey, only 4 respondents did not advise where they lived. Blackburn with Darwen had the highest level of respondents (20%), with Lancaster district also showing a significant level of response (17%). The lowest levels of response came from South Cumbria, Pendle and Chorley.

144 children and young people (CYP) completed the survey, only 1 did not advise where they lived. Fylde and Wyre had the highest level of response (29%), with Rossendale, Lancaster and Blackburn with Darwen all at 10% or higher.

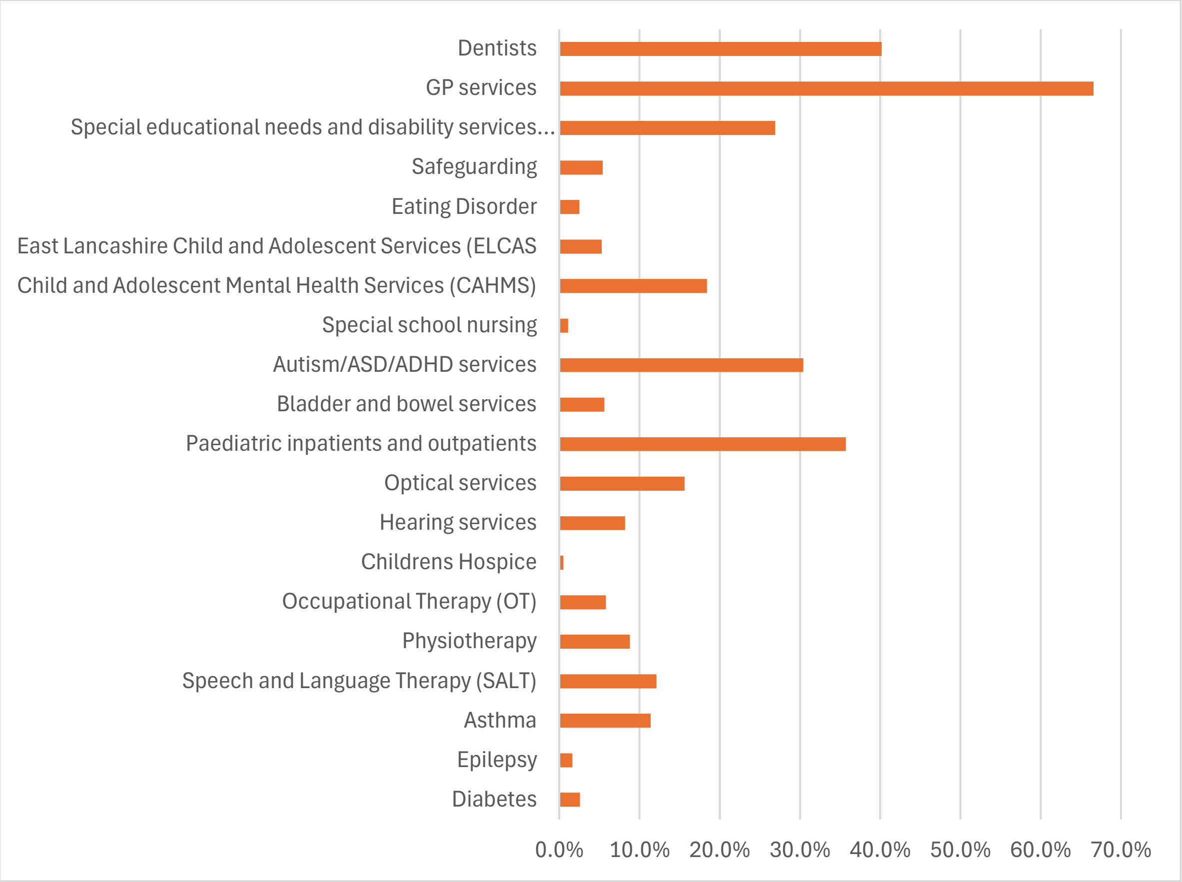
Combining the responses from both surveys on a Place footing, most localities had a reasonable representation, with South Cumbria being the Place that was significantly under-represented.

How old are you/is your child or the person you are caring for?

One of the purposes of Feedback Fortnight was to hear from children and young people directly. Therefore, both surveys identified four age groups; these were 8–12yrs, 13-15yrs, 16–18yrs and 18–25yrs; these age groups were identified on the basis that anyone under the age of 8 may struggle to understand the questions asked and articulate an answer. However, it should be noted that 168 parent and carer responses (29% of the total responses) were for children below the age of 8, many of which were below the age of 1. Combining the results from both surveys, this age group represented the second largest level of responses.

Using combined survey figures, the age group with the most responses was 8-12yrs (35%), and the lowest 18-25 (3%). It should also be noted that at least 5% of parent or carer respondents gave feedback for two or more children.

Which of these services have you/has your child used or tried to access within the past 2 years?

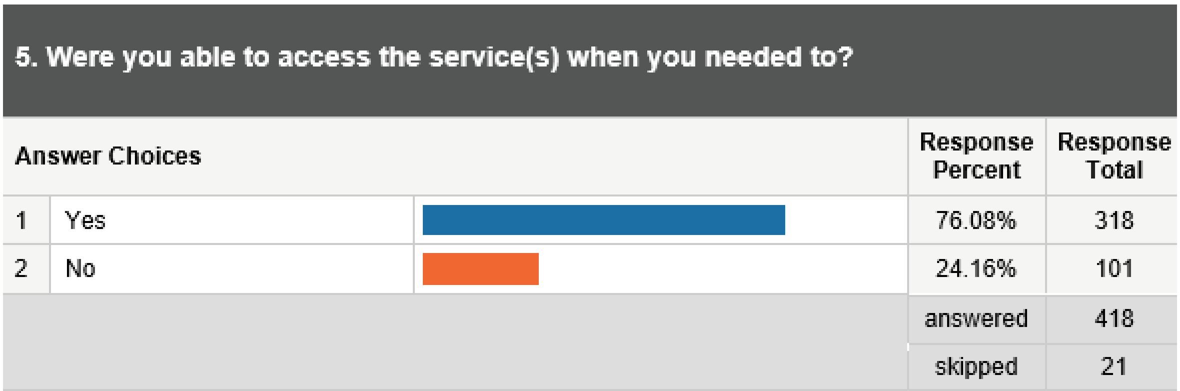


The chart above shows the combined responses from both parents and carers and children and young people to the question about which services they have used within the last two years. Respondents were asked to choose all that applied and as can be expected, some used a range of services while others only used one or two.

Overall, 569 responses were received to this question, which covered 20 services provided to children and young people. 15 of these services had 30 or more responses, with half receiving 50 or more responses. This provides a reasonable level of response for a considerable number of the services used.

GPs and dentists were the services that received the highest level of responses. 22% of all respondents (123) indicated they had only experienced their GP and/or dentist and had not used any of the other services listed. However, paediatric services, SEND, autism and ADHD services and child and adolescent mental health services all received reasonably high levels of feedback.

Were you able to access the service(s) when you needed to?



5. Were you able to access the service(s) when you needed to?

Answer Choices			Response Percent	Response Total
1	Yes		76.08%	318
2	No		24.16%	101
			answered	418
			skipped	21

Parents and carers were asked this question, several respondents (76%) were able to access the service(s) when they were needed. Although this is positive, it also highlights almost a quarter of respondents could not access services (or struggled to do so). 90 (21%) of respondents made comments regarding access to services, many of which were negative.

Some services were highlighted by respondents as being difficult to access. The services mentioned the most related to autism and ADHD. Notably Child and Adolescent Mental Health, Speech and Language Therapy, SEND provision, some paediatric services and GPs also noted comments and concerns. The main themes mentioned were:

- Waiting times to access services or assessments far too long
- Refusals to see/treat patients.
- Problems getting referred.
- No service available in the area/locality
- No qualified staff/lack of trained staff
- Services poorly connected.

Some of the issues raised need exploring in more detail.

Waiting times can cause frustration and can have a significant impact on the health and wellbeing of patients and their families / carers. Although some respondents mentioned waiting an hour or two at appointments, for other services the wait related to years. The quotes below indicate the challenges faced:

> “We have been waiting nearly 2 years for the ASD pathway”.
> “Waiting list atrocious for ADHD.”
> “Trialled for LD team, who eventually met with us, agreed to put son on autism waiting list 2 years ago - still waiting for a diagnosis”.
> “CAMHS still waiting - 18 months.”
> “Still awaiting an appointment with ELCAS after two years.”

Other services received comments relating to long waits before patients are assessed or treated; example quotes from respondents are below:

> "Took a long time for referrals to be accepted for bladder / bed wetting."
> "Quick to see at LTH, long wait at Blackpool - still waiting, referral sent January, now March. Long delay for access to Speech and Language."
> "Audiology waiting lists are ridiculous and we are still waiting to be seen from an appointment last January."

Some respondents went into more detail about the ramifications this had for their children and for them as parents, whilst others mentioned the struggles and effort that went into trying to gain access to services. This was not limited to autism/ADHD or mental health, although these were the most frequently mentioned. There are a few examples below:

"Following scans and x-rays for ongoing knee pain in my very active daughter, GP made a referral to paeds as adult physio will not see children. We have been waiting over 6 months. My daughter can no longer keep active which is also having an impact on her mental health. Seems unimaginable the extent knock on effects of not being able to access services in a timely manner and the further health issues both physical and mental this is causing."

"On the waiting list for CAMHS/ASD pathway for 2 years, unable to access any support for anxiety when struggling with accessing school. Did not meet threshold for support signposted to services that were not Neuro affirming. Discharged. Further referrals put in with support of GP. Child in burnout and in urgent need of support, triaged with staff who causes further trauma due to their lack of knowledge and awareness of an autistic child struggling the environment and in shutdown. Discharged and signposted to services we could not access due to no limited services in South Ribble (consistency needed across Lancashire)."

"We were referred into the services for diagnosis however the connection with other services e.g. SALT, OT is not there. The onus is always on the parent to push for support and chase up the support. My son was discharged from an OT pathway before having been seen by anyone and when I followed it up it was found that this was in error. It feels like it should be more joined up. When a child is neurodivergent, I would have assumed that the service dealing with the diagnosis would understand the various needs a child would have and refer to the appropriate services but often parents are left to figure it out and fend for themselves (usually after multiple attempts to access help and via a variety of roots)."

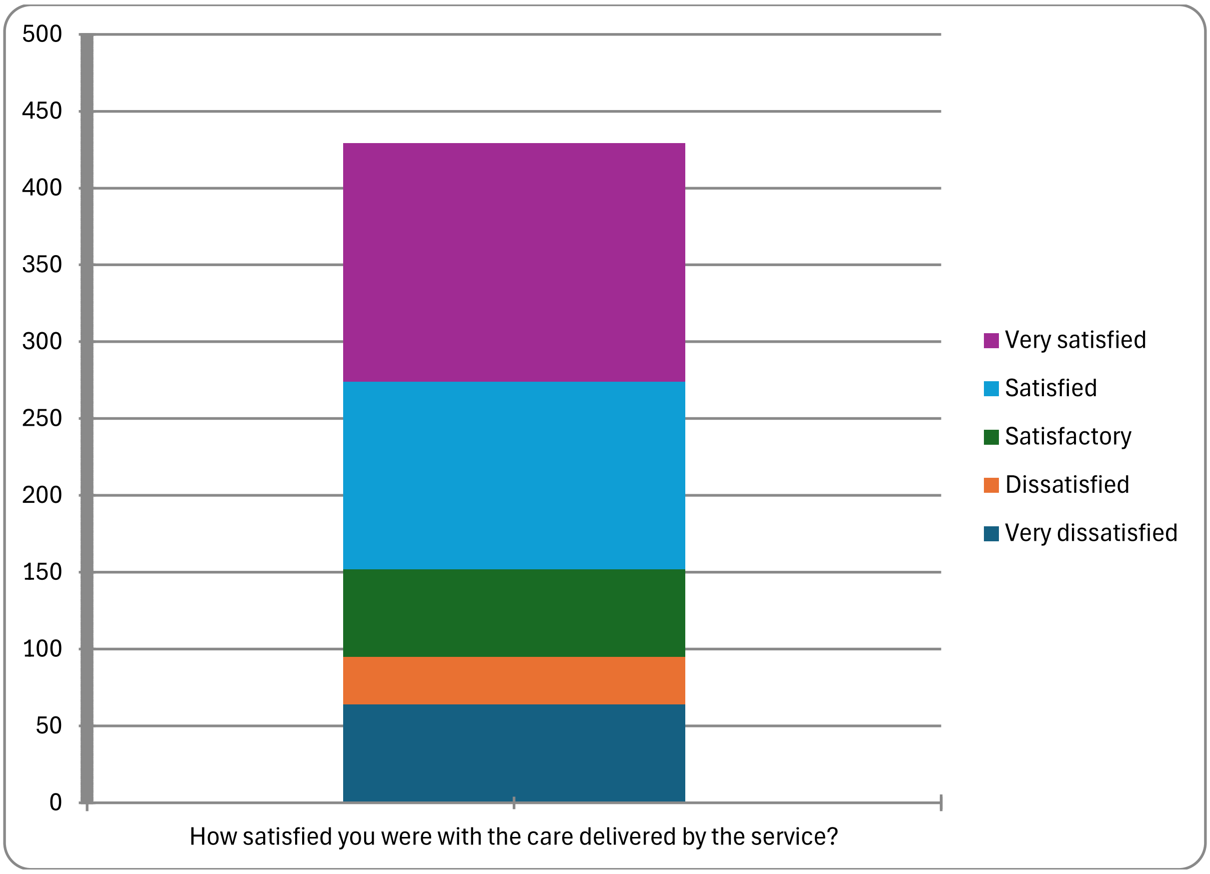
Parents highlighted other areas of concern, including support for children who are moderately to severely deaf, gaps in service provision, and a lack of understanding or support from health professionals. Further examples of these can be seen in Appendix 1.

It is important to remember individual differences when collating feedback, for example where a service receives commendations from parents, such as GP triage processes, this can be a problem for others.

“The GP now has a triage service. So, you go online, answer all the questions. Someone gets back to you and usually you have to explain again. They decide if you can speak to the GP then you have to explain it all again to the GP. The number of times you have "told your story more than once" has increased!”

Gaining access to appropriate health services for their child is something that parents and carers are frustrated about, which was evident in the responses received.

Please tell us how satisfied you were with the care delivered by the service?



Parents and carers were asked how satisfied they were with the care delivered by the service; 98% (429) of all respondents provided an answer. Over 60% of parents and carers were satisfied or very satisfied with the care provided, while a further 13% felt it was satisfactory. Over a fifth (22%) of parents and carers were dissatisfied or very dissatisfied, with a number of these being very dissatisfied.

64% of respondents provided comments or a context to their answer; over a third of these (38%) were very positive, although some of these also mentioned aspects that were less positive. Some of the positive comments included:

“Staff lovely and helpful.”
“Amazing, fast waiting times and friendly.”

“Friendly staff, engaging, good care, children’s ward clean and tidy and even smelt clean.”
“Baby was in hospital for a week after he was born with suspected sepsis from UTI. Service was fantastic with regular follow ups and scans to check progress booked.”

The remaining two-thirds of respondents identified areas of dissatisfaction and much of this, although certainly not all, related to autism, ADHD services and Child and Adolescent Mental Health services. The main themes related to:

- Waiting times
- Lack of support (both while waiting for assessments and after assessments made)
- Not being listened to by health professionals
- Fighting to access services
- Poor communication between departments/health providers
- Lack of understanding by GPs and other health professionals on how to deal with/support children with neurodiversity
- CAMHS and ELCAS declining to help some children (usually neurodiverse children) but offering no alternatives and the parents and carers extremely frustrated at the wait involved and then at the lack of support and information available.
- Transition from paediatric to adult services considered a problem for a range of services.
- Concern about the number of times parents must repeat/re-explain their child’s condition.
- Appointments do not cater for parents/carers who have more than one child and no family support to assist them in attending appointments.
- Need more time at appointments for children with various or complex needs.
- Clinicians should review notes before the patient is seen.

The examples below help illustrate and reinforce several of the points made above.

“ELCAS rejected referrals from our GP and my son's school until finally one of their trainee therapists listened to me and my son and argued for my son to be seen for weekly sessions.”

“Always have to re-explain my children's condition at every appointment, despite them being under a paediatrician for 6 years. It would seem the Doctor does not read or have time to read notes beforehand. Also do not get much of an opportunity to speak, get interrupted or talked over at each appointment.”

“Disappointed with waiting times and access to services for my child with SEND and for things that are specified in her EHCP. I have to ring to get follow up appointments and I have had to fight to get any access to physio and occupational therapy which are key therapies to support her genetic condition.”

“Parents are essentially left in limbo whilst we wait for updates, progress and decisions. Nobody contacted me at all during the process, every update I received was obtained by myself through continuously chasing up with the ASD pathway team. Everything I have learned about how to support my son has been researched by myself."

"Transition from CAMHS to adult psychiatry - multiple rejected referrals and no information about transition."

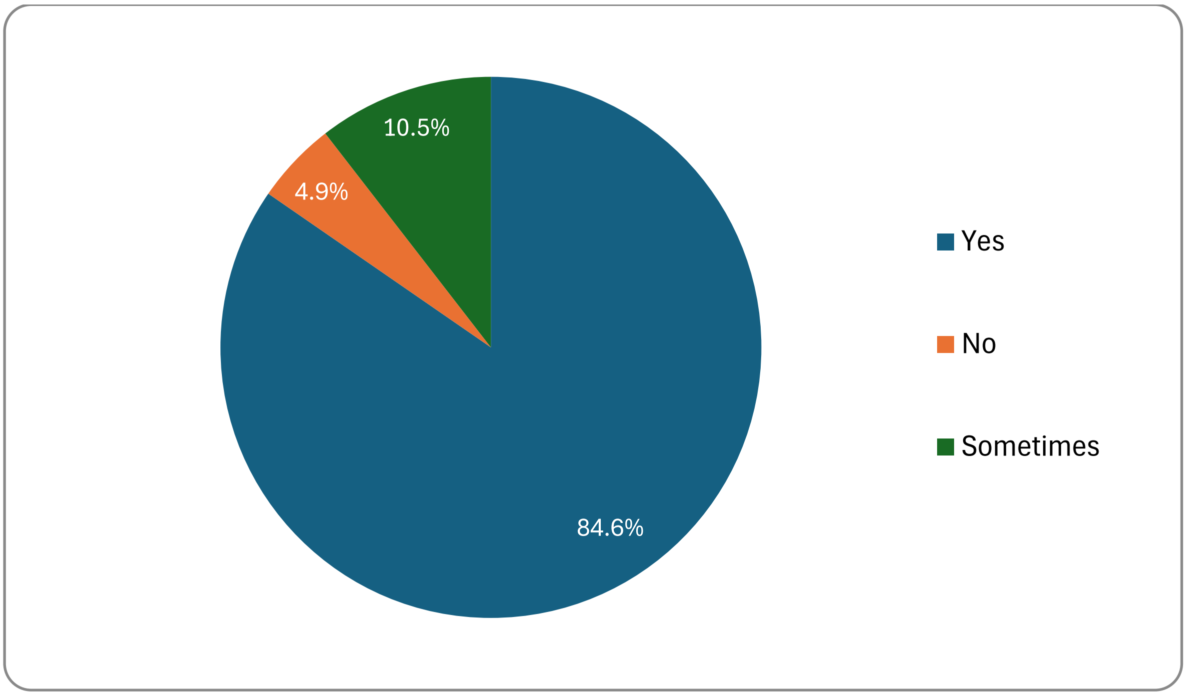
"CAMHS is not commissioned to support autistic children and young people. This means staff training is not sufficient in many cases and some very outdated views of autism can be held. It is very very difficult to navigate and access suitable mental health support in any kind of reasonable time frame. My daughter has also had multiple referrals declined in the past allowing the situation to deteriorate even further."

"I have found my experience with healthcare incredibly traumatic and draining in recent years. My youngest child has fallen through huge cracks in service provision between LTHTR and LSCFT- even within each trust the silo working is horrendous. I have tried hard to arrange multiagency meetings, but it has been utterly impossible. I feel like I have to battle and chase every step of the way or else my child is forgotten about or misunderstood."

This last quote is from a health professional, but all the above provide rich information about the frustration that long waiting lists and the lack of service provision and support for certain conditions causes, along with the impact upon the children and their families. The team would like to acknowledge that being given the opportunity to comment within a survey environment does have limitations, as the quote below identifies.

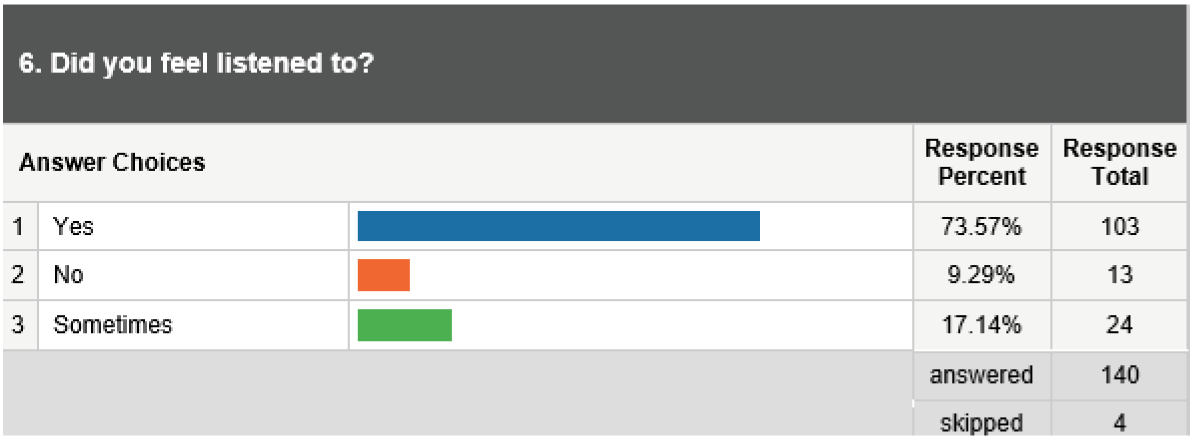
"We are talking about lots of different services, so it is hard to answer the same for each one. Some were quite easy to access, others we are still struggling with and getting nowhere. Waiting times are terrible - for example, my daughter was referred to the pain management clinic in November and we are still waiting for an appointment to come through."

Were you treated kindly?



Children and young people were asked if they were treated kindly; the chart above indicates that most children and young people (85%) felt they were treated kindly, with a further 10.5% who felt this happened sometimes. 5% of children and young people did not feel they were treated kindly. Only a few children and young people expanded on their answer, notably a third of these did not relate to a health service. Several of the other comments were about the service received rather than whether they were treated kindly or not.

Did you feel listened to?



6. Did you feel listened to?

	Answer Choices		Response Percent	Response Total
1	Yes		73.57%	103
2	No		9.29%	13
3	Sometimes		17.14%	24
			answered	140
			skipped	4

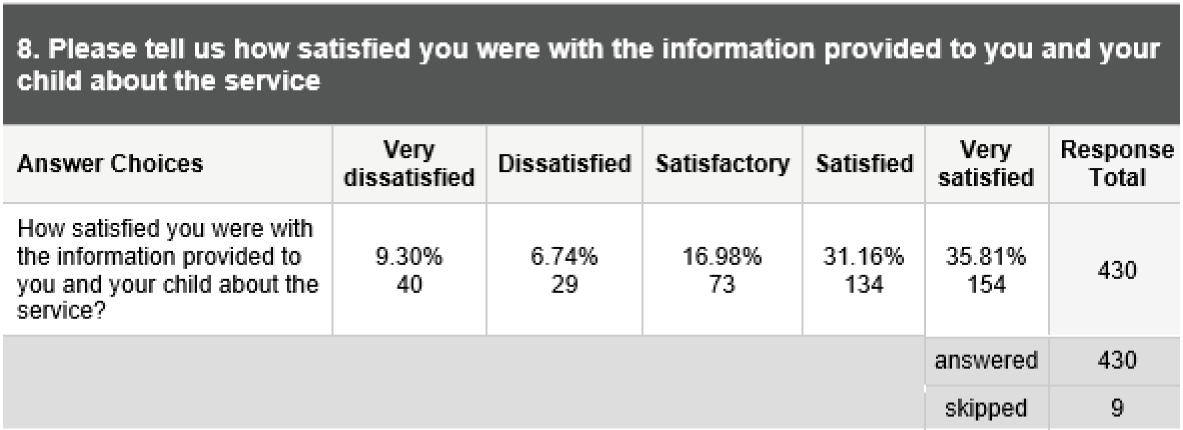
Almost three quarters of children and young people felt they were listened to, with less than 10% saying they were not listened to. Almost a fifth felt they were listened to 'sometimes'. Very few children and young people expanded on their answer, but these included:

“I told them I was scared**.”**
“Even after meeting staff I did not feel understood and not offered any help from CAMHS.**”**
“The doctor listening to what my Mum said and asked me questions about how I felt.**”**
“Only at Whitegate/South Shore.**”**

These give some indication that children and young people appreciate being involved and notice when this is not happening.

Please tell us how satisfied you were with the information provided to you and your child about the service? Were you given enough information to make decisions about your care?

Both parents and carers and children and young people were asked questions relating to the information they were given.



8. Please tell us how satisfied you were with the information provided to you and your child about the service

Answer Choices	Very dissatisfied	Dissatisfied	Satisfactory	Satisfied	Very satisfied	Response Total
How satisfied you were with the information provided to you and your child about the service?	9.30% 40	6.74% 29	16.98% 73	31.16% 134	35.81% 154	430
					answered	430
					skipped	9

Almost all parents and carers responded to their question, with over 66% satisfied or very satisfied with the information provided. Although 16% were dissatisfied to some degree, this was an improvement on some other elements of the survey.

21% of respondents provided additional comments, and as before, there was a mixture of positive and negative responses. As seen elsewhere in the feedback provided, a considerable proportion of responses were concerned with autism/ADHD service provision , however other services were also referenced. Some of the main points made were:

- Some services provide little or no information, or no information in the right format for their child.
- Parents sometimes must push, argue or complain to receive information or updates.
- Appointment letters can be wrong, inaccurate or in the wrong format.
- Some information is given verbally only, when written information would help.
- No care plan in place for their child with significant health needs
- Some services/providers provide excellent information/explain things fully.

The examples below support some of these points and a few also make suggestions for improvements or doing things differently:

“I have found you don't get good information regarding after care or places for support etc.”

“Provide more insight into what services are available and where.”

“We have seldom had information about the NHS services- let along information that is accessible to an Autistic child. In contrast, the information provided by Evolve through right to choose pathway has been brilliant and very disability friendly. The NHS has failed to offer any reasonable adjustments for my own disabilities as well as my son's.”

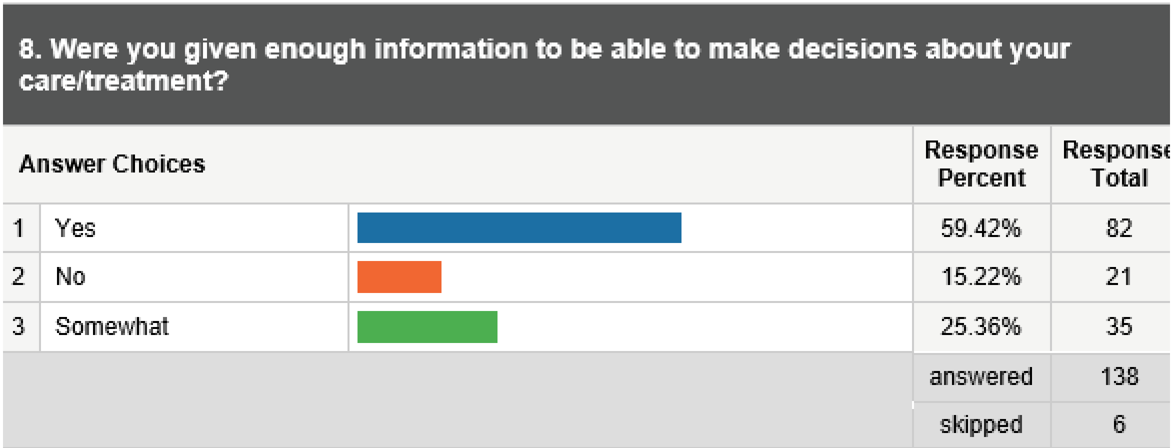
“Standard discharge letter, with reference to websites for support. Too many avenues, very overwhelming in a time of crisis.”

“Only received one leaflet when children first diagnosed regarding ADHD Northwest, nothing regarding Autism. I have had to learn and seek information myself and through research and reading. Parents/Carers are often left to their own devices once children are diagnosed.”

This last point is a recurring theme. The final comment below suggests about what may help young people with SEN before they attend adult clinics.

“There was no information provided for transition to adult asthma clinic. A booklet using comic strip conversations / or pictures needs to be created so that a young person with SEN can be taught what to expect when they visit an adult clinic.”

Parents / carers would like more information about what is available and where, information about the service provided (and the next steps), and what support is available. They would like to see this in formats that meet the needs of their children and themselves, whether this be leaflets, pictures or comic strips.



8. Were you given enough information to be able to make decisions about your care/treatment?

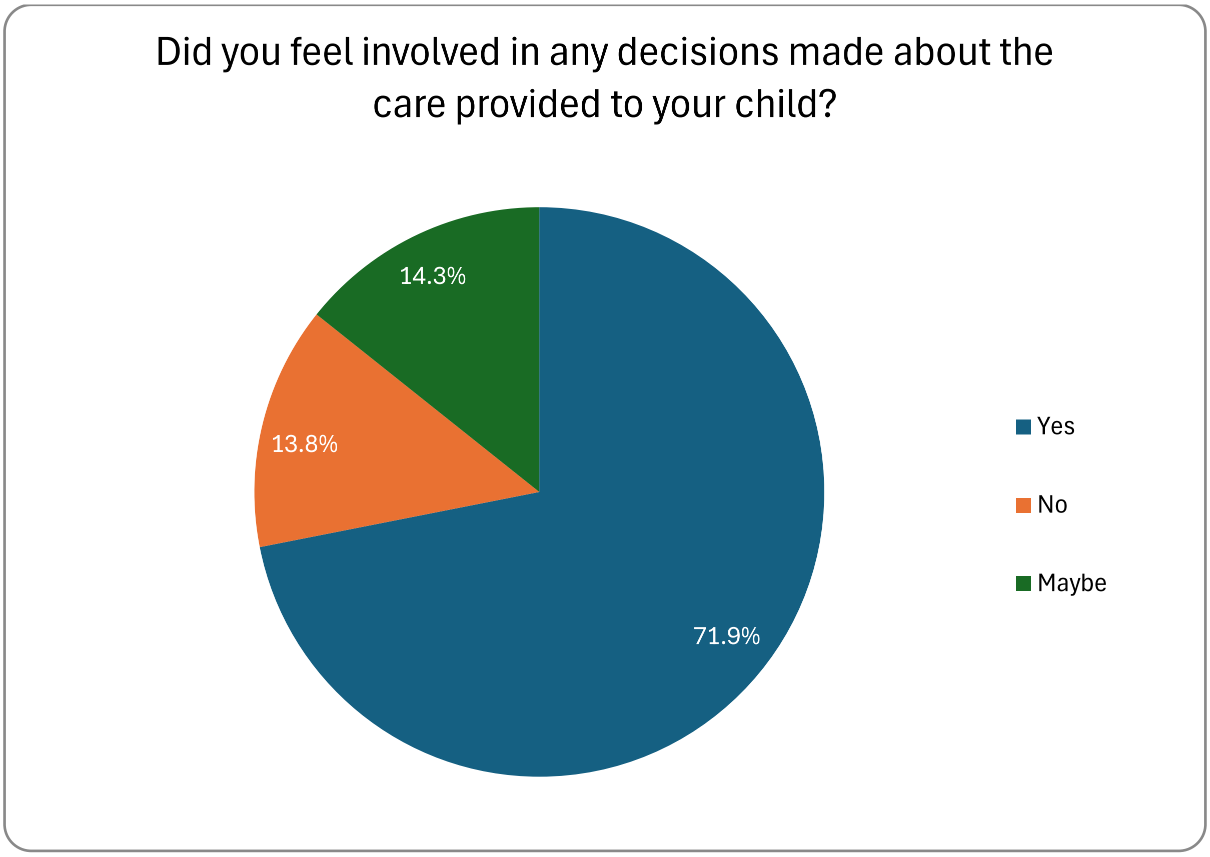
Answer Choices			Response Percent	Response Total
1	Yes		59.42%	82
2	No		15.22%	21
3	Somewhat		25.36%	35
			answered	138
			skipped	6

Almost all children and young people responded to their question about the information provided, and although the percentage who felt they were given enough information was a little lower, at 59%, the children and young people who responded negatively was almost the same as the parents and carers, at 15%.

Very few children and young people supported their response with an additional comment

Did you feel involved in decisions made about the care provided to your child? Did you feel involved in decisions about your care/treatment?

Parents and carers and children and young people were both asked about whether they felt involved in decisions about the care provided in their respective surveys.



A high proportion (72%) of parents and carers felt they were involved in decisions about the care provided to their child(ren). A further 14% felt they were somewhat involved, while another 14% felt they were not involved. 16% (68) of those responding to this question added further comments, and all three different responses were represented (yes; no; somewhat), although most comments were from those who were not involved.

Once again, autism/ADHD and mental health were mentioned although a little less prominently, but it was also evident that the long waiting times for some services left parents and carers feeling uninformed and uninvolved.

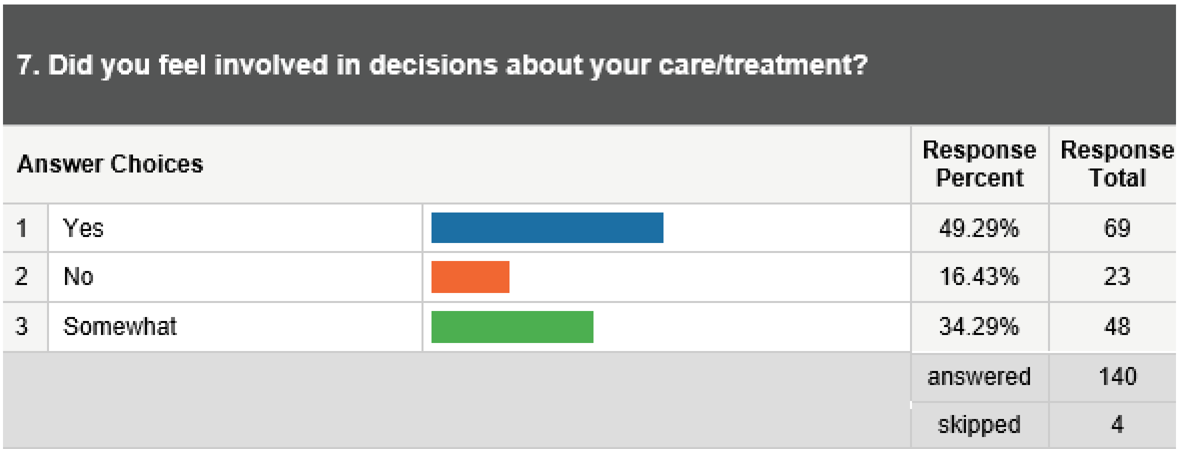
Some examples of the comments made are given below:

Positive:
“Discussed the issue together and decided on a treatment plan.**”**
“Always asked before going ahead with medication and decisions.**”**

Somewhat:
“Some services yes, but no consistency.**”**
“There are some great practitioners in our ICB, and it is a joy to encounter them. But those who truly listen to understand and involve you are rare gems.**”**
“Acute services have been able to make adaptations and provide updates and communication to support a child with a disability. Why is a specialist service like CAMHS unable to do this?**”**
“Rheumatology – felt very involved. Still awaiting input from ELCAS.**”**

Negative:
“The process doesn’t allow for parents opinion to be taken as seriously as school.**”**
“I’ve felt belittled, ridiculed, bullied and unsupported.**”**
“My daughter doesn't explain and tends to agree with professional people such as doctors. I am her appointee and have completed the form to advocate on her behalf in medical appointments, but often I feel as if I am not listened to (or listened to but not heard) when we are in appointments.**”**

Parents and carers feel strongly that they should be involved in decisions about the care of their child, and although this happens widely, there remains a number of instances where this does not happen and/or does not appear to be welcomed by health professionals.



7. Did you feel involved in decisions about your care/treatment?

	Answer Choices		Response Percent	Response Total
1	Yes		49.29%	69
2	No		16.43%	23
3	Somewhat		34.29%	48
			answered	140
			skipped	4

Less than half the children and young people who responded to this question felt that they were involved in decisions about their care/treatment, which is significantly lower than parents and carers. However, those who felt they were not involved was similar, on a percentage basis, to the parents and carers, at 16%, while those responding ‘somewhat’ was over twice as high, at 34%.

Only a small number of children and young people gave any further information. There is some evidence, within the feedback provided, which indicates that some health professionals involve parents and carers more than or instead of the young patient. This would support both the lower percentage answering yes and the higher percentage who answered ‘somewhat.’

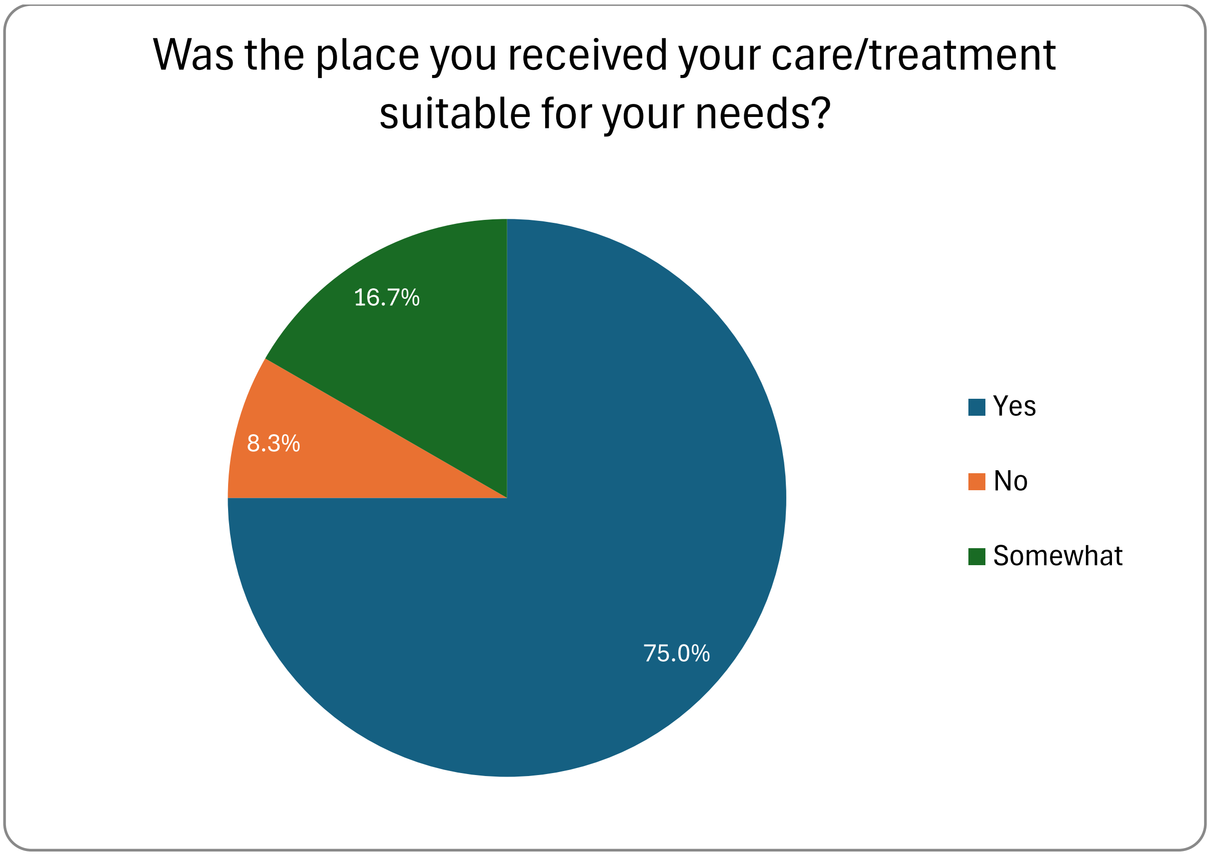
The comments below give a taste of the challenges some children face when attending appointments:

“My mummy helped me too.**”**
“I got a bit confused at times**.”**
“I was not offered anything because I do not leave the house. I was told they cannot help because I have to go to a place where I do not feel comfortable and cannot manage to go to right now.
My parents have spoken to the paediatrician, GP and dentist on my behalf.**”**

A more detailed analysis of both surveys reveals that only the Children’s Hospice service had no respondents, (parents or children), who felt they were not involved in decision making. All other services, in all locations, had some respondents who felt they were not involved in the decisions made.

The autism, ADHD and SEND services had the highest rates of respondents saying they were not involving families in decisions being made, although it should be noted there were also reasonably good numbers of practitioners involving parents and children in these services. This tends to indicate that much of the involvement of parents and children, is down to how individual clinical practitioners engage with their patients and families. Overall, the level of involvement is reasonably high, but is not universal practice.

Was the place you received your care/treatment suitable for your needs?



Children and young people answered this question indicating that three-quarters of them felt the place they received their care/treatment was suitable for their needs. Less than 10% did not think so and a further 17% felt this was ‘somewhat’ the case.

A more detailed analysis identified that children and young people felt that the service provision for autism, ADHD and SEND care was not the most suitable for their needs, however very few expanded on this. The comment below perhaps gives an indication why some children felt this way:

“Sensory overload. I was very distressed when I could go to appointments. I struggle with the environment.**”**

Responses made in other parts of the survey (what went well/not so well/what can be improved), provided more feedback on this issue, and will be explored below.

Please let us know what you feel was positive/good about the service? What did we do well?

Parents, carers, children and young people were asked similar open ended questions around what was good about the service or what went well. 60% of parents and carers responded and 63% of children and young people. Overall, this provided 353 comments. Although the question asked for feedback on what was positive/good about the service, some respondents felt unable to do so and made negative comments, however, most of the feedback to this question was positive.

Much of the feedback provided to this question primarily talked about behaviours and outcomes. The following words or phrases from parents and carers stand out:

- Amazing
- Brilliant
- Friendly and warm
- Caring
- Professional and knowledgeable
- Organised
- Efficient
- Informative
- Helpful, good advice
- Patient and thorough
- Explained well, good communication.
- Listened

Most services also received a specific mention in the parent/carer feedback provided. This included paediatrics, SALT, GPs, OTs, Midwives, Dentists, Rheumatology, ELCAS, autism, Ambulance service and others. A range of respondents qualitied their comments by adding the services were provided even ‘under constraints’, or ‘despite the system’. One theme mentioned by numerous respondents was the wait endured before receiving the service.

The feedback from children and young people used slightly different words and phrases when describing what services did well. These included:

- Everything
- Kind
- Friendly
- Polite
- Feel safe.
- Understand me
- Include me
- Make me brave.
- Listened to me

It is important to note that being listened to was something parents, carers, children and young people said on numerous occasions, which this reflects the importance of being listened to. Several children and young people also emphasised being included in discussions, or that health professionals “spoke to me rather than mum.”

Generally, respondents praised the support and care provided by staff, appreciated when services facilitated quick and easy access and were grateful for the positive outcomes that many experienced.

The following quotes give examples of the range of responses received, including the positive views expressed, some of the issues that can put limits on the positivity, and some of the negative responses received.

Positive aspects:

“Occupational Therapy were very helpful, they took time to listen, they didn't rush my daughter and tried to make her feel comfortable even though she was very anxious. We didn't have to wait too long, and they explained everything to my daughter which I think helped ease her with the tasks.**”**

“Speech and language worked really well for my daughter and her speech improved massively in such a short time. The people that worked with her were so good with her and made her feel at ease.**”**

“Explaining medical conditions in simple terms. Making me feel heard about symptoms instead of dismissing them.**”**

Both positive and negative aspects:

“Supportive professionals when you do get to see them. Who explain the options of treatment and ensure informed choices are made. The care is good, it’s the waiting for it that poses the issues.**”**

“The staff are trying but the system works against them I feel.**”**

“The professionals who did listen to me (were good). An on-call GP and an ELCAS therapist, out of a long list of professionals my son has been involved with that is a really poor amount of professionals who made me feel that my concerns were valid and worthy of further action.”

““ELCAS is working with us to help my son, and the GP have tried chasing things up and assisted with ELCAS, but the ASD pathway is letting my child down massively.”

Negative aspects:

“Navigating accessing services for disabled children needs to be a more robust process with a clear path for the family so they don't have to spend years trying to find out who to speak to, to get the services your child can access. For children with hidden disabilities, they are at a significant disadvantage and highly likely to fall through the cracks when they cannot access school etc.”

What did we not do so well?

Children and young people were asked this question and 61% (88) provided an open-text response.

The most common response was that nothing was wrong/everything was good, with over a quarter of children and young people (27%) saying this was the case. Over a fifth (21%) of respondents mentioned waiting times/getting treatment or care took too long and another 10% that they were not listened to, or their issues and needs were disregarded.

These and the other main themes arising from what was not done well are listed below, with some examples:

- Nothing was wrong/everything was good.
    - “Everything was good.”
    - “I have no problems.”
    - “Nothing bad to say.”
- Long waiting times
    - "All online and took years to hear a response to get any type of appointment."
    - "They took ages to see me."
    - “You were too full to talk to me and didn’t say where else I could go.”
    - “The waiting list.”
    - “It took like two years to get me referred.”
- Disregard for issues and needs/not listened to
    - “No help when I needed it and not listening to my needs.”
    - “I felt like I wasn't listened to, and I want them to speak to me and not my mum.”
    - “Not listened carefully.”
- Inappropriate behaviour
    - “Shouting.”
    - “Most important, a doctor was slagging my mum off.”
    - “Would not let parent speak.”
- Lack of follow-up and consistency
    - “They didn't change my cast every four weeks because I had an operation on my leg.”
    - “Little following up regarding appointments which left me in the dark. A different doctor/ practitioner every time which meant I had to reiterate my conditions over and over.”
- Inadequate facilities
    - “It was dusty and not tidy; germs.”
    - “It wasn't clean in the waiting bit.”
    - “Everything, placing me in an old storage cupboard cos there’s no spare rooms whilst at lowest point of life.”

Please provide any comments or suggestions on how you think we can improve the service. How can we improve our services?

Both parents and carers and children and young people were asked to provide comments or suggestion about how we can improve children’s services. 39% (171) of parents and carers and 56% (81) of children and young people gave open-text responses, meaning over 250 comments were made.

Parents and carers

Most of the comments made were a natural follow-on from the responses given to previous questions. The main themes identified therefore, serve as a useful summary of the issues raised by respondents throughout the survey and as an opportunity for additional points to be made about services, both in a general or in a specific context.

The main themes identified by parents and carers were:

- Reduce/improve waiting times (includes taking on more staff/increase resources)
- Provide updates whilst waiting for services/appointments/referrals – this included updates on where people are on the waiting list, offering/signposting to support, being honest about waits etc., and better communication (not leaving parents in the dark/in limbo)
- More flexible appointments structures/longer appointments, especially for children with complex needs, including SEND and autism
- Listen to parents/families and interact with children and parents.
- Provide a person-centred approach/tailor services (one size does not fit all)
- Improve communications between departments and services/improve MDT working, especially for children with disabilities, complex needs and neurodiversity.
- More training for staff, especially on autism/ADHD/SEND, including the Oliver McGowan training.
- Better information/communication with parents and carers, including providing lead professional contact details, what happens next (after appointments/assessments etc.) and more informative appointment letters.
- Equity of service provision across Lancashire and South Cumbria for all children's services, including autism/ADHD, ME, SALTs, OTs etc.
- Better support when in transition from children and young people's services to adult services
- Review discharge times.
- Doctors/staff should read EHCP/notes before seeing patients.
- Nothing to improve/all is fine as it is.

It is important to note that, although the above applies to most services, some services were mentioned more frequently or the comment made followed responses to previous questions that referenced these services. As before, these were autism/ADHD, SEND and Child and Adolescent Mental Health services.

Waiting times

Waiting times have been mentioned throughout the survey feedback. Whether waiting to be seen for an additional hour beyond the timed appointment, long waits in A&E or being on a waiting list for treatment or assessment over months (or years), this is a big concern for parents and carers, who see the impact this has on their loved ones every day. The frustration this causes is very evident in some of the responses received, in some instances this may be compounded by about a perceived lack of support, information and communication that has been experienced. An example of comments received are noted below:

"Reduced wait times. Better communication during waiting period.**"**

“Shorter waiting times and an email every so often so you know you haven't been forgotten.”

Autism, ADHD and Child and Adolescent Mental Health services

It is important to provide some examples of the concerns around accessing/waiting for autism/ADHD and mental health services. An example of comments received are noted below:

“Waiting list times for ASD and ADHD in Lancashire are so long and the support in the meantime is really sparse.”

“Commission more ADHD/ASD assessors please. This health inequity is quite shocking in 2025. Thankyou!!!”

“More capacity, consider virtual assessments. Be honest and open re waiting times and make the process simpler so all can follow it e.g. referrals between services-LD to autism.”

“CAMHS needs a huge overhaul. There needs to be far more support for neurodivergent young people and then maybe less will become as severely anxious and unable to leave the house as my daughter. Waiting times need to be addressed urgently. Staffing levels will need to be increased to cope with the demand. If CAMHS treat more young people before crisis point, this may prevent many from getting to this level rather than waiting for this to happen and then trying to help with much bigger and more entrenched issues.”

Communication, information and support

Respondents also made comments and suggestions about the levels of communication and information provided, both while waiting for assessments and in general terms. There was a clear request for children and their families ‘not to be just a number on a waiting list’, as the needs, problems and challenges faced by those with longer term physical or mental health conditions continue daily.

“Greater signposting during waiting times for referrals and diagnosis - support groups - support for child.”

“Provide clear info to family. Provide name of staff and contact details should any questions come up later on.”

“Updates on where you are on waiting lists access to fast track in cases where things are changing and going downhill.”

“Provide a better communication system so that parents aren't left in the dark for years on end. Provide a bundle of information for parents undergoing the assessment process so that they have an idea of what's available and who they can contact instead of scrolling through endless websites which can be so overwhelming especially for parents where there are barriers impacting access and communication.

Offer better support for parents, this can be such a long process that can be stressful and draining on families which impacts the child involved.”

Being listened to

There were other comments made regarding not being listened to:

“Stop treating parents like their instincts and opinions don't matter, they do. We know our children best and we don't seek further help for a bit of fun.”

“Many times, I experience lack of empathy from some of her clinicians to me as a carer. For goodness sake I know how important routine is for good sleep, do you think I haven't tried. So patronising and disrespectful.

I ended up in tears in one consultation out of sheer frustration. The clinician was actually quite nice but completely disconnected from the reality for carers.”

Joined-up care.

Several parents and carers were clear about the need for more joined up care and improved communication between services. This also aligns with requests for more person-centred services:

“Multiagency and cross team training is essential. At the minute services are pulling away from each other and this is duplicating efforts and causing system fatigue for all.”

“Some of my daughter’s clinicians need to align their care for her. for example, the community consultant paediatrician, paediatrician, dietitian and bowel and bladder nurse sometimes have provided conflicting information around diet, sleep and bowel habits.”

“It is important for care to be holistic, and family centred. Services need to stop silo working and looking at only one part of a jigsaw. Connected healthcare is essential!”

“Tailored services for children who need things explained differently and need support in other ways.”

“Make sure reasonable adjustments are being made for people with special needs - they are all different and unique and one size does not fit all.”

Staff training in autism, ADHD, mental health and SEND.

One of the significant points raised was the need for health staff across services and across locations, to have a deeper understanding of and training in recognising and delivering services to children with neurodiversity and/or mental health:

“There need to be more training for CAMHS practitioners around supporting neurodivergent young people.”

“Up to date neurodivergent training is needed and services must become neurodivergent friendly. NHS professionals and patients with lived experience should be used to inform service development.**”**

“More staff trained in SEND; more patient liaison needed.**”**

“There is no understanding of autism and learning disability including pathological demand avoidance, in any NHS services my child has needed to attend. This created barriers, misunderstandings, inappropriate communication and lack of care and respect for child and parent**.”**

“I think your staff from the receptionists , the person who weights , takes height , does lung function and finally the asthma consultant would benefit from more training so that they recognise a person with SEN / autism / communication difficulties and can then adjust how they deal with them in outpatient limited time appointments.**”**

Other suggestions:

There were a small number of service specific suggestions or requests, and it is important that these should be considered, as they will all apply more broadly across Lancashire and South Cumbria. These included:

“Medical professionals attend EHCP Annual Reviews. Medical professionals to attend TAFS. Employ a Sensory Integration Specialist team within OT service.”

“Please acknowledge sensory processing disorder as a standalone condition and provide occupational therapy for it.”

“Improve shared care agreement with accredited RTC companies for smooth transition RE medication post diagnosis.”

“Feel like parents should be involved with a range of options rather than a 'medication led approach' also need to see what options are available and allow parents to decide and not just medical professional!!”

“The level of restraint used on children who are autistic in order to take blood samples is far too strong and highly upsetting. Staff should know about/be trained on the needs of autistic children and be able to talk to patients accordingly.”

““I am very unhappy that people in Preston can get a service (OT support of children with ME) and people in East Lancs cannot and must pay privately, even though it is all under the same NHS commissioning organisation. This is grossly unfair and goes against the whole idea of one commissioning organisation for the area.”

“CAMHS (should) assess deaf children. Work with deaf specialist such as teachers of the deaf or train SALT to LEVEL 1 BSL & deaf awareness for insight. Pool resources with schools CSWs to enable thorough assessments.”

Children and young people

Although a higher percentage of children and young people made suggestions about how services could be improved, fewer themes were mentioned. 25% of children and young people who responded to this question indicated everything was fine/there was nothing to improve, whereas only 7% of parents and carers made this response.

The main themes identified by children and young people were:

- Reduce/improve waiting times.
- Listen to children and young people.
- More kindness and compassion
- Get more staff.
- Share information better.
- Provide more services locally.
- Not sure
- Everything was fine.

Much of the above dovetails with the points raised by parents and carers. It is valuable however, to finish this section with the voices of the children and young people themselves, some of which brings a personal touch to the points being made.

“Listen to me and be more kind.”

“More doctors that show compassion, sensitivity.”

“Shorter waiting time. Make it more personal. Send letters more than once year.”

“Focus on the main reason someone came in and don't disregard their needs.”

“Give the right help at the right time instead of making us wait for months for things to get worse.”

“Being more transparent about appointments and waiting times. Having the same doctor each appointment and being told prior to appointments if my doctor has changed. Having services closer.”

“Better support for autistic children. Understanding of autism and burnout and how this has affected my life. I have no school to go to, I am depressed, I struggle to go out of the house, I struggle with sleep, I have trauma.”

This feedback highlights the importance of kindness, effective communication, timely access to services, and personalised care. It also points out areas where improvements can be made, particularly in reducing waiting times, improving facilities, and providing better support for specific needs.

To see more responses from the questionnaires please see Appendices 1 and 2.

Insights we have gained from this process.

The Feedback Fortnight 2025 project event served as a pilot initiative aimed at gathering real-time feedback from children, young people, parents, and carers across Lancashire and South Cumbria. This pilot was instrumental in testing our approach to engagement and feedback collection, providing several key themes for future delivery. After the event we circulated a “lessons learnt log” to gain feedback from staff members who were involved the process, providing us with broader insight to the delivery and how this could be improved for any future feedback initiatives.

One of the primary lessons learned was the importance of clear communication and outreach strategies. The initiative's success in engaging over 500 participants and collecting 583 completed questionnaires was seen as a testament to the community's willingness to participate and the effectiveness of the engagement strategies employed. This positive reception underscores the importance of continuous engagement and feedback in enhancing service delivery and ensuring that the needs of children and young people are met effectively. However, we identified that we needed to attend more varied community venues to ensure we captured more children and young people’s voices.

To see more responses from the “lessons learn log” please see Appendix 3.

Recommendations

Below are the key recommendations to improve healthcare services for children, young people, and their families:

Enhance Communication:

Improve communication between healthcare providers and service users to ensure clear and timely information is provided.

Improve Waiting Times:

Implement measures to improve waiting times for healthcare services to enhance accessibility and user satisfaction.

Increase Service Availability where applicable:

Attend more varied community venues to capture a broader range of voices from children and young people and support care closer to home.

Continuous Engagement:

Emphasise the importance of continuous engagement and feedback to ensure that the needs of children and young people are met effectively.

Personalised Care:

Focus on providing personalised care that addresses individual needs and improves overall satisfaction with the care received.

Accessibility of Questionnaires:

Simplify the complexity and length of questionnaires to make them more engaging and accessible for younger participants.

Feedback Integration:

Integrate feedback into service improvement plans to ensure that the insights gathered lead to tangible changes in service delivery.

These recommendations aim to create a more responsive and user-friendly healthcare system that better meets the needs of children, young people, and their families.

To see more responses from the questionnaires please see Appendices 1 and 2.

Conclusion

Feedback Fortnight was overall a successful pilot initiative that provided valuable insights into the experiences of children, young people, parents, and carers. The feedback gathered will be shared with all the providers who took part and will be put on the ICB website for all participants and service users to view with the aim of being used to improve healthcare services and programs of work across Lancashire and South Cumbria.

Next steps

This report will be formally presented to the ICB via the Lancashire and South Cumbria Children and Young People Operational Leadership Group and the Lancashire and South Cumbria Children and Young People's Board with support to progress the recommendations. This will include:

- Development of ongoing engagement and feedback processes to ensure that commissioners and providers remain sited on areas of good practice and areas for improvement.
- Formal submission of report to commissioners to ensure that recommendations are considered and addressed, this includes:
    - Improving communication between commissioned services
    - Ensuring enough resource and capacity is commissioned to address wait times, increase accessibility and ensure personalised care.
    - Ensuring providers develop improvement plans to address the recommendations from feedback fortnight.
    - Communicate any improvements made as a result of the feedback from families.

This report will also be passed to the Neurodevelopmental Pathway All-age Steering Group for their consideration.

Appendices

Appendix 1 – Parent/Carer questionnaire responses

4. Where did you access the service(s) you have selected in the previous question i.e Royal Blackburn Hospital, Acorn Centre etc?

This list, which is not exhaustive, includes a variety of medical centres, hospitals, dental practices, and specialised clinics across various locations as detailed below**:**

Acorn, Burnley General Teaching Hospital
Padiham Medical Centre, dentistry for all Nelson
Royal Blackburn Hospital
Rainbow Centre
Acorn Centre
Broadoaks, Leyland
Shadsworth Children Centre
LRI, Queen Vic, Longlands
Chorley Health Centre, Blackpool Victoria Hospital, Whitegate Drive Health Centre, Royal Preston Hospital
Lancaster CAMHS, Manchester Deaf CAMHS, Longlands SALT, RLI Audiology and ENT, Fulwood Audiology, Portage Team Lancaster, Inclusion Team, Teacher of the Deaf Team Lancaster SEND
Royal Manchester Children’s Hospital, Lancaster Royal Infirmary, Royal Preston, Park View Surgery Preston
Great Harwood and Barbara Castle Way
Burnley Group Practise
Rossendale Dentist, Oswaldtwistle Doctors
Clitheroe and Burnley Hospital
Stonebridge Surgery Doctors
Berry Lane Medical Centre
Tarleton GP & Dentist, Ormskirk District Hospital
West Lancs CAMHS, Skelmersdale
Witton Medical Centre and My Dentist
Ribbleton Family Hub, Ribbleton Hall Drive, Ribbleton, Preston, PR2 6EE
Pendleside Medical Practice
Blackpool Victoria Hospital, Royal Lancaster Infirmary, Over Wyre Medical Centre
Royal Oldham Hospital, Milnrow Village Practice
Bolton
Fleetwood Hospital
Cleveleys Group Practice
Mountview Fleetwood, Safehands Dentist Cleveleys, Specsavers Blackpool, Whitegate Drive, Sameday Fleetwood, Blackpool Victoria Hospital
Baxenden Dental, Accrington PWE
Great Harwood Medical Centre, Royal Blackburn and Burnley General
Blenheim House Child Development Centre, Whitegate Drive
Blackpool Victoria Hospital, Mountview Practice
Lancaster Medical Practice, My Practice Dental Surgery Lancaster
Royal Lancaster Infirmary, Queen Vic Morecambe, Longlands
Lancaster Medical Practice (GP), Royal Lancaster Infirmary - Maternity Care
Lancaster Medical Practice, Owen Road
Lancaster Royal Hospital
Lancaster Medical Practice, Royal Lancaster Hospital Emergency Department
Lancaster Medical Practice, Owen Road Surgery, RLI, Queen Vic Morecambe, Longlands

5. Were you able to access the service(s) when you needed to?

Additional Comments:

Positives

- *“The user was able to make contact with the autism pathway and received frequent communication.”*
- *“The LD nurse has been very helpful and provided significant support.”*
- *“The user found the Our Voice service valuable and supportive of children in LA care, providing therapeutic talking therapy.”*
- *“The GP has provided appointments and support when the user's daughter was unable to attend due to autism/ADHD/severe anxiety.”*
- *“The user had a positive experience with the combined ADHD pathway through the right to choose provider Evolve.”*
- *“The hospital staff were amazing during a visit.*
  I hope this helps! If you need any further assistance or details, please let me know!”

Negatives

- *“ELCAS has refused to help the user's son twice when he needed assistance.*
  There have been significant delays in accessing services, such as waiting over six months for a referral to paediatrics.
  The user has been waiting nearly two years for the ASD pathway.”
- *“The user's son was discharged from the OT pathway before being seen, which was later found to be an error.*
  Neurodiverse services are inadequate, and children are often discharged for being unable to access services.”
- *“The user's daughter has been waiting for over six months for a referral to paediatrics due to ongoing knee pain.*
  The user has tried to refer their son to the Children's Complex Care Team but was told they couldn't apply for support due to a lack of someone to complete the referral form.
  There have been issues with accessing services for taking bloods at home due to anxiety/needle phobia.”
- *“CAMHS refused to assess the user's children because they are deaf, and the threshold for Deaf CAMHS is severe/profound hearing loss.*
  The user has faced difficulties in accessing both the Inclusion team and Teacher of the Deaf, leading to a choice between hearing or neurodivergence.
  The user's daughter was seen by a paediatric doctor who misdiagnosed her stress symptoms.”
- *“The support services within Blackburn with Darwen are inadequate, with long waiting times and multiple rejections from ELCAS*.”
- *“There is a need for expanding therapy offers, including music therapy, which is currently unavailable.”*

6. Please tell us how satisfied you were with the care delivered by the service.

Additional Comments:

Positives

- *“All appointments were on time; the care was really good, and feedback usually arrives few days after the appointment*.”
- *“Friendly and helpful staff”*
- *“Amazing, fast waiting times and friendly”*
- *“Friendly staff, engaging, good care, children’s ward clean and tidy and even smelt clean.”*

Negatives

- *“Doctor hardly speaks to the children nor give them eye contact, so they are aware she is speaking directly to them. Room has no sensory equipment and too clinical, children are anxious.”*
- *“Lack of understanding of autism and my child's needs. As a parent felt gaslighted and blamed”*
- *“No interim support”*

8. Please tell us how satisfied you were with the information provided to you and your child about the service.

Additional Comments:

Positives

- *“Dad dyslexic but info explained well enough to understand.”*
- *“Our Voice is a valuable additional service that is supportive of the children in the LA care, they are understanding of trauma related complex behaviours and provide therapeutic talking therapy which the children find helpful.”*
- *“Bowel and bladder very quick and efficient response. Thorough first assessment. Treatment within 2 weeks via GO”*
- *“No complaints at all. Nurses were excellent.”*
- *“Always feel listened to by professionals when at appointments for both boys.”*

Negatives

- *“Information was ok but not really helpful (as they didn't listen to me)”*
- *“Long waiting times. no OT support for child. Not enough frequent appointments for speech. GP have not been helpful.”*
- *“Only received one leaflet when children first diagnosed regarding ADHD Northwest, nothing regarding Autism. I have had to learn and seek information myself and through research and reading. Parents/Carers are often left to their own devices once children are diagnosed.”*

10. Did you feel involved in any decisions made about the care provided to your child?

Additional comments:

Positives

- *“School referrals - good communication. information always taken into account.”*
- *“Fully involved I. Decisions regarding treatment options.”*
- *“Good information and advice given.”*
- *“Perfect care.”*

Negatives

- *“Decisions are not being made due to terrible waits for appointments and access to care.”*
- *“My daughter doesn't explain and tends to agree with professional people such as doctors. I am her appointee and have completed the form to advocate on her behalf*

in medical appointments, but often I feel as if I am not listened to (or listened to but not heard) when we are in appointments."

- *"Some things have to go to panels and tribunals, making it difficult to feel fully involved with the process."*

11. Please let us know what you feel was positive/good about the service.

Additional Comments:

Positives

- *"Psychology- being able to speak to the psychologist and email my worries and questions."*
- *"The waiting time for appointments wasn't too long. The professionals were very nice and clear about the next phase."*
- *"Speech and language worked really well for my daughter and her speech improved massively in such a short time. The people that worked with her were so good with her and made her feel at ease."*
- *"When attending appointments, I don't feel rushed, they are very good at listening."*
- *"They really listened to me."*

Negatives

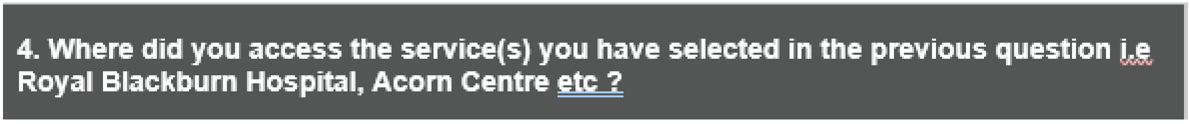
- *"Navigating accessing services for disabled children needs to be a more robust process with a clear path for the family so they don't have to spend years trying to find out who to speak to, to get the services your child can access. For children with hidden disabilities, they are at a significant disadvantage and highly likely to fall through the cracks when they cannot access school etc."*
- *"The community paediatrician is very supportive but actually getting in to see them is difficult. Otherwise, you don't get a service you are just waiting for it."*

12. Please provide any comments or suggestions on how you think we can improve the service.

Additional Comments

- *"More flexibility for children who are likely to struggle with a remote consultation. Better sharing of information and cross referral for neurodivergent patients."*
- *"I also think that even an extra 5 mins allotted appointment would be beneficial. Also, for someone with any of the above an appointment at the start of clinic would be better than later as they have difficulty coping in busy places."*
- *"A person centred approach to care particularly to the child, rather than typing lots of notes with the back to the child, face them, take interest in what they are saying and their parents, make the room less clinical more engaging with sensory toys/equipment. Children and young people will often engage in the environment feels safe and there is equipment they can play with; this will allow them to participate in dialogue."*
- *"Nil. Very great full we have such a good range of services to support the child and parents."*
- *"Always have positive experience in the NHS - Thankyou :)"*

Appendix 2 – CYP questionnaire responses



4. Where did you access the service(s) you have selected in the previous question i.e Royal Blackburn Hospital, Acorn Centre etc ?

Responses listed alphabetically along with the number of times each was mentioned:

- Acorn Centre: 2
- Adelaide General Practice: 1
- Alder Hey Pain Management: 1
- Ash Trees Surgery: 1
- Ashtree House Surgery: 1
- Bentham Road Health Centre: 1
- Blackpool Victoria Hospital: 11
- Bolton One: 1
- Boots Optician's: 2
- Broadway Medical Centre: 2
- Broadoaks Physiotherapy and Occupational Therapy: 1
- Broadoaks’ Child Development Centre: 1
- Bupa Dentist: 1
- Burnley General Hospital: 2
- Central Lancaster High School: 1
- Chorley and South Ribble Hospital, Eye Clinic: 1
- Doctor Surgery, Colne: 2
- Fleetwood Hospital: 1
- Fleetwood Medical Centre: 1
- Fleetwood Clarity: 1
- GP Practice, Burnley General Hospital: 1
- Harvey House: 3
- Hub in Rawtenstall: 1
- Lancashire and South Cumbria RAIST Team: 1
- Lancaster CAHMs: 1
- Lancaster Hospital: 1
- Lancaster Medical Practice: 1
- Moor Nook Youth Club: 3
- Mount View Fleetwood: 20
- Our Voice Project - Child Action North West: 2
- Preston CAMHS: 1
- Queen Victoria Hospital, Lancaster: 1
- Ribbleton Family Hub: 2
- Rossendale Primary Health Care Centre: 1
- Royal Blackburn Hospital: 10
- Royal Manchester Children’s Hospital Epilepsy Team: 1
- Royal Preston Hospital: 6
- Shawbrook House CAMHS: 2
- The Cove: 2
- Walk-in Centre Skelmersdale: 1
- White Gate Drive Medical Centre: 6

5. Were you treated kindly?

Additional comments:

Positives

- *"The staff was really kind to me."*
- *"Very polite."*
- *"Reception staff are always kind and take their time to sort out appointment and test results."*
- *"Receptionist was nice."*

Negatives

- *"Making me feel frightened and uncomfortable."*
- *"Shouting."*
- *“Mostly good but someone was a bit unkind.*
- *“One of the nurses was a bit grumpy to my mum at the hospital.”*

6. Did you feel listened to?

Additional Comments:

Positives

- *“The doctor listened to what my Mum said and asked me questions about how I felt.”*
- *"Feel listened to and supported through big transitions."*
- *"Doctors were nice and listened to me."*
- *"Always listened."*

Negatives

- *"Not listening to my needs."*
- *"Not listened carefully."*

7. Did you feel involved in decisions about your care?

Additional Comments:

Positives

- *“The doctor asked me if I wanted to try pills or wait for a bit or not try them at all.”*
- *“Feel involved in my support sessions.”*
- *"Always include me in the discussions about my health."*
- *"They listened to me and let me have a say."*

Negatives

- *“I was not offered anything because I do not leave the house. I was told they cannot help because I have to go to a place where I do not feel comfortable and cannot manage to go to right now.”*
- *"Disregarded my actual issues and needs."*
- *"Made me do things I don't like and not much to do just colouring. I'm often bored there."*

8. Were you given enough information to be able to make decisions about your care/treatment?

Additional Comments:

Positives

- *"Explaining medical conditions in simple terms. Making me feel heard about symptoms instead of dismissing them."*
- *"Talking to me and explaining things."*
- *"Explain well."*

Negatives

- *"Not giving me enough information."*
- *"Lack of knowledge regarding 'right to choose'."*
- *"Send information straight away."*
- *"Give people more information."*

9. Was the place you received your care/treatment suitable for your needs?

Additional Comments:

Positives

- *"Enjoy doing practical activities, I have fun. I am learning about myself too. The sessions help me find ways to manage myself."*
- *"They make me feel safe."*
- *"Treated me with my needs."*

Negatives

- *"Workmen were in the building and their drill was too loud."*

10. What did we do well?

- *"They listened to me and let me have a say."*
- *"Spoke to me rather than mum."*
- *"I was able to access the services very quickly and easily through my school."*
- "Your doctors cured my illness and made my health back to normal and made me feel like I was healthier and safer."
    - "Help with my physio."
    - "Give me good medicine and give me info about how to take care of myself."
    - "Made me feel safe."
- "My bones are fixed, and I am alive."

11. What did we not do so well

- *"Not giving me enough information."*
- *"The waiting list."*
- *"It took like two years to get me referred."*
- *"Little following up regarding appointments which left me in the dark."*
- *"All online and took years to hear a response to get any type of appointment."*
- *"You were too full to talk to me and didn’t say where else I could go."*

12. How can we improve our services?

Additional comments:

- *"Improve receptionist attitude and the way the system works."*
- *"Kinder staff."*
- *"Less waiting time."* ***(mentioned multiple times)***
- *"Make it more personal."*
- *"Send letters timelier."*
- *"Not have workmen in when I have an appointment."*
- *"Food shops in the hospitals."*
- *"Vending machine."*
- *"Making sure machines work."*
- *"More staff."*
- *"Cheaper dentists."*

Appendix 3 – Lessons learnt log.

As part of the process in conducting this Pilot for Feedback Fortnight, a lessons learnt log was distributed to the staff who took part who then fed back the following:

1. Communications:

    - Events were booked in advance, but there was pushback from some staff at the venues who were unaware that we were attending.
    - An in-depth communications plan would have helped both the team, and the providers gather feedback more effectively.

Suggestion: Produce an in-depth comms plan at the beginning of the process

2. Questionnaires:

    - The questionnaires were not designed for parent/carers who had more than one child.
    - The questions would also need to be relooked at i.e. – one question asked around venues and although this gave us an idea of which clinics they were attending, this was not necessary.

Suggestion: Design questionnaire so that parents can incorporate more children to be added. Re-look at the questions and co design again with parent/parent carers, children & young people.

3. Contribution from CYP:

    - More feedback could have been gathered from Children & Young People if one of the weeks was during school holidays or if we had booked some sessions in schools and took part in assemblies and after school clubs.

Suggestion: Incorporate schools/youth centres during school holidays and visit venues with events happening.

4. Venues:

    - Some venues had low footfall, making it challenging to gather feedback.
    - Specific venues like Fylde family hub, South family hub, and Greenlands had issues with footfall and engagement.

Suggestion: Explore other venues such as Parent/Carer events, youth centres, schools, colleges, and community events.

5. Title on Boards:

    - Change the name from "Feedback Fortnight" to something more engaging like "HAVE YOUR SAY".
    - The boards were heavy and cumbersome to carry round venues.

Suggestion: Use smaller, lighter boards and a pull-up banner with the new title

6. Digital or Printed:

    - Ensure plenty of printed copies of questionnaires as many people did not want to use the QR code.

Suggestion: Print more copies off.

7. Posters:

    - Print and distribute more posters in venues to leave once you have completed you session of engagement.

Suggestion: Print more copies off for distribution to venues

Overall, better planning, communication, and venue selection may improve the effectiveness of future feedback sessions.

Appendix 4 – Feedback Fortnight poster co-produced with CYP

NHS FEEDBACK FORTNIGHT

YOUR NHS WANT TO HEAR FROM YOU!

NHS

3RD - 14TH MARCH 2025

Are you aged 8-18 (up to 25 with SEND)??
Share your experiences and change the services you access!!
Scan the QR code!!

Designed and produced by Rossendale Youth Council
December 2024

Appendix 5 – Link to promotional video developed by CYP

Young Person promotional video

(1) Video | Facebook

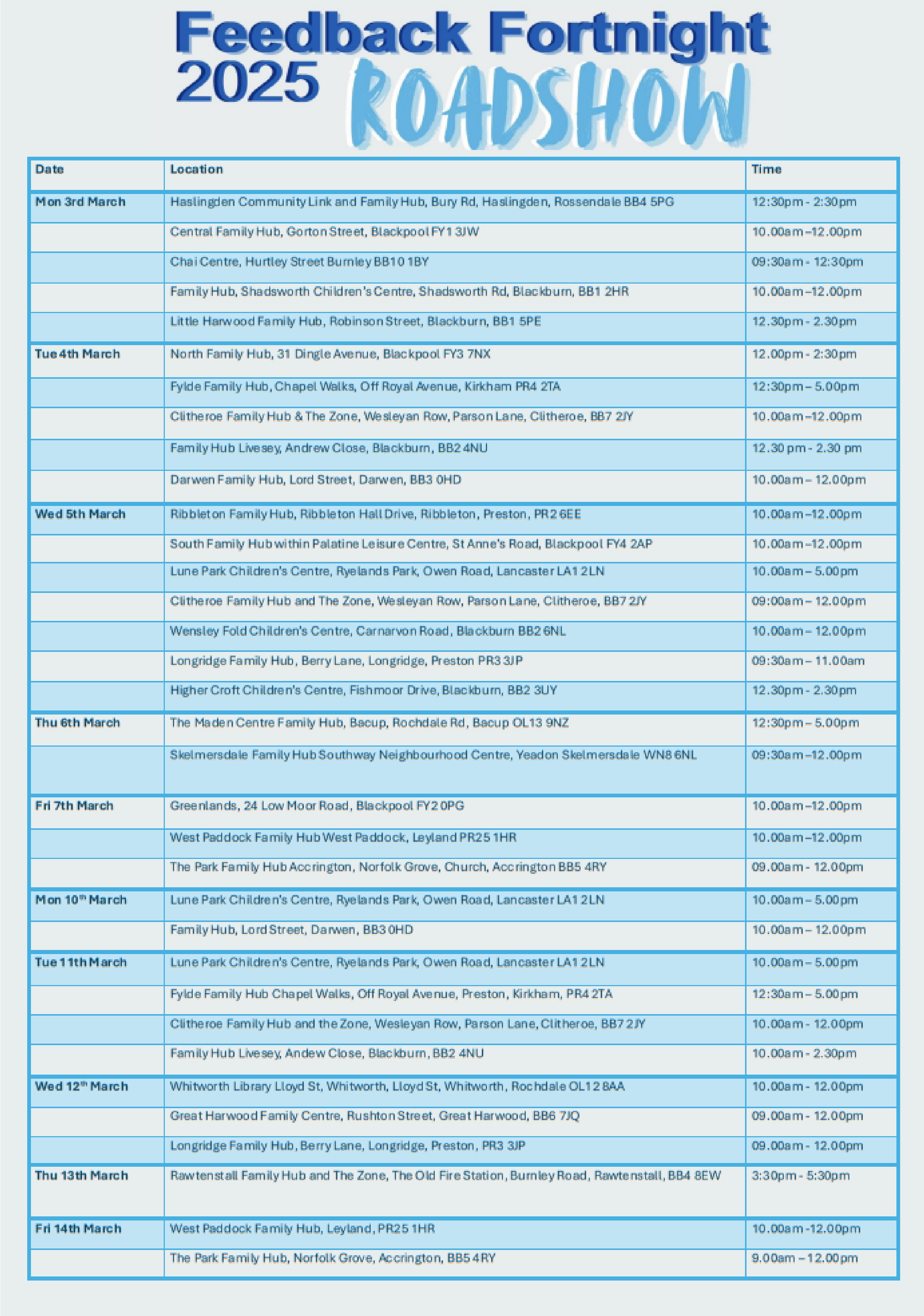
Appendix 6 – Link to TV interview

Vanessa Wilson interview with That's TV Lancashire
https://fb.watch/yS7CShpFkr/

Appendix 7 – Picture of Rossendale Youth Council receiving certificates

Rossendale Youth Council receiving their certificates for their valuable input.

Appendix 8 – Feedback Fortnight Roadshow poster



Feedback Fortnight 2025 ROADSHOW

Date	Location	Time
Mon 3rd March	Haslingden Community Link and Family Hub, Bury Rd, Haslingden, Rossendale BB4 5PG	12:30pm - 2:30pm
	Central Family Hub, Gorton Street, Blackpool FY1 3JW	10.00am –12.00pm
	Chai Centre, Hurtley Street Burnley BB10 1BY	09:30am - 12:30pm
	Family Hub, Shadsworth Children's Centre, Shadsworth Rd, Blackburn, BB1 2HR	10.00am –12.00pm
	Little Harwood Family Hub, Robinson Street, Blackburn, BB1 5PE	12.30pm - 2.30pm
Tue 4th March	North Family Hub, 31 Dingle Avenue, Blackpool FY3 7NX	12.00pm - 2:30pm
	Fylde Family Hub, Chapel Walks, Off Royal Avenue, Kirkham PR4 2TA	12:30pm – 5.00pm
	Clitheroe Family Hub & The Zone, Wesleyan Row, Parson Lane, Clitheroe, BB7 2JY	10.00am –12.00pm
	Family Hub Livesey, Andrew Close, Blackburn, BB2 4NU	12.30 pm - 2.30 pm
	Darwen Family Hub, Lord Street, Darwen, BB3 0HD	10.00am – 12.00pm
Wed 5th March	Ribbleton Family Hub, Ribbleton Hall Drive, Ribbleton, Preston, PR2 6EE	10.00am –12.00pm
	South Family Hub within Palatine Leisure Centre, St Anne's Road, Blackpool FY4 2AP	10.00am –12.00pm
	Lune Park Children's Centre, Ryelands Park, Owen Road, Lancaster LA1 2LN	10.00am – 5.00pm
	Clitheroe Family Hub and The Zone, Wesleyan Row, Parson Lane, Clitheroe, BB7 2JY	09:00am – 12.00pm
	Wensley Fold Children's Centre, Carnarvon Road, Blackburn BB2 6NL	10.00am – 12.00pm
	Longridge Family Hub, Berry Lane, Longridge, Preston PR3 3JP	09:30am – 11.00am
	Higher Croft Children's Centre, Fishmoor Drive, Blackburn, BB2 3UY	12.30pm - 2.30pm
Thu 6th March	The Maden Centre Family Hub, Bacup, Rochdale Rd, Bacup OL13 9NZ	12:30pm – 5.00pm
	Skelmersdale Family Hub Southway Neighbourhood Centre, Yeadon Skelmersdale WN8 6NL	09:30am –12.00pm
Fri 7th March	Greenlands, 24 Low Moor Road, Blackpool FY2 0PG	10.00am –12.00pm
	West Paddock Family Hub West Paddock, Leyland PR25 1HR	10.00am –12.00pm
	The Park Family Hub Accrington, Norfolk Grove, Church, Accrington BB5 4RY	09.00am - 12.00pm
Mon 10th March	Lune Park Children's Centre, Ryelands Park, Owen Road, Lancaster LA1 2LN	10.00am – 5.00pm
	Family Hub, Lord Street, Darwen, BB3 0HD	10.00am – 12.00pm
Tue 11th March	Lune Park Children's Centre, Ryelands Park, Owen Road, Lancaster LA1 2LN	10.00am – 5.00pm
	Fylde Family Hub Chapel Walks, Off Royal Avenue, Preston, Kirkham, PR4 2TA	12:30am – 5.00pm
	Clitheroe Family Hub and the Zone, Wesleyan Row, Parson Lane, Clitheroe, BB7 2JY	10.00am - 12.00pm
	Family Hub Livesey, Andew Close, Blackburn, BB2 4NU	10.00am - 2.30pm
Wed 12th March	Whitworth Library Lloyd St, Whitworth, Lloyd St, Whitworth, Rochdale OL12 8AA	10.00am - 12.00pm
	Great Harwood Family Centre, Rushton Street, Great Harwood, BB6 7JQ	09.00am - 12.00pm
	Longridge Family Hub, Berry Lane, Longridge, Preston, PR3 3JP	09.00am - 12.00pm
Thu 13th March	Rawtenstall Family Hub and The Zone, The Old Fire Station, Burnley Road, Rawtenstall, BB4 8EW	3:30pm - 5:30pm
Fri 14th March	West Paddock Family Hub, Leyland, PR25 1HR	10.00am -12.00pm
	The Park Family Hub, Norfolk Grove, Accrington, BB5 4RY	9.00am – 12.00pm

Appendix 9 – Feedback Fortnight Roadshow MS Teams poster

Feedback Fortnight 2025 ROADSHOW

Join our online Teams meeting to give your feedback and have your voice heard!

Young People

Monday 3rd March

6:30-7:30pm

SCAN ME TO JOIN

Parents and Carers

Thursday 6th March &

Wednesday 12th March

6:30-7:30pm

SCAN ME TO JOIN

NHS
Lancashire and South Cumbria
Integrated Care Board