Learning Disability Improvement Standards

Findings From Year 8 of the Benchmarking Exercise: Patient Focus Groups

Patient Focus Groups

As part of Year 8 of the benchmarking exercise, the NHS Benchmarking Network worked with Learning Disability England (LDE), to run seven regional focus groups with people with a learning disability and autistic people. The sessions were structured around the NHS Learning Disability Improvement Standards, giving participants a direct way to share their experiences of NHS care. Their feedback is intended to help shape more accessible, supportive and person-centred services.

These session were delivered in partnership with seven local organisations:

ACE Anglia (East of England)

Dudley Voices for Choice (Midlands)

Pathways Associates (North West)

Skills for People (North East & Yorkshire)

People First Forum (South West)

Lewisham Speaking Up (London)

Active Prospects (South East)

These seven organisations are all committed to improving the lives of people with learning disabilities through advocacy, inclusion, and person-centred support. Working across different regions of England, they empower individuals to have their voices heard, increase independence, and participate fully in their communities. Their work includes self-advocacy, peer support, training, accessible information, community engagement, and tailored services that promote equality, confidence, and greater involvement in decision-making. Collectively, they share a strong commitment to ensuring that people with learning disabilities are supported to live fulfilling, independent, and inclusive lives.

Patient Focus Groups

218 individuals with learning disabilities shared their experiences of using NHS services this year, a substantial increase from **46** participants last year. Participants represented a broad range of demographic groups, including diversity across gender, age, and ethnicity. The focus groups were guided by questions covering key areas such as dignity and respect, communication, access to appropriate care & support, inclusion of family & support. Demographic information was collected through an optional monitoring form. Of the **218** individuals with a learning disability who took part, **59** (**27%**) completed the form, so the figures below may not be representative of all participants.

Gender		
Male	35	59%
Female	23	39%
Non-binary	0	0%
Prefer not to say	1	2%

Ethnicity		
White / White British / White Other	48	81%
Asian / Asian British	2	3%
Black / Black British	7	12%
Mixed race	0	0%
Other ethnicity	0	0%
Unknown / not stated / prefer not to say	2	3%

Age		
Under 16	0	0%
16-17	0	0%
18-24	2	3%
25-34	2	3%
35-44	12	20%
45-54	23	39%
55-64	13	22%
65-74	3	5%
75-84	1	2%
85 and over	1	2%
Prefer not to say	2	3%

What People Told us About Their Care

The focus groups were guided by questions covering key areas such as dignity and respect, communication, access to appropriate care and support, and the inclusion of family and supporters. In total, **1,065** comments were collated and carefully analysed — **893** describing people's experiences of care, and a further **172** offering suggestions on how the NHS could improve. This represents a substantial increase on the **176** comments gathered last year, reflecting the expansion of what began as a pilot with three groups into a much wider engagement this year. From these we identified six overarching themes relating to the healthcare experiences of people with a learning disability and autistic people, aligned to the NHS England Learning Disability Improvement Standards. Participant accounts were positive, negative and mixed, spanning communication, accessibility, inclusion, safety and treatment. Findings are presented thematically, with illustrative participant quotes used to demonstrate the key patterns in the data.

Feedback was gathered through a range of accessible methods designed to make taking part as easy as possible. People could share their views one to one or in group sessions, in person or online, or complete a survey with support — by phone, via WhatsApp, or in familiar settings such as self-advocacy sessions. Larger face-to-face meetings in January 2026 were run as smaller facilitated table groups, with some participants joining via Teams. Group sessions used accessible information and prompt questions, with people sharing their own experiences and each group agreeing its "top five things to make hospital better."

1,065
Comments analysed

893
Experiences of care

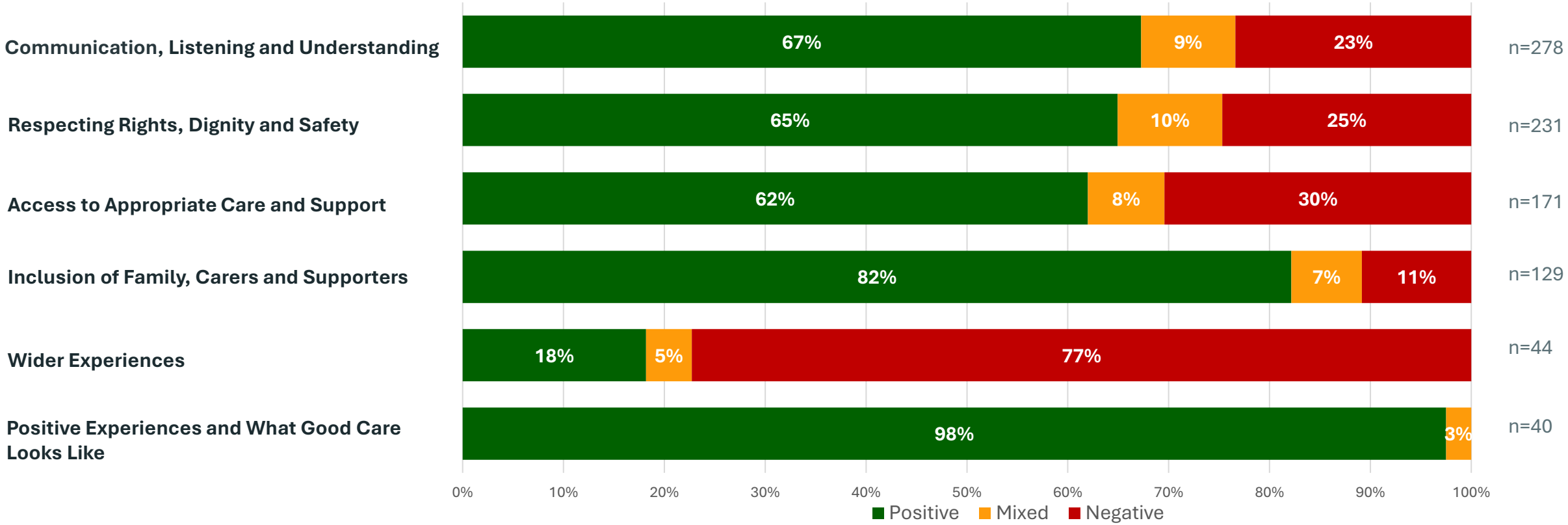
6
Themes Identified
From people's experiences of care

172
Improvement suggestions

Learning Disability
Improvement Standards

Breakdown of feedback by theme

Across **893** coded responses, the overall picture of people's hospital experiences was broadly positive, though with significant areas of concern. Two-thirds of responses were positive (**596, 67%**), a quarter were negative (**222, 25%**), and the remainder were mixed (**75, 8%**). The chart below shows how positive, mixed and negative responses were distributed within each of the six themes, ordered by the number of responses they attracted.

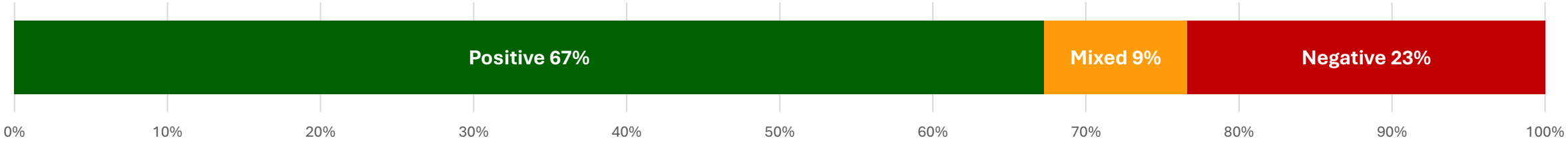


Learning Disability Improvement Standards

Each bar shows the share of positive, mixed and negative responses within that theme. Percentages may be greater than 100% due to rounding

Communication, Listening and Understanding

How people felt (278 responses)



A largely positive theme — but the positives depended on staff getting it right. Two-thirds of responses were positive, with clear explanations and feeling listened to the strongest positives in the whole dataset. The shortfalls were systemic rather than personal — accessible information, especially Easy Read, was the one major area more negative than positive, alongside jargon, pace and not always being spoken to directly.

When it went well

Communication worked when staff made it work — clear explanations, no jargon, Easy Read offered, and time taken to listen. Where that effort was there, it showed.

"They listened to me and explained what they were going to do."

"They gave me good information about my operation."

When it fell short

Where care fell short, information was hard to understand, accessible formats were rarely offered, and some felt ignored when they tried to ask questions.

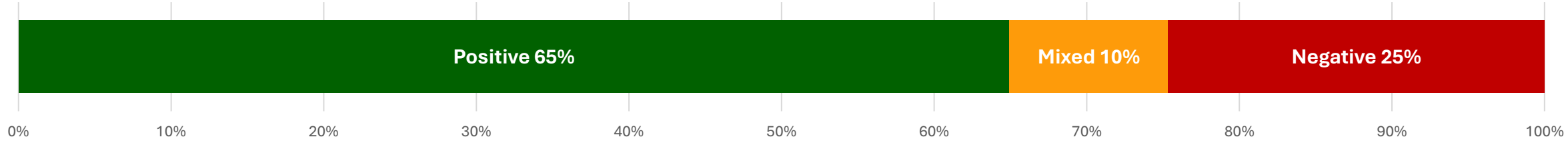
"I didn't feel they were listening to me — they made me feel like I was stupid."

"I wish I could have had an Easy Read letter."

Counts reflect coded responses, not unique individuals. Based on the 893 sentiment-coded experience comments.

Respecting Rights, Dignity and Safety

How people felt (231 responses)



Overall positive — but only where the essentials were actively put in place: Around two-thirds of responses described being treated with respect, driven above all by reasonable adjustments being recognised and met. Where people had concerns, these focused on dignity and being given a voice in their own care — and on safety, where as many people felt unsafe as felt safe, often on mixed wards or around unfamiliar staff.

When it went well

People felt respected where staff acted deliberately — making reasonable adjustments, seeking consent, and treating them as individuals. These are what people should be able to expect — the fact they stood out says they aren't yet the norm.

"I got treated like a normal person but also felt like my extra needs were accommodated."

"They always ask about reasonable adjustments before doing anything."

When it fell short

Where care fell short, people were talked down to or denied a voice in their own care — and some did not feel safe.

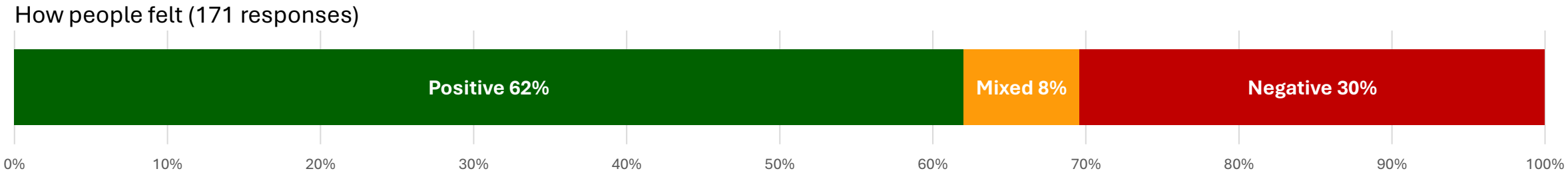
"They didn't give me a chance to speak. It felt as though they were putting words in my mouth."

"Talking to me like I was a kid."

Learning Disability Improvement Standards

Counts reflect coded responses, not unique individuals. Based on the 893 sentiment-coded experience comments.

Access to Appropriate Care and Support



Mostly positive, but with the clearest single problem. Most people felt they got the right treatment, often “in the end,” and valued staff who knew them. The negativity is strikingly concentrated in one place — waiting times and appointments, with long waits for results and operations and frequent cancellations — making this an operational problem rather than one about the quality of care itself.

When it went well

Care was good where staff made the essentials happen — the right treatment, from people who knew them, with the time they needed. It came down to people, not the system delivering it by default.

“I did get the right treatment. The service I get is good."

“Good support from the Liaison Nurse."

When it fell short

Where care fell short, people faced long waits for results, appointments and operations, with cancellations poorly communicated — fuelling anxiety and frustration.

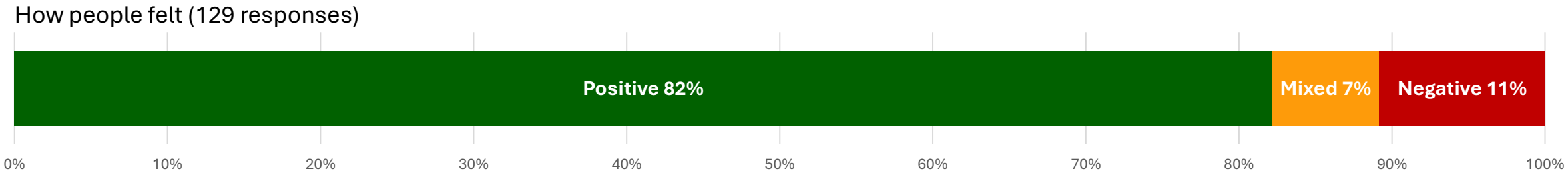
“I had to wait quite a long time for results. I wish they could have got them to me sooner.”

"Sometimes they cancel appointments at the last minute — it's difficult and frustrating."

Learning Disability Improvement Standards

Counts reflect coded responses, not unique individuals. Based on the 893 sentiment-coded experience comments.

Inclusion of Family, Carers and Supporters



The most positive theme — though the positives reflect deliberate inclusion, not a given. More than four in five responses were positive: people deeply valued family, carers and supporters being included and spoken to. The few negatives were the mirror image of the communication theme — staff occasionally speaking to family instead of the person, or leaving supporters out of key information — pointing to a balance: include supporters fully, but speak to the person first.

When it went well

These experiences were good because staff chose to include family, carers and supporters — while still speaking to the person directly. A deliberate act, not the default.

"I have carers go with me and they talk to them too."

"They included my carer who came with me."

When it fell short

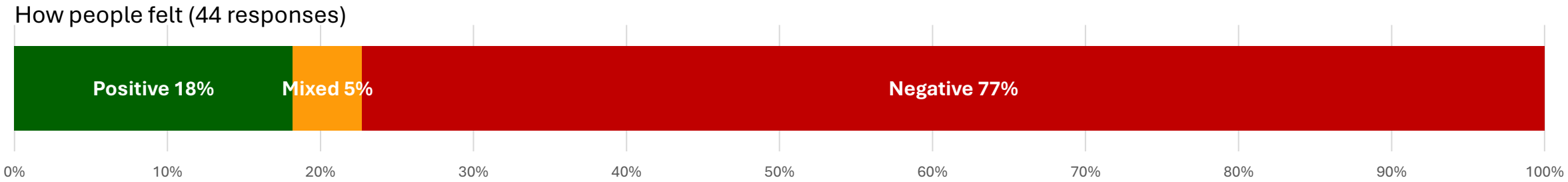
Where care fell short, people felt excluded from decisions about their care, or had a trusted supporter denied or kept from key information such as discharge.

"They talked to my family more than me."

"They refused to tell him when I was coming home."

Counts reflect coded responses, not unique individuals. Based on the 893 sentiment-coded experience comments.

Wider Experiences



The one predominantly negative theme. More than three-quarters of responses were negative, with the emotional impact of care — fear and anxiety — the largest strand, followed by busy, noisy and overwhelming environments. People also asked for more mental health and wider life support such as money and housing, while the few positives point to the remedy: quieter settings, side rooms and being given enough time.

When it went well

The few positives happened only where the environment was actively managed — a quieter space, a side room, enough time. They show what is possible when anxiety is designed out.

"It was quiet — not noisy or overwhelming, and not many people around."

"It was better when I had a side room."

When it fell short

Where care fell short, busy, noisy and overwhelming environments caused real fear and anxiety, with some wanting more mental health and wider life support.

"It was quite scary, especially since it was to do with my chest."

"They need to offer more help with things like jobs, home and money because that affects my mental health."

Counts reflect coded responses, not unique individuals. Based on the 893 sentiment-coded experience comments.

Positive Experiences: What good care looks like

This theme draws on what people said when asked directly about the good: their best experiences of an inpatient stay or outpatient appointment, what good care looks like, and any other positive reflections. Almost every response was positive, offering a clear, first-hand picture of what good care looks like — and what to protect and spread.

Kind and compassionate staff

"Staff are kind, understanding and make sure she feels comfortable."

Clear, respectful communication

"They listened to my concerns and acted on them."

Being put at ease

"I have a phobia of needles, but staff were gentle and helped distract me."

A good experience overall

"All my hospital experiences have been really positive — I felt well looked after."

What can we do better?

An additional **172** suggestions for how the NHS can do better were also received, highlighting **5** key themes

Accessible information, provided as standard With Easy Read and plain language by default, not only when asked.

Use hospital passports and act on reasonable adjustments
Read and use passports every time, and make adjustments without being asked repeatedly.

Listen to patients, communicate directly, and allow time
Speak to people directly, not just carers, and allow time to understand.

The right staff, trained and informed by lived experience
With more liaison nurses, and people with lived experience involved in training and quality checks.

Access, Environment and Hospital Processes
Cut waiting times, improve parking, signage and transport, and make discharge safer.

What can we do better?

Accessible information, provided as standard
With Easy Read and plain language by default, not only when asked.

The most consistent request was for information people can actually understand, and for it to be offered automatically rather than only when asked. Easy Read materials were mentioned most often, with people wanting them on reception counters, in waiting areas, before operations, and in appointment and discharge letters. People also asked for plain language, no jargon, visual symbols, more accessible NHS website and app content, and clear information before an appointment so they can prepare. *"Use Easy Read!" · "Easy read appointment letters" · "Easy information, no long words" · "Don't use jargon“*

Listen to patients, communicate directly, and allow time
Speak to people directly, not just carers, and allow time to understand.

People asked repeatedly to be listened to and believed, to be spoken to directly rather than through a carer or support worker, and to be treated as individuals rather than assumed to be the same. Closely tied to this was the request not to be rushed, for staff to take time and allow people to process information, and to be offered a choice of how they communicate. *"Listen to me" · "Speak to us, not just our care staff and family" · "Give time for people to understand and process the information" · "Listen to what people want and don't assume something is right for everyone“*

What can we do better?

Use hospital passports and act on reasonable adjustments
Read and use passports every time, and make adjustments without being asked repeatedly.

A clear gap between policy and day-to-day practice. Hospital and communication passports exist but are often not read or used consistently, despite the effort that goes into creating them. People asked for reasonable adjustments to be offered without having to ask repeatedly, for digital reasonable-adjustment flags to be used and to work, for needs to be flagged in advance, and for quiet, sensory-friendly spaces and tools. *"Use my hospital passport" · "Make sure hospital staff use hospital passports all the time" · "Reasonable adjustments to be offered without having to ask several times" · "More fidget tools for anxiety"*

The right staff, trained and informed by lived experience
With more liaison nurses, and people with lived experience involved in training and quality checks.

People want staff who understand learning disability and autism, delivered through face-to-face training — including Oliver McGowan training — that begins at student stage and is refreshed in post. There were strong calls for more learning-disability liaison nurses, consistently linked to better experiences, and for people with lived experience to be embedded in training, quality checking, inspections and ongoing co-production, with concern raised about the loss of Healthwatch. *"Better training on learning disabilities and autism" · "Have people with learning disabilities doing quality inspections" · "More training for staff about neurodiverse patients"*

What can we do better?

Access, Environment and Hospital Processes
Cut waiting times, improve parking, signage and transport, and make discharge safer.

The largest theme by volume, covering the practical, fixable side of the hospital experience. People raised long waiting times and wanting to be kept informed about delays better parking and disabled spaces, clearer signage and wayfinding, reliable transport, appointment letters and reminders that arrive on time, a clean and calm ward environment, and safer, less rushed discharge with the right medicines and aftercare. *"Shorter waiting times" · "Improve parking" · "Make the signage better" · "Not having to wait 24 hours for a bed"*

Facilitator Feedback

Notes from the London and North West session facilitators reinforced the themes — with a mixed picture on progress.

Passports and accessible information

Theme 3

In both areas, facilitators reported that the basics still aren't consistent in practice: hospital passports are frequently not read or used, and accessible information is not yet applied consistently.

Appointment information

Theme 4

Facilitators were particularly struck by how many people were not receiving appointment information on time — in some cases, written appointments arrived after the appointment or admission date had passed.

Getting the workforce right

Theme 5

Better experiences were consistently linked to liaison nurses, with strong support for Oliver McGowan training led by people with lived experience and for experts by experience in inspections — with concern about the loss of Healthwatch.

A mixed picture on progress

Where it is improving

Some felt hospitals now understand learning disability and autism better, and valued their reasonable-adjustment flag.

Where concern remains

Others reported longer waits and staff with less time, and worried financial pressures will make things worse.

In Summary

What good care comes down to

Across every theme, the same few things shaped people's experience — being given time, information they can understand, feeling safe, and having trusted people involved. They explain both the best experiences and the worst.

WHERE TRUSTS CAN FOCUS

Accessible information as standard

Easy Read and plain language by default, not only on request.

Talk directly, and allow time

Speak to people, not just carers — and don't rush them.

Reasonable adjustments, made real

Read and use hospital passports; flag needs and act on them.

The right workforce

Liaison nurses, quality training, and lived experience embedded.

Acknowledgements

We would like to thank Learning Disability England (LDE) for their invaluable support in facilitating the regional patient focus groups and supporting engagement throughout the programme. We are particularly grateful to the local organisations that worked in partnership with us to organise and deliver these sessions — Dudley Voices for Choice, Skills for People, ACE Anglia, Pathways Associates, People First Forum, Lewisham Speaking Up, and Active Prospects. Their commitment and expertise were instrumental in ensuring that the voices of people with a learning disability were heard and represented throughout the audit.

Most importantly, we would like to thank everyone who took part in the focus groups and completed the patient and family/carer surveys. Their willingness to share their lived experiences, insights and feedback has enriched the data and helped keep the voices of people with a learning disability, their families and carers at the heart of this programme — and their perspectives will play a vital role in informing future improvements and supporting more inclusive, accessible and person-centred healthcare.

For more information on each organisation please follow the links below:

ACE Anglia (East of England)

Dudley Voices for Choice (Midlands)

Pathways Associates (North West)

Skills for People (North East & Yorkshire)

People First Forum (South West)

Lewisham Speaking Up (London)

Active Prospects (South East)

Additional Resources

Additional resources and reports produced by some of the organisations involved. Where available, they are linked below.

ACE Anglia (East of England)

ACE Anglia Full Report Hospital and Services Experience 2026
ACE Anglia Full Report Hospital and Services Experience 2026 – Easy Read Summary Report

Skills for People (North East & Yorkshire)

Summary Report: Newcastle Hospitals Trust - Quality Checker Findings October 2025

Lewisham Speaking Up (London)

Lewisham Speaking Up NHS Learning Disability Standards Report 2026

Appendix

Breakdown by organisation

	ACE East of England (n= 51)			Skills for people North East & Yorkshire (n= 34)			Voices for choice Midlands (n= 24)			Pathways Associates North West (n= 20)			People first forum South West (n= 22)			Lewisham speaking up London (n= 37)			Active prospects South East (n= 30)		
Themes	Positive	Mixed	Negative	Positive	Mixed	Negative	Positive	Mixed	Negative	Positive	Mixed	Negative	Positive	Mixed	Negative	Positive	Mixed	Negative	Positive	Mixed	Negative
Respecting Rights, Dignity and Safety	45	5	5	1	1	7	12	8	7	8	0	0	12	7	21	26	2	9	46	1	8
Communication, Listening and Understanding	42	8	10	8	2	6	6	1	7	3	5	12	18	6	19	32	3	9	78	1	2
Access to Appropriate Care and Support	37	3	6	0	0	3	4	2	7	3	0	8	4	3	15	26	4	9	32	1	4
Inclusion of Family, Carers and Supporters	40	1	5	3	0	0	5	2	3	13	0	1	7	4	2	24	1	3	14	1	0
Positive Experiences and What Good Care Looks Like	7	1	0	0	0	0	1	0	0	2	0	0	6	0	0	2	0	0	21	0	0
Wider Experiences	1	0	1	0	0	0	0	0	6	0	0	0	7	2	20	0	0	4	0	0	3
Total	172	18	27	12	3	16	28	13	30	29	5	21	54	22	77	110	10	34	191	4	17
Total (%)	79%	8%	12%	39%	10%	52%	39%	18%	42%	53%	9%	38%	35%	14%	50%	71%	6%	22%	90%	2%	8%

Appendix

Drivers of negative experience

Sub-theme	n	%
Communication, Listening & Understanding · 65 (29% of all)		
Accessible information	19	29%
Feeling listened to	13	20%
Direct communication	11	17%
Clear explanations	8	12%
Use of jargon / language	8	12%
General communication	5	8%
Treatment understanding	1	2%
Respecting Rights, Dignity & Safety · 57 (26% of all)		
Rights, dignity & autonomy	21	37%
Feeling safe / unsafe	13	23%
Reasonable adjustments	10	18%
Choice & autonomy	9	16%
Understanding LD / autism	2	4%
Feeling listened to	1	2%
Advocacy / support with decision-making	1	2%

Sub-theme	n	%
Access to Appropriate Care & Support · 52 (23% of all)		
Waiting times & appointments	24	46%
Appropriate treatment & support	12	23%
General care & treatment	8	15%
Emergency care	4	8%
Follow-up & continuity of care	1	2%
Consistency of care	1	2%
Treatment experience	1	2%
Not specified	1	2%
Wider Experiences · 34 (15% of all)		
Emotional impact	14	41%
Hospital environment	9	26%
General care & treatment	6	18%
Mental health support	2	6%
Clear explanations	1	3%
Sensory / environment	1	3%
Treatment experience	1	3%
Inclusion of Family, Carers & Supporters · 14 (6% of all)		
Family / supporter involvement	11	79%
Communication with family / supporters	3	21%