Learning Disability Improvement Standards

Findings From Year 8 of the Benchmarking Exercise: Patient Focus Groups – Easy Read Summary

About this report

218 people with a learning disability shared their experiences of NHS care.

7 focus groups were run across England.

They worked with Learning Disability England (LDE) and local organisations.

People told us about going to hospital.

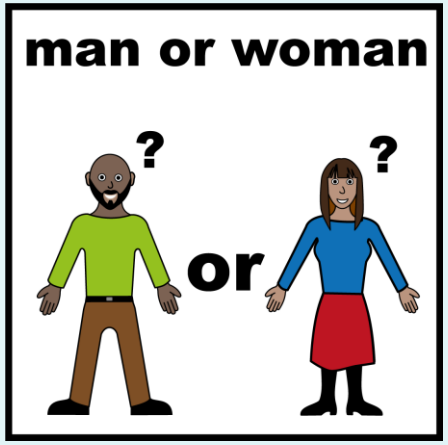
They also told us what the NHS could do better.

1,065	893	172	6
comments	experiences of care	suggestions	themes

Who took part

59 people out of 218 filled in an information form.

Gender



More than half were men

About 4 in 10 were women

A small number preferred not to say

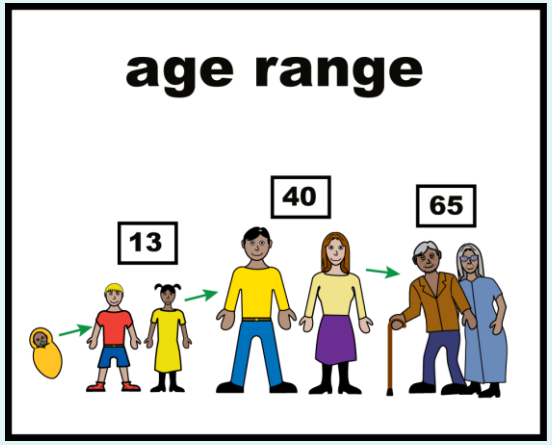
Ethnicity

Most people were White

Some people were Black or Black British

A small number were Asian or Asian British

Age



Most people were aged between 35 and 64

These figures are based on the 59 people who filled in the form.

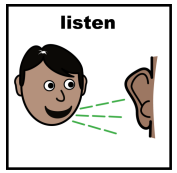
What people told us about their care

We found 6 themes in the feedback.

Most feedback was good.

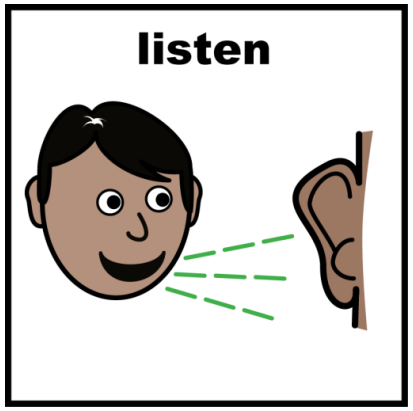
Most feedback was good	Some feedback was not good	A few said both

1	Communication, Listening and Understanding	278 comments
2	Respecting Rights, Dignity and Safety	231 comments
3	Access to Appropriate Care and Support	171 comments
4	Inclusion of Family, Carers and Supporters	129 comments
5	Wider Experiences	44 comments
6	Positive Experiences: What Good Care Looks Like	40 comments



Theme 1: Communication, Listening and Understanding

Most people said this was good



Two thirds of people said communication was good.
Where it went wrong, it was usually about systems, not individual staff.

When it went well

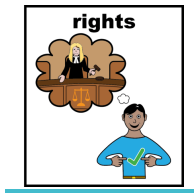
Staff explained things clearly.
People felt listened to.
Information was given in an accessible way.

When it fell short

Information was hard to understand.
Easy Read was rarely offered.
Some people were not spoken to directly.

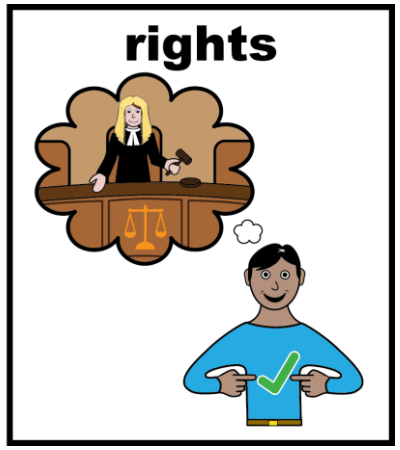
"They listened to me and explained what they were going to do."

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



Theme 2: Respecting Rights, Dignity and Safety

Most people said this was good



About 2 in 3 people said their rights and dignity were respected.
Where it went wrong, people were not given a say in their own care.

When it went well

Staff made reasonable adjustments.
People were asked for their consent.
People were treated as individuals.

When it fell short

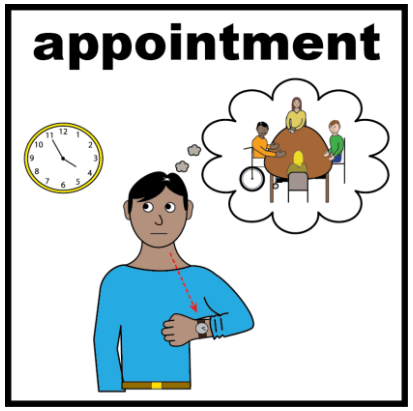
Some people were talked down to.
Some people were not given a say in their care.
Some people did not feel safe.

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

"They did not give me a chance to speak."

Theme 3: Access to Appropriate Care and Support

Most people said this was good



Most people felt they got the right treatment in the end.
Staff who knew them well made a big difference.

When it went well

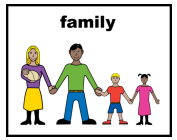
People got the right treatment.
Staff who knew them made a real difference.

When it fell short

Long waits for results and appointments.
Cancellations were common and poorly communicated.

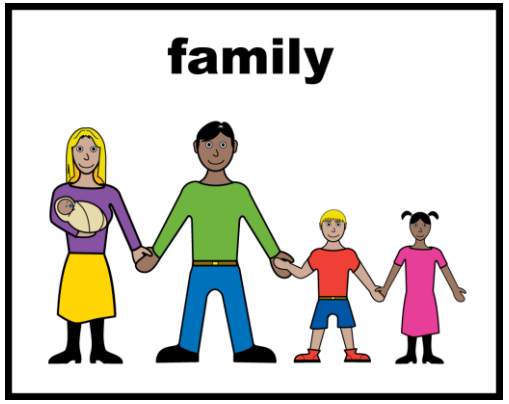
"I did get the right treatment. The service I get is good."

"Sometimes they cancel appointments at the last minute. It is difficult and frustrating."



Theme 4: Inclusion of Family, Carers and Supporters

Almost all people said this was good



More than 4 in 5 people said family and carers were included.
This was the highest score of all 6 themes.

When it went well

Family and carers were included.
Staff still spoke to the person directly.

When it fell short

Some people felt left out of decisions.
Some carers did not get important information like discharge plans.

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

"They talked to my family more than me."

Theme 5: Wider Experiences

This was the only theme where most feedback was not good.

44 comments were shared about this theme.

Busy, noisy places made people feel scared and anxious.

Where it went well, there was a quiet space or a side room.

People also asked for more help with mental health and everyday life.

When it went well

Quieter spaces and enough time made a real difference.

"It was quiet. Not noisy or overwhelming. Not many people around."

When it fell short

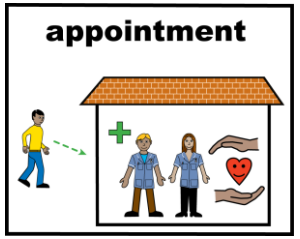
Busy, noisy places caused real fear and anxiety.
Some people wanted more mental health support.

"They need to offer more help with things like jobs, home and money."

Theme 6: What Good Care Looks Like

40 comments were shared on this theme.

Almost every response was good.

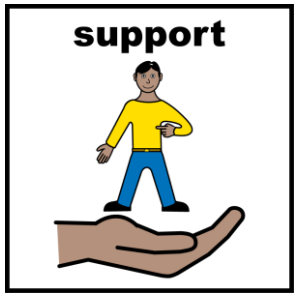


Kind and compassionate staff

"Staff are kind and understanding. They 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. Staff were gentle and helped distract me."

A good experience overall

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

What can we do better?

172 suggestions for how the NHS can do better were also received.

People told us 5 key things.

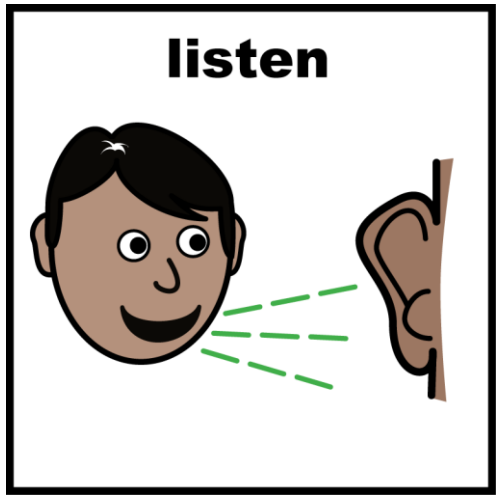
1	**Easy Read information as standard**	Plain language and Easy Read by default. Not only when asked.
2	**Listen directly and allow time**	Speak to the person. Not just their carers. Do not rush them.
3	**Use hospital passports and act on adjustments**	Read and use passports every time. Make adjustments without being asked.
4	**The right staff, trained by lived experience**	More liaison nurses and Oliver McGowan training. People with lived experience involved.
5	**Better access, environment and processes**	Shorter waits, better parking and signage. Safer discharge.

What can we do better? Suggestions 1 and 2

1 Easy Read information as standard

People want Easy Read letters, forms and information in waiting areas.
They want this automatically. They should not have to ask.
They also want plain language and no jargon.

"Use Easy Read!" · "Easy Read appointment letters" · "Do not use jargon"



2 Listen directly to the patient and allow time

Speak to the person directly. Do not just speak to their carer.
Do not rush them. Allow time to understand and process information.
Treat people as individuals.

"Listen to me" · "Speak to us, not just our care staff" · "Give time to understand"

What can we do better? Suggestions 3 and 4

3 Use hospital passports and act on reasonable adjustments

Read and use hospital passports every time. Not just sometimes.
Offer reasonable adjustments. People should not have to ask.
Flag needs in advance. Provide quiet, sensory-friendly spaces.

"Use my hospital passport" · "More fidget tools for anxiety"

4 The right staff, trained and informed by lived experience

More learning disability liaison nurses.
Face-to-face training on learning disability and autism.
This includes Oliver McGowan training. It should start when doctors are students.
People with lived experience should be in training and quality checks.

"Better training on learning disabilities" · "Have people with learning disabilities do quality inspections"

What can we do better? Suggestion 5

5 Better access, environment and hospital processes

This was the largest group of suggestions.

- Shorter waiting times and better information about delays
- Better parking, disabled spaces, signage and transport
- Appointment letters that arrive on time
- Clean, calm ward environments
- Safer discharge with the right medicines and aftercare

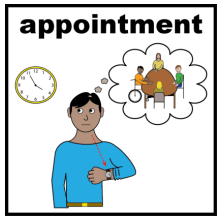
"Shorter waiting times" · "Improve parking" · "Make the signage better"

Facilitator Feedback

The people who ran the groups from London and North West gave more feedback. This is what they said.

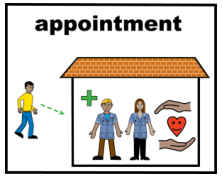
Hospital passports and accessible information:

Hospital passports are often not read or used.
Easy Read information is not always given to people.



Appointment information:

Many people did not get their appointment letter on time.
Some letters arrived after the appointment date had already passed.



Getting the workforce right:

People had better experiences when there was a liaison nurses.
Oliver McGowan training led by people with lived experience was strongly supported.

A mixed picture on progress:

Some felt hospitals are getting better at understanding learning disability.
Others worried that long waits and money problems will make things worse.

In Summary

What good care comes down to

Across every theme, the same things mattered most.

Being given time, information they can understand, feeling safe, and having trusted people involved.

WHERE HOSPITALS CAN FOCUS

Accessible information as standard

Easy Read and plain language by default.
Not only when asked.

Talk directly and allow time

Speak to people, not just carers.
Do not rush them.

Reasonable adjustments, made real

Read and use hospital passports.
Flag needs and act on them.

The right workforce

More liaison nurses, better training, people with lived experience involved in checking services.

Thank you

We would like to thank:

Learning Disability England (LDE) for their support in running the focus groups.

These are the local organisations who ran the sessions.

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)

Most importantly, we would like to thank all 218 people who took part.

They shared their lived experiences.
This will help shape better NHS care.

www.nhsbenchmarking.nhs.uk