

healthwatch
Lancashire

Learning Disability Report

May 2018



**Lancashire's learning disability communities have their
say on health and social care services.
June - September 2017**

Contents

1. Introduction

Page 2

- Project Representatives
- Project Background
- Local statistics
- Consultations

2. Methodology

Page 3

- Time scales
- Implementation: methods of engagement

3. Acknowledgements

Page 4

4. STP and LDPs explained

Page 4

5. Where we visited

Page 5-6

6. Summary of Results

Page 7

7. Results

Page 8

- From the perspective of someone with a learning disability

- From the perspective of someone who supports individuals with a learning disability
- From the perspective of family and friends of individuals with a learning disability
- From the perspective of professionals

8. Views of residents in care homes

Page 48

9. Focus Groups

Page 52

10. What else did we find out?

Page 58

11. Evaluation

Page 64

12. Appendices

Page 69-103

- Demographics
- Who we spoke to
- Questions (Appendix 1-8)
- Full analysis of results

Disclaimer

This report is only representative of the views of the people who met members of the Healthwatch Lancashire and Healthwatch Blackpool team on the dates of our engagement activities.

Introduction

Project Representatives:

Kerry Galloway, Linda Brown, Amanda Higgins, Katie Taylor, Beth Tildesley, Jess Wood, Sam Parker, Michele Chapman, Nick Colledge, Lesley Miller and Jeanette Newman.

Project Background:

Local Healthwatch identified the need to undertake a programme of work focusing on listening to the voice of the learning disability community. There is a large evidence base on a local level that supports this, and provides evidence as to why the learning disability community has a need to have their say on health and social care services in their area.

Local statistics:

www.lancashire.gov.uk - updated March 2016



- Health inequalities - we know that people with a learning disability have a shorter life expectancy when we know this should not be the case.
- Lancashire Protecting Adult Needs and Service Information System (PANSI) 2016 estimates show that in 2014 there were predicted to be 27,201 adults aged 18 or over with a learning disability and it is predicted to rise to 28,268 people by 2030.
- Nearly half of people with a learning disability live in the most deprived areas of Lancashire.
- People with a learning disability experience much poorer health outcomes across a range of health conditions.
- Life expectancy is gradually increasing which will likely lead to increased demand for social care and health services as they will outlive their parents who currently provide the bulk of informal care.
- Primary Care Trusts PCTs (now known as Clinical Commissioning Groups (CCGs)) have been required to carry out learning disability annual health checks in GPs since 2009. In 2010-11, around 60% of people with a learning disability received this health check.
- People with learning disabilities are at increased risk of many conditions: *Respiratory disease, Gastrointestinal cancer, Schizophrenia, Dementia, Oral health issues, Diabetes, Osteoporosis, long term conditions e.g. epilepsy, anxiety and depression, challenging behaviours, sensory impairment, Dysphagia, Gastro-Oesophageal Reflux Disease (GORD), injuries, accidents and falls.*

Learning isability in Adults Joint Strategic Needs Assessment (JSNA) Technical Document - September 2012

- It has been difficult to obtain data on the health needs of people in Lancashire and it is recommended that data collection is a priority.
- Anxiety and depression is common with Down syndrome.
- Number of adults (18+) with learning disability in receipt of social care = 4,756 (as of 2012).
- Number of people with a learning disability registered with a GP = 4,247 (+678 in Blackpool).

Consultations:

To determine the main focus of this project, Healthwatch Lancashire and Healthwatch Blackpool undertook three initial consultation activities. These activities were completed during the national Learning Disability Awareness Week (19th to 25th June 2017). During these activities, we asked people with a learning disability and/or autism, their carers, support workers and relatives to give us feedback about services they had used recently.

For the consultation activities, we visited:

- Learning Disability NHS Day (Chorley and South Ribble Hospital)
- Plungington Community Centre Learning Disability Awareness Week Drop in
- Learning Disability Breakfast Drop in at Disability Equality North West

Healthwatch also considered historical feedback received from the learning disability community throughout previous work programmes and community engagement.

Considering local statistics and recent intelligence collected by local Healthwatch identified that one of the biggest issues for the learning disability community was communication within hospital services, with a particular emphasis on the use of tools such as Hospital Passports.

Methodology

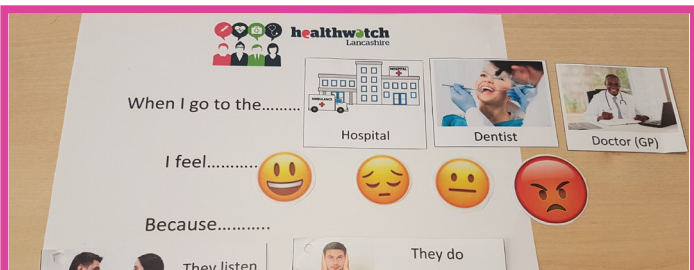
Healthwatch Lancashire and Healthwatch Blackpool completed the consultation events during National Learning Disability Awareness Week which took place across the country between 19th and 25th June 2017.

The subsequent engagement activities and online campaign were undertaken between June 2017 and September 2017.

Here at Healthwatch, we understand that the learning disability community may prefer a range of different communication tools and techniques, and so we looked at different methods we could utilise to ensure we were being inclusive and giving everybody the opportunity to have their say. For example, during the consultation phase we utilised a tool called a 'talking mat' along with easy read cards and emojis.

Healthwatch undertook Care Circle and Pop Up engagement activities. Our Care Circle activities were adapted to support conversations specifically around hospital and Hospital Passports.

This involved more direct and interactive



questions (e.g. asking people for a show of hands, or the use of red and green cards to indicate 'yes' and 'no') and also utilising a variety of examples of Hospital Passports.

Pop Up engagements were also undertaken in a wide variety of settings. During Pop Up engagements, we utilised a questionnaire. This questionnaire was also available to complete online (which was promoted via our social media channels) and in an easy-read format.

Healthwatch Lancashire's programme of 'Enter & View' delivers an innovative 'mum's test' approach, gathering views of patients, relatives and staff to provide an answer to the question: 'Would you want your loved ones to be cared for in this service?'

In total, we spoke to 330 people over 21 Care Circles and Learning Disability events, 12 Pop Ups and online engagement.

Acknowledgements

Healthwatch Lancashire and Healthwatch Blackpool would like to thank everyone that took part in the online survey and participated in engagement activities, for their feedback with regards to hospitals and also with regard to Healthwatch conduct, as this will help us to improve future projects. We would also like to thank all the staff and volunteers working at the groups we visited for supporting our visits, particularly within the more vulnerable communities, as this allowed us to reach out to people whose voices are often seldom heard. Healthwatch would also like to thank our own volunteers who helped carry out the engagement activities.

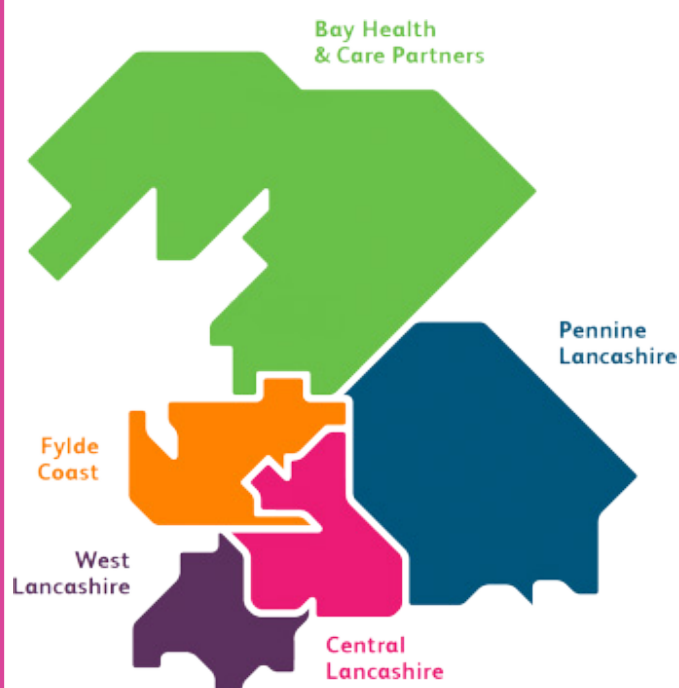
Reference for the reader: STP and ICPs explained

Throughout this report, we refer to Integrated Care Partnership (ICP) areas. The five ICPs operate as part of the Healthier Lancashire and South Cumbria Sustainability and Transformation Partnership also known as the STP.

The STP is a group of organisations including Local Healthwatch who work together to improve health and care in our region. For more information visit www.healthierlsc.co.uk.

Information in this report is provided to organisations within the STP to ensure that the public voice is used to influence change in service improvement and redesign.

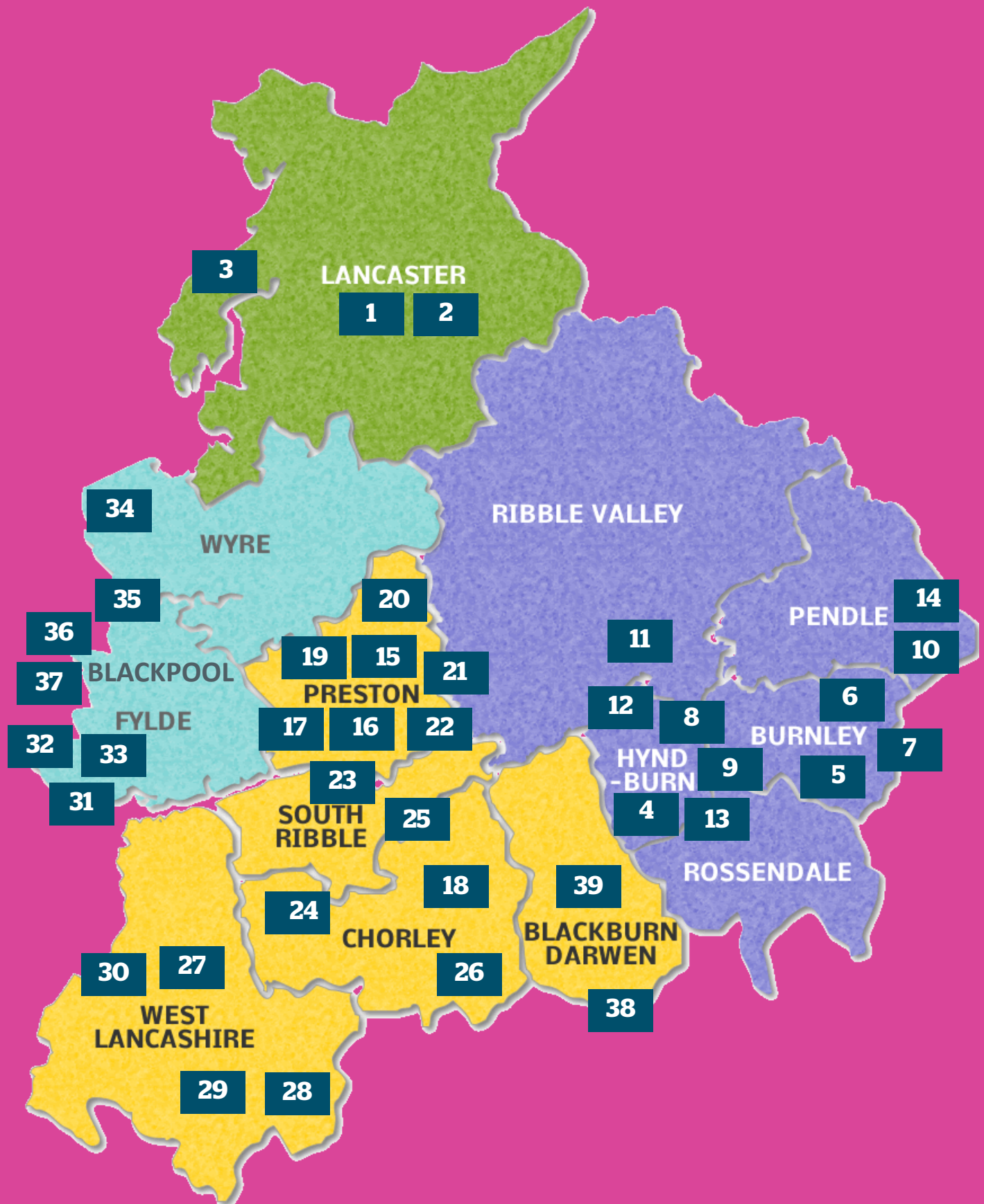
Map of Integrated Care Partnership areas



The ICP areas in Lancashire are:

- **Bay Health & Care Partners:** Lancaster and Morecambe
- **Pennine Lancashire:** Burnley, Pendle, Rossendale, Hyndburn, Ribble Valley and Blackburn with Darwen
- **Central Lancashire:** Preston, Chorley and South Ribble
- **West Lancashire:** Ormskirk and Skelmersdale
- **Fylde Coast:** Blackpool, Fylde and Wyre

Where we visited



Where we visited

Bay Health and Care Partners (North Lancashire)

1. Shaping the Future Self Advocacy Group - Lancaster
2. Health in Action Group - Lancaster
3. Shaping the Future Breakfast Club - Morecambe

Pennine Lancashire (East)

4. Self Advocates in Lancashire (SAIL) East Lancs - Accrington
5. East Lancashire People First (Salvation Army) - Burnley
6. SAIL Network Planning Meeting - Burnley
7. East Lancashire People First (Press Gang) - Burnley
8. East Lancashire People First (New Era) - Accrington
9. East Lancashire Link - Accrington
10. SAIL Pendle Link - Colne
11. East Lancashire People First - Clitheroe
12. Wheels4all - Clayton-le-Moors
13. Dance Syndrome - Accrington
14. Colourful Voices - The Zone, Nelson

Central Lancashire

15. Disability Equality North West Ladies Day - Preston
16. Face2Face Self Advocacy Group - Preston
17. Dance Syndrome - Preston
18. Dance Syndrome - Chorley
19. Disability Equality North West Drop In - Preston

20. Musical Meet - Preston
21. Spire Community Meeting - Preston
22. Wheels4All - Preston
23. Barnardos Participate Opportunity Win Achieve and Respect (POWAR) Meeting - Lostock Hall
24. Music to your Ears - Chorley
25. Link Up - Leyland
26. Voice for All Group - Chorley

West Lancashire

27. West Lancs Sun Group - Ormskirk
28. Divine Days - Skelmersdale
29. Barnardos - Skelmersdale
30. Wheels4All - Ormskirk

Fylde Coast (Including Blackpool)

31. Omerod Group Service User Forum - St Annes
32. Connections Group - St Annes
33. Omerod Drama Group - Lytham
34. Omerod Drama Group - Fleetwood
35. Warren Manor - Thornton Cleveleys
36. Omerod Group - Blackpool
37. Blackpool Council Parent Carer Forum - Blackpool

Other/Pan Lancashire

38. North West Learning Disability Summit - Manchester
39. Lancashire, Blackburn & Blackpool Confirm and Challenge Meeting - Preston

Summary of results

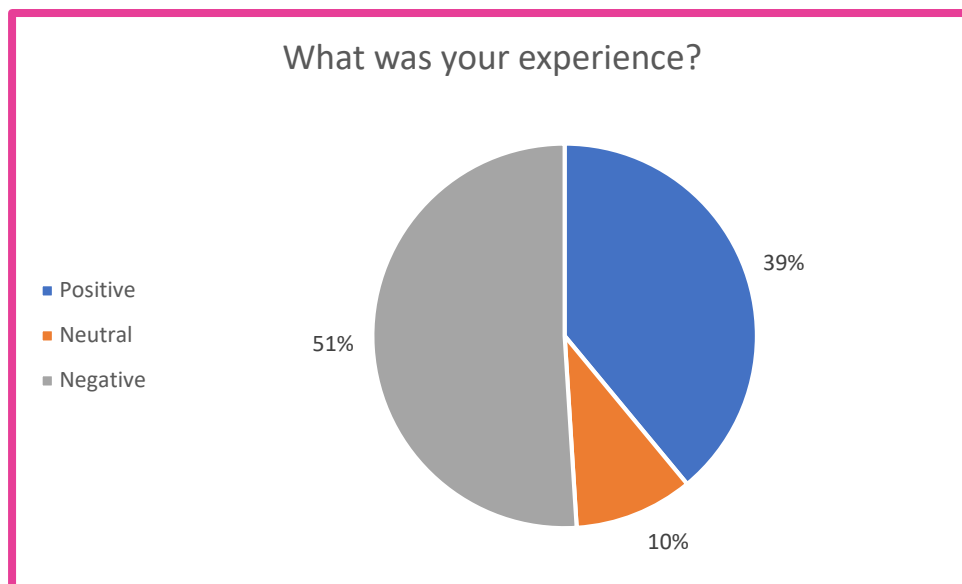
- The majority of people we spoke to were individuals with a learning disability and/or autism (66%).
- 57% of the people we spoke to said they have attended or supported someone in hospital (in the last 12 months). 77% of these attendances were routine or planned visits, as opposed to emergency or unplanned visits.
- The most negative experiences of visiting were from individuals with a learning disability and/or autism (51% of comments from this group were negative).
- Overall, from listening to the experiences of individuals with learning disabilities and/or autism, their carers and support workers and their friends and families, the most common response we received about recent experiences in hospital were negative (47%). 39% of overall experiences were positive and 14% were neutral or mixed.
- 69% of individuals with a learning disability and/or autism said they found staff to be 'excellent' or 'good'.
- The feedback shows that the majority of people we spoke to either do not have or are unsure whether they have a Hospital Passport (58%).
- The feedback shows that in the majority of cases (63%) the Hospital Passport was not used or the individual was unsure if it was used.
- Half of the people we spoke to felt that the Hospital Passport made a difference to their hospital experience. 32% were unsure, which may be related to the 18% of people who were unsure if the passport was used last time they went into hospital.
- The most commonly mentioned theme that contributed to a good hospital experience from individuals with learning disabilities and/or autism, their carers and support workers, family and friends, was the kindness and treatment from staff.
- The most common theme for individuals with learning disabilities and/or autism regarding improvements to the hospital experience by a majority (45%) is communication and awareness. This includes pre-appointment communication, such as letters, and communication during appointments: with people citing additional staff training in learning disabilities and autism, including learning to use Makaton, and promoting the use of Hospital Passports.

- The most common theme from those who support people with learning disabilities and/or autism in the hospital environment regarding improvements to the experience is communication and awareness, followed by reduced waiting times. Many of the comments regarding communication referred to being given up to date information about long delays. Many of the comments regarding the environment referred to having a suitable place to wait if there are to be long delays.

Results

From the perspective of someone with a learning disability and/or autism

1. We asked - If you have visited hospital recently, what was your experience?



- The ICP area with the most positive comments was Fylde Coast.
- The ICP are with the most neutral comments was West Lancashire.
- The ICP area with the most negative comments was Central Lancashire.

Comments:

Bay Health and Care Partners (North)

"With Royal Lancaster Infirmary my appointment came through really quickly and I didn't have to wait long."

"Royal Lancaster Infirmary were really helpful. I remember the staff well."

Pennine Lancashire (East)

"Doctors are nice."

"The 'Meet and Greet' team at hospitals are great and really helpful."

"They seem to have stopped using anaesthetics and are using cooling spray, even though things are still painful. Being in pain causes me anxiety."

"They cancel operations and procedures a lot, and you don't really get an explanation."

Central Lancashire

"I had a meal. I was checked quite often until I was discharged."

"The nurse spoke very clearly and clearly explained everything."

"The nurses and doctors were ok."

"I had problems finding out who is in charge regarding learning difficulties - there are no liaison people named for Preston, Chorley and Blackpool."

"Ward Three at Royal Preston Hospital did not read my passport. The doctors and nurses weren't interested in it. It felt like they weren't interested in me."

West Lancashire

"Ormskirk have Xbox and Playstation's and games are free to use which is good."

"I like going, staff are friendly and treat me with respect" (Ormskirk District Hospital)

"Southport Hospital from the start did not diagnose me with appendicitis but other than that it wasn't bad. The doctors don't talk to each other and I kept having to give the same information to every doctor. They didn't use the passport. I was in for 11 days. I was able to sleep, it wasn't too bad. The food was okay. They treated me with respect."

"I hate waiting around."

Fylde Coast (Blackpool)

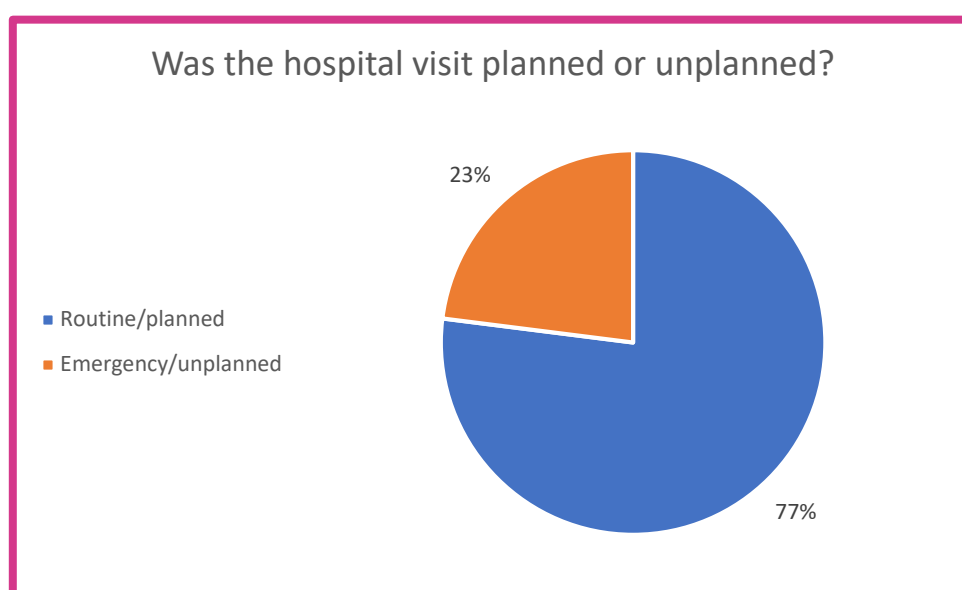
“Talking to the doctors and nurses is good. They listen to me.”

“It’s not as bad when you know what to expect.”

“The doctors and nurses could try to understand you better. They talk too quickly.”

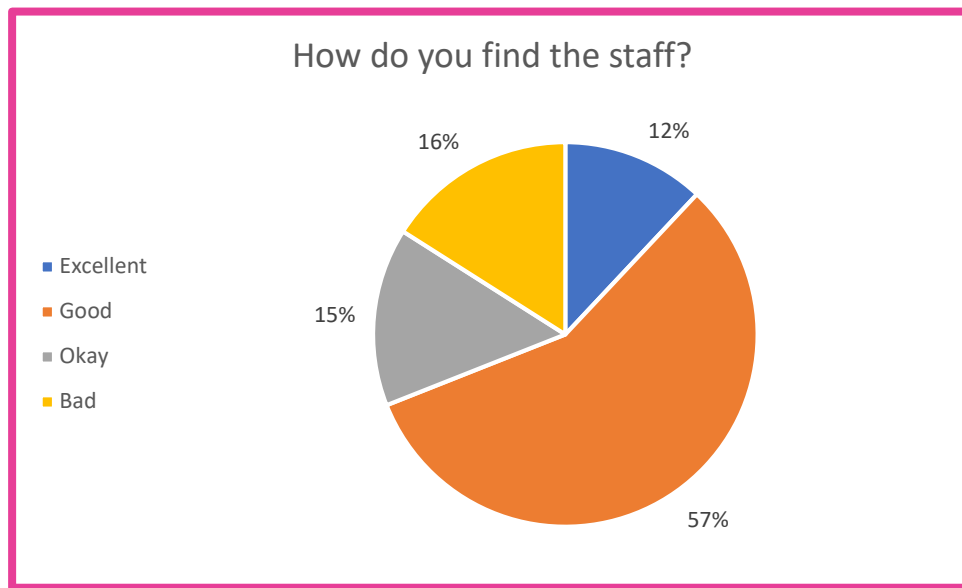
“I get letters for appointments and they’re not easy to understand. I have to wait for my family to visit to explain them or bring them here (to the day service).”

Of those who chose to tell us whether it was a routine/planned visit or an emergency/unplanned visit (43 out of 210):



Later in this report, we will investigate opinions around how useful Hospital Passports are, and whether those who don’t currently own one thinks it would be useful to have one. Some of the feedback received stated that Hospital Passports may not be as useful in emergency situations, as an individual may not carry it around all the time. In light of this, it is interesting to note here that over three quarters of hospital visits we were told about were routine appointments, and therefore planned in advance.

2. We asked – How did you find the staff at the hospital?



Comments:

"The diabetic nurse and other staff were very good and friendly. When I fell over and went into A&E they were very good and talked to me. Mum was with me and the staff were very friendly."

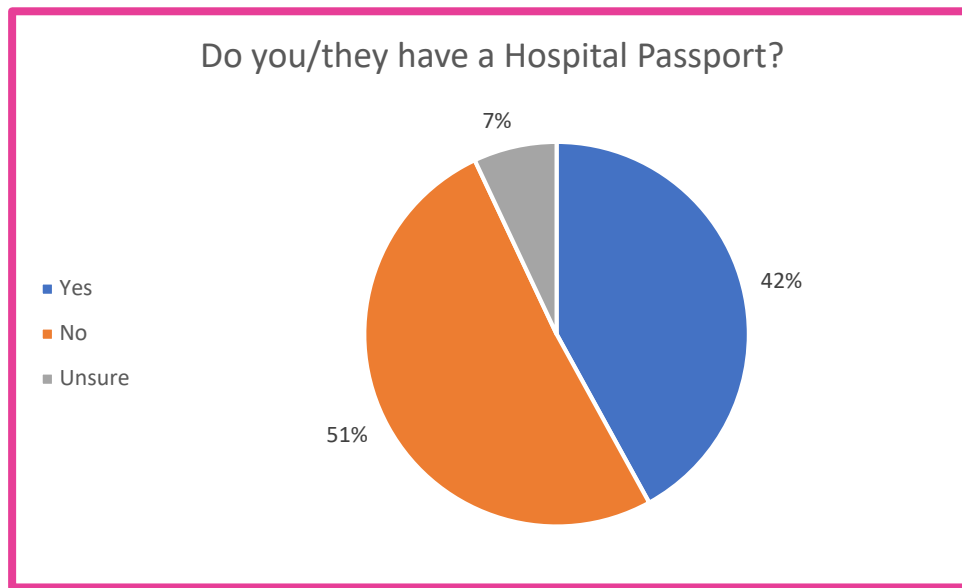
"Excellent, they explained what was happening to me."

"The staff kept me informed and let me know what was happening. What was difficult for me was trying to explain things to them and telling the same story over and over to different people, especially as I was in hospital independently."

"I've got no faith in them at all. How could they not know I was sitting there in hospital? I was suicidal and crying. They gave me a syringe as I was shaking and left me with it. I could have snapped it and stuck the plastic rod into my neck to end it all."

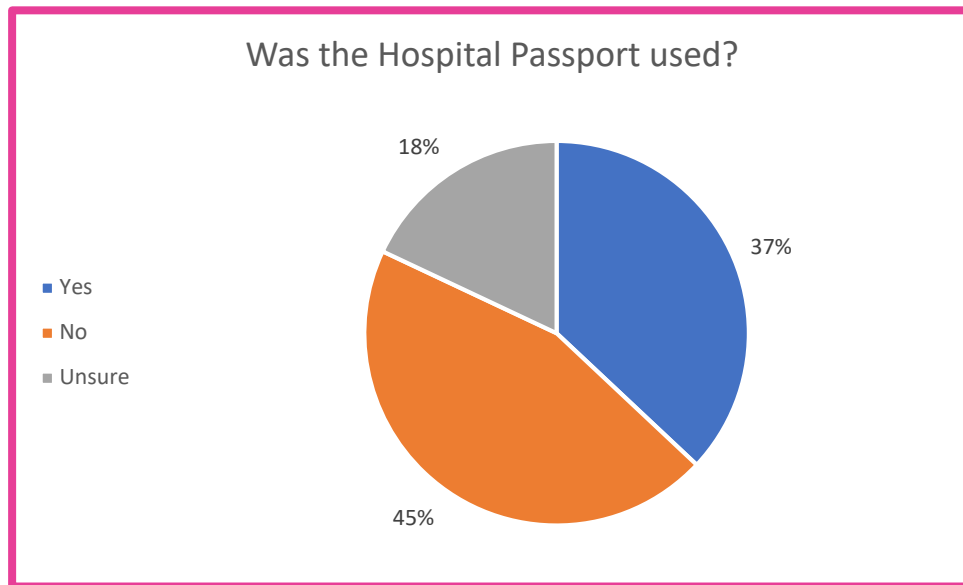
"They moved me to another ward and didn't explain anything to me. They only talked to my brother and not me. The physio people tried to get me out of bed, but I couldn't walk."

3. We asked - Do you have a Hospital Passport?



- The feedback shows that the majority of people we spoke to do not have or are unsure whether they have a Hospital Passport (58%).
- The ICP area where the most people reported they or the person they know does have a Hospital Passport is Central Lancashire (41% of people who said 'yes' were from Central Lancashire).
- Less than 20% of people in the remaining ICP areas (Pennine, Fylde Coast, Bay Health and Care Partners and West Lancashire) reported having or supporting someone who has a Hospital Passport.
- When looking at the responses from individuals with learning disabilities and/or autism, we can determine that the age group with the most people reporting that they have a Hospital Passport is 22-35 year olds (43% of people who said 'yes' were in this age bracket), compared to 56+ year olds (just 4% of people who said 'yes' were in this age bracket).

4. We asked - if yes, was the Hospital Passport used last time you attended hospital?



- The feedback shows that in the majority of cases (63%) the Hospital Passport was not used or the individual was unsure if it was used.
- The ICP area where the Hospital Passport was most used is Central Lancashire, compared to Pennine Lancashire and West Lancashire where it is used the least.

Comments from those who said yes:

“Yes, it was really helpful.”

“Yes, but they need more Learning Disability nurses.”

“I have my own personal passport which I carry around with me.”

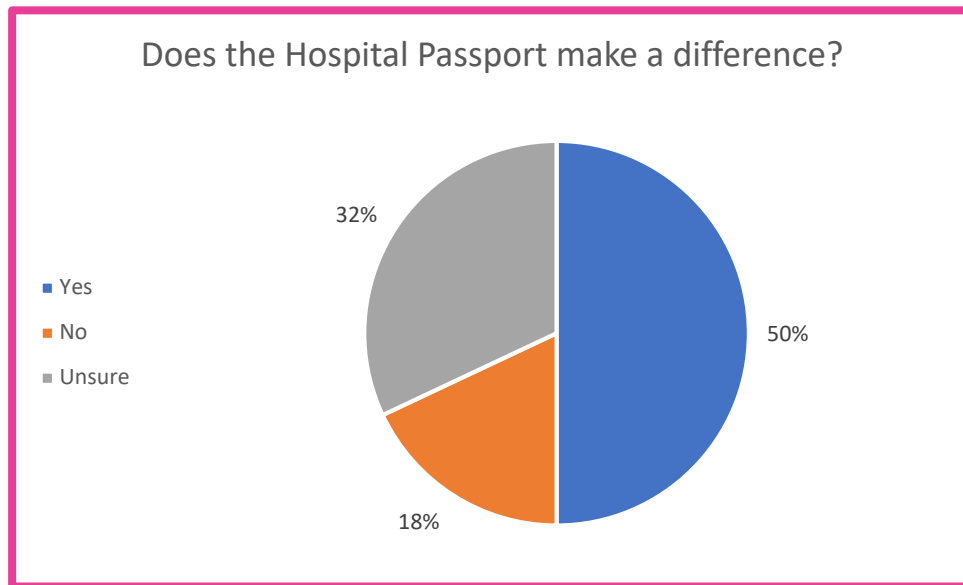
Comments from those who said no:

“No, I had an appointment with diabetic clinic and they know me well.”

“No time and they had an issue in reading them.”

“Nobody has ever asked about the hospital passport at the hospital as my daughter has had dental work under anaesthetic several times in the last few years at Chorley hospital.”

5. We asked - If you have a Hospital Passport, does it make a difference to your experience?



- Half of the people we spoke to felt that the Hospital Passport made a difference to their hospital experience. 32% were unsure, which may be related to the 18% of people who were unsure if the passport was used last time they went into hospital.
- The ICP areas where people find the Hospital Passport makes the most difference are Pennine Lancashire (East) and Central Lancashire (54% of those who said 'yes' were from these areas) compared to Bay Health and Care Partners where only 7% of people from this area answered 'yes'.

Comments from those who said yes:

Pennine Lancashire (East)

"It would help if they actually used it."

"It helps."

Central Lancashire

"There are things in the passport that you as the carer might forget."

"It ensures essential details are not overlooked."

Fylde Coast

"If it is used! It is EVERYTHING they need to know. I know people are stretched for time but in the long run it could help."

"I have a compact and personal one with all previous operations, detailed admissions, airway sizes, medications list etc. Doctors always tell me it is a brilliant compact information tool."

West Lancashire

"They've got all the information about them in it for staff to give the right care and attention."

"The Hospital Passport is a good thing if medics used them before meeting. It should be the very first page on their notes."

Comments from those who said no:

Pennine Lancashire (East)

"Doctors don't want to see Hospital Passports."

"(At Blackburn Hospital) Doctors don't want to know. They work if the stay is planned or elective but not in emergency or urgent cases."

Central Lancashire

"It just wasn't read. They were doing their own paperwork."

"Staff never read it properly in the hospital."

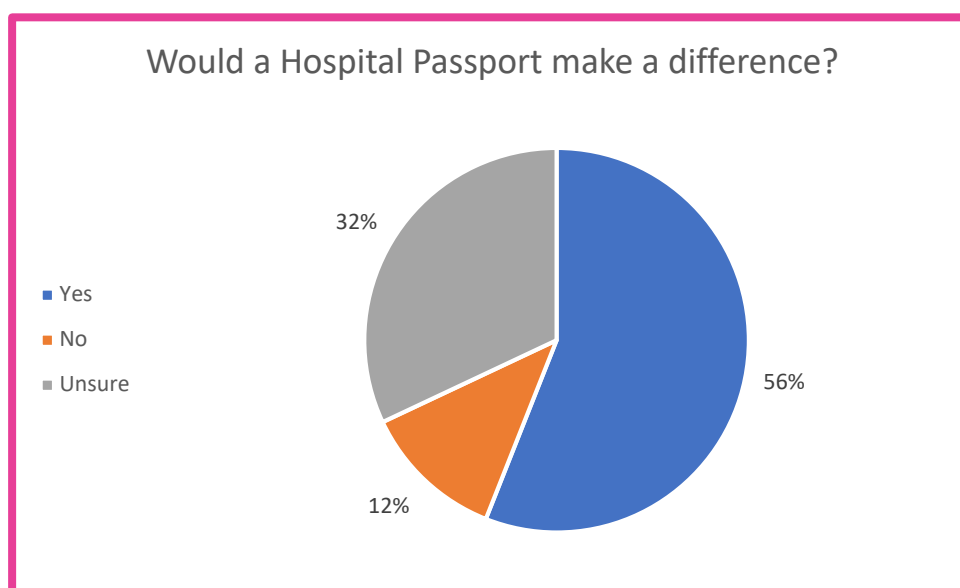
West Lancashire

"The staff at Southport Hospital didn't use it. I had to tell every doctor that came to me the same thing as they don't talk to each other either."

Fylde Coast

"They only glanced at it and I tried to inform them how important it was. The questions they asked me, they would have known the answers to if they read the passport. Maybe asking me is quicker than reading a passport?"

6. We asked - If you do not have a Hospital Passport, do you think it would be useful?



- The ICP area that reported feeling that a Hospital Passport would be useful the most was Central Lancashire (49% of those who said 'yes' were from Central Lancashire) compared to Fylde Coast (2% of those who said 'yes' were from Fylde Coast).
- Out of those with a learning disability and/or autism, the age bracket who felt Hospital Passports would be most useful was 22-35 year olds.
- The majority of those who said 'yes' were either individuals with learning disabilities and/or autism or carers/support workers (37% from each of these groups answered 'yes').

Comments from those who answered yes:

Bay Health and Care Partners (North)

"It will help because they'll know what is wrong with you."

"It's good if there are strange people that you can't talk to."

Pennine Lancashire (East)

"A passport will be helpful (person currently doesn't have one)."

"Because staff would then already know the situation, I wouldn't have to keep explaining."

Central Lancashire

“People can find out more about you.”

“Staff will know more about you quickly. It makes you less fearful.”

West Lancashire

“Now I have seen one I think it would make a difference.”

“I think it would make a difference. I have never been offered one.”

Comments from those who answered no:

Central Lancashire

“It’s quite a big document, it might not be updated, or I could lose it.”

West Lancashire

“It’s not something you carry around with you.”

“Staff should talk to me and ask the right questions and they should have the information anyway.”

Fylde Coast

“Doctors and nurses don’t know what they are”

“People are too busy to read them.”

7. We asked – If anything, what was good about your last hospital experience?

By analysing the responses to this question, we can establish the common overall themes. These are shown below:



Between individuals with learning disabilities and/or autism, their carers and support workers, family and friends, the kindness and treatment from staff was the most commonly mentioned theme that contributed to a good hospital experience. It is worth noting that only one response mentioned the use of the hospital passport.

Bay Health and Care Partners (North)

“Staff were very pleasant, and the environment was clean”

Pennine Lancashire (East)

“Staff.”

“The learning liaison person who came to see me after I had been in urgent care for about 14 hours.”

Central Lancashire

“It was quick otherwise I become agitated.”

“I didn't feel frightened.”

West Lancashire

“Staff are friendly and know me. They are very good with me.”

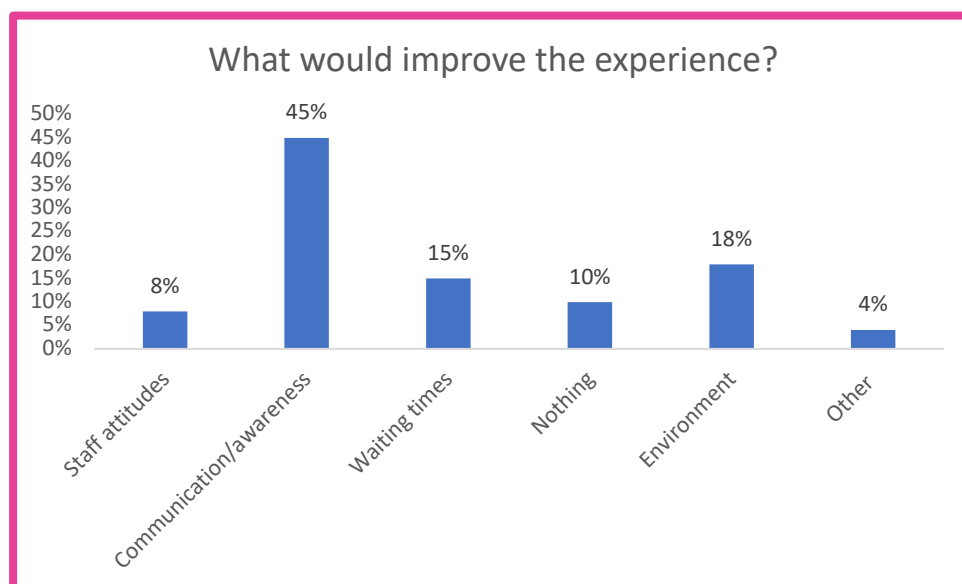
“Kind staff and it was clean.”

Fylde Coast

“I was treated with kindness.”

8. We asked - Is there anything that could have improved your hospital experience? This includes before, during and after the hospital experience.

By analysing the responses from individuals with learning disabilities and/or autism, we can identify the most common themes regarding improvements to the hospital experience as follows:



The most common theme for individuals with learning disabilities and/or autism regarding improvements to the hospital experience (45%) is communication and awareness. This includes pre-appointment communication, such as letters, as well as communication during appointments.

Many people cited additional staff training in learning disabilities and autism, including learning to use Makaton, and promoting the use of Hospital Passports.

Communication and awareness was the most common theme regarding improvements to the hospital experience across all of the ICP areas. The next most common themes for each ICP area are:

- In Bay Health and Care Partners (North) the most common themes after communications and awareness were improving staff attitudes and improving wait times.
- In Pennine Lancashire (East) there were no other common themes, however, many of the comments regarding communications cited desired improvements to signage throughout the hospitals.
- In Central Lancashire the most common themes after communications and awareness were staff attitudes and requiring improvements to the environment in the hospital, particularly around having appropriate places to wait for appointments.
- In West Lancashire the most common theme after communications and awareness was required improvements to the hospital environment, most specifically around car parking charges.
- In Fylde Coast, the most common theme after communication and awareness was required improvements to the hospital environment, particularly around having appropriate places to wait for appointments.

Bay and Health Care Partners (North)

“People to communicate better, for example more eye contact.”

“Learning disability training for NHS staff.”

“Doctors to be more lenient with people with learning disabilities.”

“Talk to the person, not the disability.”

Pennine Lancashire (East)

“Communications around the forms/payments/and entitlements need to be made clearer.”

“Signs need to be made clearer. They need to be easy read.”

“Hospital Passports need to be made easier to get hold of.”

Central Lancashire

“Having a quiet room, like the ‘Dinosaur room’ they used to have at Chorley Hospital. It could help with sensory needs as well as people with learning disabilities, you could even be treated there.”

“Getting communication levels right, not treating me like a baby.”

“Having the Hospital Passport as an app.”

“I need letters from the doctor quicker than six to eight weeks, especially if it requires my medication to be amended.”

West Lancashire

“Not keep me waiting, I don’t like that when it is busy and lots of people everywhere.”

“Put a free music channel on the T.V.”

“Don’t wake you up when your asleep.”

“Talk to me to let me know what they are doing [treatment].”

Fylde Coast

“Would like us, as service users, to have first aid training”

“Somewhere we can go and there are no waiting times”

Natalie's Story

Natalie Vranjes – Self Advocate with Shaping the Future

Royal Lancaster Infirmary

15th August 2017

“This was a planned appointment. The hospital sent me a letter asking me to come in for a check-up. The letter was quite clear as there were not too many words, but I also had a support worker who helped me to read it.

When I got to the hospital, I was sent straight to the x-ray department. I was waiting for about 30 minutes to be seen, the waiting wasn't too bad but the x-ray itself was a little bit uncomfortable. The staff were absolutely brilliant, they were helping me into the right positions for the x-ray so I was more comfortable. They weren't patronising and they were very helpful.

I thanked the staff for helping me and I went back to the Orthopaedics Department where I handed in my x-ray card. I saw a consultant, who knew about my learning disability. He spoke to me and not my support worker, and he wasn't distracted by his phone or his computer (as some consultants can be), so I felt that he was really listening to me. He was very polite too.

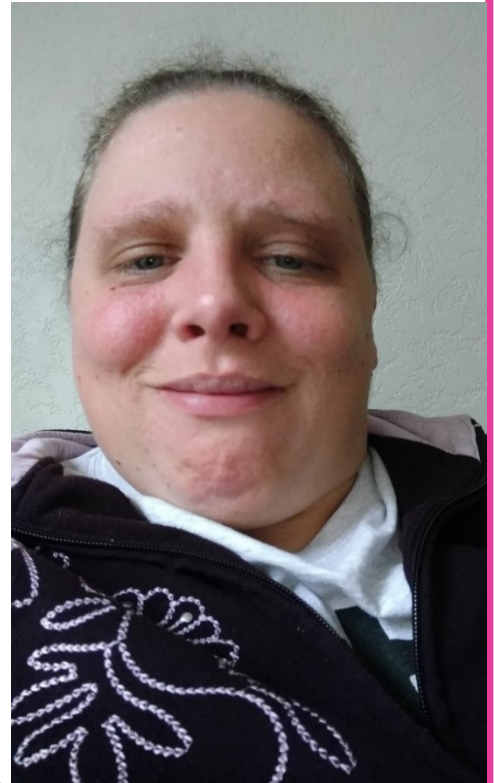
I was given my diagnosis and some advice on things I could do to help myself, like exercises. The consultant took the time to go through different exercise sheets with me and my support worker so I would remember when I got home. The consultant said if I was experiencing any pain I could go back to my GP and get another referral to the hospital.

I couldn't fault the receptionists, there were no negative or detrimental attitudes. The nurses and assistant nurses were amazing. Overall, I would say it was a very positive visit and a positive experience.

I wouldn't say any improvements could be made to my experience, but I would say for the hospitals to make sure to keep this standard of care up for everyone with a disability and also for elderly people too because of a lot of elderly people visit this hospital.”

Natalie also told Healthwatch she had recently attended an event at the University of Morecambe Bay Hospital Trust event called ‘Improving Care in Hospitals Day’ (12th October 2017).

Natalie said; *“I was given a copy of a Hospital Passport to fill in, I think it's absolutely brilliant. I will try filling it out as much as possible on my own and then ask my support worker to help me out with the rest. We also got some information about flagging systems in the hospitals and annual health checks at GPs. I think the ‘reasonable adjustments’ section is great. It was a very good event and very informative.”*

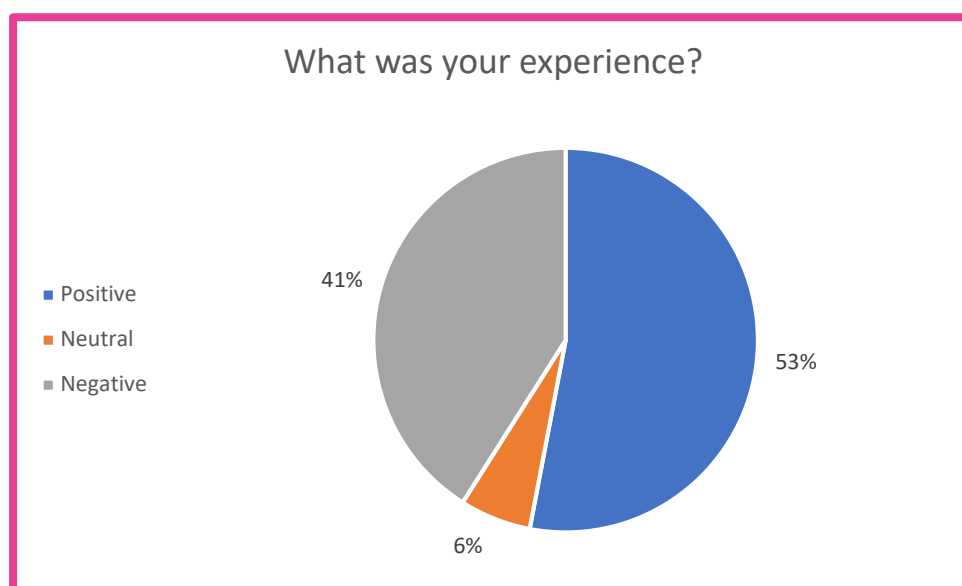


Results

From the perspective of someone who supports individuals with a learning disability and/or autism

1. We asked - If you have visited hospital recently, what was your experience?

By analysing the feedback, we are able to show the hospital experience from the perspective of carers and support workers as the following:



- The majority of positive comments were not attributed to any particular ICP area, however, comments that were attached to an ICP area came from Central Lancashire and Fylde Coast.
- All of the neutral/mixed comments were not attributed to any particular ICP area.
- The ICP area with the most negative comments was Central Lancashire.

Comments about hospitals in:

Central Lancashire

"I feel things have changed positively over the past 15 years that I have been supporting people with learning disabilities. The Passports weren't invented then and they are so good now!"

"There's a huge difference between NHS hospitals and Ramsey Care, Ramsey is cleaner, brighter, has free parking, and is a nicer environment. There is less pressure from the staff when supporting someone."

"The food was left on a tray for a service user I supported. She couldn't feed herself and needed support. The nurse said, 'Oh she mustn't want it, or she just isn't hungry'. As her support worker I explained she needed help and support to eat. If I hadn't arrived she wouldn't have been fed."

Fylde Coast (Blackpool)

"There is a representative for capacity/best interests at Blackpool Hospital. This really helps us all. The hospital sends this person at MD [multi-disciplinary] meetings and at discharge. However, you have to fight for an MD meeting usually"

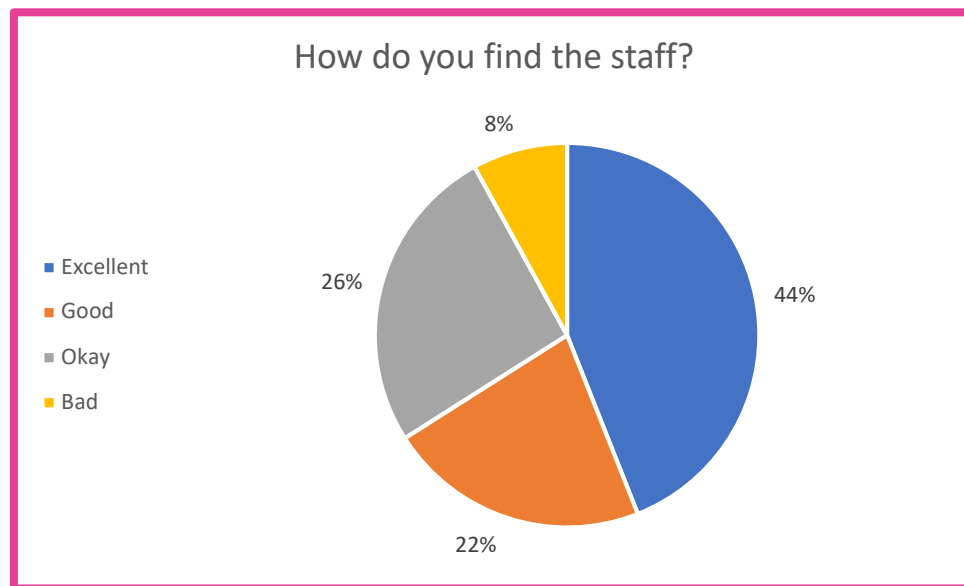
"As carers we attach a risk assessment about that person with the Hospital Passport, we have found that this makes the hospital staff take more notice of it. Without the risk assessment the Hospital Passport isn't taken seriously"

Other/undisclosed hospitals

"Pretty good. The child felt safe and treated well."

"Positive experience, they make a fuss of him."

2. We asked - How did you find the staff at the hospital?



Positive comments:

“Helpful and friendly.”

“Very helpful, good at explaining things to the service user, speaking directly to them.”

“Communication was really good; the staff took time to explain patiently what was happening.”

Neutral comments:

“Nurses were really nice. Receptionist was lovely. Doctor came across as rude and impatient.”

“Different staff, some good, some okay. The ambulance staff were good as they spoke to the husband as well as the person directly.”

“Once some staff accepted she had a disability some were good others very good others inadequate.”

Negative comments:

“Staff appeared scared by disability. Hospital staff were not prepared to make a Best Interest Decision.”

“Rude reception staff and inexperienced nursing staff.”

“Reception staff at all departments were sadly lacking in skills when dealing with people with learning disabilities. There was a poster on the wall nowhere near entrances and the reception area saying in small letters on busy coloured background to “tell a member of staff if you have a learning disability”. I question that! When I challenged the hospital about the poster I was told the speak with

patient partnership. The poster remains on the wall at Chorley Hospital and the staff remain insensitive. We have NEVER had a learning disability nurse with us at any hospital appointment.”

3. We asked - What was good about your/their last hospital experience?

Comments about hospitals in:

Pennine Lancashire (East)

“One of the ward staff and the anaesthetist (that’s all).”

Central Lancashire

“When she had surgery the ward sister sorted everything, and the staff took time and it went well.”

“Very good at explaining the procedure.”

“Some staff were very attentive. Quiet area to calm service user.”

West Lancashire

“Staff are nice. They are always good with him and let me go home. I ask for appointments as early as possible, so he can get to school as he loves going and doesn’t want to miss out as they will look after him.”

“Staff are friendly - mainly the auxilleries who seem to do most the work. Some staff aware of how to deal with learning disabilities.”

“They were treated well.”

Fylde Coast

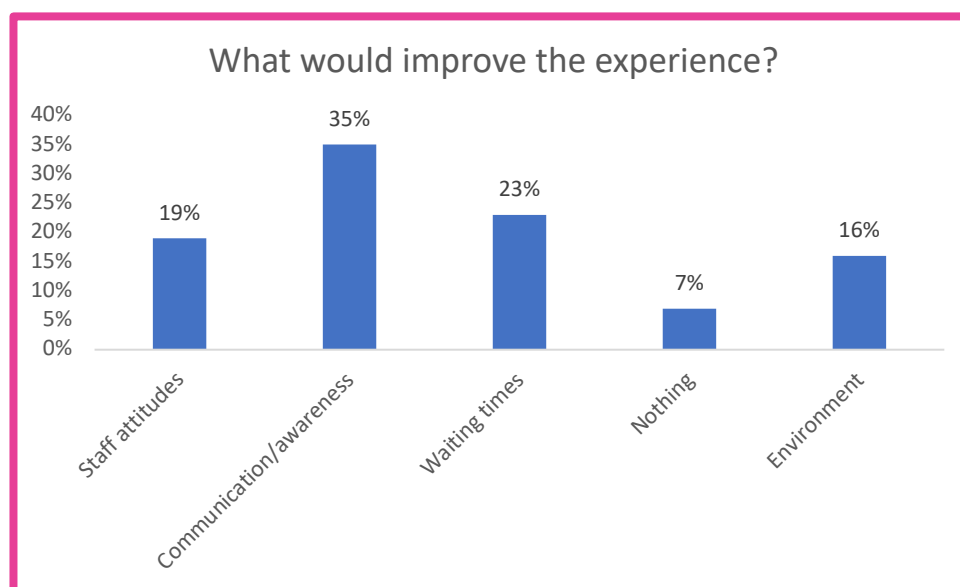
“The staff were really caring towards him. They had a lot of compassion.”

“They were great when they got to know him and as soon as we turned up they made sure we didn’t need to wait long.”

“Good communication.”

4. We asked - Is there anything that could have improved your/their hospital experience? This includes before, during and after the hospital experience.

By analysing the responses from carers, support workers, family and friends, we can identify the most common themes regarding improvements to the hospital experience as follows:



The most common theme from those who support people with learning disabilities and/or autism in the hospital environment regarding improvements to the experience is communication and awareness, followed by reduced waiting times. Many of the comments regarding communication referred to being given up to date information about long delays. Many of the comments regarding the environment referred to having a suitable place to wait if there are to be long delays.

Comments about hospitals in:

Pennine Lancashire (East)

"Waiting times."

"Explaining why there was such a long delay to start that surgery. Having a quiet place to wait would have helped too."

Central Lancashire

"More communication from the last appointment to the recent appointment and more of a handover."

"Recommendations: Hospital must look at appointment times for people/carers with learning disabilities due to the fact of "time" association and the possibility of becoming agitated if the appointment is late or they are kept waiting too long. It makes the carer's job even more difficult to keep their patient

amused/busy/occupied and sometimes the person can become unruly or loud. There are not enough distraction tools. I suggest that patients with learning disabilities be seen at the "correct" time, or at least inform them of expected waiting times, as they can come back at a later time rather than waiting."

"More knowledge of learning disabilities given to hospital staff."

"Better communication between carers and patients and departments or wards. Staff actually reading the information given to them."

West Lancashire

"Doctors manners and awareness of impact on young person with ADHA and autism."

"Appointments on time and not having to wait. Costs of car parking could be reduced even if you have a disabled badge you have to pay."

"Staff awareness of learning disabilities, especially waiting times can be challenging. Cut waiting times or offer a separate area to wait in if they can't shorten the waiting period."

"Yes. I needed to visit the hospital beforehand to do a 'reccy' of where to park, which was the best route into the hospital with the least amount of distractions (shops, cafes, not busy) and getting to the ward. We have been recently made aware of a company in Leigh who create interactive video tours to support patients with Autism and anxiety issues to explore hospitals and wards online before they visit. This helps them to prepare for their visit as best they can from home. They're called Access Social and the videos are called iRoam www.accesssocial.co.uk."

Fylde Coast

"More awareness. Less waiting times."

"Letting service users with autism and/or learning disability look around the ward beforehand. Have 'open days' for service users and their carers."

"Nurses and staff ought to go on more training days run by people with learning disabilities, I know this used to happen at Morecambe Bay."

Pan Lancashire

"All letters should be in plain English and be available in easy read on request. The language is not patient friendly for anyone let alone someone with a learning disability."

"It's important to give you time. It shouldn't be a five-minute appointment it should be however long it takes for me to understand."

A Support Worker's Story

"I am a part time worker with West Lancashire Council for Voluntary Service on the Syrian Resettlement Project. In the course of my work I support one family with a teenager who has learning difficulties and a physical condition.

All the services (GP, Hospital, School Nurses, Dentists) have been fantastic in welcoming and supporting the Syrian Refugees to access their services. I didn't know about the "Hospital Passport" so haven't used it yet. It would be useful, and I think it would be great to roll it out to all the Refugees with interpretation as well as for people with learning disabilities.

However, the recent experience I had taking a teenager for their blood tests, I feel, would not have been different even if the information was on a Hospital Passport. They were treated according to their age (14) rather than their small 97cm frame. I did request for them to have the blood taken in Children's Services because of their size but was informed the teenager would have to go to the Adult Phlebotomist because of their age. Although the patient was upset when having their blood taken, I may have wrongly assumed the needles were too big for her physical frame because the nurses did go looking for smaller needles. I did feel that because of the learning difficulties and the small frame Children's Services would have been more appropriate. One benefit was that the Phlebotomist spoke a little Arabic and was able to communicate with her which was fantastic, and it made a huge difference.

I have since had an experience with another Syrian Refugee child who had their blood taken in Children's Services and their experience was not good. The staff appeared nervous, presumably because of the language barrier. Mum, an interpreter and myself were present with three staff making a total of six adults in a room with one small child. I feel it would have been helpful to have a conversation with mum first rather than trying to explain in the room with an interpreter (Sit him on your knee; hold his arm around your back.... etc). The process made the child very upset and I think this could have been avoided. A simple explanation with a pictorial demonstration (photo) would have helped.

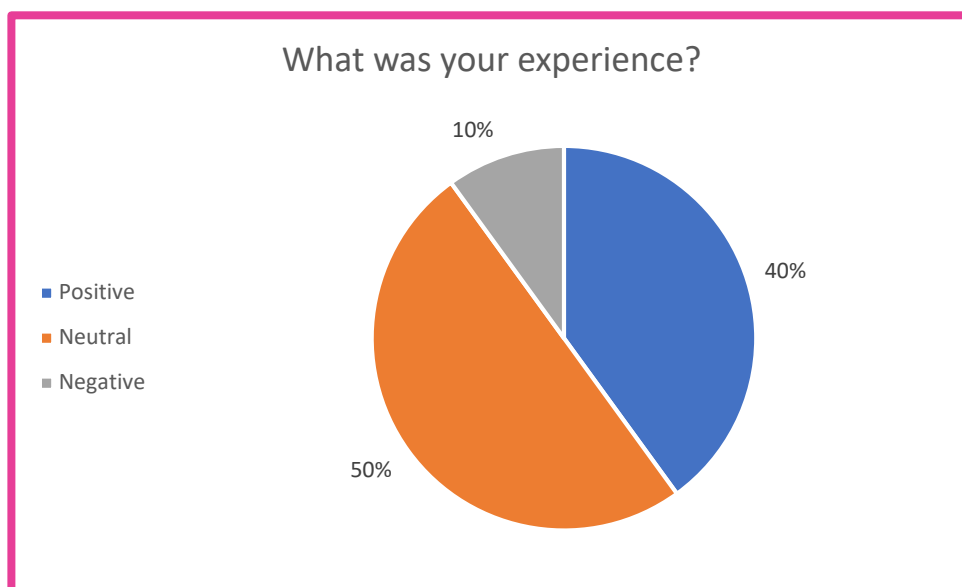
I have worked in the field of special needs for 24 years and appreciate the work the hospitals do. I do think the Hospital Passports are a great idea, but they need to be used and I feel it is the staff attitude which will play the greatest part in the experience of patients with learning difficulties."

Results

From the perspective of a family member or friend of with a learning disability and/or autism

1. We asked - If you have visited hospital recently, what was your experience?

By analysing the feedback, we are able to show the hospital experience from the perspective of friends and family as the following:



Comments:

"Excellent, staff are very good at explanation but not patronising, which is very refreshing."

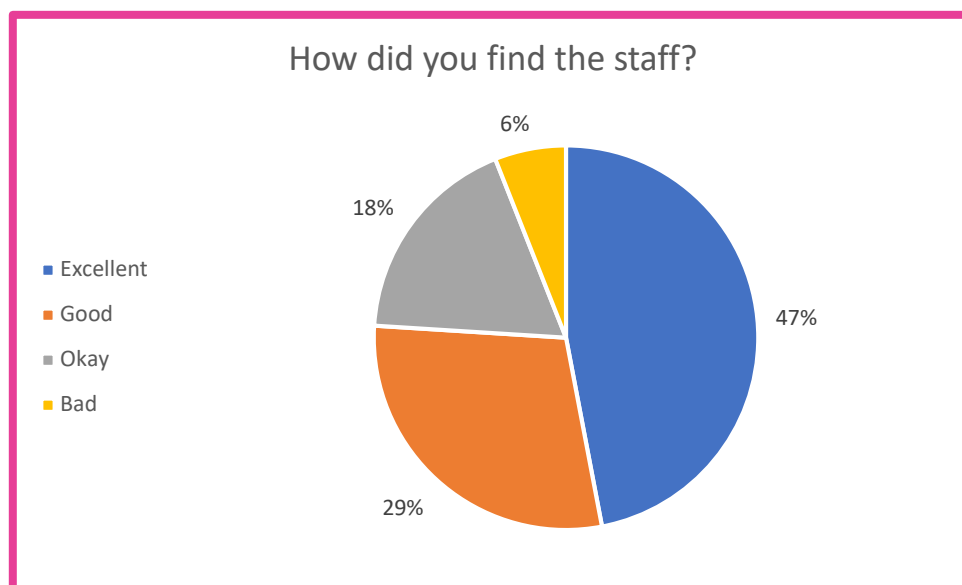
"The staff were very helpful and aware of her learning difficulties, it went ok."

"We went in as a day patient, it took a long time to be seen as our notes were at the wrong hospital when we arrived, but the doctors etc. were great and they did have word searches etc to keep busy."

"It was a negative experience because she was having psychotic episode, but the outcome was positive."

"It was clear that staff were unaware of how to deal with my sister."

2. We asked – How did you find the staff at the hospital?



Positive experiences:

“The diabetic nurse and dietician are always the most helpful, explaining things carefully to my son, and helping him to try and understand his condition.”

“Each and every member of staff explained everything to her in terms she understood as they know her difficulties thoroughly.”

“They listened to all our needs and how to best support my sister. This makes a refreshing change to our previous experience in healthcare.”

Negative experiences:

“Very little awareness of my son’s autism leading to a highly distressing experience of the hospital as I was not allowed to be with him when he came around. He had a massive sensory meltdown as a result.”

3. What was good about your/their last hospital experience?

Bay Health and Care Partners (North)

“Steps were put in place. For example, put first on the list; medical correspondence being redirected, link nurse spending one to one time, preoperative assessment clinic bypassed and care transferred to another hospital.”

Central Lancashire

“Staff are all fantastic.”

“Patience of the staff.”

“We were seen within half an hour of arrival. The doctor understood about learning disabilities and talked to him rather than me, even though my son could not understand or speak. He did not once call me mum and the staff in the department were helpful but not intrusive.”

“Nothing really.”

West Lancashire

“The staff were great and saw to all of her needs.”

“Not sure, my parents didn’t say.”

Fylde Coast

“Good staff.”

“Staff were helpful.”

4. We asked - Is there anything that could have improved your or their hospital experience? This includes before, during and after the hospital experience.

Bay Health and Care Partners (North)

“Staff being educated to deal patients with a learning disability and being aware of link nurses and passports.”

Central Lancashire

“Shorter waiting times and a wheelchair accessible dentistry room.”

“Information regarding the length of the delay to be seen, we were seen about three hours after the appointment time.”

“Yes - understanding that he would need careful handling to deal with the sensory aspect of his treatment.”

West Lancashire

“Seeing to all of her needs with learning disabilities and mental health issues. Which they did but it was horrible.”

“Public transport could be better because I know my parents struggle with this and I often take them in my car.”

Fylde Coast (Blackpool)

“Having knowledge prior to appointments about her difficulties would be useful and for future visits.”

Other/Pan Lancashire

“As a family carer I want to attend to help my child explain their medical history. When you see someone different each time they don’t know you and most of the time they aren’t reading the information on file.”

“If you can’t read like some of my friends it’s important to use other ways to communicate with them like ringing them to tell them when their appointment is rather than sending a letter.”

“It would be great to have a list of dentists and opticians who are truly ASD [Autism Spectrum Disorder] or learning disability friendly. This would be really useful when trying to find a service. Some dentists let you sit in the car and text you when you can go straight through, so you don’t have to sit in the waiting room.”

Our Care Circle Results

Date: 13th September 2017

Group: Blackpool Council Day Services Parent Carer Forum, Centre for Independent Living, Whitegate Drive, Blackpool

Attendees: Six parents/carers

During this Care Circle activity, parents and carers were asked a variety of questions about their experiences of supporting someone with a learning disability and/or autism in the hospital environment. All of the feedback relates to Blackpool Victoria Hospital or specialist dental services at Royal Preston Hospital (RPH).

1. What has not worked well whilst supporting someone in hospital?

"He was sent home because they couldn't cope. To them he was violent, he's not. He was bleeding everywhere and had to go to A&E."

"RPH explained what they were going to do for the dental procedure, he bolted. Had to walk to theatre which was terrifying."

"I avoid taking service users to urgent care or GPs. It's horrible when they're ill because I don't know where to take them. He has to go for an annual check-up and we avoid them."

"Royal Preston consultant comes to Blackpool Victoria. At the appointment the consultant doesn't listen to you and his attitude wasn't good. We asked for a different consultant and asked the GP to refer. It takes a long time to get an appointment. It can be six months."

"They don't always listen to family about what they think is best."

"At Blackpool Victoria while under anaesthetic, they said they would perform another procedure which they didn't. We had to go back and have another anaesthetic. It was departments not talking to each other."

"I feel there is a gap because there is no dedicated room for learning disability services who can get to know someone."

2. What has been your experience of using hospital services as a carer supporting someone with a learning disability? What has been working well?

"They were great when I had to be in and wonderful when he went back in, we had a separate room for A&E. I stayed with him for four days by his side. They remembered he didn't like the beds."

"Always been great for our appointments at the clinic, she can't wait and becomes very loud."

"Working with a department rather than against them is better. Clinical staff are better than admin staff. Both with ENT [Ear Nose and Throat] and dental staged visits over several months has worked really well. Dentist has moved from practice to practice." [RPH]

"The specialist surgeon was fantastic, they kept searching for the problem despite. There were experiences early on, such as being restrained, that had a huge impact."

"Very good at going through all the consent forms."

"I've offered to volunteer around desensitising visits but there aren't any opportunities."

"Often it's about having someone to come and give you a tea break."

3. What could the hospital do to help you more?

"More parking spaces particularly for people who use wheelchairs."

4. Are you aware of any dedicated support services at Blackpool Victoria Hospital or other hospitals that you have visited? What has been your experience of using these services?

"I believe there is a learning disability nurse in charge. It was all publicised and then it disappeared."

"We've refused screening because it's very invasive, it wouldn't be possible. During the anaesthetic, they did a smear."

"We wanted to take pictures of the "journey through hospital" but came up against problems not being able to take pictures."

"Our learning disability nurse now comes with us and supports us in the hospital."

"I haven't had anyone for years and I've got nothing."

"One person for a hospital is not enough."

"I have never used a Hospital Passport. Don't know what one is."

"I've got one but never used it."

Results

From the perspective of professionals working with individuals with learning disability and/or autism

Identifying best practice

We reached out to professionals working within the hospital trusts as well as other learning disability and/or autism services to identify areas of good practice that were occurring across the county, we aim for these findings to enable the voice of the learning disability community to have as big of an impact as possible.

Andrew Heath

Experience and Engagement Lead Blackpool Teaching Hospitals Trust [BTH]

“In brief, we have the following support mechanisms in place:

- BTH have a dedicated have learning disability guidelines (policy).*
- BTH have an identified group of staff that, in addition to their existing roles, are identified as Learning Disability Guides. The guides meet the 2nd Wednesday of every month. If Healthwatch would like to attend one of these meetings and describe the role of Healthwatch in relation to learning disabilities, then I am happy to arrange this.*
- Dedicated learning disability page on the intranet site.*
- Flagging system on the hospital system.*
- Close working relationship with LCT (Lancashire Care Trust) Learning Disability Service and Blackpool Local Government Learning Disability Service, the latter includes a shared learning disability specialist nurse post.*
- Day case surgery have a dedicated list for dental surgery for people with learning disabilities. Please find the link to the most recent Patient Story which features this service:
<https://www.youtube.com/watch?v=EQfOyxahzmg>”*

In response to this, Healthwatch felt the need to ask further questions to clarify some of these support mechanisms:

- What does the Learning Disability Guides role entail and how would a patient get in touch with and be supported by these specialist staff?
“The guides have existing roles and are a point of contact for staff that are caring for people with a learning disability to provide additional guidance. As they are in existing roles, they are only available within their existing roles and duties.”*

- Is there anything else a patient, their support worker or family could find out about prior to attending hospital in terms of support they can receive whilst there? (e.g. quiet waiting areas, volunteer support, etc) *“People with learning disabilities are encouraged to contact the Trust prior to attending so that any difficulties can be addressed. Both the learning disability services also encourage this.”*
- Is easy-read information provided e.g. appointment letters or information on how to take any new medications? *“There are limited easy read documents available.”*
- Does BTH utilise the Hospital Passport or similar tool, if so how do you use it and promote it? *“The passport is promoted by both learning disability services and is supported by and available from the Trust. As this document is typically produced whilst people with learning disabilities are in their normal surroundings, they tend to attend with this document. Staff are encouraged to reference this on admission.”*

Stephanie Iaconianni
Equality and Involvement Lead
Lancashire Teaching Hospitals NHS Foundation Trust

Information obtained from Lancashire Teaching Hospitals, who state:

They have a Hospital Passport template available.

There is a hotline number available for Lancashire Teaching Hospitals. This is available for those with a learning disability and/or autism or those supporting individuals who are attending the hospital for elective treatments. They can contact the hotline to inform the hospital of any additional needs the patient may have, and as a result of this reasonable adjustments can be put in place to support them. For example, if an individual with a learning disability and/or autism struggles within the waiting room environment their appointment could be changed to first/last in the clinic to alleviate this. Another example would be to complete multiple treatments under general anaesthetic to minimize anxiety with going under more than once. The hotline number is 01772 524847 (please note, this number is subject to change once this report has been published).

There is a learning disability folder on the Trust’s intranet on the Equality, Diversity and Involvement site. Here, Trust staff have access to tools such as a ‘Communications Book’, which contains pictures to support individuals who may not be able to read. There are also contact details for all managers, community and national learning disability links. The learning disability information is also available via GP’s through the ‘extranet’ site. Information can be downloaded as appropriate for patients who the GP intends to refer, and we encourage that the GP highlights any additional requirements as part of the hospital referral.

The Trust holds an annual event, ‘Our Health Day’, in conjunction with Lancashire Care Foundation Trust. This is an opportunity for the learning disability community

to be open and honest, and let services know what they think, and if there are additional requirements to support their community.

The Trust is also working to recruit learning disability nurses across different areas. There are also a number of trained 'Learning Disability Champions' within the staff teams that can be allocated to patients. There is also the opportunity for a patient to come in prior to their appointment to meet their allocated champion and become more familiar with the hospital environment.

Chorley and South Ribble District Hospital currently have a 'Changing Places' facility. This facility provides an environment for adults with a disability to carry out personal care tasks with some assistance whilst protecting their dignity. The facility consists of an accessible wet room environment with additional access to a disabled toilet and hoist. This facility is also currently available at the Specialist Motability Rehabilitation Centre (SMRC) in Preston. There are plans in place for this to be available at Royal Preston Hospital.

Stephanie has also been doing some work with participants from REACT (Research in Action - Caritas Care - for more information please visit: <http://www.caritascare.org.uk/for-people-with-disabilities/research-in-action-react/>). The Trust have been working on the 'Ward Board', which will sit behind a patient's bed and will alert staff to any additional needs of the patient. The 'Ward Board' will contain pictures so that patient dignity is protected. The Trust have worked with a graphic designer to mock up some symbols to represent that a patient has a learning disability/additional needs, and Stephanie has been working to consult the REACT group and community disability organisations on these symbols and asking them to choose the symbol they feel is most suitable.

Lyndsey Wood and Tracy Green

Surgical Division Learning Disability Nurses

Lancashire Teaching Hospitals NHS Foundation Trust

"We realised upon starting for the trust that there was no service specifically for people with learning disabilities, to ensure they receive the correct healthcare while staying in hospital. This was a concern as the mortality rate of people with learning disabilities in the country is still high (LeDeR 2015). LeDeR programme was devised following a confidential inquiry into the premature deaths of people with Learning Disabilities (CIPOLD, 2013)

The Disability Rights Commission (2006), states that people with a learning disability are four times as likely to die from preventable causes compared to the general population, so anything we could do to help patients, families and staff would be beneficial.

Our vision for this service is to ensure that people with learning disabilities receive equal healthcare thus improving patient health outcomes. This will be

achieved by us spending time on the wards, working closely with staff and offering training/ support where applicable.

We have already been working closely with ward staff and patients to raise awareness of the importance of delivering a person centred approach and making reasonable adjustments for people when they come into the hospital, as it is a legal requirement.

We are lucky to have support from outside agencies that have assisted in helping us get feedback from people with LD, to find out what good and bad experiences they have had while in hospital. This has been very useful in determining where the service needs to go.

There is still a lot of work to do, but with hard work and dedication to deliver the best healthcare possible, the future is bright for Lancashire Teaching Hospitals and the services it provides for all patients.”

Michelle Kitson **Matron/Acute Liaison Learning Disability Lead** **Southport and Ormskirk Hospital Trust**

Michelle is the lead in the Trust for learning disabilities Acute Liaison (Operationally and Quality Improvement) who states:

Accident and Emergency departments will only flag up a person with learning disability to the liaison services if they have a significant issue. For known patients, an alert is put on the administration system ‘MEDWAY’ (with patient consent if they have mental capacity to agree). Michelle can do a report daily to pick up every current patient who has a learning disability in the Trusts care. Patients with a mild learning disability might not be picked up by staff on admission unless they/family/carers highlight it.

There are currently two planned routes within the hospital system:

- Through the Treatment Centre for investigation. The booking office will let Michelle know if this is the case. It may result in Michelle phoning carers if needed but relevant Trust staff are made aware of a patient with learning disabilities by email from the booking office.
 - There are ‘additional needs’ stickers and/or magnets on ward boards and patient notes that let staff know about a patient’s learning disability. Whilst being discreet and maintaining patient’s dignity, if the treatment involves an overnight stay then Pre-Op Clinic will notify relevant staff.
- Pre-Op Clinics - Michelle will ring or email the appropriate people. Alex Stokes (LCFT - see below) will have asked patients who have a planned

appointment to take in their Hospital Passport. The Pre-Op Clinic give Hospital Passports out to be completed.

- Michelle will give Hospital Passports out on wards. It is dependent on people who know the person with a learning disability completing them. They can be used anywhere, and they can be downloaded from the hospital website. When staff see the 'hands' sticker it should alert them to the Hospital Passport.

Michelle thinks it may be a good idea for Hospital Passports to be on the end of every bed and to be used by anyone, not just patients with a learning disability. At the moment, the Hospital Passports are too long with information that is in the patients' records, so Michelle is developing a 'one page profile' to improve patient experience and to reduce the "missed opportunities for providing individualistic care".

There are more patients with a learning disability and dementia coming into hospital now, so it would be good to have something to use for distraction. An example is the Twiddlemuff, which works well with learning disabilities and dementia. A Twiddlemuff is a double thickness hand muff with bits and bobs attached inside and out. It is designed to provide a stimulation activity for restless hands for patients suffering from dementia. The staff from the hospital recently had a stand at the Southport Flower Show and gave out the Twiddlemuff pattern for people to knit. It was so popular they had to do a reprint.



Other considerations for patients with a learning disability

- Communication - we will find somewhere quite to talk

- Joint working - we work well with Departments and Quality Leads - because of the established links we will then decide who takes the lead on any joint work
- Continuity - As Michelle has been in situ for three years she will know a lot of the learning disability patients and the staff know them as well
- Sharing needs and best practice - we are part of the learning disability network
- Consideration of individual needs - if a patient/parent doesn't want something in place then staff cannot do it
- Visiting - Carers have open visiting. The Trust support the John's Campaign [for more information please visit <http://johnscampaign.org.uk/#/>] for dementia patients. There are also two-day beds for parents and unpaid carers
- Training - all staff get training around learning disabilities (as part of their clinical induction). Mencap [for more information please visit <https://www.mencap.org.uk/>] have supported the development of a foundation level learning disability network training package

Monitoring mechanisms

- Patient feedback, compliments and complaints (although it is very rare that the Trust have complaints from patients with learning disabilities)
- Annual case notes and audits
- Quality Department have a learning disability steering group
- MerseyCare Trust have annual dementia screening for patients with Downs Syndrome

Alexandra Stokes

Integrated Service Manager for Adult Learning Disability Services Lancashire Care Foundation Trust

Alexandra Stokes is the Learning Disability Lead for Lancashire Care Foundation Trust [LCFT] covering West Lancashire and Preston Hospitals, who states:

She supports patients with learning disabilities and staff of Southport and Ormskirk Hospital by supporting the induction training for staff. This includes how to work with and communicate with vulnerable adults (including learning disabilities and dementia).

Alexandra also sits on the Southport Adults at Risk Team, sitting on the steering group and covers safeguarding issues.

Michelle, the lead at Southport and Ormskirk Hospital, will phone Alexandra to see if a person is known to the Lancashire Care Foundation Trust (LCFT) team and get

the relevant advice in order for the clinical staff to offer support appropriately, hence they have a good working relationship.

Other considerations for patients with a learning disability

- GP Registers - These registers validate someone with a learning disability by a 'tag', which LCFT can view. However, not everyone is flagged. One suggestion could be that GP's ask patients with a learning disability if they have got a Hospital Passport
- LCFT give out the Hospital Passport and promote the usage when patients are going to providers. When Alexandra knows a person has a planned appointment they will ask them to take their Hospital Passport with them. Alexandra would like to train GP's in how to support people with learning disabilities and how to work together with other professionals, as people with learning disabilities would benefit from this
- As the contract which was held by LCFT for the Hospital Trust has gone to Virgin Care District Nurses. There could be a question over whether LCFT will still have access to the same patient information as before
- Bank and agency staff tend not to ask clients to take Hospital Passports this doesn't mean they do not have them. There is still a role for the promotion of and training in the use of Hospital Passports

Brian Evans

Clinical Nurse Specialist for Learning Disabilities University Hospitals of Morecambe Bay Trust

Brian Evans is the Clinical Nurse Specialist for Learning Disabilities across the Bay Hospitals, who states:

This is a new specialist nursing role established to support people with a learning disability while they are in hospital, to make sure they get the care they need.

He has many years' experience in learning disability nursing, including managing a learning disability supported living service and community learning disability nursing in the challenging behaviour pathway and most recently the Registered Manager of a nursing home for individuals with learning disabilities, mental health issues, complex needs, autism and challenging behaviour. He has a BSc Hons degrees in behaviour analysis and intervention and supporting individuals on the autistic spectrum.

His goal is to ensure the support for individuals with learning disabilities is person-centred and proactively planned at pre-admission stage and during the initial stage of admission to hospital in an attempt to minimise the anxiety and stress of having to come into hospital. At this stage, there should be provisions to make reasonable adjustments (Equality Act 2010) to ensure care is successfully facilitated, this includes identifying any environmental needs, interpersonal needs, communication

requirements and specific support needs. A fundamental aspect of care provision is obtaining consent to treatment, this may involve assessing capacity and subsequently applying the principles of the Mental Capacity Act (2005) in relation to best interest decisions for individuals who lack capacity to consent to a specific intervention or treatment. The admission process may involve applying for Deprivation of Liberty Safeguarding (DoLS) authorisation for individuals who may need certain restrictions in place to safeguard them or others from harm (Mental Capacity Act 2005). Another aspect of the role includes identifying and developing resources including accessible information designed specifically to enhance a patient's understanding. We intend to offer and provide advice and where appropriate training to enhance staff understanding to ensure care provision is effective and safe.

Brian liaises with hospital staff, GP surgeries, Community Learning Disability teams, social services, service providers, advocacy services and allied health professionals to discuss any specific needs and gather ideas and suggestions on how to enhance service provision for individuals with learning disabilities, all input and ideas would be most welcome.

If a person with learning disabilities is admitted to hospital or is being referred to hospital by their GP, Brian would like to be made aware at the earliest opportunity to enable him to meet the person as soon as possible after they arrive at hospital. This will enable him to find out as much helpful information about the patient's learning disability and their preferences, and to understand the help they may need while in hospital. It may be possible to arrange a meeting before the hospital stay.

Hopefully all individuals with learning disabilities will come into hospital with a Hospital Passport. These are available from the local community learning disability teams, alternatively Brian is happy to provide passports and support people to complete them. Hospital Passports are specifically designed to give hospital staff helpful information that isn't only about illness and health it's specific to everyone's individual needs.

Julie Clift

Specialist Nurse (Learning Disability and Autism) East Lancashire Hospitals Trust

Information obtained from East Lancashire Teaching Hospitals:

Different processes are followed depending on how people with learning disabilities come to hospital, for example:

Planned admissions

“I would usually know if someone is coming in for a planned admission has a Learning disability. In part because I can check on the learning disability register however identifying that a patient has a learning disability is the biggest problem

Identification that a person has a learning disability can occur at various stages along the patient journey:

- At outpatient consultation
- Preoperative assessment
- Admission to ED department
- Admission to ward

Once patients are on the ward and they have been identified with a learning disability we would commence a learning disability care bundle.

Outpatients

“Occasionally I will know that a patient is coming to outpatients and they have a learning disability, but often I don’t, unless they need me to be there or there’s an issue in clinic. Reasonable adjustments can be made if possible, such as patients getting early or late appointments. If people ask, we can try to accommodate. We have had a young man recently who is coming in for dental treatment and wants a later appointment, but the dental clinic is only open in the morning, so we are struggling to accommodate him. He can’t have a late morning appointment because then he would have to wait, and he can’t do that. It is extremely difficult to accommodate sometimes.”

Emergency

“When people are coming through A&E we probably would not know they have a learning disability unless they have been before, then they would be flagged. The Hospital passport should be asked for and used.

If we don't know they have a learning disability it is difficult. It is so busy in emergency and hard for everyone. We have an area that we try to keep free which is part of 'enhanced care' - we are in the process of making it friendlier. We are trying to allocate that space for people that need it more, such as people with learning disabilities.

Recently when someone was coming into hospital through A&E, the support staff contacted me to say he was on his way. So we knew he had a learning disability and could support him. We use the Manchester triage system, so there is

consideration for people with a learning disability or autism and whether they will be prioritised, but it is mainly about clinical care, so we must prioritise amongst the clinical needs of other patients. Where we can do something, we will.

Following the Hospital Passport may not be possible, such as someone may write that they don't like to be touched, but they need to be turned every two hours to stop pressure sores, so we cannot commit to not touching the patient."

Communication tools

"Access to communication tools to help people to understand are available on the intranet using the hospital communication book which is used with the patient. People often bring their own communication aid with them. Not all leaflets are in easy read as there are thousands of them, but we can adapt them to meet the needs of patients individually and we do this." (Julie showed a Healthwatch representative an example of an adapted easy read leaflet created for an individual).

Staff training in learning disabilities awareness

"Learning disability awareness is part of the safeguarding Adults training and this is mandatory. We encourage all wards to have a safeguarding champion and they will also have the brief introductory training. Training for other staff on learning disabilities is not mandatory.

The challenges are:

- Identification that a person has a learning disability
- Identifying what reasonable adjustments are required
- Empowering staff to have the confidence to care for people with a learning disability"

Working with learning disability service users

“Service users designed a video to use within the safeguarding training. I have just done a learning disability audit and am trying to push learning disability training to see if more people can get access to the training, such as for newly qualified staff.”

Care bundle

“The care bundle is a set of directions based around national guidelines for nurses looking after patients as to what they need to do when they are in hospital.

There are a few stages to it:

- Is the patient flagged on our system as having a learning disability?
- If not, but it is suspected, use a flow chart to determine if they are considered to have a learning disability. The patient would be referred to me and I would verify if they have a learning disability or a learning difficulty.
- Do they have a Hospital Passport?
- Create a hospital care plan - hospital care needs, speaking with care providers and planning for discharge.

My role is to support people directly. The hospital does look at commissioning additional support when it is needed, for example, the hospital may be able to commission the patient’s support staff to do more whilst they are in hospital.

However, if they have a good Hospital Passport, our staff can often provide this.

Hospital Passports

A good hospital passport can be vital in helping us to provide effective care. Knowing simple things such as what the person likes to eat and drink can make a difference.

Summary

It is our aim that these professional case studies will provide each Hospital Trust or organisation and local Clinical Commissioning Group with useful information to be used as 'good practice'. The main themes are summarised below.

Organisation	Main themes
Blackpool Teaching Hospitals NHS Foundation Trust	• Learning disability policy • Staff training/champions • Learning disability page on the Intranet • Flagging system • Joint working
Lancashire Teaching Hospitals NHS Foundation Trust	• Reasonable adjustments • Learning disability page on the Intranet • Communication tools • Community events • Staff training/champions
Southport and Ormskirk Hospital NHS Trust	• Flagging system • Pre-attendance communication • Joint working • Staff training • Patient feedback
Lancashire Care Foundation Trust	• Staff training/champions • Safeguarding • Joint working • Promotion of Hospital Passports
University Hospitals of Morecambe Bay NHS Foundation Trust	• Pre-attendance communication • Reasonable adjustments • Accessible information • Joint working • Flagging system • Promotion of Hospital Passports
East Lancashire Hospitals NHS Trust	• Pre-attendance communication • Flagging system • Care bundles • Communication tools • Staff training/champions • Promotion of Hospital Passports

Views of residents in care homes

For this project, Healthwatch Lancashire we conducted two Enter and Views. The aim of these was to consult with service users and their carers to evaluate their experiences in the hospital environment, and to interrogate the effectiveness of the Hospital Passport scheme. It is part of Healthwatch's rolling programme of work to listen to seldom or never heard groups, which is why we targeted engagement with people in residential care settings.

Prior to our visit a poster inviting participation from service users, friends, family and carers was delivered alongside examples of the type of questions we intended to use. Representatives were asked a series of questions in respect of patient experience from which identified qualitative themes.

Due to the level of learning disability, residents' responses were supported by care workers. We also spoke to staff and managers independently and recorded their observations of the service users experience.

Throughout the report:

- LD refers to Learning Disability
- HCA refers to Health Care Assistant
- HLNLD refers to Hospital Liaison Nurse Learning Disability

At the time of our visit we spoke to nine staff members, five of which were managerial, and three service users whom could provide some minimal feedback.

Acknowledgements

Healthwatch Lancashire would like to thank all the staff and residents at Hollydale and Rowandale Care Homes for making us feel welcome and engaging in the visit.

Hollydale and Rowandale residential homes are dedicated Learning Disability facilities and part of the Dalesview Partnership Ltd.

Hospital Services

Most of our responses focused on the experiences of support workers and service users communicating within the hospital environment.

Feedback was mixed, reflected in the response of one manager, "*There is a mixture of good and bad practice.*"

Training and communication emerged as recurring themes as did a clinical method of delivery of services as opposed to a person-centred delivery. Several support workers believe that nurses prioritise routine over basic empathy and this is demonstrated by "*unnecessary observations*". This impacts disproportionately on those with learning disabilities, and those who are vulnerable and inarticulate.

Several support workers felt that the needs of those with learning disabilities were “*not properly met*” and described observing other vulnerable patient’s experiences in formulating this opinion.

For example, one manager described observing three dementia patients in the same hospital bay having food and drink left for them but not eating it as they had no assistance. She reported that later, another member of staff cleared the untouched food away but made no enquiries to why it wasn’t eaten.

One manager concluded, “*We feel obliged to offer lots of support. We did not feel our service users’ needs would be met otherwise*”.

Conversely one support worker reported “*a very good experience as there were three people there with him, Mum, a key worker and a physiotherapist*”. The service user added that he “*had a good time and likes his keyworker going with him into hospital*”. The support worker added that it was “*really helpful as there were plenty of people there who knew the service user really well and they could help the hospital staff communicate with him*”.

In terms of funding, managers described how this support in hospital was largely unfunded by social services and had a negative impact on the care and staffing levels in the residential environment. One support worker reported that she stayed with service users until 10.00pm; “*if I did not stay I feel the service user would not get the care they require*”. Respondents also identified that the admission and treatment of people with learning disabilities may be delayed by them having to engage with more internal services, for example, speech and language assessments. One support worker said she generally had good experiences at Preston and Chorley Hospitals.

Negative comments:

“Staff need to use more common sense regarding care whilst in hospital, for example, not taking blood samples multiple times upsetting patients.”
(support worker)

“We need better communication and sharing of information on admission.”
(manager)

“Unfortunately waiting for speech and language input is an extra hurdle that some LD patients have to navigate prior to treatment.” (support worker)

“There is a fear that because a patient has LD sometimes medical professionals make assumptions about their quality of life, and this can lead to significant decisions about their treatment.” (manager)

“It may be that additional training is required for HCA grade because I saw an HCA supporting a lady with dementia, when the lady spoke to her she responded without looking at her and continuing to use her mobile.”
(manager)

“Hoist availability on wards is a major problem, sometimes service users have to wait a long time for a hoist to be brought from another ward and in that time, they had soiled their pad when really they wanted to be moved to a toilet.” (manager)

“There is a very clinical view of support in hospitals, they are not very person centred. They have improved over the years though.” (manager)

“There is a mixture of good and bad practice.” (manager)

Positive comments:

“We tell medical staff if a person has challenging behaviour and they are generally seen quite quickly.” (support worker)

“Some HCAs had time and were appreciative of our support of the patient.” (support worker)

“It was a great experience, the hospital staff let the key worker take the lead.” (support worker)

“I was pleased that the nurse had as much interest in the service user as I did. I thought “Wow! they care as much as we do”.” (support worker)

“The nurse brought a teddy in to comfort the patient who was scared and anxious, she still has that teddy today.” (support worker)

Hospital Passport

Generally, respondents felt that the Hospital Passport was a valuable resource, but that hospital staff were inconsistent in their use of the information.

Support staff suggested that they preferred liaison “on some wards” to assist nurses to understand the information given on the passport and one-page profile.

“It’s a fantastic tool which captures important information but its only good if it’s being used.” (manager)

“The Hospital Passport is not used by hospital staff.” (support worker)

“Chorley Hospital are really helpful when it comes to profound needs and challenging behaviours. A&E love Hospital Passports.” (manager)

“The Hospital Passport that we have is clear and easy to use.” (deputy on nursing unit)

“It’s not useful because it wasn’t used.” (manager)

“Our resident wasn’t drinking when I went to visit her. I asked if she had sweetener in her drink as the passport advised. They hadn’t looked at the passport and hospital staff assumed our resident was declining the drink.” (support worker)

“The care provider uses their own and these are taken with the service user along with their support plan to the hospital.” (support worker)

Hospital Liaison Nurse Learning Disability (HLNLD)

It seemed that the specialist role of Hospital Liaison Nurse (Learning Disability) was largely indistinct. One Learning Disability Manager thought that there was just one nurse available in the whole of Chorley, Preston and Blackburn.

More than one of the learning disability staff we spoke to were unaware that there was a learning disability specific nurse lead, nor were they told about this when service users were admitted.

Other concerns were raised around the role being replaced by “Learning Disability Champions” which was not regarded as clinically skilled as HLNLD.

One learning disability staff member knew of Liaison in Day Services but not in Inpatient Care, stating that Inpatient Liaison would be very helpful.

“I suggest more staffing around this role.” (manager)

“Learning disability managers told us that the role of HLNLD was being supplemented by the role of ‘LD Champions’ and that this role was not as clinically skilled as HLNLD.” (support worker)

“The LD liaison nurse wasn’t mentioned when we attended hospital.” (manager)

“A positive experience was when a liaison worker at the hospital helped us to get a side room and avoid our service user having to wait. It would be really beneficial if there were more liaison nurses.” (manager)

Conclusion

Responses to hospital services were more mixed. Training needs and poor communication emerged as a recurring theme as did provision of care being service led rather than person-centred resulting in resident's disability and health needs not being met.

“We feel obliged to offer lots of support. We did not feel our service users' needs would be met otherwise.” (support staff)

Staff highlighted that extra funding is unavailable to help the provider when residents need to access hospital as an inpatient, explaining that this can impact negatively on the care and staffing level in the residential environment.

Some positive comments were reported in respect of staff implementing person centred care.

There appeared to be a general lack of information about the Hospital Liaison Nurse for Learning Disability (HLNLD) with the role being unclear. However, where the HLNLD was encountered in hospital this had proved to have a positive impact for both the service user and supporting staff.

The introduction of Learning Difficulty Champions has caused some concerns with staff as they feared that the role would not be as clinically skilled as the HLNLD.

Generally, staff and managers felt that the use of Hospital Passports was very beneficial and helpful but unfortunately, they were very rarely used by hospital staff.

Focus Groups

The last phase of this project was for Healthwatch to identify two groups that wanted to ‘have their say’ on what was important to them through each phase of the hospital journey and what the hospital service could do to support them further.

Focus Group One (8 participants, living in the Bay Health and Care Partners area):

We asked: What is important to you before you go into hospital?

“For those who are unsupported to be met by a chaperone or a volunteer.”

“Allay fears and nerves, for example, when getting into an ambulance. Talk and reassure.”

“Having a text or phone call reminder.”

“Having a named nurse to meet me at the door, not necessarily staying with me at the appointment though.”

“Knowing where reception is so I can ask where to go.”

“Staff should talk to me nicely.”

We asked: What is important to you during your time in hospital?

“Last time I went, I went alone via hospital transport. I knew about hospital transport because of the contact number on the letter. When I was dropped off I was not sure where to go, I’d like to know where the toilet is and where to get a drink.”

“At Royal Preston Hospital, I waited from 10am-5pm and they didn’t tell me why, luckily I had money and a carer with me so I could get some lunch, but I wouldn’t always have enough money or support.”

“They don’t always explain what is going to happen.”

“Communication is essential, one of my experiences was waiting all day and nobody told me about the delays.”

“Staff attitudes, and they need to explain why a patient is there and what is involved in the treatments.”

We asked: What is important to you after you have been to hospital?

“After my last trip, the physiotherapy department gave me a sheet of paper with exercises on it which they explained to me very well. Sometimes ‘easy read’ information is hard, some of the words are still really big, I can’t understand big words so the information they give you needs to help with that.”

“I got a phone call on my house phone to tell me about the tablets because I couldn’t read the box.”

We asked the eight participants to look at three different Hospital Passports designed by various Hospital Trusts across the country; Lancashire, Bristol and Morecambe.

We asked the participants what they liked and disliked about each passport:

The Lancashire Hospital Passport

"I prefer the black print and bigger letters."

"I like the Red, Amber and Green."

"I don't think this is easy read."

"The words aren't easy to see, and the black writing is hard to see, the writing is small."

"The pictures should be bigger, some of the pictures are unclear. Both writing and pictures are equally important. These aren't proper pictures."

"I think they should talk to you about what you've been through."

"It's hard to understand and it's too long. Also, having information about discharge isn't important."

"It is not easy read."

The Bristol Hospital Passport

"The pictures and writing stand out, the pictures are very good."

"This form isn't too long."

"I think it better because you can get more information on one page."

"I think it's good, the information would help me. I get nervous sometimes. The pictures are clear, I like the pictures."

"There's plenty of information in it, I like all the little pictures. It's still quite a lot to read but there's plenty of information, it's more understandable and it's not missing anything."

"The pictures aren't as good, challenging behaviour isn't always associated with anger and the child holding a teddy isn't representative for an adult. I think pictures should be of real life and not cartoons."

"There isn't any space on here to detail whether an individual has specific communication needs, for example, if they use their own hand signs."

"It might be easier to have tick boxes rather than blank spaces."

The Morecambe Bay Hospital Passport

"I like the colours on this one."

"The length is okay."

"The communication section is good."

“The pictures are alright.”

“It is very important they know how I feel.”

“In this picture section there isn’t enough representation of different religions.”

“There’s too much to read in the beginning section, this isn’t good for people who can’t read.”

“I like the pictures but I can’t read so I would need support with this.”

“The choking picture looks like they’re strangling themselves!”

“The writing is small and because I shake I can’t read it. The big writing on the front is good.”

“Mental Capacity isn’t easy, it’s much harder to understand.”

“The ethnicity picture is a mosque which is confusing.”

Suggestions for improvement

“It might be good to have a ‘pen picture’ of the service user on the front, which can identify what that person is normally like.”

Focus Group Two (15 participants, living in the Central Lancashire area):

We asked: How many people have hospital passports?

Three people were confident that they had a Hospital Passport.

We asked: Tell us about a recent hospital experience, positive or negative.

Liverpool Hospital: “I saw people on Monday and got a quick service, I rang on Tuesday and I was back in for my operation on the Thursday. The only problem was when I needed to take my medication during my stay, because I need to take it at certain times and sometimes with food, but luckily my mum was there and able to tell staff when I needed to take my medication.”

Chorley Hospital: “They are lovely people, very kind. I am very comfortable with the people who know me because I see them quite frequently.”

Royal Preston Hospital: “I had an operation behind my ear to remove a piece of bone which wasn’t nice. I have been going to hospital all my life, I know I have to go but I don’t like going because I get quite nervous about it. The procedures aren’t too painful and it’s been a quick service.”

Chorley Hospital: “I have had two operations at Chorley Hospital (on my eye and face), it was very uncomfortable and I found it hard to understand the doctors.”

Royal Preston Hospital: "I had fluid on one of my joints. I went to Royal Preston Hospital and waited all day for an operation, which is a very long wait. My parents ended up having an argument with the surgeon about why and whether the operation was needed, as there were questions about whether or not I could consent. I was also embarrassed by having a male doctor when I feel more comfortable with female doctors."

Regent House Surgery (GP in Chorley): "My wheelchair wouldn't fit through the door so I had to have my flu jab done in a corridor and I didn't like that."

We asked: What is important to you before you go into hospital?

"Help for people with a visual or hearing impairment so that they know when they are being called into a clinic appointment."

"Having an easy read letter so I know what is going to happen."

"Helping people with anxiety before going in, maybe relaxing medication or reassurance from staff who understand that I have a learning disability."

"Having good signage so I can follow signs to a department, I like the signs with green backgrounds as they are easy to understand and see."

We asked: What is important to you during your time in hospital?

"Having a drink and a biscuit whilst waiting."

"Explaining why we may need to be kept in hospital for a long time, so explain why we might not be able to leave at a certain time. I want to know when I can leave and the doctor explaining the reasons why is very important."

"Explaining what is going to happen when I go in for an operation, I want to know what it is and what is going to be used."

"Support through the actual treatment including personal care, relieving nervousness."

"Feeling comfortable and having a choice of people caring for you so you feel less anxious/nervous."

"Sometimes it's hard to explain my problems to the doctor, it's important to be able to make the doctor understand so I always use my support staff, I always need to have someone there to communicate."

"There's sometimes problems with car parking, we always need to allow a lot of time just to find a space because there isn't enough."

"It's important to be accompanied so I can understand the doctors. As I have a visual impairment I don't even have the luxury of seeing peoples body language."

Unfortunately, on this occasion the time permitted did not allow us to ask what is important after a hospital visit.

The group informed Healthwatch that they had completed a piece of work with the local Clinical Commissioning Groups earlier in the year around what is important to them whilst accessing services. Healthwatch made contact with local CCG's to find out how this work came about and how it is being used, in order to share this as good practice within the report, however to date no response has been received.

Focus Group Conclusions:

We asked people what they feel is important *before* they go into hospital and found out that the most common themes were being able to arrange support (i.e. from a chaperone), feeling reassured and having enough information about the appointment (e.g. a text reminder).

We asked people what they feel is important *during* their hospital visit and found out that the most common themes were knowing where to go and knowing what would happen (including communication around treatment and any potential delays), staff having positive attitudes and having a feeling of comfort and reassurance.

We asked people what they feel is important *after* their hospital visit and found that the most common theme was having easy-read information to take home, including information on any new medications.

When we asked people to look at different templates of Hospital Passports from different Hospital Trusts, none of the templates provoked a majority of positive comments. In light of this, Bristol's template was the 'most' successful as positive and negative comments were 50% each. The 'least' successful template was Lancashire Teaching Hospitals, with 75% of comments being negative.

The majority of positive comments about templates were referred to large, black print letters, use of the red, amber and green colour scheme, clarity and size of pictures and the template not being too long.

The majority of negative comments about templates were referred to writing and pictures being too small and not easy-read, the template being too long and the pictures not being representative of the words they correlated to.

What else did we find out?

Through engaging with vast numbers of people within the learning disability community, we spoke to many who wanted to share their experiences in other areas of healthcare besides hospital access. Here are some examples of case studies that were conducted to capture those experiences.

Mental Health Services

From someone with a learning disability and/or autism (North Lancashire)

Which service do you attend?

"I have recently been going for mental health sessions in Lancaster for the last few weeks. I go once every one to two weeks, it depends on availability of appointments. I always take my diary with me to sessions, so I can book the next one in before I leave. I'm not meeting them for another three weeks now, but I've been given a contact now, so I can get in touch with them if I need them in the meantime."

How did you access this service?

"My first concern was with my stuttering. I found I kept repeating myself when I was getting nervous or anxious, and so I went to a speech therapist. I found speech therapy really helpful, I saw them twice. During those therapy sessions, we spoke a lot about shocks (traumatic experiences) that I've had over the last few years, and that's when the speech therapist suggested I got some support from the mental health team."

What was your experience of the referral process?

"I did have to wait a few weeks for my first session. I went to my doctor at the beginning of September and had my first session in early October."

How do you find the service?

"I felt a bit nervous going to my first session, but I was also happy to be getting the help. It's been really nice to have someone to talk to about those shocks, things that I find really difficult to talk about because they made my speech more difficult."

At the beginning of each session, the staff goes through a questionnaire with me asking me how I've been feeling since I last saw them. There's one question about worrying ("Over the last two weeks, how often have you been bothered by any of the following problems: Worrying too much about different things") - I find this question quite difficult because I don't know what 'worrying too much' really means, how does anyone know if they're worrying too much, you know? I think that question could be worded so it's easier to answer, but then you don't want to go questioning the questions because it's awkward and otherwise you'll be in

there forever and I think an hour is already plenty of time because I want to be out and about doing different things too.

I also would have liked it if I'd been asked more about my sleeping patterns after they asked the questions about getting enough sleep, as this might have prompted me to talk more about what was worrying me.

Overall, I'm really happy with the support I'm getting, I think that member of staff is a really good person."

Cervical Screening

From someone with a learning disability and/or autism (Central Lancashire):

"I have had a difficult experience arranging a cervical screening at my local GP. I had had quite a few letters through that I didn't really understand, so eventually I had support from one of my support workers to go through it with me. It would have been really good if an easy read version of the letter had come.

I had no knowledge whatsoever of what a cervical screening was or what it was for, again my support worker explained a bit to me and the leaflet that had come with the letter. I also rang my mum and had a chat about it with her, she explained how important it is to have done, even though it's not pleasant but it would make sure that I'm alright.

The GP I usually see is female and knows me very well, but when I rang and made the appointment I didn't know who it was going to be with. This would have really helped to know first because I struggle speaking to males and it makes me feel really uncomfortable.

When I turned up for my appointment, it was with a male doctor and I was uncomfortable. He asked me why I was so frightened, and I struggled to communicate with him. The male GP then asked me to do a pregnancy test and I was unsure why, it was a bit much to take in! I actually mentioned it to my regular female GP and she couldn't understand why he had asked me to do that either. He just kept saying, 'Well, why are you scared?' and it wasn't very helpful. Eventually the male GP suggested that I book an appointment to see the nurse, which I haven't done yet, but I am going to.

I also wasn't given any information about what happens after you've had it done, so I wouldn't know what to expect from my results.

I really like and trust my regular female GP. She's spoken to me in the past about reducing my anxiety medication, but when I explained that I didn't want to because they were helping she really listened to me and agreed to let me continue with them for another three months.

I think there are lots of things that could have gone better in my experience, and for other women with a learning disability:

- *Providing an easy read letter and easy read information*

- *Having more awareness for women in general before they even receive the letter, I didn't know anything about it!*
- *Knowing which GP you are going to see before your appointment and having a choice in who you see*
- *Be understanding and accept that fact that we are not different from anyone else, but we do have disabilities*
- *Being able to see the room/equipment and be able to talk it through beforehand*
- *Having the option to have it done from home*
- *Being given information about what happens after you've had it done*
- *Having something to relax you, like medicine that calms you down*
- *Having a nurse come out to a group to talk us through it*

Other feedback from Care Circle activities:

Central Lancashire

"Boots pharmacy are very good."

"I see the same doctor and nurse each time."

"I see different doctors which I like seeing different people."

"If you are shy or don't like talking the doctor needs to speak to the support worker to find out what is wrong."

"Lostock Hall doctors take time with people and are very positive."

"I like my doctor at Docklands he does lots of checks on me."

"Chiropodist is fine, private, do a good job."

"Eating disorder clinic - very positive experience in Ashton. The staff were alright, good to talk to."

"Cottam Lane Pharmacy slow and you have to wait ages."

"At Lloyds, Lytham Road my medication is not always right, I have to check them. There's problems with MAR [Medical Administration Record] sheets sometimes."

"Getting some things from pharmacy is difficult, there are disjointed services between GPs and pharmacy. Lloyds, Boots HBS all have communication problems."

"At Lytham Road Practice it's hard to get appointments."

"At Docklands it's impossible to get appointments."

“Appointments have to be in the afternoon due to people’s medication, this can cause problems if surgery don’t understand this.”

“There’s a problem with our GP phone system, previous person could access it independently, now with the new GP system staff now have to do it (Park Medical Practice).”

“The doctor looks and talks to the support worker rather than person.”

“I have problems with seeing a different GP each time, I have to start again explaining health issues, it’s quite frustrating.”

“Having a named GP was a good thing as they got know the person better and their health problems.”

Fylde Coast

“I go to the doctors for my flu jab. It’s okay.” (GP)

“I go to the doctors for check-ups. It’s like a health MOT. I ring up and book the appointment myself.” (GP)

“When my blister pack is nearly empty I just ring up its quite easy.” (Pharmacy)

“My mum phones the pharmacy and it’s delivered. It’s in a syringe and I drink it. It works well for me.” (Pharmacy)

“Someone came to the day centre, and she only came for ten minutes.” (Chiropody)

“They don’t tell me very much. They should send me a letter to tell me what’s going on.” (GP)

“They talk too fast and don’t give me chance to understand.” (GP)

“I have to wait ages for my appointment in the waiting room, then my appointment is over in two minutes.” (GP)

“My sister reminds me about my appointment, not the doctors.” (GP)

“When you get in there they should explain things more.” (GP)

“They spend all the time on the computer and they use medical terms I don’t understand.” (GP)

“It’s hard to open my medication, it’s not user friendly it’s too fiddly. There is an aluminium packet that I have to tear open and I often drop my tablet.” (Pharmacy)

"I can't get an appointment at my dentist. You have to wait for months and months for a simple job." (Dentist)

Pennine (East Lancashire)

"My doctor and dentist are not too bad. I have had a GP appointment in the last two weeks and two carers have set up prescriptions on an app and someone picks up for me because I struggle with my walking. I won't go to one doctor because they sit too close to me."

"I have difficulties booking appointments at my doctors - Dr Jha in Colne. I phone in the mornings but by 8.20am all the appointments have gone, and I have to ring up the next day and it is really hard. I have a dentist appointment in September - 'MyDentist'. I get a text to say I need a check-up. If I need an appointment I ring up and they send me a text to remind me."

"I would use a health passport at other places as well. I go to Accrington Victoria Hospital to the walk in or GP. My mum takes me there when I have backache or knee ache. They speak to me and my mum when we go. They are all nice. I go to the dentist, but it is a long way away towards Rawtenstall because I couldn't get into the one in Great Harwood. They are nice."

"I go to St Peters Centre, St Nicholas GP. I feel a bit rushed. They didn't listen to me and I didn't feel like I got anywhere. I was trying to explain to the practice nurse about having hot flushes, but I didn't get anywhere. When I went for my health review the nurse said it would take about a year. It was a bit unhelpful. They didn't give me anything and it is still ongoing. They did a blood test and said they'd ring it there was any problems, but they haven't phoned yet."

"I go to Dr Allens in Rawtenstall on Bacup Road. They don't wear a mask and I think they should. They don't ring up anymore to check about me paying. I'm not supposed to pay but accidents happen because it is all done on a blue form now. We don't send them off to dentist anymore it's on computer. Nothing to do with dentist. The dentist puts it on a form when he's seen me or on computer, but the NHS doesn't register it properly and we get letters saying we have to pay and it is not fair."

"I used to go to a dentist on Padiham Road. I cancelled an appointment I phoned up myself, but they said I didn't cancel it and they chucked me off the list. Now I don't have a dentist and my teeth are a mess."

"My doctor is at Rosegrove Medical Practice. It is really difficult to get an appointment. If I ring at 8.30am they don't answer. If my mum rings up I can get an appointment for that day. I have someone that comes with me which makes it easier because they can tell me about it and my mum explains it later."

“I go to my doctors at Pendleside Medical Practice in Clitheroe every year. I have a few appointments every year. Some are nice, and some are not. Some doctors don’t listen and are a bit ignorant. Some don’t look into my eyes always look at computer. Some don’t.”

Evaluation

Conclusions

Just over half of the people we spoke to with a learning disability and/or autism told us their experiences in hospital had been negative. Less than half of experiences reported by everyone we spoke to were positive.

Individuals with a learning disability and/or autism told us they value hospital staff and speak of them positively, although there is a request for more person-centred care and a need for more learning disability specific training. Staff attitudes are a recurring theme throughout the feedback, as this is important to people with learning disabilities both before and during hospital attendance.

Most people do not or are unsure if they have a Hospital Passport they can utilise when attending hospital. Of those who told us they do have a Hospital Passport, the large majority told us they are not being used. Around half of people said they think the Hospital Passport is useful, and many who told us they do not think Hospital Passports are useful said this is because they aren't being utilised by hospital staff.

The learning disability community told us that Hospital Passport templates should; have black and large print lettering (be easy-read), utilise the red, amber and green colour scheme, have pictures that are representative of the community with corresponding wording, and not be too long.

To improve the hospital experience for the learning disability community based on the feedback we have received, we have identified a need for improved communication (prior to, during and post appointment, inclusive of verbal and non-verbal communication) and that this could be assisted by additional training for staff around learning disabilities, autism and challenging behaviour.

The overall experience for support workers and family members could be improved by working to reduce waiting times for the learning disability community and where this is not possible to provide a suitable waiting environment.



On reflection

At the end of each project, the Healthwatch team meet to reflect on how the work was undertaken. This provides Healthwatch with the opportunity to identify areas that were successful, and where things could be improved, allowing us to continually develop our programme of work. Here are the team's reflections:

- To make the data analysis process smoother, we will (where possible) endeavour to involve target communities in writing surveys and pilot any engagement tools to ensure these are fit for purpose.
- In future, we will keep a record of organisations we have made contact with and organisations we engaged with, so that we can better understand how stakeholders respond to invitations to engagement and work on improving these working relationships to show the value of community engagement.
- We will also aim to include more demographic research within the planning process, so that we can better identify targets for representing the population of a given community or group.

What's next?

This report will be sent to:

- Each local Clinical Commissioning Group across the county
- Each Hospital Trust across the county
- NHS England
- NHS Improvements
- Each ICP Lead by area

Healthwatch will continue to attend local Hospital Trust patient experience meetings to confirm and challenge any actions and responses made to this report.

Healthwatch is working with learning disability nurses at Lancashire Teaching Hospitals to support the design and development of a Learning Disabilities Liaison Service and utilising the findings of this report to improve service delivery.

Healthwatch Lancashire and Healthwatch Blackpool will endeavour to further develop and trial new engagement methods and tools in future projects, in order to continue reaching the public and seldom or never heard communities.

Healthwatch will further consider the findings from this project to inform more specific projects in future. To date this will include work with our local Healthwatch partners to undertake a learning disability cancer screening project.

Healthwatch will utilise the additional feedback received to make a start on a reactive 'mini-project' that considers the experiences of individuals with learning disabilities whilst accessing psychological therapies.

Responses

NHS West Lancashire Clinical Commissioning Group

NHS West Lancashire Clinical Commissioning Group (CCG) would like to thank the authors of the report for taking the time out to listen to the voice of the learning disability community, especially in West Lancashire. It was pleasing to note that the hospital passport is recognised by the learning disability community as a good thing and that having one can make a difference. It was also heartening to note that the attitude of staff; being friendly, caring and treating people well, is really valued and important to people with a learning disability and/or autism and that the learning disability community in West Lancashire commented positively about their experiences with both clinical staff and admin staff when attending hospital.

However, as a CCG we would like to work with the learning disability community in improving access to health services and therefore would like to commit to the following improvements:

- To ensure hospital passports are also available to people with a learning disability aged 50+ and make these more accessible to both the patient and clinicians.
- Make improvements to our training programme needs around learning disabilities and autism.
- Develop easy read information for GP's to be able to share with patients.
- Develop better communication strategies for learning disability/autism patients within a hospital setting.
- For the CCG's engagement with the learning disability community in West Lancashire to improve.
- To create quiet areas in A&E for people with learning disabilities and/or autism to wait.
-

Blackpool Teaching Hospitals NHS Foundation Trust

Blackpool Teaching Hospitals NHS Foundation Trust would like to thank Health watch Lancashire & Blackpool for their 'Learning Disability Report'.

- The Adult Learning Disability team is an integrated service between Blackpool Teaching Hospitals and Blackpool Council. The team consists of nurses, social workers and psychologists with a lead nurse actively providing hospital liaison support into the hospital and ensuring there is an in-reach support function for any people with a learning disability who are admitted to hospital either in an emergency or for planned treatment. The integrated nature of the team enables the support to be offered from the most appropriate team member.

- The team work very closely with the MCA lead in the hospital and ward staff to ensure that issues of capacity and best interest are considered and discussed in a timely manner and the LD team can if needed offer further specialist support to the person with a learning disability to ensure that reasonable adjustments have been made and information has been provided in a person centred accessible format to enable decision making.
- The Lead Nurse has worked with the patient experience team and safeguarding team to develop a pod cast which is available for all staff at induction to provide an insight into the LD liaison role and the specialist input that can be received from the LD team.
- There is also a comprehensive LD awareness e-learning module which was developed by the Lead Nurse in conjunction with North West Specialist Network which is available to frontline staff.
- As part of the LD guides sessions there has been work completed around hospital passports, encouraging staff to ask for access to these. The LD team have recently been working on uploading passports and relevant complex care guidelines / behaviour support plans for complex people with an LD onto hospital/GP care records.

The feedback received will help the Trust to continue to develop the support we can offer to people with Learning Disabilities accessing our services. From this report it is wonderful to read that service users found our staff to be kind, caring and compassionate. The positive developments that have been made in regard to the Dental service are fantastic examples of how anticipated treatment can be provided effectively.

Thank you Healthwatch Lancashire & Blackpool for the information you have provided.

East Lancashire Hospitals NHS Trust

The findings of the report were fed back to Christine Pearson, Director of Nursing for East Lancashire Hospitals NHS Trust.

“East Lancashire Hospitals NHS Trust would like to thank Healthwatch Lancashire for the work they have undertaken with the learning disability community.

The report highlights feedback relating to Royal Blackburn Teaching Hospital and Burnley General Teaching Hospital which is defined in the report as “Pennine Lancashire (East)” and the themes identified have been shared with Senior staff via our Nursing and Midwifery Leaders Forum. However, as some of the feedback is not specific to a particular ward / department or hospital it is difficult to comment in any detail.

We take all feedback very seriously and constantly strive to ensure all our patients and relatives have a good experience and receive safe, personal and effective care when using the Trust’s services.

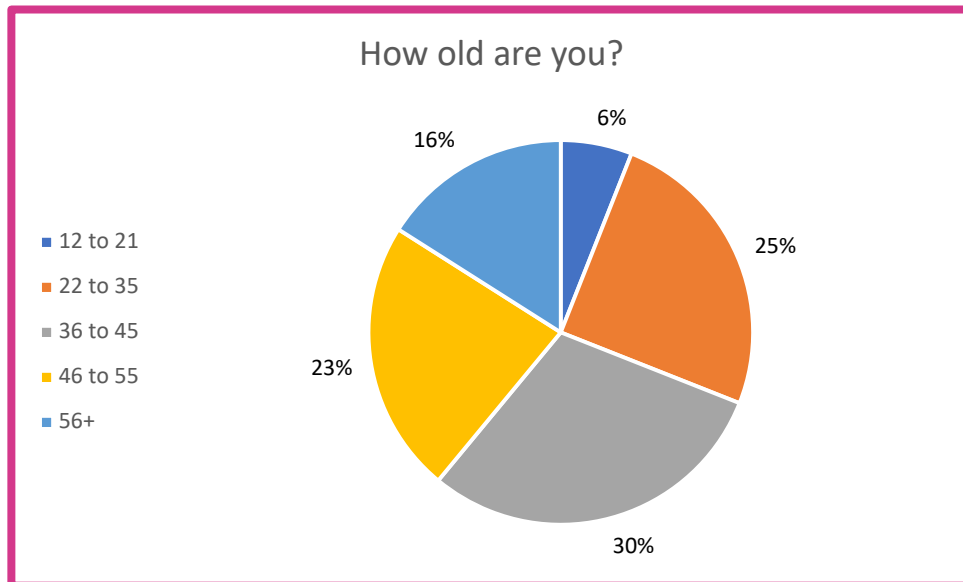
The information provided by Julie Clift, our Specialist Nurse for Learning Disabilities and Autism highlights some of the actions undertaken at the Trust including the introduction of a Learning Disability Care Bundle, the availability of communication tools for staff, training and safeguarding champions on the wards.

It is pleasing to hear that service users say the Hospital Passport makes a difference during their admission. From the comments it is clear that there is work to be done around promoting Hospital Passports with service users and families. We also need to ensure that medical staff are made aware and encouraged to make use of them. Promotion of the Hospital Passport is the focus for Learning Disability Awareness week in June this year.

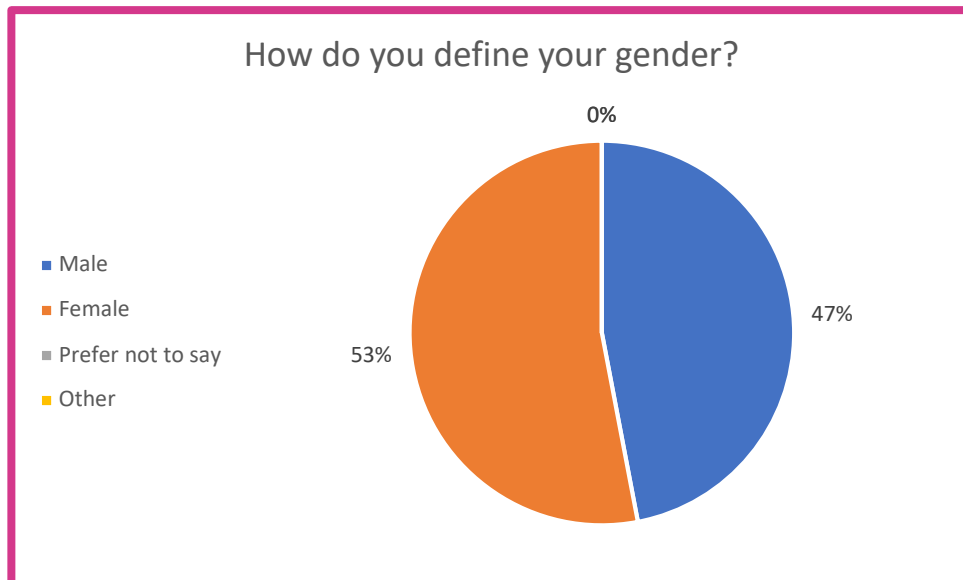
APPENDICES

APPENDIX 1: General demographics

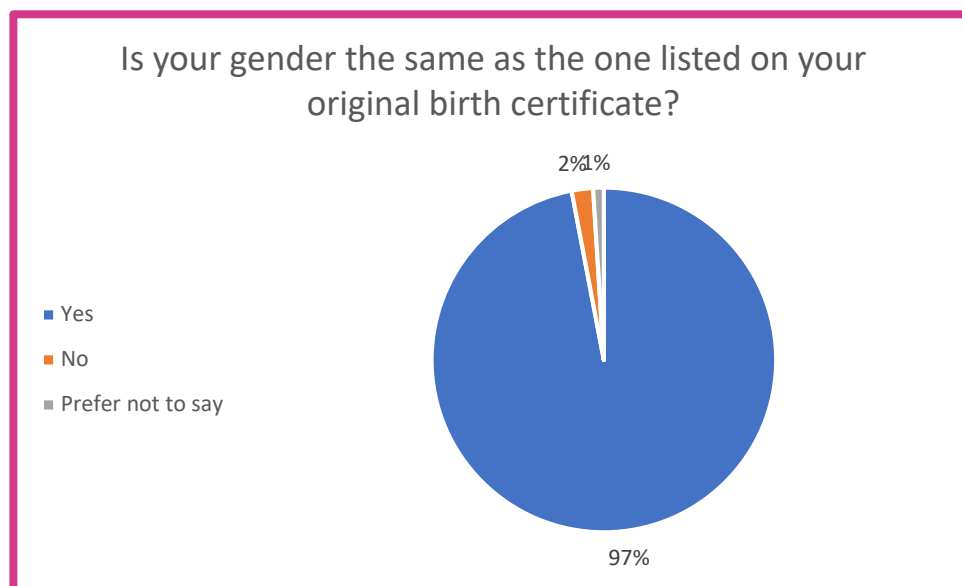
We asked: How old are you? (218 of 330 specified)



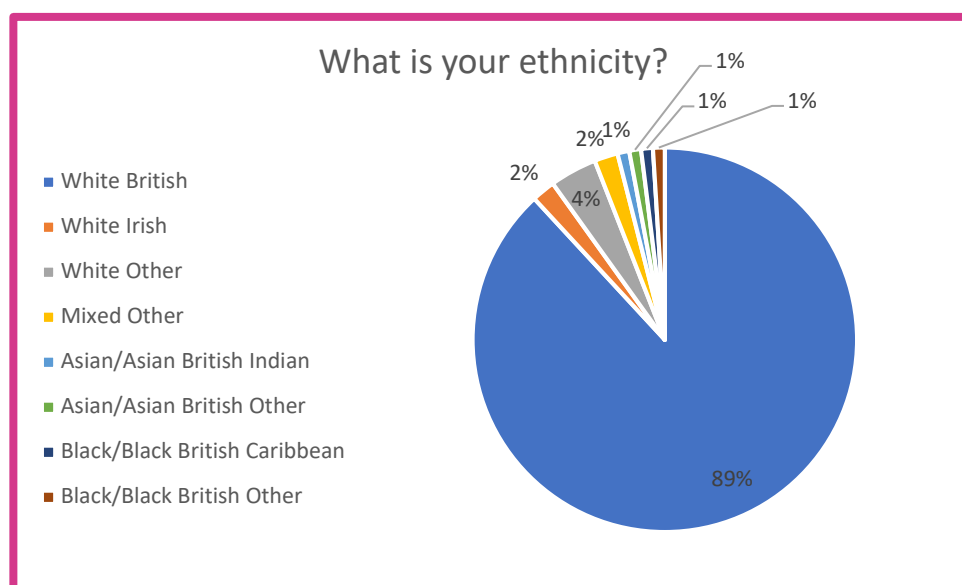
We asked: How do you define your gender? (270 of 330 specified)



We asked: Is your gender the same as the one listed on your original birth certificate? (132 of 330 specified)

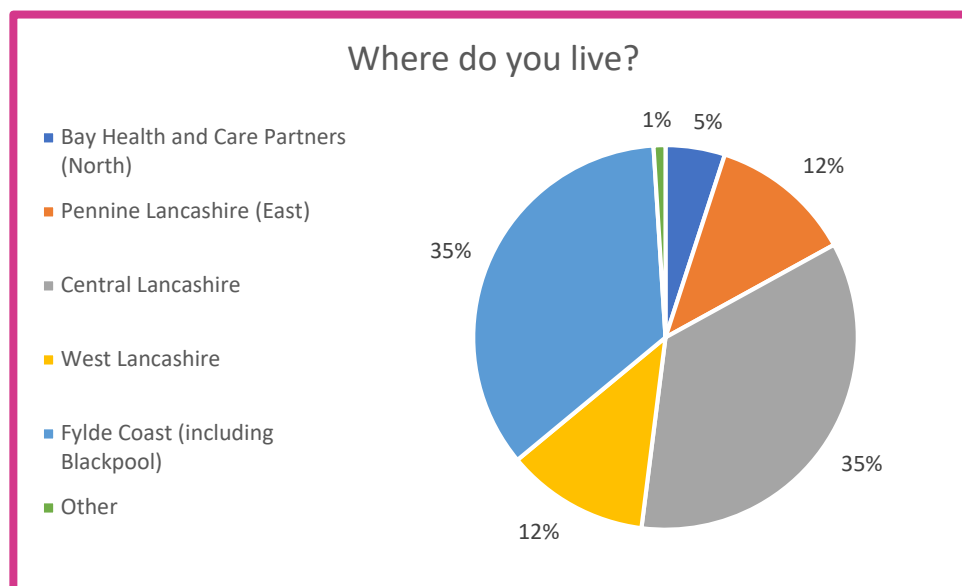


We asked: What is your ethnicity? (241 of 330 specified)

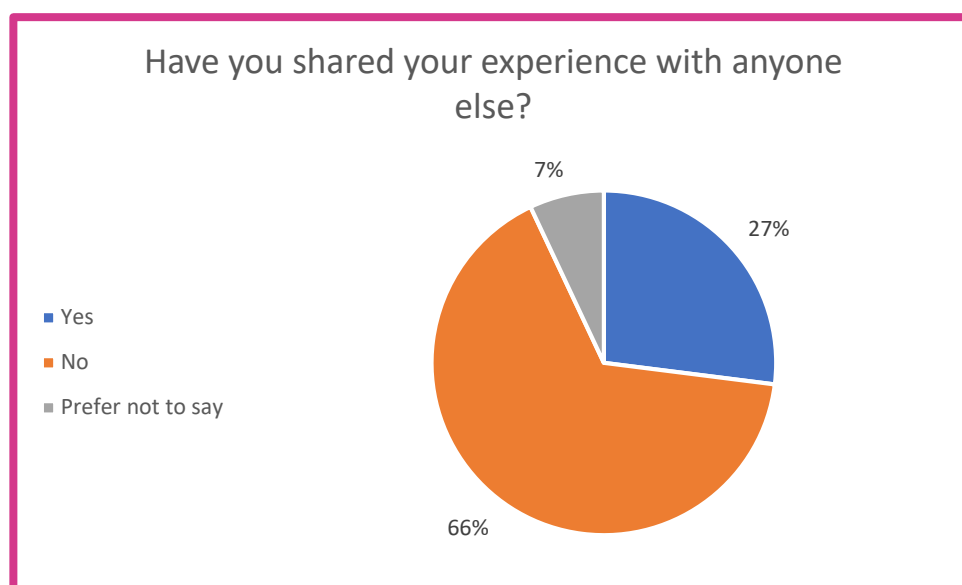


Please note: due to small numbers of answers to a large range of ethnicities, we have rounded up to the nearest percent, therefore the total does not always add up to 100%.

We asked: Please tell us the first half of your postcode (330 of 330 specified). From this, we identified the percentage of respondents that came from each of the ICP areas. (Insert explanation for ICP areas).



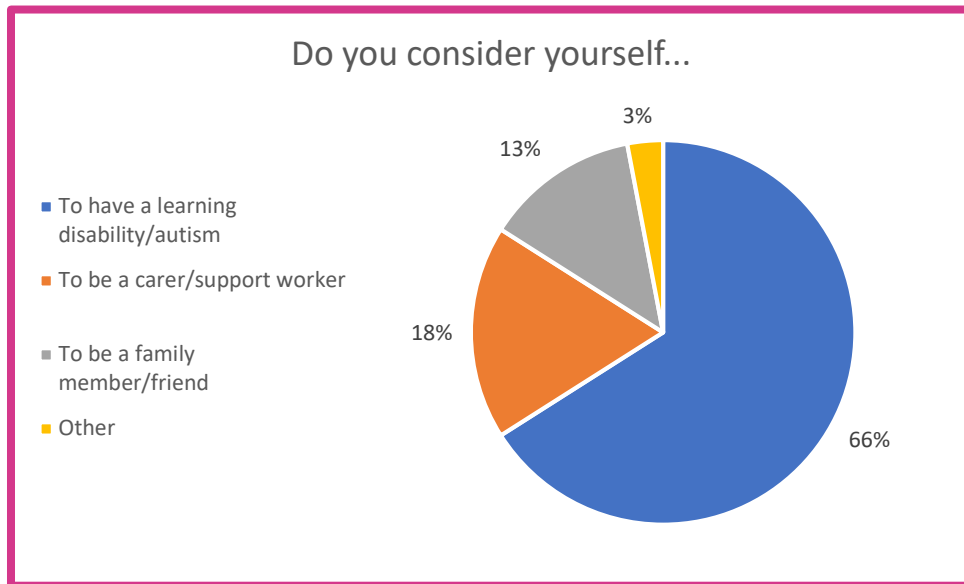
We asked: Have you shared your experience with anyone else?



Of those who chose to comment, 87% told us they had shared their feedback with service providers whilst the remaining 13% told us they had shared their experiences with family and friends.

APPENDIX 2

We asked: Do you consider yourself to be an individual with a learning disability/autism, to be a carer/support worker for someone with a learning disability/autism, to be a family member or friend of someone with a learning disability/autism or other? (244 of 330 specified)

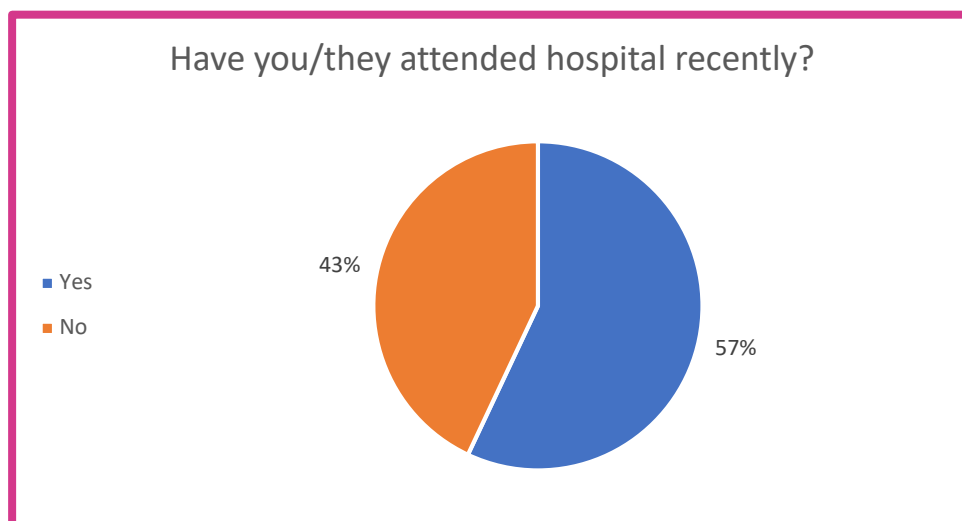


Here is a sample of comments from those who answered 'Other':

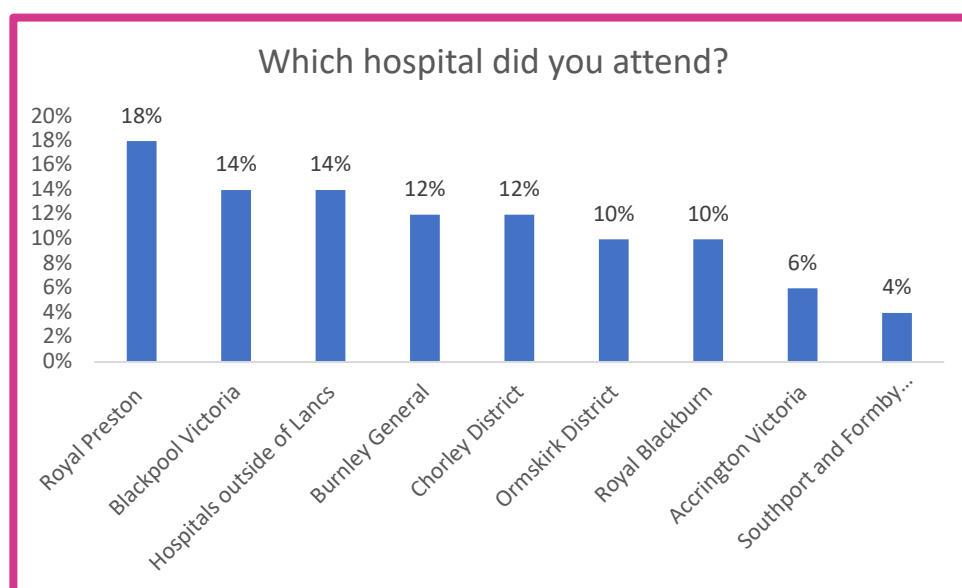
"Creative Arts Practitioner"

"Volunteer Support Worker for Asylum Seekers"

We asked: Have you/the person you know attended hospital recently? If you feel comfortable to do so, please tell us which hospital you went to, when you attended and whether this was routine or urgent/which department you attended. (210 of 330 specified).



Of those who chose to tell us which hospital they attended (50 of 210):



APPENDIX 3

We asked: If you have visited hospital recently, what was your experience?

Responses from individuals with learning disabilities/autism:

Positive Experiences

Bay Health and Care Partners (North)

“With Royal Lancaster Infirmary my appointment came through really quickly and I didn’t have to wait long.”

“Royal Lancaster Infirmary were really helpful. I remember the staff well.”

“I went to see my flatmate at Royal Lancaster Infirmary and the staff were brilliant with him. They were really understanding of his autism.”

“I cut my fingers and was seen really quickly at A&E at Royal Lancaster Infirmary.”

“Queen Victoria Hospital [Morecambe] are absolutely fantastic with people with learning disabilities.”

Pennine Lancashire (East)

“Doctors are nice.”

“The ‘Meet and Greet’ team at hospitals are great and really helpful.”

“The dietician at the hospital is good and friendly.”

Central Lancashire

“I had a meal. I was checked quite often until I was discharged.”

“The nurse spoke very clearly and clearly explained everything.”

“I had a little operation, I had my tea there and they looked after me, I liked everything.”

“At Chorley Hospital, the nurses and doctors are good. They don’t talk too fast and take time to explain to me.”

“Chorley Hospital is one of the best. The wards are clean, nurses are good, and the wards are calm which really matters to me.”

“When I was in a car accident, the ambulance service to Royal Preston Hospital A&E were brilliant.”

“I am diabetic, and I received excellent care at Chorley Hospital.”

“The theatre nurses at Royal Preston Hospital are amazing!”

“Staff are nice.” (Royal Preston Hospital)

“Royal Preston Hospital has an Xbox - I like playing.”

“The nurses were good and the doctor was ok.” (Chorley and South Ribble Hospital)

*“I was put to sleep to have an operation. This made me worry less about having the operation.”
(Chorley and South Ribble Hospital)*

West Lancashire

“I love hospitals, they do all kinds for me. They are nice and friendly, and I love going, everyone helps you at Alderhey and Ormskirk hospitals.”

“Having healthy food in hospital is good.”

“Ormskirk Hospital have Xbox and Playstation and games are free to use which is good.”

“I like going, staff are friendly and treat me with respect” (Ormskirk Hospital)

“I get my appointments when I want, and the hospital is clean.”

“When I was in Ormskirk Hospital my doctor and consultant were fantastic at giving me the right treatment for my finger, I couldn’t fault it. They decided to keep me in for a few extra days after my treatment because of my epilepsy and they wanted to keep an eye on me which was really good.”

Fylde Coast (Blackpool)

“Talking to the doctors and nurses is good. They listen to me.”

“It’s not as bad when you know what to expect.”

“They looked at my fits at the same time as something else which is good.”

“I feel like they listen to me. I got a Christmas card from them.”

“They take my blood pressure and explain my tablets.”

“I feel brave when I have come out.”

“I was treated well at the walk-in centre. They spoke to me well and listened to me.”

“The doctors are nice at the hospital.”

“The ‘Meet and Greet’ team are brilliant.”

“I feel the service at Blackpool Victoria Hospital is getting better. There is more understanding about learning disabilities now. However, higher up staff still don’t fully understand”

Other/undisclosed hospitals

“Very good, staff talked with me and my mum and look after me very well. I go to the diabetic clinic regularly and they know me well.”

“It was good, they monitor my heart. I felt better because my heart had self-mended.”

“Good.”

“Superb.”

“I have a phobia of needles and needed to have some in my back, they were good because they told me exactly what they were doing and explained why they were doing it to me. This went well.”

Neutral/mixed

Central Lancashire

“I attended Royal Preston Hospital after a car accident. I also had a second experience with a follow up operation at Royal Preston Hospital.”

“The nurses and doctors were ok.”

West Lancashire

“I go to Southport and Royal Preston hospitals.”

“Southport Hospital from the start did not diagnose me with appendicitis but other than that it wasn’t bad. The doctors don’t talk to each other and I kept having to give the same information to every doctor. They didn’t use the passport. I was in for 11 days. I was able to sleep, it wasn’t too bad. The food was okay. They treated me with respect.”

“I find the hospitals alright.”

“I don’t mind hospital - they woke me up in the night to put a mask on which woke me up.”

“The TV is free but there’s no music channel.”

Other/undisclosed hospitals

“It was alright.”

“Great service run by amazing but very over stretched staff, I don’t know how they do their job and still appear calm! Confusing direction signage, particularly X-ray department signage and information was particularly poor.”

“The food was not good. I can’t eat it, I’m not keen. The staff were friendly. Every time I see the doctor he comes up with things like ‘you’re going home’, but then they change their mind. I’d prefer to be at home. My mum is there, and carers come to help at the doctors as well.”

“I did not have a passport at Airedale General Hospital. A social worker in the hospital came to see me every day and just had a chat and kept an eye on me and seeing if I was ok. I didn’t have any visitors because it was too far away so that is why the hospital social worker came every day.”

Negative Experiences

Pennine Lancashire (East)

"I would like people to be friendly - as we have anxiety, people also don't recognise the disability."

"They seem to have stopped using anaesthetics and are using cooling spray, even though things are still painful. Being in pain causes me anxiety."

"They cancel operations and procedures a lot, and you don't really get an explanation."

Central Lancashire

"I spent four days in Royal Preston Hospital last April after a fall. I went in through casualty, which was very stressful and unexpected."

"I use a passport and hospital didn't really look at it, they didn't know what it was. One got lost and so they had to generate a new one. I've had experiences at Royal Preston, Chorley and Blackpool hospitals."

"I don't like mask used to put me to sleep."

"I had medicine and it made me feel sick, but they did explain this. The surgeon wasn't as good with me, he frightened me with the mask."

"I had problems finding out who is in charge regarding learning difficulties - there are no liaison people named for Preston, Chorley and Blackpool hospitals."

"The food is rubbish." (Royal Preston Hospital)

"They don't cater for vegans or other special diets." (Royal Preston Hospital)

"Sometimes they have students with them and no one asks me if I want them there." (Royal Preston Hospital)

"Chorley A&E is shut at certain times, I went there originally then was diverted to Wigan and then again to Preston."

"The nurses didn't understand my autism, they didn't understand that I can't feel pain in the same way as others." (Chorley and South Ribble Hospital)

"It gets a lot more stressful the longer you have to wait, I've had to wait four to five hours before." (Chorley and South Ribble Hospital)

"There's a really strict division in hospital between adults and children. Despite our age we would still prefer to be on the children's ward as it's a better environment and often quieter." (Chorley and South Ribble Hospital)

"I had an experience in Chorley Hospital where I had to sit there, there was no explanation about the length of the wait, and there were nurses and doctors without any specialist training."

"I had an appointment at Royal Preston Hospital at 11am but didn't get seen until 5pm."

"The hospital lost my Hospital Passport (Ward 3 Royal Preston Hospital). They didn't bother reading either. It was just put in my file."

“Ward 3 at Royal Preston Hospital did not read my passport. The doctors and nurses weren’t interested in it. It felt like they weren’t interested in me.”

“A&E doctor (Royal Preston Hospital) focused on speaking to my carer not me.”

“I don’t like it when doctors and nurses stand around my bed in a group. It makes me feel claustrophobic.”

“There is a lack of explanation as to what is happening with me. I think just because I have a learning disability they don’t think I will understand.”

“Parking is a nightmare at Chorley and Royal Preston hospitals. And now we will have to pay for parking too! I can’t always get an accessible space.”

“Parking makes me feel really stressed when I go to hospital.”

“When I got back on the ward after theatre no-one checked on me. I had to keep pressing my bell for some help when I needed it. No-one came to check on me for hours after my operation”

“A nurse wouldn’t feed me on my ward (Royal Preston Hospital) as I need help and my carer had to come in and do this. If my carer didn’t come in I would have starved.”

“I felt worried and nervous before my operation. Nothing was really explained to me.” (Chorley and South Ribble Hospital)

“Professionals speak to people with a learning disability like they don’t understand. It is really frustrating!”

West Lancashire

“I’m not a fan of the food.”

“I hate waiting around.”

“They stuck a needle in my arm to make me sleep and I don’t like needles.”

“Waiting times is an issue when you go in for an appointment.”

Fylde Coast (Blackpool)

“The doctors and nurses could try to understand you better. They talk too quickly.”

“I get letters for appointments and they’re not easy to understand. I have to wait for my family to visit to explain them or bring them here (to the day service).”

“My family or carers have to help me, they take their time to explain what’s happening.”

“They don’t speak in English, they speak in medical language.”

“They should tell you about the medication and they don’t.”

“I have diabetes and before I was diagnosed I kept ringing my GP as I didn’t feel well. I was then listed as a ‘nuisance’ at my GP surgery. My carer had to intervene to help me. I finally got an appointment and went to hospital and found out I had diabetes.”

“The walk-in centre is not accessible. There is no parking.”

“The minor injuries unit won’t see a service user with a learning disability if they don’t have a staff member/carer with them.”

“Hospital staff don’t always see that service users need support from a carer and they can’t stay with them.”

“The hospital food is bad. It always arrives late.”

“Parking is not easy. We have to park a long way away.”

“Doctors don’t understand my learning disability.”

“Waiting times for emergency care is too long.”

“There are not enough wheelchairs in the hospital. I had to wait over an hour for a wheelchair to help me out of the hospital as I was still a bit wobbly. I was using a bed when someone else could have had it.”

Other/undisclosed hospitals

“I was in waiting room for eight hours as I was suicidal, and they told me I couldn’t leave. I needed to wait to see the psychiatrist. They rang my mum to see where I was even though I was sitting in their view.”

“Alright at first as I thought I was getting help. I had a scan quickly, but the following physiotherapy finished when I was no way better. I was told by my mum that they do that to everyone still not better.”

“I had broken my leg and it was in a metal cage and the doctor asked me to walk when it hurt.”

“In A&E they put in a catheter with the curtains open.”

“I have type 2 diabetes and was being discharged from hospital. I was waiting and waiting and didn’t get any food.”

“I feel like they speak to my support worker and not to me. That doesn’t make me feel good.”

“I had lots of fits and asthma attacks. The staff were nasty and didn’t believe me. I had an accident and called someone to help with personal care. The matron came and said, ‘This isn’t my job’ then left me for ages. My brother wasn’t allowed to visit me.”

“Not talking to the patient happens in GPs and hospitals, it makes me feel frustrated. They talk to you in medical jargon, it’s not easy to understand and they don’t tell you what’s happening. Any leaflets are hard to understand too and not in easy read.”

“Medication is really complicated. It’s hard to ring up and say what I want or need because the names are hard to say.”

“I went into Leigh hospital when I wasn’t well, and I waited for five hours. They didn’t explain why”

Responses from carers/support workers for individuals with learning disabilities/autism:

Positive Experiences

Central Lancashire

"I feel things have changed positively over the past 15 years that I have been supporting people with learning disabilities. The passports weren't invented then and they are so good now!"

Fylde Coast (Blackpool)

"There is a representative for capacity/best interests at Blackpool hospital. This really helps us all. The hospital sends this person at MD [multi-disciplinary] meetings and at discharge. However, you have to fight for a MD meeting usually"

Other/undisclosed hospitals

"Pretty good. I visited but good service/practice. The child felt safe and treated well."

"Positive experience, they make a fuss of him."

"Treatment and respect from the nurses."

"The experience overall was great."

"Very positive experience."

"Really good - they are patient."

"It was over all good."

Neutral/mixed

Other/undisclosed hospitals

"The staff are nice. I don't like the doctor much as he comes across as rude, which is not necessary with young children with ADHD and autism."

"Some positive experiences, some very negative."

"They were discharged at midnight from A&E, but the appropriate treatment was given the day after."

Negative Experiences

Central Lancashire

"There's a huge difference between NHS hospitals and Ramsey care - Ramsey is cleaner, brighter, free parking, nicer environment and less pressure from the staff when supporting someone."

"The food was left on a tray for a service user I supported. She couldn't feed herself and needed support. The nurse said, 'Oh she mustn't want it, or she just isn't hungry'. As her support worker I explained she needed help and support to eat. If I hadn't arrived she wouldn't have been fed."

“On the medical assessment unit at Preston Hospital I was not allowed to stay with my relative [who had been admitted]. It was late on a Friday night and I couldn’t get a bus home.”

“The client I was with had a fall at home and had to be admitted to Royal Preston hospital. They were not allowed to walk to the toilet when in hospital and had to use a wheelchair. This resulted in them not being able to walk when they came out of hospital.”

Fylde Coast (Blackpool)

“As carers we attach a risk assessment about that person with the hospital passport, we have found that this makes the hospital staff take more notice of it. It makes ‘funding’ found to support that person’s needs. Without the risk assessment the hospital passport isn’t taken seriously”

Other/undisclosed hospitals

“We didn’t get the correspondence from Virgin to say the appointment was going to be elsewhere so we arrived in the wrong place. Apparently, we should have received a letter but didn’t. I think that others hadn’t received a letter either because there was someone at the hospital to tell people where to go for their appointment because the venue had changed. We were told this was because Virgin should have sent out letters but didn’t. The thing is she has to use a hoist so it’s not easy and we should have been told so as not to go to the wrong place for the appointment.”

“Waiting for appointments that run late with no explanation.”

Responses from family members or friends of individuals with learning disabilities/autism:

Positive Experiences

“Good.”

“Excellent, staff are very good at explanation but not patronising, which is very refreshing.”

“The staff were very helpful and aware of her learning difficulties, it went ok.”

Neutral/mixed

“It was a negative experience because she was having psychotic episode, but the outcome was positive.”

“I don’t know, I didn’t go in with them [family member] just dropped them off.”

“We went in as a day patient, it took a long time to be seen as our notes were at the wrong hospital when we arrived, but the doctors etc. were great and they did have word searches etc to keep busy.”

Negative Experiences

“It was clear that staff were unaware of how to deal with my sister.”

APPENDIX 4

We asked: How did you find the staff at the hospital?

Responses from individuals with learning disabilities/autism: (67 responses)

Positive Experiences

"The diabetic nurse and other staff very good and friendly. When I fell over and went into A&E they were very good and talked to me. Mum was with me and the staff were very friendly."

"Understanding and kind."

"Polite, informative, calm whilst working really hard to run and under resourced service."

"The staff were very caring and good with my support workers. They talked to my carers because I do not communicate well, and they were very busy."

"They help you to get better and they look after you."

"They're nice to me."

"Excellent - they explained what was happening to me."

"Waiting time was five minutes tops, they couldn't do enough as always."

"I like the play leaders on children's wards. They always make you feel at ease."

"I got treated well when I was classed as a kid. I quite like Preston hospital, though I got treated better as a child than I do now as an adult."

"I think Preston hospital have gotten better over the last year."

"Ormskirk staff are great they do everything for me."

"Staff are friendly and give you good treatment."

"I think the hospital staff are good because they see me straight away." (Ormskirk District)

"The staff are very quick and very good with people with a learning disability." (Ormskirk District)

Neutral/mixed

"I had to leave before treatment finished. It's still not right and I didn't want to finish but they would only give me five sessions. I might not have done the right exercises as it has gone worse."

"The staff kept me informed and let me know what was happening. What was difficult for me was trying to explain things to them and telling the same story over and over to different people, especially as I was in hospital independently."

"It was a long time ago since I was in hospital and there was plenty of staff to deliver services, but my father looked after me for things other than medical and medication. But now I believe that things are different, and nurses and doctors are rushed off their feet, so perhaps family members/carers can deliver the everyday needs of people with learning disabilities when staying in hospital."

"There's differing standards in different hospitals."

Negative Experiences

"I've got no faith in them at all. How could they not know I was sitting there in hospital? I was suicidal and crying. They gave me a syringe as I was shaking and left me with it. I could have snapped it and stuck the plastic rod into my neck to end it all."

"They moved me to another ward and didn't explain anything to me. They only talked to my brother and not me. The physio people tried to get me out of bed but I couldn't walk."

"They need more awareness on learning disabilities and autism."

"I fight the doctor I hate hospitals I don't like people touching me"

"I was given the wrong food at Ormskirk hospital."

Responses from carers/support workers: (27 responses)

Positive Experiences

"Helpful and friendly."

"Very helpful, good at explaining things to the service user, speaking directly to them."

"Communication was really good, took time to explain patiently what was happening."

Neutral/mixed

"Nurses were really nice. Receptionist was lovely. Doctor came across as rude and impatient."

"Different staff, some good some okay. The ambulance staff were good as they spoke to the husband."

"Once some staff accepted she had a disability some were good others very good others inadequate."

"Great - but some need some more awareness, but I think this will come with experience as the nurse and doctor seemed to be quite new."

"Mixed report here. Reception staff rude and not prepared to listen, help or understand our difficulty in waiting for seven hours! Same with the consultant -brisk and brief. The anaesthetist was different and once informed that my son has Asperger's syndrome he took time to explain his procedures in detail - this was much appreciated. One of the ward staff was very patient and kind to him following surgery."

Negative Experiences

"Not a lot of communication between staff members."

"Staff appeared scared by disability. Hospital staff not prepared to make a best interest decision."

"Rude reception staff and inexperienced nursing staff."

"Reception staff at all departments sadly lacking in skills of dealing with people with learning disabilities. There was a poster on the wall away from entrances and even reception area saying in small letters on busy coloured background to "tell a member of staff if you have a learning disability". I question that! When I challenged the hospital about the poster I was told the speak

with patient partnership. The poster remains on the wall at Chorley hospital and the staff remain insensitive. We have NEVER had a learning disability nurse with us at any hospital appointment."

Responses from family members and friends: (17 responses)

Positive Experiences

"Seen to all her needs. Hospital environment fine and staff great with her."

"The dentist was friendly and explained the treatment plan and arranged a follow up appointment."

"The Diabetic Nurse and Dietician are always most helpful, explain things carefully to my son, and help him to try and understand his condition."

"Each and every member of staff explained everything to her in terms she understood as they know her difficulties thoroughly."

"They listened to all our accommodations and how to best support my sister. This makes a refreshing change to our previous experience in healthcare."

Neutral/mixed

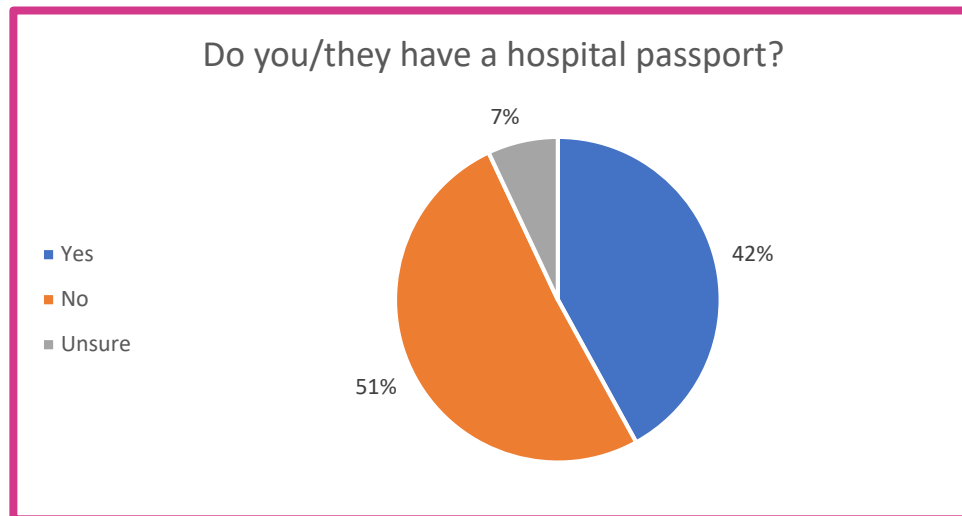
"Just a shame our notes hadn't arrived."

Negative Experiences

"Very little awareness of my son's autism leading to a highly distressing experience of the hospital as I was not allowed to be with him when he came around. He had a massive sensory meltdown as a result."

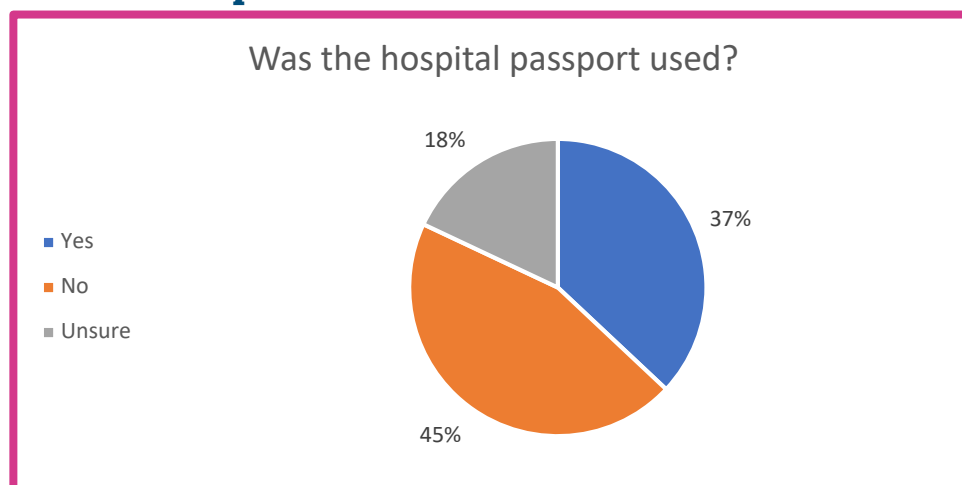
APPENDIX 5

We asked: Do you or the person you know have a Hospital Passport?



- The feedback shows that the majority of people we spoke to do not have or are unsure whether they have a Hospital Passport (58%).
- The ICP area where the most people reported they or the person they know does have a Hospital Passport is Central Lancashire (41% of people who said 'yes' were from Central Lancashire).
- Less than 20% of people in the remaining ICP areas (Pennine, Fylde Coast, Bay Health and Care Partners and West Lancashire) reported having or supporting someone who has a Hospital Passport.
- When looking at the responses from individuals with learning disabilities and/or autism, we can determine that the age group with the most people reporting that they have a Hospital Passport is 22-35 year olds (43% of people who said 'yes' were in this age bracket), compared to 56+ year olds (just 4% of people who said 'yes' were in this age bracket).

We asked: If yes, was the Hospital Passport used last time you/they attended hospital?



Comments from those who said yes:

"Yes, when needed."

"Yes, and given back."

"Yes, it was really helpful."

"Yes, but they need more Learning Disability Nurses."

"I have my own personal passport which I carry around with me."

"Yes, as a Health Champion I would tell them about the Hospital Passport."

Comments from those who said no:

"No, I had an appointment with diabetic clinic and they know me well."

"No time and they had an issue in reading them."

"Nobody has ever asked about the Hospital Passport at the hospital as my daughter has had dental work under anaesthetic several times in the last few years at Chorley Hospital."

"It was a follow up appointment and it was used a few times before, but they know him now."

"They didn't see it. It's very hard if people don't understand my condition."

"I had to copy the hospital passport five times as they moved wards five or six times, and no one seemed to have it. Eventually on discharge one copy was found in their patient records."

- The feedback shows that in the majority of cases (63%) the Hospital Passport was not used, or the individual was unsure if it was used.
- The ICP area where the Hospital Passport was most successfully used is Central Lancashire, compared to Pennine Lancashire and West Lancashire where it is used the least.

APPENDIX 6

We asked: If you or the person you know have a Hospital Passport, does it make a difference to your experience? (88 responses)

Comments from those who answered yes:

Pennine Lancashire (East)

"It would help if they actually used it."

"It helps."

"The passport is helpful for me."

"Nurses like to see the passport."

"Passports are helpful."

Central Lancashire

"There are things in the passport that you as the carer might forget."

"It ensures essential details not overlooked."

"It provides all the information about what I like and who I am."

"Nurses and doctors should use them more often."

Fylde Coast

"If it is used! It is EVERYTHING they need to know. I know people are stretched for time but in the long run it could help."

"I have a compact and personal one with all previous operations, detailed admissions, airway sizes, medications list etc. Doctors always tell me it is a brilliant compact information tool."

"I like the hospital passport"

West Lancashire

"They've got all the information about them in it for staff to give the right care and attention."

"The Hospital Passport is a good thing if medics used them before meeting. It should be the very first page on their notes."

"It speeds up service and helps to explain the person I am supporting."

Comments from those who answered unsure:

Central Lancashire

"The last treatment my daughter had was traumatic and by then staff knew her difficulties. Although staff were repeatedly told what would make things worse several members ignored what we asked for, she locked herself in the bathroom as staff pushed her. My daughter was very scared and needed time to process information and if the information was not complete she would panic and stop cooperating."

"I am well supported by a team of carers so they know my needs."

West Lancashire

"Never used for an appointment. We went in an ambulance and didn't take a Hospital Passport. I would know if they had one if it had been asked for so not sure that having one would make a difference if it isn't asked for."

"I have my Mum with me and the staff know me anyway."

"I don't go into hospitals with them."

"Not sure if they have one."

"They're only as good as the person who fills them in or reads them."

Comments with those who answered no:

Pennine Lancashire (East)

"Doctors don't want to see Hospital Passports."

"(At Blackburn Hospital) Doctors don't want to know. They work if the stay is planned or elective but not in emergency or urgent cases."

Central Lancashire

"It just wasn't read. They were doing their own paperwork."

"Staff never read it properly in the hospital."

"No because despite asking for it no one could ever find it."

West Lancashire

"The staff at Southport Hospital didn't use it. I had to tell every doctor that came to me the same thing as they don't talk to each other either."

Fylde Coast

"They only glanced at it and I tried to inform them how important it was. The questions they asked me, they would have known the answers to if they read the passport. Maybe asking me is quicker than reading a passport?"

"I gave the nurses my Hospital Passport and they didn't know what it was. They took it off me and then just lost it anyway."

Pan Lancashire/not specified area

"Doctors have no time to read them, the nurses read them and they're the main communicators."

We asked: If you or the person you know does not have a Hospital Passport, do you think it would be useful? (73 responses)

Comments from those who answered yes:

Bay Health and Care Partners (North)

"It will help because they'll know what is wrong with you."

"It's good if there are strange people that you can't talk to."

"They're good for people with speech problems."

"They tell people about what does your head in."

"Morecambe Bay want to scan and upload them with your medical details, that would be important."

"I have been investigating this and think it could prove most useful."

Pennine Lancashire (East)

"A passport will be helpful (person currently doesn't have one)."

"Because staff would then already know the situation, I wouldn't have to keep explaining."

Central Lancashire

"People can find out more about you."

"Staff will know more about you quickly. It makes you less fearful."

"Why not have it as an app on your phone?"

"They seem useful."

"They are a good idea."

"It would mean that all the initial information needed would be there for easy access without having to put the patient through unnecessary anxiety."

"It would have been helpful to have one to help me explain things. I take medication for depression and I forget things, so I find it really difficult."

"Date of birth, address, next of kin, health history etc. which means it should be an easy process for the person being admitted, as most of the initial questions will be answered within the passport."

"I don't have one, but I think it would be okay."

West Lancashire

"Now I have seen one I think it would make a difference."

"I think it would make a difference. I have never been offered one."

"It would be good for us to have as well, I am going to take it back to my organisation."

"Think it would be better as a swipe card."

"It is handy to let staff know what he likes and doesn't like and what his needs are. However, his mum does go in with him."

"The Hospital Passport is a good thing if medics used them before meeting. It should be the very first page on their notes."

"Especially as the family [I work with] are attending ESOL [English as a second language] classes so they would have problems anyway. I think it would be good for all the Asylum Seekers to have something like this."

"As English is not the parents first language it would be useful - with interpretation. It would be useful for every refugee even if they didn't have a learning disability."

Pan Lancashire/not specified

"It would make a difference as it would reduce the form filling and give staff a better understanding of how to support my sister."

"It could be useful for someone if I struggle to communicate in the future."

"Hospital Passports should be part of your NHS records, so everyone can see them."

"I think for any form of disability it would be helpful."

Comments from those who answered unsure:

Central Lancashire

"Never having had one I am unsure how effective they are."

West Lancashire

"If she is having issues she probably wouldn't take it with her anyway and she wouldn't be the person in the Hospital Passport as she isn't herself."

"His parents go with him."

"I wouldn't go on my own anyway."

"I don't go on my own to hospital."

Comments from those who answered no:

Bay Health and Care Partners (North)

"I'm concerned hospitals would lose them or forget about them."

Central Lancashire

"It's quite a big document, might not update it or could lose it."

West Lancashire

"It's not something you carry around with you."

"Staff should talk to me and ask the right questions and they should have the information anyway."

"Don't have one and don't like hospitals anyway."

"Staff should talk to you."

"Don't need one, they can talk to me, it should be on record and I have my parents with me."

"She would have someone with her anyway."

"I don't need to use it because all the staff at the hospital know me so well already."

"They look difficult to read, I would need support to fill that in."

"I can talk for myself."

"I can talk for myself. It won't change the staff."

"I don't go by myself anyway."

"She is never alone."

Fylde Coast

"Doctors and nurses don't know what they are"

"People are too busy to read them."

"What happens if you're ill abroad and they don't have it?"

Pan Lancashire/not specified

"I don't think I need it because my Mum knows everything about me and she can tell the staff."

APPENDIX 7

We asked: If anything, what was good about your or their last hospital experience? (58 responses)

Responses from individuals with learning disabilities and/or autism

Bay Health and Care Partners (North)

"Staff very pleasant and the environment was clean"

Pennine Lancashire (East)

"Staff."

"The learning liaison person who came to see me after I had been in urgent care for about 14 hours."

Central Lancashire

"It was quick otherwise I become agitated."

"I didn't feel frightened."

"The food has improved (Royal Preston Hospital). The discharge process into rehab was good but sometimes I felt like I didn't need rehab. I didn't like rehab and it was a bad experience (Meadowfield, Fulwood, Preston). I couldn't go anywhere without support and I felt like I was in prison."

"It was quick."

"Staff friendly and had an understanding of autism."

"I was seen quickly."

"My father was allowed to stay with me, even during the night."

West Lancashire

"Staff are friendly and know me. They are very good with me."

"It was okay - it was a long time ago."

"Nothing, I didn't see anyone because they thought I had gone missing. I have been told to go to Bickerstaff House next Saturday. This is someone who is suicidal and not seen anyone!"

"The scan was very quick. Just seen one consultant then had a scan."

"Kind staff and it was clean."

Fylde Coast

"I was treated with kindness."

Responses from carers/support workers for those with learning disabilities and/or autism:

Pennine Lancashire (East)

"One of the ward staff and the anaesthetist (that's all)."

Central Lancashire

"When she had surgery the ward sister sorted everything, and the staff took time and it went well."

"Very good at explaining the procedure."

"Some staff very attentive. Quiet area to calm service user."

"Nothing."

"We contacted them prior for support."

West Lancashire

"Staff are nice. They are always good with him and let me go home. I ask for appointments as early as possible, so he can get to school as he loves going and doesn't want to miss out as they will look after him."

"Staff are friendly - mainly the auxilleries who seem to do most the work. Some staff aware of how to deal with learning disabilities."

"They were treated well."

"Staff fuss over him."

"Respect and treatment from nurses. Hospital passport was used, and staff couldn't have been better."

"The staff were brilliant."

"Not been since she was born."

"Lots of toys in waiting room."

Fylde Coast

"The staff were really caring towards him. They had a lot of compassion."

"They were great when they got know him and as soon as we turned up they made sure we didn't need to wait long."

"Good communication."

"Blackpool Victoria chest and St Mary's genetics hospital specialists staff behave in a much better caring sensitive gentler slower less frantic way."

Responses from family members and friends of individuals with learning disabilities and/or autism:

Bay Health and Care Partners (North)

“Steps were put in place. For example, put first on the list; medical correspondence being redirected, link nurse spending one to one time, preoperative assessment clinic bypassed and care transferred to another hospital.”

Central Lancashire

“Staff are all fantastic.”

“Patience of the staff.”

“We were seen within half an hour of arrival. The doctor understood about learning disabilities and talked to him rather than me, even though my son could not understand or speak. He did not once call me Mum and the staff in the department were helpful but not intrusive.”

“Nothing really.”

West Lancashire

“The staff were great and seen to all of her needs.”

“Not sure, my parents didn’t say.”

Fylde Coast

“Good staff.”

“Staff were helpful.”

APPENDIX 8

We asked: Is there anything that could have improved your or their hospital experience? This includes before, during and after the hospital experience.

Responses from individuals with a learning disability and/or autism: (62 responses)

Bay and Health Care Partners (North)

- "Staff that can speak to us properly."*
- "People to communicate better, for example more eye contact."*
- "Learning disability training for NHS staff."*
- "Doctors to be more lenient with people with learning disabilities."*
- "Talk to the person and not the carer, support worker or family member."*
- "Talk to the person, not the disability."*
- "Improved waiting times."*

Pennine Lancashire (East)

- "Communications around the forms/payments/and entitlements need to be made clearer."*
- "Signs need to be made clearer. They need to be easy read."*
- "Hospital Passports need to be made easier to get hold of."*
- "Better signage, repeated text messages requesting feedback, how much does this cost to do and evaluate? Do less of this and spend money on nurses, doctors and equipment instead."*
- "Not really."*
- "Tell me things so that I understand."*
- "I don't want them to hurt me, they don't explain things to me."*
- "I find big words difficult, it would help if they explained. And make appointments a lot quicker so we don't have to wait."*
- "Explaining things better."*
- "A Hospital Passport, someone to liase with the different departments I visit and someone I could contact prior to appointment, maybe a quiet place to wait not a busy waiting room."*

Central Lancashire

"Speak to me, not my carer or support worker."

"Young people could help raising awareness and help with staff training."

"Having a quiet room, like the 'Dinosaur room' they used to have at Chorley Hospital. It could help with sensory needs as well as people with learning disabilities, you could even be treated there."

"Getting communication levels right, not treating me like a baby."

"More staff to help so there's less 'coming and going'. Staff need to be able to explain what's going on."

"Maybe designated staff for a person."

"Having the Hospital Passport as an app."

"I get really anxious when I'm put on an adult ward, I'm already anxious enough about being in hospital, I need some familiarity."

"Disability services go up to 25 years old, this should apply in the NHS too."

"Let people know that the pain will be controlled or reduced, this helps anxiety."

"Cancellations make me more anxious, that never used to happen when I was a kid."

"Would be nice to have a social room to watch TV and socialise with other patients on the ward rather than just sitting or lying in bed."

"Would like to see more eye to eye contact with service users. I am there as a support worker and they talk to me rather than the service user I am supporting."

"It was terrible."

"Not on this occasion."

"No."

"Not on the day but no other information obtained."

"They could improve the waiting times, I felt like I was waiting ages in A&E."

"I need letters from the doctor quicker than six to eight weeks, especially if it requires my medication to be amended."

"Staff to keep calm."

"I would like to talk to someone about my depression."

"Better knowledge of autism."

"No, they do a very good job."

West Lancashire

"Not keep me waiting I don't like that when it is busy and lots of people everywhere."

"Put free music channel on T.V."

"Don't wake you up when your asleep."

“Talk to me to let me know what they are doing [treatment].”

“Appointments to be on time.”

“Don’t keep you waiting.”

“Reduce the parking charges, it is terrible.”

“They could give you a refund on a weekly parking pass if you don’t need it, as you don’t buy one thinking you may not need it only to find that you have already spent over £15 and the person is still in hospital or attending appointments.”

“They should really do something about the parking charges you now get charged even if you have a disabled badge.”

“They should slow down and speak clearly.”

“I have been in hospital lots of times, but they don’t always know about it when I go in.” - comment about ensuring medical history is present and correct.

“The staff should learn some Makaton to help people who can’t communicate.”

“I don’t like it when I’m in the hospital bed and the curtain isn’t pulled across so there’s lots of people walking past all the time.” - comment about the importance of patient privacy.

“The waiting times are too long, especially when I don’t like going to hospital.”

“The letters they send are not good for blind people, they should send more braille or other things to help them.”

“There should be two hospital passport forms, one should have pictures for people who can’t read like me, and lots of other people who can’t read. There should be more pictures on all the hospital forms.”

“Parking can be difficult and public transport is not great, but support worker takes me and my mum.”

“Move the hospital to Skelmersdale as Southport is too far away. Bus fares are too dear, and the trip is too long.”

“Everything - how could they leave me there for 8 hours?”

“Talking to me and not leaving me on my own would be a good experience.”

“I didn’t think the five sessions was enough before I was finished. I told them I didn’t want to finish. You should be called back to check on you again. I have had to get private help as I still can’t play football.”

“Kind staff and a clean place.”

Fylde Coast

“No.”

“Would like us as service users to have first aid training”

“Somewhere we can go and there are no waiting times”

Responses from carers/support workers for individuals with learning disabilities and/or autism: (26 responses)

Pennine Lancashire (East)

"Waiting times."

"Explaining why there was such a long delay to start that surgery. Having a quiet place to wait would have helped too."

Central Lancashire

"Listen and act on what you're told."

"I don't think there was, they've come a long way."

"More communication from last appointment to recent appointment/more handover."

"Recommendations: hospital must look at appointment times for people/carers with learning disabilities due to the fact of "time" association and become agitated if appointment is late or kept waiting too long. it makes the carer's job even more difficult to keep their patient amused/busy/occupied and does sometimes become unruly or loud. Not enough distraction tools. Suggest that patients with learning disabilities be seen at the "correct" time, or at least inform of expected waiting time - if an hour they can come back."

"More knowledge of learning disabilities given to hospital staff."

"Better communication between carers and patients and departments or wards. Staff actually reading the information given to them."

"No had great service."

"Staff being aware in advance that someone with a learning disability was checking in, taking a little more time, having eye contact, reducing delays of appointment times and hanging around for people who find things difficult, a better waiting environment."

West Lancashire

"Doctors manners and awareness of impact on young person with ADHA and autism."

"Appointments on time not having to wait. Costs of car parking could be reduced even if you have a disabled badge you have to pay."

"Staff awareness of learning disabilities, especially waiting times can be challenging. Cut waiting times or offer a separate area to wait in if can't shorten the waiting period."

"Getting correspondence from Virgin to say appointment was going to be elsewhere. Should have received a letter."

"Maybe a hospital passport, I don't know."

"He has been bullied and is shy so friendly caring staff are essential. Parents need to stay with him."

"Good communication with patient and their carers. Timeliness. Good bedside manner - being respectful of carer and speaking directly to patient."

"Materials they could have to explain to the person about their illness/condition."

“Yes. I needed to visit the hospital beforehand to do a ‘reccy’ of where to park, which was the best route into the hospital with the least amount of distractions (shops, cafes, not busy) and getting to the ward. We have been recently made aware of a company in Leigh who create interactive video tours to support patients with Autism and anxiety issues to explore hospitals and wards online before they visit. This helps them to prepare for their visit as best they can from home. They’re called Access Social and the videos are called iRoam www.accesssocial.co.uk”

“Communication. She likes to be with company and not left alone.”

“More warnings about what is going to happen.”

Fylde Coast

“More awareness. Less waiting times.”

“Letting service users with autism and/or learning disability look around the ward beforehand. Have ‘open days’ for service users and their carers.”

“Nurses and staff ought to go on more training days run by people with learning disabilities, I know this used to happen at Morecambe Bay.”

Pan Lancashire

“All letters should be in plain English and be available in easy read on request. The language is not patient friendly for anyone let alone someone with a learning disability.”

“It’s important to give you time. It shouldn’t be a five-minute appointment it should be however long it takes for me to understand.”

Responses from family and friends of individuals with learning disabilities and/or autism: (8 responses)

Bay Health and Care Partners (North)

“Staff being educated to deal with learning disability patients and being aware of link nurses and passports.”

Central Lancashire

“Shorter waiting times and a wheelchair accessible dentistry room.”

“Information regarding the length in delay to be seen, we were seen about three hours after the appointment time.”

“No.”

“Yes - understanding that he would need careful handling to deal with the sensory aspect of his treatment.”

West Lancashire

“Seeing to all of her needs with learning disabilities and mental health issues. Which they did but it was horrible.”

“Public transport could be better because I know my parents struggle with this and I often take them in my car.”

Fylde Coast (Blackpool)

“Having knowledge prior to appointments about her difficulties would be useful and for future visits.”

Other/Pan Lancashire

“As a family carer I want to attend to help my child explain their medical history. When you see someone different each time they don’t know you and most of the time they aren’t reading the information on file.”

“If you can’t read like some of my friends it’s important to use other ways to communicate with them like ringing them to tell them when their appointment is rather than sending a letter.”

“It would be great to have a list of dentists and opticians who are truly ASD or learning disability friendly. This would be really useful when trying to find a service. Some dentists let you sit in the car and text you when you can go straight through, so you don’t have to sit in the waiting room.”

APPENDIX 9: Summary of results

The majority of people we spoke to were individuals with a learning disability and/or autism (66%).

57% of the people we spoke to said they have recently attended or supported someone in hospital (in the last 12 months). 77% of these attendances were routine or planned visits, as opposed to emergency or unplanned visits.

Based on the comments received to the question ‘What was your experience?’, we can determine:

- The group that shared the most positive experiences was carers and support workers (53% of comments were positive).
- The group that shared the most neutral or mixed experiences was family and friends (50% of comments were neutral or mixed).
- **The group that shared the most negative experiences was individuals with a learning disability and/or autism (51% of comments from this group were negative).**

Looking at the responses across the different ICP areas, we can determine:

- Looking at responses from individuals with learning disabilities, the ICP area with the most positive comments was Fylde Coast. The ICP area with the most neutral comments was West Lancashire. The ICP area with the most negative comments was Central Lancashire.

As the majority of negative comments came from individuals with learning disabilities and/or autism, we chose to look at any comparisons between the different age brackets:

- The age group of individuals with learning disabilities and/or autism that reported the most positive experiences was 22-35 year olds.
- The age group of individuals with learning disabilities and/or autism that reported the most negative experiences was 46-55 year olds.

Overall, amongst the experiences of individuals with learning disabilities and/or autism, their carers and support workers and their friends and families, **the majority of the feedback we received about experiences in hospital was negative (47%)**. 39% of overall experiences were positive and 14% were neutral or mixed.

Based on the comments received to the question, ‘How do you find the hospital staff?’, we can determine:

- **The group that said they found hospital staff to be ‘excellent’ or ‘good’ the most was individuals with learning disabilities and/or autism (69% of individuals with a learning disability and/or autism said they found staff to be ‘excellent’ or ‘good’).**
- The group that said they found hospital staff to be ‘okay’ or ‘bad’ the most was carers/support workers (34% of carers/support workers for those with learning disabilities and/or autism said they found staff to be ‘okay’ or ‘bad’).

- The ICP area that said they found to be ‘excellent’ or ‘good’ the most was Central Lancashire (31% of these answers were from Central Lancashire) compared to Bay Health and Care Partners (just 7% of these answers were from Bay Health and Care Partners).

The feedback shows that the majority of people we spoke to do not have or are unsure whether they have a Hospital Passport (58%).

The ICP area where the most people reported they or the person they know does have a Hospital Passport is Central Lancashire (41% of people who said ‘yes’ were from Central Lancashire). Less than 20% of people in the remaining ICP areas (Pennine, Fylde Coast, Bay Health and Care Partners and West Lancashire) reported having or supporting someone who has a Hospital Passport.

When looking at the responses from individuals with learning disabilities and/or autism, we can determine that the age group with the most people reporting that they have a Hospital Passport is 22-35-year olds. 43% of people who said ‘yes’ were in the 22-35-year-old bracket, compared to 56+ year olds where just 4% of people who said ‘yes’ were in this age bracket.

The feedback shows that in the majority of cases (63%) the Hospital Passport was not used, or the individual was unsure if it was used. The ICP area where the Hospital Passport was most successfully used is Central Lancashire, compared to Pennine Lancashire and West Lancashire where it is used the least.

Half of the people we spoke to felt that the Hospital Passport made a difference to their hospital experience. 32% were unsure, which may be related to the 18% of people who were unsure if the passport was used last time they went into hospital. The ICP areas where people find the Hospital Passport makes the most difference are Pennine Lancashire (East) and Central Lancashire (54% of those who said ‘yes’ were from both of these areas) compared to Bay Health and Care Partners where only 7% of people from this area answered ‘yes’.

The ICP area that reported feeling that a Hospital Passport the most useful was Central Lancashire (49% of those who said ‘yes’ were from Central) compared to Fylde Coast (2% of those who said ‘yes’ were from Fylde Coast). Of those with a learning disability and/or autism, the age bracket who felt Hospital Passports would be most useful was 22-35 year olds. The majority of those who said ‘yes’ were either individuals with learning disabilities and/or autism or carers/support workers (37% from each of these groups answered ‘yes’).

Amongst individuals with learning disabilities and/or autism, their carers and support workers, family and friends, the kindness and treatment from staff was the most commonly mentioned theme that contributed to a good hospital experience. It is worth noting that only one response mentioned the use of the Hospital Passport.

In response to the question, ‘**What could be improved about your/their hospital experience?**’, we can determine:

The most common theme for **individuals with learning disabilities and/or autism** regarding improvements to the hospital experience by a majority (45%) is communication and awareness. This includes pre-appointment communication, such as letters, as well as communication during appointments. Many people cited additional staff training in

learning disabilities and autism, including learning to use Makaton, and promoting the use of hospital passports.

Communication and awareness was the most common theme regarding improvements to the hospital experience across all of the ICP areas. The next most common themes for each ICP area are detailed below:

- In Bay Health and Care Partners (North) the most common themes after communications and awareness were staff attitudes and improving wait times.
- In Pennine Lancashire (East) there were no other common themes, however many of the comments regarding communications cited improvements to signage throughout the hospitals.
- In Central Lancashire the most common themes after communication and awareness were staff attitudes and improvements to the environment in the hospital, particularly around having appropriate places to wait for appointments.
- In West Lancashire the most common theme after communication and awareness were improvements to the hospital environment, most specifically around car parking charges.
- In Fylde Coast, the most common theme after communication and awareness were improvements to the hospital environment, particularly around having appropriate places to wait for appointments.

The most common theme from those who support people with learning disabilities and/or autism in the hospital environment regarding improvements to the experience is communication and awareness, followed by reduced waiting times. Many of the comments regarding communication referred to being given up to date information about long delays. Many of the comments regarding environment referred to having a suitable place to wait if there are to be long delays.