

Listening to people living with a learning disability

“Our Hospital and GP Care”



Better Things Group, Woodhouse Park Lifestyle Centre, Wythenshawe



Manchester People First Group, Cheetham Hill

Background

Following an action from the South Manchester CCG Quality and Performance Committee, engagement sessions were arranged with the following groups:

- Better Things (Mencap), Wythenshawe
- Manchester People First, Cheetham Hill

Judith Jones, Lay member for Patient and Public Involvement and a member of the Engagement Team attended the sessions to talk and listen to the patient experiences.

Group members were asked to share their experiences of using local hospitals and feedback was given on the following sites:

- Wythenshawe Hospital
- Manchester Royal Infirmary
- North Manchester General Hospital

A total of 29 people were listened to from two engagement sessions held on:

- Tuesday 17th March 2015
- Thursday 25th March 2015

A patient experience questionnaire was also adapted from a version developed by the North West Regional Health Equality Group, the Manchester Learning Disabilities Research Group and the Clear Communications People Limited. 8 people in total completed the questionnaire.

A copy of the questionnaire can be found on pages 8-11.

As well as hospital experience, group members shared their experiences regarding visiting GP practices.

This report provides a snap shot of experiences from people living with a learning disability.

Recommendations

- Promote the use of the [“Hello, my name is...”](#) campaign so staff introduce themselves to patients when talking to them
- Improve the use of the [traffic light passport/handbook](#) so there is a consistent approach across the city for people with a learning disability
- Increase the use of easy read information so informed choices can be made by people living with a learning disability
- Provide awareness training for healthcare professionals (hospitals and GP practices) to understand how to communicate with people living with learning disability
- Improve communication in hospitals on waiting times at clinics
- Provide support to patients who may have low literacy skills to choose from the food menu

Group Discussion

The group were asked to share their experiences of being a patient in hospital or visiting a hospital as an outpatient.

What worked well when went to hospital

- Getting better
- Nurses and doctors – friendly sometimes
- Sharing results with me was good
- Staff nurse was very good

What needs to improve when we are in hospital

- **Communication**
 - Could explain better
 - Communication from staff to keep patient up to date on what is happening
 - Recognise that patients will be worried and may not be able to understand or retain information
 - Nurses talk to my parents and ignore me, this is annoying
- **Waiting Times**
 - Waiting too long in hospital
 - Waiting for too long at the eye hospital, over 3 hours
 - I get nervous the longer I wait and I want to go home
 - Lack of information at A&E about how long you have to wait
 - Tell people how long they have to wait
- **Information**
 - Provide more information especially around discharge
 - Should use more easy read pictures leaflets and posters
- **Feeling safe**
 - Can be scary
 - Ask and give reassurance that you are ok as a patient
 - Perhaps visiting the hospital before the appointment
 - Not feeling safe in A&E
 - My parents stay with me in hospital but they cannot always find a bed for them
- **Appointments**
 - Stop booking so many people in for outpatient appointments – waiting for 2-3 hours is not good
 - There should be a ticket system for outpatients
 - Stop changing the date of my appointment
- **Training and Awareness**
 - Staff training to improve awareness
- **Clinical care and Treatment**
 - Lack of consistency of care across hospitals

- Not all hospitals use traffic lights for people with a learning disability
- Why doesn't everyone use the traffic light approach – getting fed up repeating information to different staff
- Explaining pain can be difficult
- Make sure consent is asked for
- When having a scan or x-ray have sides on the bed so you don't fall off – I am too scared to lie down
- **Dignity and Respect**
 - Feel they don't want to spend time with you
 - More personal touch needed
 - Staff introducing themselves by their name "Hello, my name is..."
 - Need to speak to me as an individual
 - Personal touch can be lost on the higher grades of staff
- **Medication**
 - Ask about existing medication
- **TC costs**
 - Free TV, some people cannot afford to pay for this
- **Car Parking**
 - Cost of car parking is too much
- **Food**
 - Food not good
 - Burnt sausages
 - It all tasted very salty – porridge and mash potato
 - No help to make choices of food on the menu
 - Not having the literacy skills to read the menu and no support offered

What worked well when we visited the GP practice

- GP listens to you

What needs to improve with our GP care

- **Appointments**
 - People not turning up for their appointments
 - Being able to see the same GP who knows me
 - Ask for consent if a student doctor is in the room, give the patient a choice
 - The GP talking to you directly, it is rude if they do not
- **The Receptionists**
 - Attitude of the receptionists – they are a barrier and need training
 - Nasty, not good, terrible
 - I think they are scared of me
- **Communication**
 - GPs need to listen to me and must not ignore me

- **Information**
 - Easy read information – not able to read check in screens or the digital ones that have your name on them
- **Feeling safe**
 - Visiting the GP makes us nervous, scared of the diagnosis and the if it is the big C

Other health experiences

- Improve waiting times to see a podiatrist for treatment to feet
- Need easy read information on epilepsy for patients so they can understand what is wrong – difficulty in finding any
- Health bus is good for health checks
- Opticians not patient with people with a learning disability – not a good experience

Questionnaire Responses

Following the group discussion in Wythenshawe, 8 members completed the questionnaire and the results are below:

Information about you

- **How old are you?**
 - 38 years old
 - 39 years old
 - 47 years old
 - 53 years old
 - 54 years old x 2 people
 - 60 years old
 - 66 years old
 - 67 years old
- **Are you a man or a woman?**
 - A woman x 6 people
 - A man x 5 people
- **Were the hospital staff friendly?**
 - Yes x 11 responses
- **Did they listen to you?**
 - Yes x 9 responses
 - No x 1 response
 - Sometimes x 1 response
- **Did they answer your questions?**
 - Yes x 8 responses
 - No x 2 responses
 - Sometimes x 1 response

- **Did you know who your named nurse was?**
 - No x 9 responses
- **How did the hospital staff help you understand information? Did they use easy words?**
 - Yes x 6 responses
 - No x 2 responses
- **Did they use pictures?**
 - Yes x 4 responses
 - No x 5 responses
- **Did they use leaflets?**
 - Yes x 2 responses
 - No x 7 responses
- **Did they show you what would happen to while you were in hospital?**
 - Yes x 5 responses
 - No x 3 responses
 - Sometimes x 1 response
- **Treatment and Tests – Did you know why you were having treatment and tests?**
 - Yes x 8 responses
 - No x 2 responses
- **Did people who knew you well help you make decisions?**
 - Yes x 7 responses
- **Did you sign to say you agreed to the treatment and tests?**
 - Yes x 7 responses
 - No x 1 response
 - I don't remember x 1 response
- **Were you told the results of your treatment and tests?**
 - Yes x 4 responses
 - No x 2 responses
 - I don't remember x 1 response
- **Did you understand the results of your treatment and tests?**
 - Yes x 5 responses
 - No x 1 response
 - I don't remember x 1 response
- **Getting the help you needed from hospital staff - Did you get help with pain?**
 - Yes x 4 responses
 - No x 1 response
 - I don't remember x 1 response
 - I didn't need help x 2 responses
- **Did you get help taking your medication?**
 - Yes x 5 responses
 - No x 2 responses
 - I didn't help x 1 response

- **Did you get help from staff to look after your privacy and dignity? This is things like undressing in private and talking to doctors in private.**
 - Yes x 5 responses
- **Did you have to wait long?**
 - Yes x 3 responses
 - No x 4 responses
 - Sometimes x 1 response
- **Do you have a hospital passport?**
 - Yes x 2 responses
 - No x 7 responses
- **Did you take your hospital passport with you?**
 - Yes x 2 responses
 - No x 6 responses
- **Did the doctors and nurses use it?**
 - Yes x 1 response
 - No x 3 responses
 - Don't know x 1 response
- **When it was time to go home, did you understand how to stay well and look after yourself?**
 - Yes x 6 responses
 - No x 1 response
- **How was your hospital visit?**
 - Good x 4 responses
 - Ok x 5 responses



Tell us about your visit to a Hospital

Manchester Clinical Commissioning Group wants to know how well hospitals care for you.

Information about you

How old are you?



Are you a man or a woman?



Were the hospital staff friendly?



Yes



No



Did they listen to you?.



Yes



No



Did they answer your questions?



Yes



No



Did you know who your named nurse was?



Yes



No



How did hospital staff help you understand information?

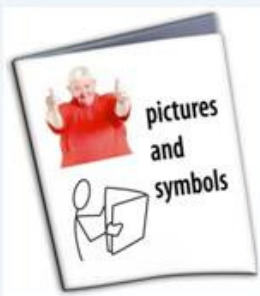
Did they use easy words?



Yes



No



Did they use pictures?.



Yes



No



Did they use leaflets?



Yes



No



Did they show you what would happen to while you were in hospital?



Yes



No



Treatment and Tests

Did you know why you were having treatment and tests?



Yes



No



Did people who knew you well help you make decisions?



Yes



No



Did you sign to say you agreed to the treatment and tests?



Yes



No



Were you told the results of your treatment and tests?



Yes



No



Did you understand the results of your treatment and tests?



Yes



No



Did you take your hospital passport with you?



Yes

No



Did the doctors and nurses use it?



Yes

No



When it was time to go home, did you understand how to stay well and look after yourself?



Yes

No



How was your hospital visit?



Good

Bad

OK

This questionnaire has been adapted from the a version developed by the North West Regional Health Equality Group, The Manchester Learning Disabilities Research Group and The Clear Communication People Ltd.