Report: Stroke Rehabilitation Engagement

Leeds Voices

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Summary

In June 2021 Leeds Voices spoke to 116 people, in 8 focus groups from South Asian, Black Caribbean, Black African and Eastern European communities about the move of Stroke Rehabilitation Services from LGI to Chapel Allerton Hospital.

Overall, participants were positive about the changing the Stroke Services from LGI to Chapel Allerton. The Hospital was seen as easier to get to, more welcoming, less stretched and that it was a hospital with *"a lot of potential"*.

The communities we spoke to had reported negative experiences with staff where they had experienced *"prejudice"*, with some staff being *"aggressive"* when faced with a language barrier. More therefore needs to be done to make hospitals inclusive.

These communities also felt the main reasons they are less likely to use stroke rehab services is mainly down to a lack of awareness or education about the services. Therefore these communities need to be more targeted in any information that is sent out about the services.

Barring some minor additions such as community languages/dubs and a more thorough display of how the equipment works, participants were positive about the LTHT Stroke Rehabilitation video when it was shown to them and that it was *"really positive"* when they saw how the hospital looked.

The new Stroke Rehab Unit in Chapel Allerton overall is a service that different communities would use and find more accessible than the LGI. However, from the feedback gained, more can be done to help make this service inclusive and to spread awareness of its existence.

Recommendations

- The FAST campaign was unknown to many focus group participants. The imagery could be more powerful and language more accessible.

- Information about the service should be widely available in different languages (Although we recognise that it is not possible to provide translation for all languages some suggestions for the Stoke Association materials were: French, Arabic, Kurdish, Tigrinya, Farsi, Swahili and Amharic).

- Most participants said that a shop in the hospital would be important for them, even with shops nearby.

- The use of a video to give a visual representation of what the hospital was like alleviates the 'unknown'. Some suggestions were made to dub a voice over or create subtitles. Lots of participants suggested this should be shown to all patients and families before admission.

- People were happy with the hospital environment compared to LGI both inside and outside and valued the green surroundings.

- The provision of items to make people feel at home if they didn't have family support is really important.

- The importance of staff who can help the patent emotionally was emphasised, and the reassurance that staff will behave in a way that respects cultural diversity.

- Carers and family members wanted to receive more information and education around how to look after the patient once they had been discharged from the rehab unit. It was also important for them to be offered mental health support and regular updates on the state and progress of the patient; something that had not been accessible in the LGI

1. Background

In June 2021 Leeds Voices were tasked with carrying out a short engagement using focus groups to speak to 55 people seeking their opinion about the relocation of all stroke Rehabilitation Services from LGI to Chapel Allerton Hospital.

2. Description of the Engagement & Method

The aim of the Leeds Voices Involvement work was to: 'to support the relocation by engaging with communities most likely to be affected by a stroke'

We were asked to seek the opinions of people from South Asian, Black Caribbean, Black African and Eastern European communities and their carers because we know that people from those communities are more likely to suffer from a stroke.

We wanted to know what barriers people might face getting to Chapel Allerton Hospital, what they thought about the local area and amenities, what facilities they may need inside the hospital and how the hospital can make their stay as welcoming and comfortable as possible to the patients and visitors. The focus groups were asked a series of questions based on the information above, and were shown a video of the new unit.

We worked closely with the Stroke Association and used the FAST material to talk to groups about recognising the signs of a stroke. This information will be shared with the Stroke Association and is included here as it gives useful insight into public health material for these communities.

Despite the disproportionate number of people from Black, South Asian and Eastern European background who experience strokes, the Stroke Association users are predominantly white British, we included this question with participants and have recorded their feedback.

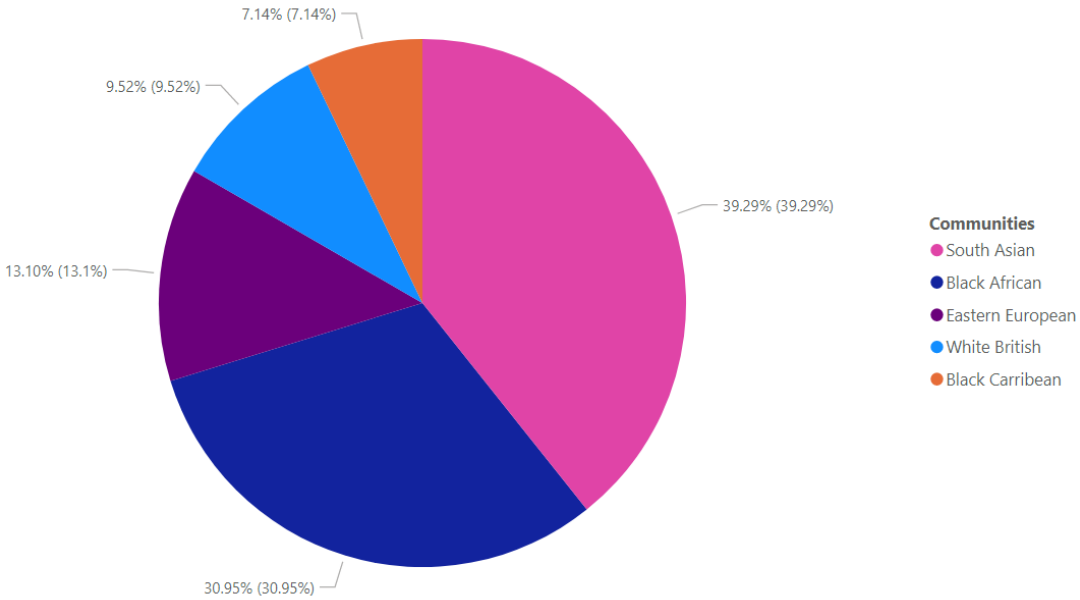
3. Who was involved?

We ran 8 focus groups with a total number of 116 people from the following community organisations.

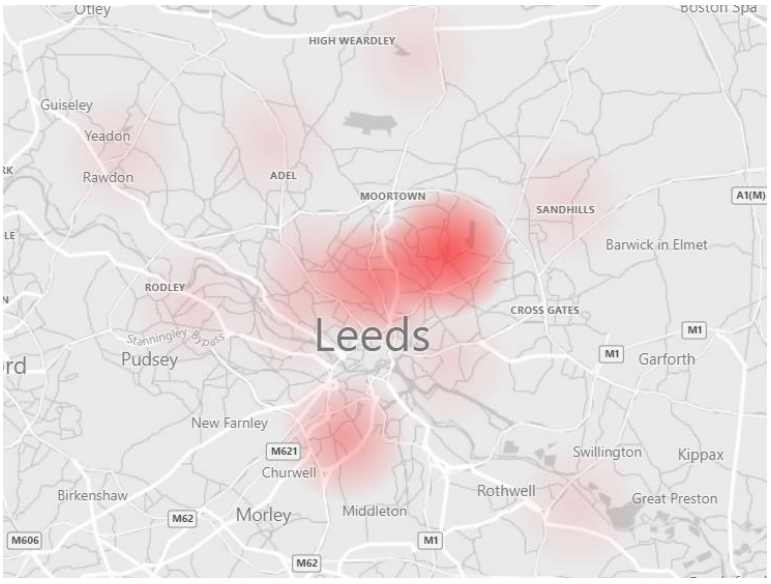
Feel Good Factor
Shantona Womens Centre
AME Roma
Peaceful Mind
Circles of Life
Hamara Healthy Living Centre
Leeds Refugee Forum
The Stroke Association

Seven of the focus groups we ran took place with groups that were already established and met regularly. Most of the groups were formed as communities of interest by ethnicity, geography or culture. The Stroke Association group was the only group that met up due to their experience of stroke. It was also valuable to get the opinions of staff at the Stroke Association focus group, which has been recorded in the findings.

Participant Communities Pie Chart



Participant Postcodes Heatmap



A large number of attendees had lived experience of a stroke. This included two women who were under 40 at the Roma group and one woman, from an African background who had lost all 6 of her siblings and her mother to stroke and suffered 5 strokes herself.

Main Findings

1. **FAST Campaign Poster**

Groups were shown a poster which was part of the FAST Campaign from the Stroke Association. When asked about what they knew from the campaign and the poster shown they had the following feedback:

Campaign distribution

While some participants who had strong English had seen the FAST campaign on television, many of them hadn't seen the poster, with participants from all communities expressing that there was a lack of visibility for the campaign amongst their communities.

"I know about FAST but haven't seen that particular poster...we (the organisation) have been supporting someone that had a stroke a year and a half ago, but throughout the LGI stroke unit I have never seen this poster."

"(the campaign) is not publicised enough in our communities (Black African & South Asian)"

When speaking about how best to get this information out to all communities, it was recommended that the Stroke Association should link up directly with organisations such as the ones included in this report to run zoom sessions where they can distribute information to communities.

"The approach (to sending guidance out) is a big problem...using flyers and emails etc. doesn't work with the majority of these communities because they don't think these methods of communication are for them due to language and cultural barriers. From covid we've learned that zoom is a good way of letting communities use their voice. So I think with more consultancy and more communication with these people, we will be able to capture the right way."

It was also expressed that there needs to be a targeted campaign for participating communities so that the information can reach those who have experienced a “lack of education” or are new to the country and therefore aren’t engaged in the services. Participants suggested that community radios would also be a good platform to get this information out, due to it being in the communities’ own languages and a verbal method of communication.

“To my mind it’s a problem of a lack of awareness, which I think needs to be addressed with a specific campaign targeting black communities to make them more aware of what’s available in terms of facilities and also the symptoms and danger of having a stroke.”

Key points

- The poster needs to be distributed to **all** hospitals and GPs across Leeds
- The Stroke Association can link up with the organisations included in this report to see how they can get information directly to their service users
- There needs to be a targeted campaign to target Black British, Caribbean, African, South Asian and Eastern European communities to better engage them with the Stroke services

Changes to make to the poster

Multiple groups expressed that some of the language used in the poster was not clear enough. The term ‘Facial Weakness’ seemed vague and unhelpful for spotting a stroke, therefore it was suggested ‘**Facial Drooping’** should be used as the main ‘F’ title, while ‘Facial Weakness’ should be moved to the smaller print.

"Instead of saying 'facial weakness' it could say 'facial drooping', because the symptom isn't that the face becomes 'weak', but that there's actually a shift because the mouth starts to droop."

"I would say 'facial droop' or 'facial drooping' is a better way to describe the effects of a Stroke (than 'facial weakness')."

“I feel ‘droop’ or ‘drooping’ is better because it has more of a meaning already attached to the word when compared to ‘weakness’.”

Participants felt the poster was missing images of real-life people that demonstrated the signs of a stroke and each aspect of 'FAST' such as facial defects, or checking for numbness of arms etc. Using these pictures would be more *"eye-catching"* and make people more likely to take notice of the information in the posters.

"I think especially with the BAME community they say 'a picture paints thousand words'… I would say that if you got the images correct then language is not a barrier, it doesn't really matter what terminology you use or what text is on there, it already tells us a story, it gets people engaged and they will read through- whether it's someone from a BAME community and it takes them a few extra minutes to read through."

"If you have actual pictures of people from different ethnic backgrounds it catches your eye when you see a real person, the way the adverts (on TV) do it to capture an image like that would probably be quite striking, you'd probably take more notice of it"

The colours used on the poster was also seen as not conveying a sense of urgency or being eye-catching. This was an important aspect as it would stand out more with a colour such as red that conveyed danger and would be more likely to be picked up and read by communities.

"I think colour needs to be more eye catchy, the colour is a little bit dark, it needs to be like an emergency so maybe a red colour."

'I agree that this F.A.S.T bit does not stand out, maybe it should be in another colour from the rest of it, so that it sticks out? But really for me there is nothing that draws you into the picture, it's a bit dull."

"It looks more like a sign that you have over your sink saying 'Wash your hands'…you glaze over it without giving it a second thought."

Key points

- Change the wording on the poster from **'Facial Weakness'** to **'Facial Drooping'** to make it more clear
- Include pictures of people from diverse backgrounds displaying the stroke symptoms as with the TV advert in order to make it more eye-catching

- The colour should be altered from blue to something that communicates danger such as red

2. Getting to Chapel Allerton Hospital

Participants were positive about getting to Chapel Allerton Hospital when compared to the LGI. Those who had experienced both said getting to Chapel Allerton Hospital was easier as it is “much quieter with less traffic”.

In terms of parking, Chapel Allerton was also seen as more favourable than LGI. Participants who had been to Chapel Allerton said that parking was “not an issue, as “there is lots of parking literally on-site”. The parking was also described as “not as compact as at LGI”, with “better wheelchair access”.

One issue however that was raised by a participant was the pricing and having to top up the car parking charge due to the doctor running late. The participant had in the past had to go and top up the money they had spent parking due to this but at the same time this risked them missing their appointment if the doctor suddenly came to call them whilst they were topping up their parking payment. It was suggested that this could be resolved if the hospital could somehow use your registration number to see if your appointment had been late and provide a discount to instead charge you what you originally would have paid if the appointment had been on time. This would reduce anxiety and be reassuring for patients during their appointment.

Some participants who were based in South Leeds did mention that getting to Chapel Allerton Hospital “could be a bit of an issue” for their family members who don’t drive as it would “probably be a bus into Leeds city centre and then out of it” rather than one bus to the LGI, while getting a taxi “could be quite expensive” due to the further distance.

Key points

- Most participants saw Chapel Allerton as easier to get to than LGI. Those who had experience of the hospital said that there is less traffic and more spacious parking as well as nearby on-street parking.
- One participant suggested using patients’ car registration number to give them a parking discount if their appointment is running late.
- Chapel Allerton would be more difficult to get to for those living in South Leeds that use public transport

3. Chapel Allerton as an area

Participants were familiar with the area around Chapel Allerton hospital, with pictures also shown during the groups to give them an idea of what was there.

There were positive views expressed about the area when comparing it with the LGI.

"I know that area, it's less busy (than LGI) and I think it would be good to help a patient relax".

The area around the LGI meanwhile was seen as *"a concrete jungle"* and therefore not as relaxing for rehab patients.

The local shops such as Lidl and Tesco Express were also seen as much cheaper and convenient in Chapel Allerton.

"You don't have to spend a mortgage to get something to eat".

Some participants however did feel that the walk to the shops may be difficult for those recovering from a stroke, therefore they may not be able to use the local shops or their family members may have to go and get items for them.

"It's quite a busy road to get to the Tesco Express and if you're a but unsteady on your feet then that might be a factor (in stopping people from using the shops)"

Key points

- Chapel Allerton overall is seen as a better area than the area around the LGI. It is quieter, more relaxing and the shops are cheaper, so this is a positive change
- There are some concerns however that patients will not be able to use the shops or at least will find difficulty getting there due to the shops being on a busy road with lots of crossings

4. LTHT Stroke Rehabilitation Video

Positive Aspects

During focus groups participants were shown a video released by Leeds Teaching Hospitals to give patients an insight into the Rehabilitation unit at Chapel Allerton and what to expect.

Overall participants were positive about this video, finding it *"very informative"* about how different aspects of the care will benefit patients and were reassured that *"they do look like they're making improvements"*.

"The video is very good very informative."

"The good part about it too is that they actually extended it to home care, in that the experience that the patient would have in the bays they are in with the various equipment would familiarise themselves with this equipment, so that when they go home they are familiar with it…the patient leaves the hospital familiar with what the new home situation is going to be."

The visual aspect was also seen as very beneficial for patients, with one participant saying *"It's amazing, there still some language barriers but it's good to have something visual where you can see it and imagine what is there".*

Improvements/Adjustments

Some participants felt that the video could have been improved if viewers could *"see the use of the hoists"* to paint a clearer picture of how they will operate.

Communities were also keen to have the video available in different community languages, with the Roma Community in particular expressing that for them it would need to be dubbed in Romanian as most of the community do not read.

More information could have been provided "*about the length of stay and what the rehabilitation process is"* as there was one participant who was confused about this.

One participant also felt that the video should have included more details about childhood strokes as they *"can be quite common and often misdiagnosed as epilepsy, which was the case for me, so there should be something in the video about childhood strokes"*.

Key Points

- The overall format, look and content of the video was well received by participants who were happy for it to be used as a way of informing patients about life in the hospital
- The video needs to be translated in different community languages, with Roma Communities requiring a Romanian dub due to not being able to read

- The video could include a demonstration of how to use the hoists, a segment on child stroke services and details about the length of stay or rehabilitation process

5. Feeling at home in the hospital

Overall Environment of Chapel Allerton Hospital compared to LGI

Those who had stayed at the LGI reported many negative experiences of it, with one patient describing the ward they stayed in as a *"dungeon"*, situated on a lower floor with the windows high up so they couldn't see outside.

"As soon as I saw the door (to the room) I cried my eyes out."

"That place was so depressing, and if you've had a stroke, you don't want to be there."

"I believe, well I know that there was a lot of prejudice going on. There was just abuse to me all the time, especially at night. I did say to them ''Please I haven't slept all night, can I have another room please? They said '' sorry you cant'' But the at the end I discharged myself, I said I don't want to stay here any longer I'd rather stay at the hotel. But in the end my memory was down, I was depressed and there was nobody there who I could speak to."

By contrast views about Chapel Allerton, especially compared to LGI were positive, reflecting this change as a well-received one for stroke rehab patients.

"(my wife) was in Chapel Allerton for five months and the service she got there was of a far higher standard than the LGI. At the LGI they were stretched with physios, therapists, everything and she was getting physiotherapy maybe twice a week. At Chapel Allerton it was every day, they make you feel so welcome.

"as an in-patient it's got a lovely garden, it's just a lovely place to be"

From the Leeds Teaching Hospitals Video that was shown during the group, participants were very reassured that the ward would provide a nicer environment that was *"worlds apart"* from their previous experiences.

"Looking at (the video) now the process that they have got is worlds apart, so thank God that we've got somewhere like that."

"It's amazing....great to have something visual where you can see it and imagine what is there."

One participant whose wife had used the hospital's neuro rehab services was full of praise for Chapel Allerton hospital comparing it very favourably to LGI. One factor that particularly helped with recovery was that the return back home was more gradual, with the patient returning on the weekend and then going back to the hospital during the week. This was *"a massive part of her recovery"* as it was easier to adjust to life back outside and meant that she could *"see the light at the end of the tunnel"* and would therefore be a very important feature of the Stroke Rehab service in Chapel Allerton.

Some participants from multiple groups did point out that Chapel Allerton Hospital no longer had a shop inside whereas LGI did, therefore this was a negative factor as it meant patients couldn't have a short walk down from their ward to pick up some items and would have to rely on family members bringing it to them.

"When my mum was in LGI I was able to go and get her stuff from the shop...it's good practice as well for people when they're preparing to go back to normal life."

There was also a slight concern raised by some about whether the Stroke Rehabilitation unit would cause Chapel Allerton to lose its standard of service, therefore eliminating the positive experiences that people had reported about the hospital. It would therefore be useful to acknowledge this risk in any communications sent out and provide some reassurance that the hospital will have this under control or at least in mind.

Key Points

- The inside of Chapel Allerton Hospital is also seen as a nicer environment than LGI
- Participants had positive views about Chapel Allerton Hospital describing it as *"welcoming"* and *"of a much higher standard"* than the LGI, which was described as being *"stretched"* and *"depressing"*, therefore this is seen as a positive change
- The lack of an inside shop at Chapel Allerton was seen as a concern, with suggestions that they could bring in people who had stalls as a quick substitute for a shop
- Some were concerned this new service could make the hospital more stretched, therefore there needs to be some reassurance provided around this

Helping Family members/carers to be part of their loved ones' recovery

Participants who had English as their second language felt much more comfortable having a close family member/friend able to attend the hospital with them in order to provide interpretation for them.

"If it's my husband or my cousin (interpreting), then I feel a lot more confident."

Similarly, family members/carers wanted to be able to accompany the patient to the hospital and interpret for them, so that they can make sure the doctors could understand their family members' condition.

"I want to interpret for my wife because I don't want her condition being exploited by someone else."

In terms of how the change in hospital would affect family members/carers, all participants who had experienced both the hospitals said that they felt the care received at Chapel Allerton was *"of a much higher standard"* than the LGI and would be reassured that their family member or friend would have stringer rehabilitation in Chapel Allerton.

"As a carer (Chapel Allerton) kept me well informed with what was going on and everything that I needed to expect when (my wife) came back out. It was a lot easier for me to get to than the LGI and on a great bus route."

The mental health of family members was also an important aspect for participants due to the distress felt at having a family member having to recover from a stroke. One community leader spoke about the struggles that members of the South Asian community had faced when their family member had suffered a stroke.

"I have had so many calls because of distressed family members that have not been able to go and see loved ones in hospital. I think it's going take a long time to help them and it's sad to say that we have lost so many members. The question is now how are we going to support these people who have had such distressing times and how can we now support our community and safely say 'right, we have got all this information, all protocols are in place and you don't need to be intimidated'."

Education about what precautions to take in order to avoid a stroke is also important for family members and carers, as it would they can continue to support the patient once they are discharged from the rehab unit.

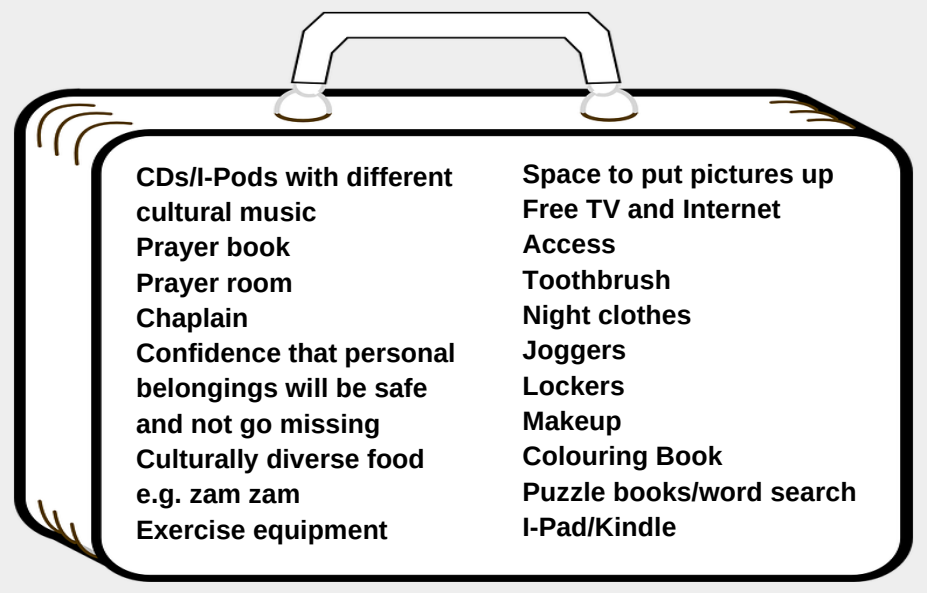
"When the patient returns home there will be a continuation of the patients care at home, so family members need to be part of this process so they can then learn things like what to eat and what not to eat in order to avoid triggering a stroke."

Key Points

- Chapel Allerton hospital was received more positively from carers/family members who had experienced the hospital as they felt informed and involved in the patient's recovery.
- Those with language barriers would prefer to have their carer/family member interpret for them in hospital as they are more comfortable and trusting towards them than a hired interpreter.
- Education needs to be provided fromt eh hospital to family members/carers about what measures to make in order to minimise the risk of future strokes for the patient.
- If visits are restricted then there needs to be regular communication to the family members from the hospital about the treatment their family member is receiving and what the next steps will be.
- Mental health support should also be an option to family members/carers to help them with the distress involved with having the patient in the rehab unit.

Resources that the hospital can provide

Participants were all asked what provisions people from their community would require in the rehab unit to make them feel at home during their stay and ultimately recover quicker. The overall results are compiled below along with quotes from participants who suggested items:



“Music has got to be a must and with technology now it is limitless. Easy to provide for all backgrounds and promote familiarity as well as stimulation.”

“As a people we are very religious, so greater access to our religious beliefs (prayer rooms, Bible, pastor) if we are going to have a long-term stay”

“(access to African food) made me feel like I am getting better and I am ready to go home, something was happening in my mind like I am ok and I am getting better”

Experiences of culturally diverse communities in the hospital

- **Discrimination from staff**

All communities had participants who reported negative experiences in the hospital that were caused by a language barrier and not feeling like the hospital staff were being understanding about this.

“Sometimes I feel straight away when (staff) treat me this way. When I don’t understand something a staff member has said they then shout it at me and it feels aggressive towards me.”

"I didn’t say thankyou for my cup of tea because I couldn’t speak the language – the lady shouted at me that she’s like my mum’s age and I should be grateful – I was shocked/nervous. I didn’t know what to do"

There was a suggestion from multiple groups that staff could undergo culturally sensitive training or have staff screening dedicated to addressing cultural barriers experienced by communities. That way it would at least be reassuring for patients to know that they were in an environment that is addressing these issues and trying to create a more inclusive environment regardless of the attitudes of some staff.

“You can’t change people’s opinions overnight. But what you can do is say ‘look, keep your opinions to yourself or take it outside, but in the hospital the patient is our customer and the customer’s always right’.”

“They just need to think to themselves, if they were in hospital how would they like to be treated?”

Key points

- When faced with language barriers staff often display a lack of sensitivity to this, sometimes shouting, talking too fast and making the patient feel uncomfortable and upset.
- While racism is still an issue in hospitals, communities would find it reassuring to know if staff had received culturally sensitive training as it would at least display that the hospital are acknowledging and confronting it.

- **Interpreters in the hospital**

Communities that faced language barriers were reluctant to use interpreters in the hospital, partly due to having to pay for them, meaning *"they tend to avoid them because of the cost."*. However a larger factor was that communities were often uncomfortable with explaining their symptoms to a stranger to interpret it on their behalf due to the very private nature of it. Therefore it is much preferred to use a family member who can speak English and interpret for them as there is more trust.

"It's degrading (explaining health issues to a hired interpreter) so friends/family are always preferred for interpreting."

This is still a barrier however, as participants reported that staff at hospitals, including Chapel Allerton initially didn't allow them to interpret for one of their relatives as they would *"not interpret correctly"*. This made a lot of participants confused as to why they weren't being allowed to interpret and it also made them feel uncomfortable having to let their relatives rely on someone who they haven't met before to listen to and interpret their personal conditions to the doctor.

"I don't understand why they don't accept that their husband is telling you what (their wife) is saying"

"I want to interpret for my wife because I don't want her condition being exploited by someone else"

An alternative suggestion to this from one of the groups was that patients could use an interpreter from a community organisation, which would be a more trusted source than an interpreter from the council or hospital.

"If (family interpreters) isn't an option you can arrange for someone from a place like Hamara to help with this."

One group also suggested that volunteer interpreters from local communities could also help patients with rehabilitation as they would be able to be on hand to speak to them regularly as part of a befriending service to comfort and reassure them during their stay in the hospital if they are anxious. This is especially important as they recognised that hospital staff are *"stretched"* and therefore nurses aren't always on hand to help the patients in the ward.

"There is a need for volunteers who speak the languages of the people who are in the hospital as a befriending service, because if you have had a stroke you need lots of stimulation, you need to have practice talking and thinking about things."

"Countless times you'd go into the ward (to visit a family member) but often in the opposite bed there would be somebody from the BAME Community and you'd end up going over to them and saying 'you're gonna be fine, look (my relative) has been in X weeks and look how far he's got.' and just encouraging them because you could see the fear on their faces. Nurses don't have time for that one-to-one."

There was also a suggestion that hospitals could utilise the "third generation" medical professionals from diverse backgrounds as they are generally multi-lingual, having been brought up in the UK, therefore could provide trusted interpretation services.

"A lot of the third generation (from our background) are really into medical occupations, so having doctors and nurses available would make it better because there's more trust there with a professional."

Due to most interpreters in hospitals being women, this provided a large barrier for the male participants in the group, who said that they feel uncomfortable having to explain a very personal condition to a female who isn't a medical professional.

"I find that 99.79% of interpreters are female, because male interpreters won't be accepted by females because of privacy…however If I had to explain a very personal bodily condition to a female, I would feel embarrassed and she would also be embarrassed, so I just think with interpreters in hospital than man should have man and female should have female."

This was also the same for female participants when talking about male interpreters, with participants reporting that *"we feel shame if we have to ask a man to interpret our health issues in a hospital."*

Key Points

- People with language barriers would like to be allowed to have a family member interpreting for them as it makes them feel more comfortable
- If family members aren't available then volunteers from local community groups could be used and assigned to patients as a befriending service
- Interpreters should be the same sex as the patient they are interpreting for due to the personal nature of the information the patients are sharing

- **Why participating communities are less likely to use the stroke services**

Throughout this engagement we have developed a positive working relationship with The Stroke Association who take referrals from the team at Chapel Allerton. The Stroke Association recognise that their membership does not reflect the diverse communities of Leeds.

When asked about the disparity between White British and Black British, Black African, South Asian, Eastern European communities of accessing community services, participants mainly pinned the disparity down to differences in culture and in education.

Culturally, both Black African and South Asian participants said that there is a *"duty of care"* amongst their communities for relatives who are ill. Therefore, rather than use the hospitals and seek professional help, they would rather stay at home and be cared for by family members in a familiar environment.

"What I think is that our community have a duty of care to our elders, and as we know there are different generations living under one roof so if anybody had become ill there are different generations that can look after that person and maybe that is another reason why you won't find as many seeking to go into a home or rehab or things like that."

As previously highlighted in the report, there is also a general lack of *"awareness"* and *"education"* in participating communities around Stroke Rehabilitation. Information and communications sent out about Rehab services therefore needs to be part of a campaign that specifically targets people from backgrounds.

Key Points

- There is a general lack of awareness amongst culturally diverse communities that Stroke Rehab services are available
- Those from South Asian and Black communities usually choose to have rehab in their home as it is a familiar environment with family members of multiple generations who can look after them
- There is a ‘cultural pressure’ for families to be seen to care for their loved ones at home.
- The Stroke Association has since presented to the Leeds Voices monthly drop-in to promote their service and also supplied all community groups who attended focus groups with translated booklets with information about Stoke and the services they offer.