

# Report: Leeds Community Neurological Rehabilitation Service Review

**Leeds Voices**

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**October 2021**

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## Background Information

### The NHS Leeds Clinical Commissioning Group (CCG)

NHS Leeds CCG is responsible for planning and buying (commissioning) most of the health services for people in Leeds. The CCG commissions a range of services for adults and children including planned care, urgent care, NHS continuing care, mental health and learning disability services, and community health services. The CCG works together with NHS England to commission GP primary care services.

### Community Neurological Rehabilitation Service

The Community Neurological Rehabilitation Service provides specialist rehabilitation support for adults in Leeds with neurological conditions such as Multiple Sclerosis, Stroke, Parkinson's and people who have experienced a trauma to their brain. The teams described below bring together the expertise and skills of different professionals to assess, plan and manage care jointly. Over the last few years there has been increasing demand with long waits to access the service. This engagement will contribute to a wider review exploring new ways of working to try and address the challenges.

## Leeds Voices

Leeds Voices was set up by Voluntary Action Leeds to ensure that local people and communities have their say on changes to services in Leeds.

Working with partner organisations and volunteers from across the city, Leeds Voices reaches out to a diverse range of people including underrepresented communities, working people and the general public. This means that public organisations which make decisions about how their services can best fit the needs of Leeds communities can be confident that the views of under-represented communities have been included.

The work of Leeds Voices is split into three parts:

- **Engaging Voices** – A network of charities and voluntary groups, which supports those who use their services to ensure that their voices are heard.
- **Working Voices** – A network of employers, which enables and encourages their employees to be part of conversations about service provision in the city.
- **Leeds Health Ambassadors** – A team of volunteers who help run engagement activities and connect with people and communities.

## Outline of Engagement

Between July and September 2021 Leeds Voices conducted an engagement targeting people who have a neurological condition, which included gathering the views of carers. We wanted to know people's experience of the Community Neurological Rehabilitation Service in Leeds, and also hear from those who are eligible but had not accessed the service previously.

## Types of Engagement

The engagement took the form of focus groups, 'one-to-ones' and paper and electronic surveys, with the surveys made available in easy-read format. The Engagement was promoted widely on social media and Leeds Voices visited support groups and member organisations to gain interest. Four open-focus group sessions were also promoted for members of the public not attached to a support group or organisation.

A total of 66 people took part. Individuals' conditions were not recorded in the survey, but within the focus groups and one-to-ones we spoke to people living with conditions including MS, Lupus, Stroke, Parkinson's and brain injury.

The greatest number of respondents came from established support groups such as Different Strokes, the MS Society or Giving Voice Choir. A full table of focus groups and events attended can be found in appendix A.

## Accessibility

Recognising that many people with neurological conditions can suffer a range of sensory deprivation, we took extra care to accommodate different communication styles. We took a person-centred approach to the engagement, making sure we understood individual needs.

Leeds Voices were able to offer support to 3 people who were non-verbal in their communication. We communicated via email and using the chat function in online

focus groups. This was presented as an alternative to just filling out an on-line survey as it involved a more interactive option.

We used the easy-read version of the survey with 1 participant who had a learning disability.

We designed a clear graphic PDF of each question (see appendix B) and we were able to enlarge the questions in online focus groups, to adjust the print size ensuring people could read the text and see the visual cues.

We also worked with colleagues at the CCG and the Neurological Rehabilitation Team to develop examples of a Patient Journey through the service to explain of some of the difficulties faced by the service and its patients (an example can be found in appendix C). This was useful to give context to people who had a neurological condition, but who were not familiar with the service.

## Limitations

### Numbers

Our target number of participants for this engagement was 100 people with neurological conditions. A total number of 66 people took part in the engagement, with 37 of these being focus group participants and 29 survey respondents.

Low attendance at groups, and suspension of some groups over the summer holiday was cited as a reason for this. We found that on average lower numbers of attendees at focus groups than would be normally expected, and it was also cited that covid concerns were a reason why 'in person' attendance has remained low.

### Online survey

The total number of respondents from the online survey was 29, but many respondents did not list their answers in the way that was requested on the form. Participants were asked to rank answers in order, for example as follows:

*3. Thinking about the service you have received or may receive, what matters to you about the staff who care/treat you? (1 being the most important, 6 being the least important) Please do not use the same number twice*

*Quality of care*

*Good communication*

*Being involved in your care*

*Receiving my therapy/care from the same therapist/nurse*

*Receiving my therapy/care from a range of different staff with appropriate skills*

*Being seen in non-working hours*

Nearly all respondents did not rank their answers in the way requested, but we were still able to extract useful data from the responses and generally understand what

participants saw as the most important points. Free text boxes were also used and we were able to understand more reasoning behind people's answers.

For future surveys, it would be recommended to use a setting where participants can only allocate one score to each item, this could also be piloted before with a small focus group.

For question 3, some focus group members did not want to rank the options against each other, stating that, quality of care should be 'a given' and not weighted against the other options.

## Methodology

So that information gathered could be processed as objectively as possible, all staff and volunteers were briefed about the engagement and ways of collecting data. Where possible, note-takers were assigned different tasks, one person to note overall themes and points of discussion and a second person to write 'verbatim' what the participant had said. Where focus groups took place online, most groups agreed for the session to be recorded so detailed notes could then be made retrospectively.

All focus groups and one-to-one discussions were recorded on a template which gathered themes and quotes. Recommendations were then formed from each discussion and are presented below. Detailed quotes and summary of themes then follow, for each of the 8 questions posed.

Our summary of numerical survey data is expressed in graphs in the main body of the report. Comments from the online survey have also been grouped thematically and integrated into the body of the report.

At the end of each group, participants were asked if they would like to take part in a short video to summarise discussions, 5 groups took part in this. (Ctrl+Click on image).



## Summary of Recommendations:

Many focus group respondents were complimentary of staff and the quality of care and rehabilitation they received; participants often commented how they understood the pressures that services are facing and were thankful of provision received. High waiting lists and a lack of understanding of how to refer into the different services provided where often cited as barriers.

- **Use of local community hospitals and venues**
  - Community Hospitals such as Chapel Allerton should be prioritised for patients using the service, with free wifi, radio, TV, books and other materials provided for patients.
  - Community venues in the patient's locality, for example religious buildings, charities or community centres, could be considered for patients who need to receive therapy away from home.
- **Consistent use of just one venue, therapist and staff team for a patient**
  - Where possible therapy sessions should be run in the same location.
  - Consistency of therapist is important and should be prioritised. We heard how changes in staff has a negative impact on patients both physically and mentally.
  - Consistency of staff at follow-on appointment is also important, patients wanted to see the same face at repeat appointments within a single discipline.
- **Link up with advocacy services to help address patient complaints**
  - While thoughts on staff are overall positive, complaints from patients about individual staff members need to be followed up and addressed more effectively.
  - Offer patients independent advocacy services such as Advonet to help address any complaints
- **Provide a higher range of options for patients during their care**
  - Patients should have the option to visit the hospital and meet staff before their overnight stay to familiarise themselves with the environment.
  - Preferences varied, with strong opinions between single or shared rooms, if possible, patients should be able to choose the type of bed they have.
- **Provide a higher range of options for the patient when booking on to the service**
  - Patients would like to be able to use their local GP to be referred to services.

- An alternative to online referrals/consultations must be offered, including telephone calls and face-to-face appointments to accommodate (sometimes subtle) sensory deprivations caused by a condition.
  - There should be a range of methods in place for patients to make a referral, to accommodate different communication needs.
  - Alternative therapies could be recommended or offered. Some groups felt this would appeal to diverse communities where use is traditional.
- **Higher cultural sensitivity from hospitals**
- We heard that many people from South Asian communities fear staying overnight in hospitals. Communities therefore need more reassurance from the hospital, as well as culturally appropriate or faith-appropriate materials being available to them.
  - Language barriers could be addressed by allowing family members/carers to interpret for patients. If this is not possible, then patients could be assigned befrienders or doctors who are from the same background and/or speak the patient's language. Different dialects need to be considered. Any written materials given to the patient should also be translated.
  - Community organisations and support groups could be considered to provide volunteer befrienders.
- **Further involvement of carers, family and friends**
- Visiting times should be more flexible for inpatients' family and friends, with either broader times available or freedom to pick a preferred time.
  - Family members/carers should be regularly informed about the patient's condition and treatment, particularly because some patients may struggle to process information, due to their condition.
  - It should be recognised how key carers are to many peoples rehabilitation, and they should be supported and included in all possible aspects of the care and rehabilitation programme.
- **Further support for the Patient beyond their discharge**
- Patients expressed disappointment that there was no follow-up from the final review and wanted to stay in touch with the services in case their condition worsened or they had questions.
  - Peer support groups should be promoted and shared with patents more widely and at different points of their journey.
  - Some patients expressed 'frustration' of having to repeat information to each new consultant or therapist they see, closer working between teams may help to reduce such occurrences.
  - Due to technology being a barrier for some patients, an advice line would be easier for those looking to gain professional support while managing their condition.
- **Address the lengths of waiting lists for patients**

- Waiting lists are often years long for patients despite people being recorded as 'would benefit from neuro rehab', therefore, funding should be put in place to reduce current waiting times.
  - If the waiting lists are long, then patients should be regularly informed where they are on the list and understand why there is a delay.
- **The Spasticity Service should be promoted, and clear referral pathways communicated to those who would benefit.**



## Main Findings

### i. Staying overnight

- **Allowing pre-visits to hospitals for inpatients**

Patients felt that anxiety about their stay would be significantly reduced if they had the option to visit the hospital, meet the staff who were taking care of them and get an overall feel of the hospital before their stay began. Staying in an unfamiliar environment had made patients feel *“isolated and scared”*, therefore having a pre-visit in place would be much more assuring for the patient and make their stay - and ultimately their recovery - easier.

*“I had to stay for 5 nights, I wasn’t aware of this environment, or the staff that were going to be looking after me.”*

*“I think my wife would really worry if she wasn’t well prepared for an overnight stay, she would need to visit before so she knew what to expect.”*

### - **Community hospitals**

Those who had experience of inpatient neurological rehabilitation services felt that community hospitals were a much more welcoming and *“chilled out”* environment than a central hospital such as LGI and St James’.

People felt community hospitals had outside spaces with trees and flowers that were pleasant for patients to sit out in, while central hospitals cannot offer this.

Ultimately, community hospitals such as Chapel Allerton need to be prioritised for patients using overnight neuro services, as they will be much more beneficial towards helping the patients recovery.

*“I have found that they look after you better (in community hospitals), they talk to you nicely, and there is a very personal touch, you can talk to them. In St James’ I couldn’t do that”*

*“I preferred Seacroft Hospital to LGI...more chilled out.”*

It is also important for these hospitals to have free access to Wi-Fi, radios, books and TVs so that the patient can stay stimulated in between hospital activities and independently recover their senses whilst they are in hospital. Many patients have had to pay for these features, meaning that sometimes they could not get the stimulation they needed whilst in hospital.

*“(patients need) access to T.V radio for mental stimulation, and the help to enable use them, especially if patient is unable to do so.”*

*“In LGI they charged you £6 each day to use the Wi-Fi...it feels like they’re just rinsing you.”*

### - **Addressing stigmas from diverse communities**

Those from South Asian backgrounds expressed that there is often a stigma – particularly from elderly members - towards staying overnight in hospitals, mainly due to a fear that they will stay there in an unfamiliar environment and not come back out alive, meaning they would rather be at home.

While this stigma is incredibly difficult to break down, it was suggested that the neuro wards could have a video that introduced the hospital and the staff so that patients can have a preview of what the hospital is like, which may reassure them if they are having doubts about staying. This video would also have to be translated into multiple community languages, as it would encourage the potential patient to trust that the hospital is considering their interests and welfare.

*“My middle-aged next-door neighbour was reluctant to go to hospital, [saying that] if I go to hospital I will never come back, I will just die. I had to convince her for months to just go have a look.”*

*“Each department could have a video explaining who they are, then adding videos in different language. People with technical knowledge in the family can share this with family who do not.”*

Religious considerations, such as chaplains or holy books, could be provided as well, so that patients who are reluctant can at least use these for comfort and reassurance. If chaplains, or religious representatives, cannot be present at the time, then it could be arranged for them to take part in a video shown to patients before they enter the hospital.

*“Utilising chaplains, as they are seen as spiritual people, would be brilliant to do a video and deliver it, that would be really good because they would have a stronger part to play in a video, already having a degree of trust.”*

### - **Flexible visiting times**

During their stay in the overnight services, patients found that visiting slots for friend and family members were too “strict”, making it “difficult” for patients to see family members during their stay. If possible, more convenient timescales could be provided for patients to have visitors, or ideally, the patient could choose themselves which times generally work best for them to have visitors in

*“They have a set time for people to visit. It’s difficult for people to get to there. They have such a strict timetable with lots of activities.”*

### - **Choice over own room or shared room**

Opinions were split on whether having a shared room or a single room would be better for patients during their hospital stay. Some liked the “privacy” of a single room,

whereas others felt “lonely” in a single room, while some in a shared room developed bonds with patients they were with. Therefore, while there is no consensus on the room arrangement, it would be preferable to have both arrangements as an option for patients, giving them the freedom to choose based on what works best for them.

*“I’ve had a room that was shared with someone we used to meditate together.”*

*“Own room is preferable and more private when you’re unwell with a brain injury. You don’t want to be disturbed all of the time...need peace for body and brain to heal.”*

*“I would prefer to be around other people, because when you’re going through something the last thing you want is to feel like you’re on your own.”*

If being placed in a shared room then, each room would need to be single sex, as some “couldn’t cope” with having to mix in shared rooms.

*“I liked being in a room with other people, other women. I couldn’t cope with men being there.”*

*“I think if its more than a few days I would feel lonely on my own, I would like to be on a small ward, but not with men.”*

## **Key Points**

- Patients should have the option to visit the hospital and meet staff before their overnight stay, to familiarise them with their environment.
- Community Hospitals such as Chapel Allerton should be prioritised for patients using the Neuro Rehab services, with free Wi-Fi, radio, TV, books and other materials provided for patients.
- Many from South Asian communities fear staying overnight and therefore need more reassurance from the hospital as well as culturally sensitive or religious materials available to them.
- Visiting times should be more flexible for patients, with either broader times available or freedom for patients to pick a preferred time.
- Due to differing preferences between single and shared rooms, patients should be able to choose the type of room they get placed in, with shared rooms being single sex.

### ii. **Location**

**If you were unable to receive your therapy at home, what would be important to you from an alternative venue?**

#### **- Community venues**

Ideally, therapy received outside of the patient’s home could take place in a more familiar environment which was close to where they lived and was used for community activities, for example religious buildings, charities, libraries and community centres. As well as being more convenient, this would also be more relaxing for the patient, due to

its familiarity and the lower number of staff and visitors present when compared to a hospital.

*“I’m not sure if it would work, but could they use a room in the Mosque or the community centre? I would rather go somewhere I know.”*

Nursing homes were also seen as a good alternative venue for therapy, due to them being based in the community and having the clinical equipment already available to carry out the required therapy. This would mean that it covers both the community and clinical aspects of receiving therapy from a familiar location.

*“It’s close, they’re familiar with where they are going, GP surgeries and nursing homes”*

*“At nursing homes they will already have all of the facilities.”*

#### - **Ideally in one fixed location**

One patient who had received therapy sessions described how they would often have to travel to different hospitals around Leeds and sometimes in Dewsbury to access their therapy. While they had their own form of transport, it felt inconvenient to have to go to different hospitals around the city that were a significant distance away from each other (such as Dewsbury and Otley), therefore ideally, therapy should take place in a fixed location for each patient.

*“For some of my appointments I had to drive over to Dewsbury but then one other time I went up to Otley...it’s not near my end (of Leeds) so harder for me to get to.”*

### **Key Points**

- Community venues such as religious buildings, charities or community centres should be utilised for patients who need to receive therapy away from home. These should also be close to the participants’ home.
- Each therapy session should be run in the same location to avoid patients having to travel to multiple venues away from their locality.

#### iii. **Staff**

**Thinking about the service you have received or may receive, what matters to you about the staff who treat you?**

#### - **Keeping the same therapists for patients**

Several participants felt *“fed up”* during their rehabilitation due to being assigned multiple different staff members, meaning that they would *“never speak to the same person”* about their condition. This was a common experience shared by participants in focus groups and was a highly negative aspect of the care they received, which also caused more stress for their family/carers, as they also needed to know how their

relative was coping during the rehab. It was therefore more difficult to talk to a therapist who had only started partway through the rehab.

#### - **Complaints from patients not followed up**

While patients' overall perception of staff in community hospitals was very positive, some patients we spoke to had negative experiences with staff that were not followed up by the hospital. When they had attempted to make a complaint, they received "no apology" or "nobody believed (them)". In this case, the mistake from the staff caused significant damage for the patient, stating they were "being set back two years" because of it. More accountability needs to be held towards individual staff in situations such as this therefore, as it can have a long-lasting effect on both the patients' health and their trust towards the hospital. Complaint procedures should be shared and access to independent health advocacy, such as Advonet, should be promoted so that patients have somewhere to contact that is not associated with the health service.

*"I was moved into a private room and the nurses moved my bed and I was struggling to walk, and they didn't put the brakes on, so when I tried to get into bed the bed moved and I ended up on the floor. There was no apology."*

*"My physiotherapy was done by the team leader who put me back 2 years in my life because he did something to me I never wanted...there was no apology, I even told my consultant that it was due to this physiotherapist, and nobody believed me, he never once said I'm sorry. Because he was a team leader, nobody questioned him."*

*"I complained to departmental manager about negligence, but the hospital did not ring my family about what had happened."*

#### - **Addressing language barriers**

Patients who had English as a second language expressed that they would prefer to have their family members interpret for them in the hospital, mainly due to some being uncomfortable describing their situation to an interpreter or the interpreter speaking the wrong dialect.

*"Last time they got us an interpreter and I still had to help because the person spoke the wrong dialect."*

*"The patient may not feel comfortable with an interpreter and would prefer a member of family."*

Patients however found that services were reluctant to involve family members with interpreting, with one even feeling that the staff were "suspicious" of them whilst they were trying to help their family member who could not speak English.

*"I went to the session with my wife because she doesn't speak English, but sometimes I feel the staff are suspicious of me when I try and translate."*

Ideally, there could be befrienders in place from community organisations who can speak the patient's language and be there support the patient emotionally during their stay as well as communicating information to the doctors.

This is particularly important for neuro services as the condition can often cause those with good or reasonable English to forget their second language and only speak in their mother tongue. However, if this is not possible then staff members who are from the same background as the patient and can speak their language should be specifically assigned to treat that patient.

*“We as an organisation have been approached by quite a few vulnerable women who have stated that when they have been in hospital and seen by an Asian doctor who can relate to their language and culture then why do they not communicate to their patients in their mother language. Even though the doctors are unable to speak their mother tongue language but just to greet the patients breaks the ice, their fears, concerns and misconceptions.”*

Any leaflets or materials that are provided for the patient should also be printed in their first language both to make it easier to read for the patient and to provide reassurance that their needs are being met.

### **Key Points**

- It is vital that patients' therapists are not switched as this has a negative impact on patients both physically and mentally.
- While thoughts on staff are overall positive, complaints from patients about individual staff members need to be followed up and addressed more effectively.
- Offer patients independent advocacy services such as Advonet to help address any complaints
- Language barriers could be addressed by allowing family members/carers to interpret for patients. If this is not possible, then patients should be assigned befrienders or doctors who are from the same background and/or speak the patient's language. Any materials given to the patient should also be translated.

#### **iv. Discharge**

- **Would you benefit from a Final Review once your therapy had finished?**

Patients had varying preferences on what length of time they wanted to have a final review. However, a more unanimous view was that having a 'final review' was seen as negative for patients, as it meant that it would then be more difficult for them to get back into treatment if their condition suddenly changed. Instead, participants wanted to still be able to stay in touch with the service after the review, with the option for regular check-ups or details on how to access peer support groups.

Some felt that the lack of any follow-ups brought the overall service down, with those who had positive experiences of community neuro services soon becoming disappointed once they had been discharged.

*“After the 6 weeks intervention, which was excellent. It felt like I was thrown out with no support.”*

*“I don’t think there should be a ‘final’ review it means that they are getting rid of you and then you have got to deal with it yourself and I struggled with that, meaning I missed out on treatment.”*

*“I think it’s very important to remember that rehabilitation never finishes - it is an ongoing process.”*

#### - **Keeping an updated written record of neuro conditions**

A common, negative aspect of using the services was that patients would often have to explain their condition to every new GP, nurse or doctor that they encountered. Due to the complexities and trauma involved in their condition, this was a *“frustrating”* aspect for patients and left them vulnerable to having their condition *“brushed over”* by the doctor and not taken seriously enough as it required a verbal explanation from the patient.

If the patients’ condition was kept regularly updated in writing and shown to the patient to make sure it matched how they felt, this would avoid patients having to re-explain their condition to doctors, easing the frustration and helping the doctor or nurse to understand their condition more clearly.

*“Needs to be written, detailed and able to show easily.”*

*“It gets frustrating having to repeat yourself even years on from the injury, which is traumatic even now...when I rung the doctor recently the first thing I tried to do was to notify the GP that I have a brain injury; he just brushed over it and didn’t seem to take it into consideration, talked really quickly and used words that I didn’t understand. and carried on the consultation regardless.”*

### **Key Points**

- Patients were disappointed that there was no follow-up from the final review and wanted to stay in touch with the services in case their condition worsened.
- An updated written record of the patient’s condition should be provided to avoid the *“frustrating”* prospect of the patient having to describe their condition to every new doctor/therapist they meet.

## v. Current Day Service

**Following a review, it has been identified that the day service is not clinically meeting patients' needs. Thinking about if/when you may have used the Day Service, what elements of the day service do you really value?**

### - **Helping the patient beyond their discharge**

As detailed above, patients who had left this service also felt that there should have been more guidance provided from the service for any next steps that the patient could take such as groups available, or any offer of further contact/support from the hospital if the patient's condition worsened.

*"6 weeks and if felt like "good night god bless", I never heard from them again."*

### - **Long waiting times**

Despite qualifying for rehabilitation on their records, several participants had not accessed the service due to the length of the waiting lists. Some had even been categorised as 'would benefit from neuro rehabilitation' but had yet to get a referral, which had even led one patient to switch to a private therapist instead to gain the rehab required.

### - **Positive experiences with the staff at St Mary's Hospital**

Those who had used the day service at St Mary's hospital were positive about the staff who took care of them, which added to an overall positive environment at the hospital and ultimately a more comfortable rehab.

*"Staff talk to you rather than at you. They have more time to talk to you."*

*"You don't feel like you're in a zoo, when you're in a hospital there's always someone taking your bloods etc. When you're in St Mary's you feel like you're there to receive help. It's not a surgical place it doesn't look like a hospital."*

This could therefore imply that the issues with the day service stem from the accessibility and communication issues described above, rather than with the care received in the hospital, meaning that those aspects should be given more focus meet patients' needs.

### **Key Points**

- More contact should be kept with patients following their discharge so that they can continue to improve once out of the hospital
- Waiting lists are often years long for patients despite them being recorded as 'would benefit from neuro rehab', therefore, funding should be put in place to make sure waiting times are cut down or that patients can stay informed whilst they are waiting



- Patients were positive about the level of staffing received in St Mary's, implying that the above aspects were a bigger contributor to the day service not meeting patients' needs

## vi. Managing your own condition

### What would help you self-manage your condition in between therapies and treatment from the service?

#### - Communicating more closely with carers/family members

From experience, patients had felt that family members/carers weren't given enough involvement and information about the patient's condition. This was an important aspect as the nature of the patient's condition made it harder for them to process information they were given, whereas a family member who was in a more stable condition could remember and remind the patient about it so that they could stay informed.

Therefore, any updates and information provided to a patient also need to be given to their designated carer/family member to ultimately provide the patient more understanding and someone to speak to if they ever forget anything that the doctor has told them.

*"It's all fair and good telling me exercises but I won't remember - it's my wife they need to show."*

#### - Access and awareness of peer groups

Patients who had accessed peer groups felt they were hugely important for their mental wellbeing, giving them an environment where they could express their difficulties and feel understood.

The main negative of these peer groups however was that patients had not been made aware of them during their treatment, instead having to look for the groups themselves rather than being signposted by the hospital. Hospitals therefore need to be more proactive in linking up with community groups and organisations to help signpost patients to peer support groups so that it eliminates the difficulty for patients having to look themselves.

*"Going to a group saved me really, being with people in the same boat."*

*"There was a group in the hospital I was staying but I was never told about it...I found out by asking people there."*

## - Advice Line

Due to a lack of familiarity with online services, or the added difficulty for those with neurological conditions, many felt that there could be a phone-line available for patients to access whenever they needed advice about managing their neuro condition. Some with neuro conditions preferred this option to peer groups as it would allow them to speak to someone “clinical” who had “information” that they could take on board, while peer groups cannot always provide this support.

Once participant acknowledged that this may be “unrealistic” to expect a phone-line to be set up and regularly available for patients. However, there was still a strong feeling that this would be highly beneficial and reassuring for patients who were still getting used to living with a neuro condition once leaving hospital.

*“The ability to speak to someone directly, clear communication is key.”*

Reception staff at St Mary’s were praised for offering support and advice over the phone and signposting people.

*“Even if they don’t know the answer they will find out and ring you straight back”*

## **Key Points**

- Family members/carers should be regularly informed about the patient’s condition and treatment, particularly due to the patient being unlikely to take everything in due to their condition.
- Patients need to be provided information by the hospital about peer groups available rather than having to look themselves.
- Due to technological barriers for neuro patients, an advice line would be easier for those looking to gain professional support while managing their condition.

## vii. Self-referral

### - Transparency about waiting lists

With the long waiting times required for patients referring to services, it would be useful if the hospital could communicate more effectively about what the situation was with a patient’s waiting time and the processes required before they can be admitted.

Communication from services was described as “really poor”, with patients not knowing why there was such a delay on them accessing the services despite it being recommended to them.

Some clarification and ultimately reassurance is therefore required from the services so that the patient can understand why they are given a lengthy waiting time for services.

*“Communication is really poor, I’m down as ‘would benefit from Neuro Rehabilitation’ but no-one’s following up on it. Might be down to staffing so they’re too busy to refer but I don’t know. If it is then there needs to be more time to communicate with the patient.”*

### - Self-referral through GPs

For many patients, a GP was the “*first point of call*” when they felt unwell and needed treatment. It was therefore suggested that the referral process should begin at the GP surgery, as it is a more familiar process for patients and saves them having to look online for where to go for a referral.

One participant also suggested that this could be made easier, explaining that an app called “check & book” is a good concept but never seems to work as intended. Therefore, more investment into this app could ease the referral process for patients wanting to go through a GP.

*“I’d like to be able to go to the GP and get referred...there’s an app you can do it on called ‘Check & Book’ - it’s good but it just never works though.”*

### - Range of options e.g. online, over the phone or in-person

When it comes to suggestions about what methods would be best for self-referral, participants generally felt that all options from the list should be available to them to cater to different patients. Some may be more comfortable with technology and looking online whereas others may find it easier to speak over the phone or face-to-face. If all these options are available, it would increase accessibility for patients wanting to self-refer.

*“Best to have a variety of ways for referring as strokes lead to a variety of sensory deprivations.”*

### **Key Points**

- If the waiting lists are long, then patients need to be informed on why the wait is long and what processes still need to be completed.
- Patients would like to be able to use their local GP to be referred to services.
- There should be a range of methods in place which patients can use to accommodate personal preferences and the different senses that are affected by different neuro conditions.

## viii. Spasticity Services

### If you have used or may use the service, what is important to you?

#### - Not wanting the Botulinum injection

We asked all 36 focus group respondents if they had accessed or might be eligible to access the service. Only two people had accessed it, while a few people who said that they might be eligible due to tightening of the muscles after stroke expressed that they “don’t want botox”.

#### - Not able to re-refer due to severity not being believed

Two people with MS who had previous experience of the service both tried to re-refer themselves, but felt that they were not believed that their spasms were severe enough because they had had a pump fitted.

*“They keep saying, you can’t spasm - you have a pump.”*

*“I have a pump too and my spasms are worse for some reason.”*

#### - Accessing the service

It was felt that the service is not promoted widely enough with eligible patients, with access still difficult even if you have been advised that you would benefit from the service.

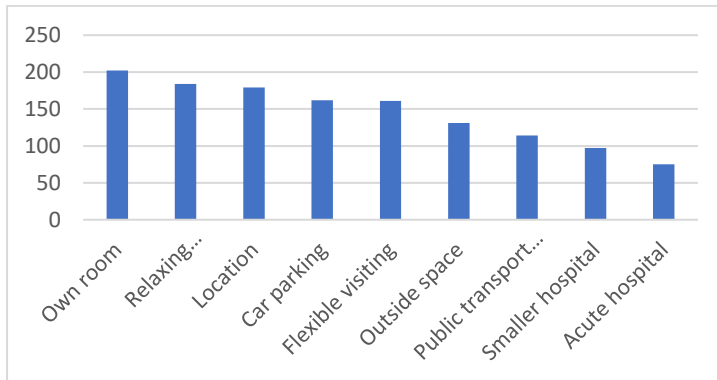
*“I only heard about this from Sarah my physio.”*

*“I was told I needed botox. They put it in your tummy. I’ve not heard anything since.”*

## Survey Responses breakdown

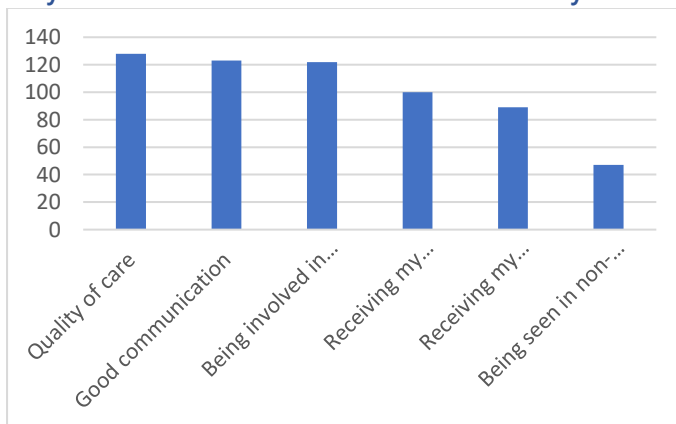
The following section breaks down the responses for each question on the Community Neuro survey, with results ranked in a graph and compared to the responses collected during focus groups.

### Q2) What is important to you if you have to stay overnight in a health care setting?



Having their own room was considered the most important aspect for patients, with ‘relaxing, comfortable environment’ placing second. However, it did seem that this particular aspect was too broad, as it could encompass features such as ‘Own room’, ‘Outside space’ and ‘smaller hospital’, which participants had outlined in our focus groups as being important in making them feel safer during their stay. Location was also very close behind this factor in 3<sup>rd</sup>, with a score difference of only 5, whilst ‘Car Parking’ and ‘Flexible Viewing’ only had a score difference of 1, making a strong case for the top five options in the list to be highly prioritised during this service.

### Q3) Thinking about the service you have received or may receive, what matters to you about the staff who care/treat you?



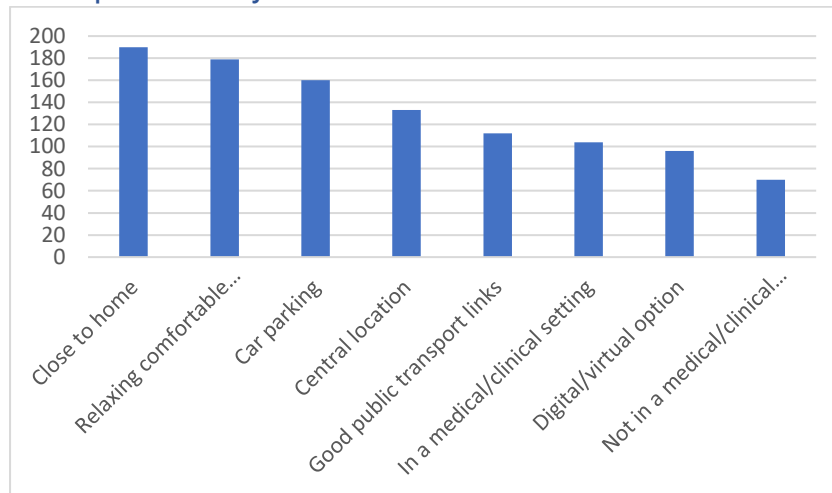
The free text responses saw one participant mention “*being kept informed about what is happening to me, in terms of treatment and hospital stay, preferably with at least approximate timescale.*”, reflecting, as described in the focus groups, that transparency from staff is important for patients in the hospital to build a sense of trust.

This can also match up with ‘**Good communication**’; considered to be the second-most important aspect for patients from the options listed.

However, the top option ‘**Quality of care**’ once again seemed too broad, as many of the other options in the list can fall under other aspects in the list such as ‘**Good communication**’ and ‘**Receiving my therapy/care from a range of different staff with appropriate skills**’.

The free text responses also saw one participant claim that is it “*Important for you to be involved and a two-way conversation*” which, combined with the above rankings, implies that the main aspects patients value in staff is transparency, flexibility, a range of skills and the same therapist for every session.

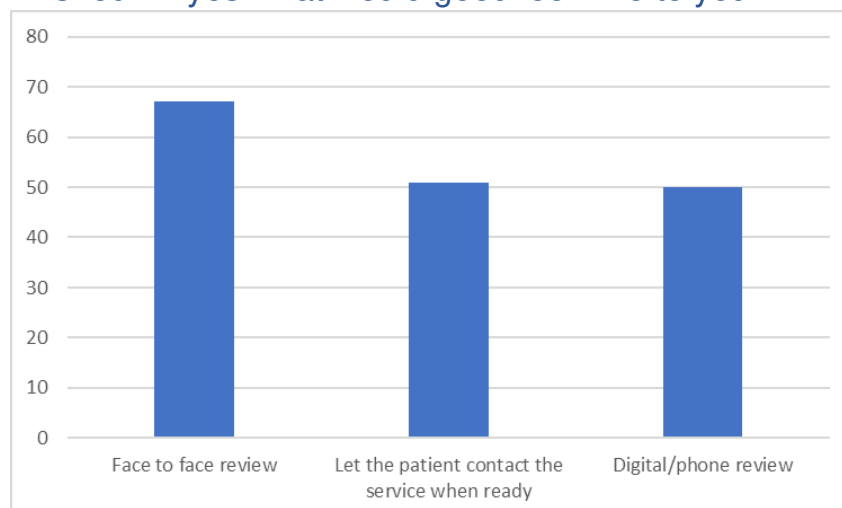
#### Q4) Location - If you were unable to receive your therapy at home, what would be important to you from an alternative venue?



As with our focus group responses, patients receiving therapy away from home wanted to do so in a place close to where they lived that was relaxing and accessible (good car parking and transport links). The free text responses echoed this, stating “*the less distance the better*” and mentioning “*good transport links*” as a must due to being unable to drive.

Participants in focus groups stated that community setting such as religious buildings, charities and community centres would be their preferred option for these visits due to their locality and familiarity to patients, while nursing homes were also mentioned again due to their locality and the medical equipment available there.

#### Q5) Discharge - Would you benefit from a final review once your therapy has finished? If yes what would good look like to you?



The above results were weighted slightly towards a face-to-face review, reflecting how neurological conditions impact a patient’s ability to use digital technologies. However, this result wasn’t particularly conclusive, with only scoring 16 and 17 more than the two other options in the list.

Therefore, it can be suggested from these results that face-to-face reviews should be the default option, but with digital/phone offered as an option if the patient wishes and to let them get in touch when they are ready.

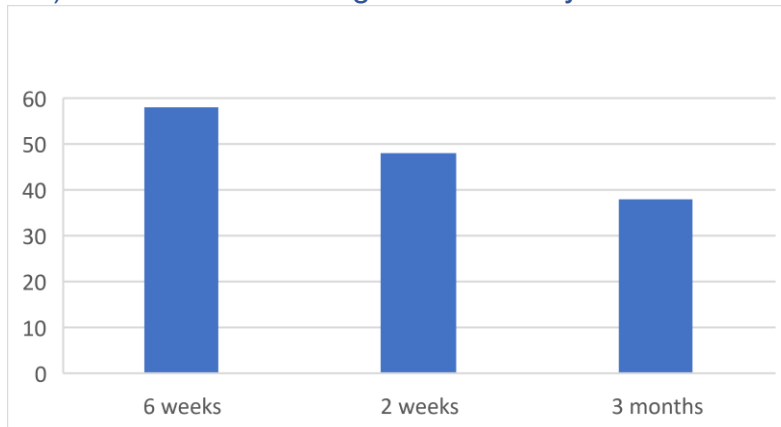
### Q6) If you wouldn’t benefit from a review following discharge please explain why below

Only three participants answered this question, with one contradicting it by asking “*why wouldn’t a person want a review (?)*” describing it as “*essential*”.

The other responses meanwhile echoed the sentiments described in our focus groups that a ‘final review’ is negative due to its implications that the patient will not receive any more help following a review despite still requiring it. Therefore, a final review was described as “*not needed*” and participants instead want to “*clarify what more they can do*” once they are discharged.

Therefore, as with the focus group responses, a strong suggestion for final reviews is that the patients are kept in touch with the service in case they need more help such as information about peer support groups and advice about managing their condition.

### Q7) When would be a good time for your review after discharge?



The responses to this question displayed a slightly significant preference towards a 6 week wait for patients to have their review. Our focus groups displayed a more varied response to this question, with stating that having a ‘final review’ felt like they were being cast aside by the service, suggesting alterations such as giving patients multiple reviews over a number of months or keeping them in touch with the service following the review, so they have the option to return if their condition becomes worse.

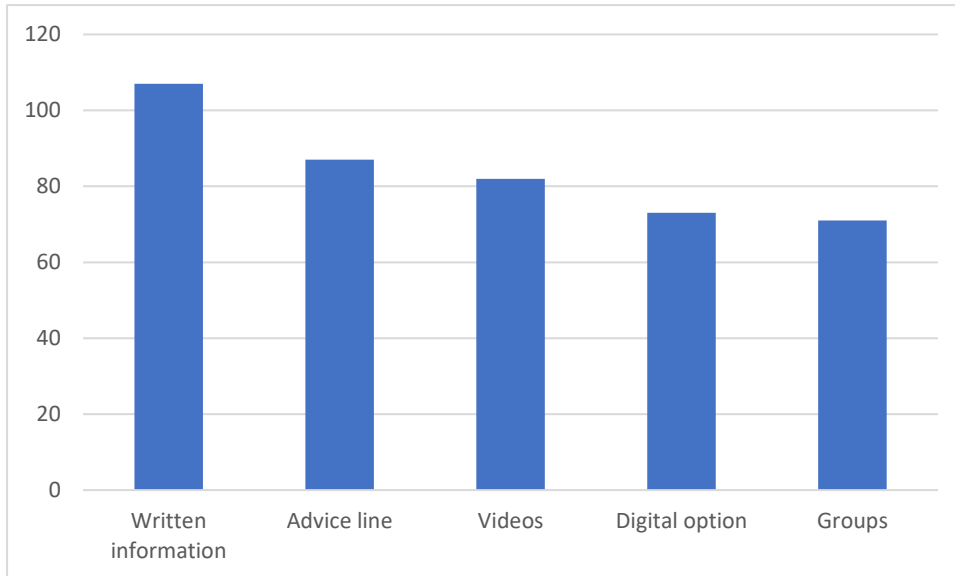
### Q8) Thinking about if/when you may have used the day service, what elements of the day service do you really value?

For those that had used the service, “*flexible appointments*” such as “*being seen in your own home*” or a “*mix of home and hospital therapy*” were important aspects, which again relates to providing patients with more choice. Transport related issues such as “*good parking*” and “*The location*”, were also mentioned, with one participant mentioning that there was “*lots of time wasted travelling to and from treatment, making patients very tired and frustrated*”. This

perhaps also re-emphasised the need for flexible appointments as this could make the parking and location less of an issue.

One participant also mentioned their dissatisfaction with the referral process, stating that they hadn't been able to refer to the service through their GP as they were *“unable to do so”*, which also echoes comments returned in our focus groups that the waiting lists for referrals were often years long and that ideally, they would like to use the GP to refer to the service.

### Q9) What would help you self-manage your condition in between therapies and treatment from the service?

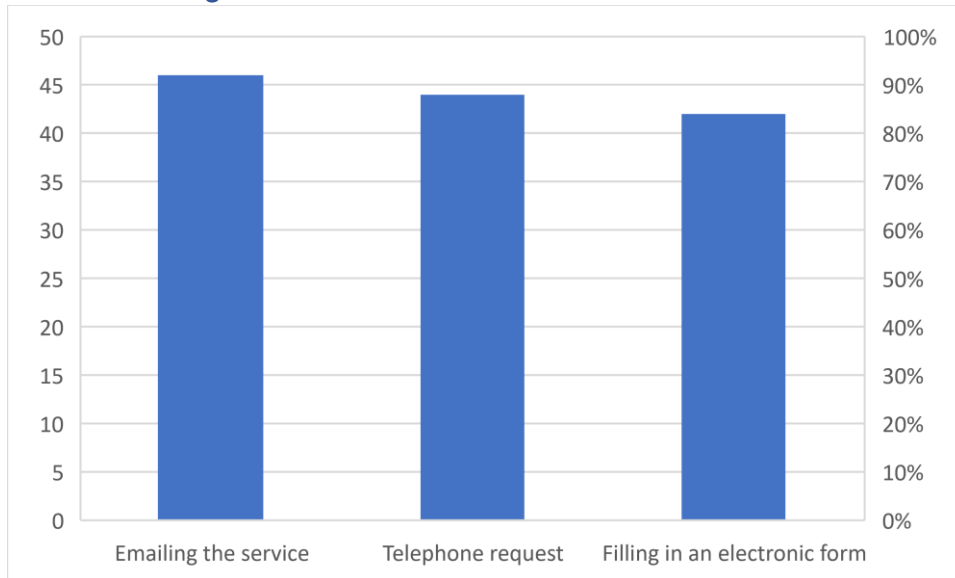


‘Written Information’ such as books and leaflets was considered the most useful option, with an advice line being second, closely followed by videos. This was also echoed during focus groups, where participants felt an advice line was something they would use if they had a concern and wanted to speak to someone for professional advice.

It should be emphasised however that the other aspects, especially groups, should still be promoted to patients as ways that they can manage their condition, with participants in focus groups talking about how valuable they found peer support groups and would have like to have found out about them whilst they were in the hospital.

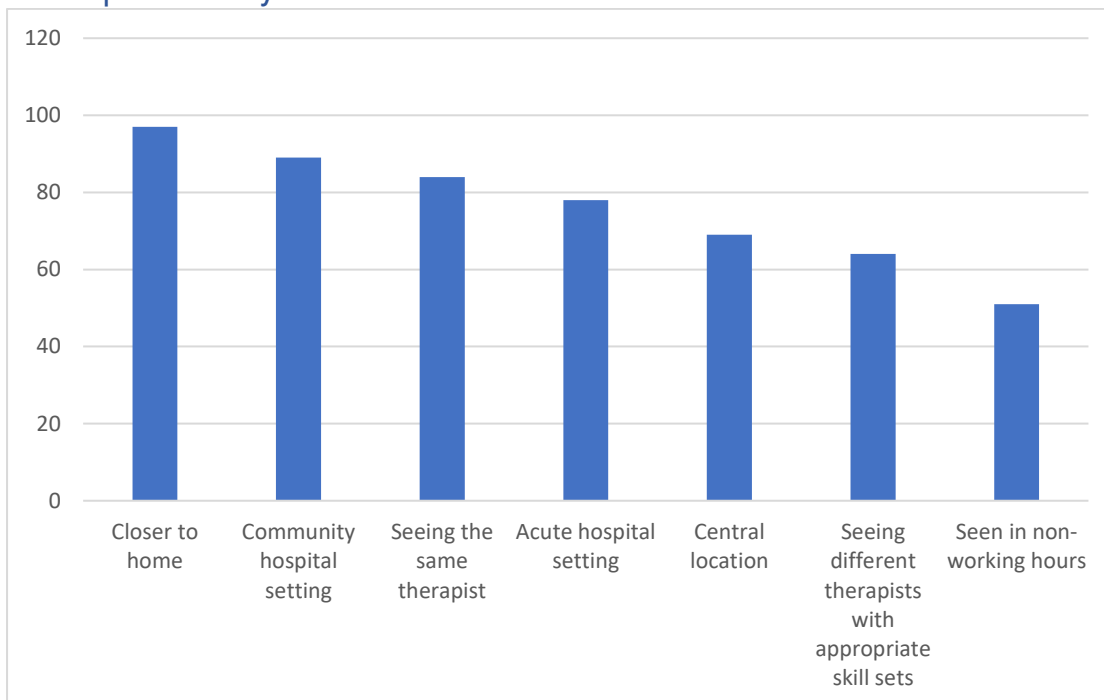


Q10) Self-referral: What would make it easy for you to return to the service once discharged?



The differences between these responses were minimal, implying that all options should be considered and echoing the view collected during focus groups that it would be “best to have a variety of ways for referring as strokes lead to a variety of sensory deprivations.”

Q11) If you have used or may use the spasticity service, which of the following are important to you?



The main theme from the answers to this question appears to be ‘familiarity’, with patients preferring a hospital that is close to home, in a community setting with the same therapist for all their sessions. This would save them time spent travelling, with a setting that is smaller and less busy with a therapist that they are familiar with and can trust to recognise any changes in between sessions.



It can therefore be recommended from these responses that Spasticity Services should take place in community hospitals close to the patient's home, with the same therapist used for all of their appointments.

## Appendix A - Details of Focus Groups

<u>Date</u>	<u>Organisation/Event</u>	<u>Location</u>	<u>Type of session</u>	<u>Priority group</u>	<u>Numbers achieved</u>
<b>1<sup>st</sup> Aug</b>	<b>Leeds Pride</b>	<b>City Centre</b>	<b>Market Stall</b>		<b>0</b>
<b>Tues 7<sup>th</sup> July</b>	<b>Circles of Life Women</b>	<b>Zoom</b>		<b>South Asian Women</b>	<b>4</b> Women – 4 South Asian – 4 26 – 35 – 1 36-45 – 1 46 – 55 – 2 – 3 Stroke/MS
<b>Sat 17<sup>th</sup> July</b>	<b>Beeston Farmers Market</b>	<b>Cross Flats Park</b>	<b>Market stall</b>	<b>LS11 / South Asian</b>	<b>1</b>
<b>Tues 20<sup>th</sup> July</b>	<b>Circles of Life men</b>	<b>Zoom</b>	<b>FG</b>	<b>Men, mixed/ South Asian</b>	<b>6</b> Men – 5 Women – 1 White British – 3 South Asian – 3  Lupus Neuro?
<b>Fri 6<sup>th</sup> Aug 12.30 - 2</b>	<b>Different Strokes</b>	<b>Armley Leisure Centre FG</b>	<b>FG – in person</b>		<b>11</b> Focus group  2 carers  <b>5</b> - Surveys
<b>Monday 23<sup>rd</sup> August 2pm Canceled</b>	<b>Leeds Brain Tumour Society</b>	<b>On-Line Time: Aug 23, 2021 01:45 PM London</b>  <a href="https://us06.web.zoom.us/j/82764211575">https://us06.web.zoom.us/j/82764211575</a>	<b>FG</b>	<b>Canceled</b> Hi Claire, - Really sorry, we have so much going on in September as we are launching all our new support groups, I just can't fit anything in sadly.  Best Wishes,  Marie	

<u>Date</u>	<u>Organisation/Event</u>	<u>Location</u>	<u>Type of session</u>	<u>Priority group</u>	<u>Numbers achieved</u>
				Marie Peacock   Chief Executive Officer	
Tues 24 <sup>th</sup> Aug 1-2	The Stroke Association	Zoom	Use Brogans link		6 Mix of men and women and ethnicities. 5 stoke survivors. 1 carer.
26 <sup>th</sup> and 30 <sup>th</sup> Aug	Open sessions	Zoom	Rearranged 8 <sup>th</sup> and 16 <sup>th</sup>		
8 <sup>th</sup> Sep 6pm	Giving Voice Choir				1 X1 white male
8 <sup>th</sup> Sep 12.30-1.30 & Thursday 16 <sup>th</sup> 6.30-7.30	Open Session				1 person did 121 with LHA
Visited group 14th July to get interest.  21/09 2pm on Zoom	MS Society				X3 Women
	Leeds Parkinsons Uk Group Meeting	Email sent and phone calls over Aug and Sep.			Rang twice and emailed—no response
Friday 17 <sup>th</sup> 6.30 – 8.30	Leeds United Disability Sport		10 mins to talk to group and then 121 interviews		Spoke to whole group, in detail chat with 1 person, no

<u>Date</u>	<u>Organisation/Event</u>	<u>Location</u>	<u>Type of session</u>	<u>Priority group</u>	<u>Numbers achieved</u>
Sikh Centre					people with Neuro condition wanted to take part. 0
	Individuals Carl Randolph Bev Rachel				2
Dropped in x2 sessions Sep	Hamara – older men's group (has a few people with Neuro Conditions)	In person either 121s or FG– but has to be outside	Visited 26th		1 South Asian Male carer
	William Merit  Sent 10 Surveys and poster to up at the centre		Surveys posted – 6 <sup>th</sup> (maybe visit to pick up?)		Rang 20/9 – none to return  0
Possible 121s	Carers Leeds				
Ongoing	Members of public 121 survey/chat				Original list of people who expressed an interest were set the online survey and information about the open FG sessions.

## Appendix B – Focus Group Graphic Questions

### Focus Group Discussions The Community Neurological Rehabilitation Service Review

**1** What does a good over night stay look like to you?

- Location of the hospital
- Flexible visiting
- Public transport links
- Car parking
- Relaxing comfortable environment
- Outside space
- Your own room
- Anything else
- A smaller hospital
- Acute hospital

**2** Staff  
Thinking about the service you have received or may receive, what matters to you about the staff who care/treat you?

- Receiving my therapy/care from the same therapist/nurse
- Receiving my therapy/care from a range of different staff with appropriate skills
- Good communication
- Being involved in your care
- Quality of care
- Receiving my therapy/care in non-working hours
- Anything else

**3** Location  
If you were unable to receive your therapy at home, what would be important to you from an alternative venue?

- Close to home
- Car parking
- Relaxing comfortable environment
- Digital/virtual option
- Anything else
- Central location
- Good public transport links
- In a medical/clinical setting
- Not in a medical/clinical setting

**4** Discharge  
Would you benefit from a final review once your therapy has finished?

No  Yes

A final review happens after you have input from the service

Let the patient contact the service when ready

OR

After 2 weeks  
6 weeks  
3 months

Digital/phone review  
Review in non-working hours  
Face to face review

What would a 'good' final review look like?

Is there anything else that would make your discharge and final review better?

## Appendix B (cont.) – Focus Group Graphic Questions

### 5 Improvements to day service

Following a review, it has been identified that the day service is not clinically meeting patient's needs. Thinking about if/when you may have used the Day Service, is there anything that you would still like to see?

**Current Day Service**

### 6 Managing your own condition

What would help you self-manage your condition in between therapies and input from the service?

### 7 Self Referral

What would make it easy for you to return to the service once discharged?

### 8 Spacicity Service

Which of the following are important to you?

The Spacicity Service is a city wide service to address severe muscle spasticity: interventions includes injecting botulinum toxin into the muscles as well as therapy support and guidance

## Appendix C – Patient Journey example

