

Report to Adults, Health and Active Lifestyles Scrutiny Board: 5th October 2021

Title of report:	An update on the Community Neurological Rehabilitation services engagement and redesign
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Presenters:	<p>Helen Knight, Head of Service (Clinical) for Neurology & Adult Speech and Language Therapy, Leeds Community Healthcare NHS Trust</p> <p>Gillian Meakin, Service Development Lead – Business, Change and Development Service, Leeds Community Healthcare NHS Trust</p>

BACKGROUND

Colleagues from the Leeds Community Healthcare attended a Scrutiny Board Working Group on 26 April 2021 to inform the Board of its plans for patient, carer, staff and stakeholder engagement as it develops a new model of delivery for community neurological rehabilitation services.

A further update paper was sent to Scrutiny Board members in June to update on progress against the engagement plan and provide referral and activity data as requested by Board members.

Based on discussions had at the 26th April meeting, members wished to receive a further update on the neuro rehabilitation engagement and redesign, later in the year, to provide an update on the engagement and findings thus far, to allow an opportunity for feedback from members on themes identified to date.

AN UPDATE ON THE COMMUNITY NEUROLOGICAL REHABILITATION SERVICES ENGAGEMENT AND REDESIGN

1. Update on staff engagement

1.1. Between March and June, staff engagement was undertaken on the current interim offer (**appendix 1**) and what a future offer might include, looking at clinical evidence as well as patient, carer and family feedback to draft proposed options for the new service model. Staff engagement concluded:

- The Home First model is supported by staff
- The service needs to be more responsive in general and also an urgent/rapid response offer needs to be included in the new service model
- There are patients that are not appropriately managed by the old and current interim service model
- The service needs to accept referrals that require specialist rehabilitation from only one discipline
- Inpatient demand is not fully understood however it is evident that there are patients who require this setting to meet their rehabilitation needs
- Self-management needs to be embedded within the service offer and support a robust self-re-referral pathway
- The service needs to provide rehabilitation over a defined period of time and patients discharged in a timely manner which will support the flow of patients coming into the service

1.2. To focus on some of the areas above, working groups were established to explore these areas further to then support and inform demand and capacity work. The aim of all the groups was to work up a pathway, including criteria, and begin to identify demand and resource that would be required to meet this specific pathway. These working groups ran throughout July and in August a detailed review of the outcomes of the working groups was undertaken to ensure sufficient information was available to support the next steps. In some instances, further work was identified which was completed through August and September. These working groups included the following:

Response pathways

- 48 hour response pathway – exploring how the service can build on and expand the successful Community Neurological Discharge Team
- 2-4 week response pathway – to identify criteria and cohorts of patients that require this level of response and understand demand for this pathway. This would be a timeframe within which the patients would access the service. The rehabilitation offer and the resource required to deliver this will be worked up through the other pathway work.

Clinical Pathways that fit outside the core standard offer:

- Transition Pathway
- Functional Neurological Disorder
- Dietetics
- Vocational Rehabilitation
- Psychology

2. Update on stakeholder engagement

2.1. Via focus groups and a survey monkey questionnaire, 162 stakeholders/staff from across organisations, primary care and third sector were engaged with. However, it must be noted that there will be duplication across the survey monkey and focus groups as some staff will have contributed to both. With this in mind the breakdown of engagement was:

- 117 completed survey monkeys
- 45 attended focus groups

2.2. There were some strong themes that came out from stakeholders about what they felt was important for a community neurological service to offer. These include:

- 1) A service that has the ability to provide a rapid response to a referral when clinically indicated (e.g. timeframe of 48 hours to 5 days)
- 2) A Service that has the ability to respond to a referral in a timeframe that appropriately meets patients' needs
- 3) A service that is able to provide the level of intensity that a patient requires to meet their rehabilitation goals
- 4) A service that provides specialist rehabilitation in the patient's own home
- 5) A service that provides coordinated Multi-Disciplinary Team (MDT) interventions
- 6) A service that has Speech and Language Therapy (SLT) embedded within the MDT
- 7) A service that accepts patients that require specialist rehabilitation from only one discipline
- 8) A service that has clear easy referral process potentially utilising electronic methods
- 9) A service that provides clarity around criteria and offer

2.3. 50% of stakeholders indicated that provision of inpatient rehabilitation is a key element of a community neurological rehabilitation service however there was minimal specific free text comments around this element. Stakeholders also stated that provision of an episode of care (rehabilitation delivered within a defined timeframe) model was less important than the key elements outlined above.

2.4. There were 2 key themes that came out specifically through the focus group sessions:

- 1) IT - how IT systems currently impact on services effectively communicating with each other. Leeds Community Healthcare NHS Trust (LCH) staff highlighted that how the IT system is set up currently creates duplication and if it was set up differently this would improve how patients are effectively managed across LCH services.
- 2) How the service provides specialist support and advice to other services. Suggestions included having a point of contact within the service, having open and honest conversations around which service best meets the needs of the patient at that time and potentially offering joint visits.

3. Update on patient and carer engagement

3.1. Since attendance at the April Scrutiny Working Group meeting, engagement activities as outlined to members for Community Neurological Rehabilitation Services have been progressed.

3.2. Our plan for engagement was agreed by CCGs Patient Advisory Group in June. Since then, patients and carers have been engaged with via:

- A survey (appendix 2) which was distributed to patients within services and promoted via LCH/Leeds CCG websites/communications and social media routes. To date, 29 surveys have been completed. An easy read version of the survey (appendix 2) was also created for patients and carers.
 - Focus groups led by Leeds Voices. To date, 32 people have participated in focus groups.
- 3.3. Survey and focus group questions were designed to allow/focus on the areas that patients and carers can influence, focusing on the overnight stays for inpatient rehabilitation, staff, location of service delivery, patient discharge from the service, patient self-management, self-referral and spasticity services.
- 3.4. At the time of submitting this paper, survey responses have closed however there are still some outstanding focus groups to be held in the latter half of September. Key themes to date emerging from patient and carer engagement aligned to the question areas are summarised below:

General feedback

- Those that had accessed the service were complimentary and provided positive feedback from their experience
- Feedback specifically mentioned the kindness and patient centred approach

Waiting times

- Due to the long waits patients are not referred to the service and some patients have sourced private physiotherapy as a result

Inpatient overnight stays in hospital/care setting

- For those requiring an inpatient stay, a community bed/setting/small hospital is most favourable setting – patient anxiety increased if located within a secondary care setting
- Inpatient rehabilitation stays could be reduced in length if appropriate intensity of therapies is provided (historically there are periods of time that is not utilised when patients are an inpatient)
- Inpatient stays should incorporate equipment that patients need to use/adopt, with demonstrations on how to use equipment

Staff Skills

- Staff need to be able to identify and manage hidden disabilities

Location of services, if care unable to be delivered at home

- For those requiring an inpatient stay, a community bed/setting/small hospital is most favourable setting – the setting should be close to home where possible
- Car parking and transport links must be considered carefully

- Location was not a priority for many people, more were concerned with the treatment they received

Patient Discharge from the service

- Rehabilitation never ends, patients should be able to self-re-refer into services if needed
- Patient and staff goals need to align
- Carers and family need to be involved in the final review process, as people with these conditions often have memory problems / articulation challenges
- 'Final review' appointment – feels too final and causes anxiety; this needs to be considered

Managing your own condition

- Peer support is highly important and needs to strengthen/be facilitated
- Language barriers and translation require focus, along with cultural considerations
- Support networks need to be promoted by professional staff to support access alongside signposting to these

Self-referral

- Digital routes for self-referral should not be provided in isolation
- Need to have clear guidance as to how to re refer after an episode of care has been completed

Carers

- Provision of information and training to carers is a key aspect to support continuation of rehabilitation
- Staff need to consider the importance of the carer in the process of rehabilitation and be skilled in supporting carers

In addition to the above themes, a strong reflection shared by patients and carers during the engagement is that people either love or hate the new digital delivery modes expediated as a result of the pandemic, i.e. online consultations. The new model needs to consider this.

4. Incorporation of the themes from the three areas of engagement into the developing model

4.1. This redesign is being undertaken within existing financial resources, and therefore a selection of options will be considered as the final service model is developed and agreed. The final model is not yet known with options to be debated and agreed during October via the Governance/Sign off approach outlined below. The very strong themes from this engagement which will be included within the model, include:

- The Home First offer is supported by staff and stakeholder groups and will remain a key element of the new model

- From staff, stakeholders and patients/carers feedback - the length of inpatient rehabilitation needs to be tailored to individual patient needs, with the home first approach and a more responsive community offer a reduction of inpatient beds is likely
- A route for self-referral into the service is essential for those known to the service
- To deliver a more responsive service in order to provide rehabilitation in the right place at the right time for the patient
- To be able to deliver the appropriate intensity of rehabilitation at the right time to meet patients goals effectively.
- Clear outline and criteria of what the Community Neurological Rehabilitation Service offers available to all stakeholders
- Speech and Language Therapy is embedded in the service
- To accept patients that require only one discipline to meet their specialist rehabilitation needs

As noted above it has been identified that there are patients that require inpatient rehabilitation and engagement has indicated that that this needs to be tailored to individual patients needs. However, demand analysis has indicated that less beds will be required due to the home first approach and a more responsive rehabilitation by the community offer. Further engagement is not planned around this however the views regarding inpatient rehabilitation delivery will be taken into account when discussing and agreeing the final model.

5. Sign-off of the model / governance

- 5.1. The patient and carer engagement formally closes on the 30th September. Engagement reports will be written and finalised within the first two weeks of October.
- 5.2. The developing model is to be discussed and debated by Executive team of LCH in the first two weeks of October, with a session also scheduled for the city's Leeds Long Term Conditions Board on the 12th October to consider the developing options and a very draft version of the proposal.
- 5.3. Options will be debated and considered during October, with a final decision on the model to be agreed mutually between Leeds Community Healthcare and NHS Leeds CCG by the end of October. The organisations executive teams will be engaged in the process. At this point a final Equality Impact Assessment (EQIA) will be completed on the final model.

6. Implementation

- 6.1. A phased implementation of the new model is expected from November 2021, with full implementation of the model in early 2022.
- 6.2. A 'You Said, We Did' report will published at this point outlining the new service model, and ongoing satisfaction from the service.

7. Conclusion

- 7.1. Scrutiny members are asked to note the significant engagement undertaken to date, and to reflect on the themes and the emerging priority areas which we aim to incorporate within the final model.

Appendices

Appendix 1: Community Neurological Rehabilitation Service Offer Details

<u>Service Offer Within Leeds (prior to COVID-19)</u>	<u>Service Offer in Leeds (as of 1st September 2020) – Interim Offer</u>
<ul style="list-style-type: none"> • Immediate Occupational Therapy intervention to facilitate earlier discharges from hospitals (patients who have sustained a Traumatic Brain Injury or Neuro Oncology condition) • Multi-disciplinary rehabilitation in a community setting i.e. care homes, leisure centre, community facilities – work place, educational facilities or healthcare settings • Regional inpatient 5 bed unit, based at St. Mary’s hospital, provision of multidisciplinary rehabilitation through planned short-stay admissions for those with complex neuro conditions. • Day-unit service for individuals who require more intensive multidisciplinary input than that provided in community settings. • Consultant-led clinics for assessment and management of spasticity. • Out of area referrals accepted (a small number per annum). 	<ul style="list-style-type: none"> • Home First offer • Implementation of new prioritisation criteria • Up to 6 sessions of each profession (as required) over 3 months (extended in cases of risk/safety issues in patient episodes – on an individual basis) • Inpatient unit at St. Mary’s not currently open to admissions • Priority patients / those waiting over a year are being prioritised • Pilot of new triaging role • <i>Spasticity and Review clinics</i> restarted at St. Mary’s Hospital – currently led by medics and only linking with therapists when an urgent/priority therapy need is identified. • All new patients have face-to-face appointments • For review and follow up appointments alternatives to face to face are considered (e.g. phone calls, video calls or face-to-face if required) • <i>Therapy Clinic</i> slots available at St. Mary’s Hospital where therapists are able to provide interventions that cannot be provided at home e.g. where environment that is not conducive to rehabilitation, or if a patient requires specific equipment. Clinic use is being reviewed as part of service review. • Out of area referrals redirected back to the referrer to explore alternative local services provided within the patients area or advise referral to Leeds Teaching Hospitals NHS Trust.

The Community Neurological Rehabilitation Service (CNRS) delivered by Leeds Community Healthcare NHS Trust has historically the following elements of service provision.

- *Community Neurological Rehabilitation Team (CNRT)* which aims to provide rehabilitation in a community setting. This can include within the home, leisure or community facilities, work place, educational facilities or healthcare settings. Within this remit, the team offers rehabilitation in order to optimise function, participation, quality of life and enhance independence.
- *Community Neurological Rehabilitation Centre (CNRC)* which is a regional inpatient unit that provides multidisciplinary rehabilitation through planned long-stay admissions (2 week blocks of rehabilitation) for individuals with complex needs due to a neurological condition who are medically stable. Additionally, the inpatient unit also offers a day service for those who require a more intensive input than what is available from the community facilities.
- *Community Neurological Discharge Team (CNDT)* within CNRS. This team has been running since January 2019 providing immediate occupational therapy input on discharge from hospital for patients that have experienced a traumatic brain injury. The team works alongside therapists and medics in Leeds Teaching Hospitals NHS Trust (LTHT) supporting and facilitating earlier discharge from hospital for this cohort of patients. They provide 8 weeks of intervention once the patient leaves hospital supporting the individual to reintegrate into society, return to work, provide rehabilitation and providing advice and support as the patient transitions to home life.

Appendix 2: Patient Engagement surveys

The following documents are appended as follows:

- Appendix 2a - Patient Engagement Survey
- Appendix 2b - Patient Engagement Survey – easy read version
- Appendix 2c - Voluntary Action Leeds patient and carer poster
- Appendix 2d - Voluntary Action Leeds – patient journey used within focus groups
- Appendix 2e - Voluntary Action Leeds – questions used to support focus groups

We want to involve you in redesigning the Community Neurological Rehabilitation Service (CNRS)

Background Information

The Community Neurological Rehabilitation Service (CNRS) is delivered by Leeds Community Health Trust. They provide 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 on the following page, 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. We are reviewing and exploring new ways of working to try and address the challenges.

The Teams

Community Neurological Discharge Team provide immediate Occupational Therapy which aims to improve a patient's ability to do everyday tasks to help with earlier discharges from hospital.

Community Neurological Rehabilitation Team provide rehabilitation in a community setting, this can include home, leisure or community facilities, workplace, educational facilities or a healthcare setting.

Community Neurological Rehabilitation Centre is the regional inpatient unit, based at St Mary's hospital which provides rehabilitation through planned short stay admissions and offers a day service for people who need more intensive input than is available in the community.

We are interested in hearing from everyone, even, if you haven't used the service as your views can help shape this development.

If you would like to be kept informed about the survey feedback we received please provide your contact details at the end of the survey. Your personal data will be stored securely in line with data protection rules and regulations.

**This survey closes on
10 September 2021.**

Please return this survey using our Freepost address:

Helen Butters CNRS Survey
FREEPOST RTEG-JRZR-CLZG,
NHS Leeds CCG, Suites 2-5 Wira House,
Wira Business Park, West Park Ring
Road, Leeds, LS16 6EB

1

I am filling in the survey as:

- Patient who has attended the Community Neuro Rehabilitation Service (CNRS)
- Patient who has not attended the CNRS
- A carer
- A member of the public

Other:

2

Hospital Stay

If you required rehabilitation in an inpatient setting what is important to you?

	Most important					Least important			
	1	2	3	4	5	6	7	8	9
Own room:	<input type="checkbox"/>								
Location:	<input type="checkbox"/>								
Car parking:	<input type="checkbox"/>								
Public transport links:	<input type="checkbox"/>								
Outside space:	<input type="checkbox"/>								
Smaller hospital:	<input type="checkbox"/>								
Acute hospital:	<input type="checkbox"/>								
Flexible visiting:	<input type="checkbox"/>								
Relaxing comfortable environment:	<input type="checkbox"/>								

Other:

3

Staff

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

	Most important			Least important		
	1	2	3	4	5	6
Receiving my therapy/care from the same therapist/nurse:	<input type="checkbox"/>					
Receiving my therapy/care from a range of different staff with appropriate skills:	<input type="checkbox"/>					
Good communication:	<input type="checkbox"/>					
Being involved in your care:	<input type="checkbox"/>					
Quality of care:	<input type="checkbox"/>					
Being seen in non-working hours:	<input type="checkbox"/>					
Other:						

4

Location

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

	Most important				Least important			
	1	2	3	4	5	6	7	8
Close to home:	<input type="checkbox"/>							
Central location:	<input type="checkbox"/>							
Car parking:	<input type="checkbox"/>							
Good public transport links:	<input type="checkbox"/>							
Relaxing comfortable environment:	<input type="checkbox"/>							
Digital/virtual option:	<input type="checkbox"/>							
Not in a medical or clinical setting:	<input type="checkbox"/>							
In a medical or clinical setting:	<input type="checkbox"/>							
Other:								

5

Discharge

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

If yes what would good look like to you?

	Most important 1	Least important 2	Least important 3
Let the patient contact the service when ready:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Digital or phone review:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Face to face review:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other:

When would you want a review after your input from the service:

2 weeks 6 weeks 3 months

Other:

If you wouldn't benefit from a review following discharge please explain why below:

.....

.....

.....

.....

.....

6

Current 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, what elements of the day service do you really value?

.....

.....

.....

.....

7

Manging your own condition

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

	Most important			Least important	
	1	2	3	4	5
Written information:	<input type="checkbox"/>				
Videos:	<input type="checkbox"/>				
Digital option:	<input type="checkbox"/>				
Advice line:	<input type="checkbox"/>				
Groups:	<input type="checkbox"/>				
Other:					

8

Self-referral

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

	Most important			Least important		
	1	2	3	2	3	1
Telephone request:	<input type="checkbox"/>					
Emailing the service:	<input type="checkbox"/>					
Filling in an electronic form:	<input type="checkbox"/>					
Other:					

9

Spasticity Service

Some patients with neurological conditions experience muscle spasticity: interventions include injecting botulinum toxin into the muscles as well as therapy support and guidance.

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

	Most important			Least important			
	1	2	3	4	5	6	7
Acute hospital setting:	<input type="checkbox"/>						
Community hospital setting:	<input type="checkbox"/>						
Closer to home:	<input type="checkbox"/>						
Central location:	<input type="checkbox"/>						
Seeing the same therapist:	<input type="checkbox"/>						
Seeing different therapists with appropriate skill sets:	<input type="checkbox"/>						
Seen in non-working hours:	<input type="checkbox"/>						
Other:						

Equality Monitoring

We deliver a wide range of services and we need to know who is benefiting from our services and who might be missing out. We would really appreciate you answering the questions below by ticking the boxes that you feel most describes you. Some questions may feel personal, but the information we collect will be kept confidential, secure and kept separately from any personal information you might have provided elsewhere.

Please tick here if you would prefer not to answer any of the equality monitoring questions.

10

What is the first part of your postcode (e.g. LS11, LS23 etc.)?

What is the second part of your postcode?

11

What is your age?

Under 16

56-65

16-25

66-75

26-35

76-85

36-45

86+

46-55

Prefer not to say

12

Are you disabled?

(The Equality Act 2010 defines disability as ‘a physical, sensory or mental impairment which has, or had a substantial and long-term adverse affect on a person’s ability to carry out normal day to day activities’.)

- Yes No Prefer not to answer

If yes, what type of disability? (tick all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Long-standing illness | <input type="checkbox"/> Visual impairment (such as blind or partially sighted) |
| <input type="checkbox"/> Physical impairment | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Learning disability | <input type="checkbox"/> Mental health condition |
| <input type="checkbox"/> Hearing impairment (such as deaf or hard of hearing) | |

Other:

13

What is your ethnic background?

- Prefer not to answer

White

- | | |
|--|-----------------------------------|
| <input type="checkbox"/> British (English/Welsh/Scottish/Northern Irish) | <input type="checkbox"/> Irish |
| <input type="checkbox"/> Gypsy or Traveller | <input type="checkbox"/> European |

Any other white background (please state):

.....

Mixed or multiple ethnic groups

White and Black Caribbean

White and Black African

White and Asian

Any other Mixed or Multiple ethnic (please state):

.....

Asian or Asian British

Indian

Pakistani

Bangladeshi

Chinese

Any other Asian background (please state):

.....

Black, African, Caribbean or Black British

African

Caribbean

Any other Black, African or Caribbean background (please state):

.....

Other ethnic group

Arab

Any other ethnic group (please state):

.....

14

Pregnancy and maternity

(The Equality Act 2010 protects women who are pregnant or have given birth within a 26 week period)

	Yes	No	Prefer not to say
Are you pregnant at this time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you recently given birth (within a 26 week period)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are you a parent or carer of a child or children under the age of five years old?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15

What is your religion or belief?

- | | |
|--------------------------------------|--|
| <input type="checkbox"/> Buddhism | <input type="checkbox"/> Christianity |
| <input type="checkbox"/> Hinduism | <input type="checkbox"/> Islam |
| <input type="checkbox"/> Judaism | <input type="checkbox"/> Sikhism |
| <input type="checkbox"/> No religion | <input type="checkbox"/> Prefer not to say |

Other:

16

What is your sexual orientation?

Bisexual (both sexes)

Gay man (same-sex)

Lesbian/gay woman (same-sex)

Straight/heterosexual (opposite sex)

Prefer not to say

Other:

17

What is your relationship status?

Civil partnership

Co-habiting (live with partner)

Divorced

Married

Single

Widowed

Prefer not to say

Other:

18

What is your employment status? (please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Student | <input type="checkbox"/> Student – at college |
| <input type="checkbox"/> Student – at university | <input type="checkbox"/> Employed – full time |
| <input type="checkbox"/> Employed - part time | <input type="checkbox"/> Apprenticeship/training |
| <input type="checkbox"/> Unemployed – looking for work | <input type="checkbox"/> Unemployed – unable to work |
| <input type="checkbox"/> Unemployed – not looking for work | <input type="checkbox"/> Retired |
| <input type="checkbox"/> Prefer not to answer | <input type="checkbox"/> In receipt of state benefits (e.g. Personal Independence Payment (PIP), Universal Credit (UC)) |

Other:

19

Carers

(A carer is someone who provides unpaid support/care for a family member, friend, etc. who needs help with their day to day life; because they are disabled, have a long-term illness or they are elderly.)

	Yes	No	Prefer not to say
Are you a carer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you have unpaid responsibilities for children as a parent/grandparent/guardian?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20

Would you describe yourself as homeless?

Yes No Prefer not to answer

21

What gender best describes you?

Woman (including trans women) Man (including trans man)
 Non-binary Prefer not to say

Other:

22

Are you transgender?

(Is your gender identity different to the gender you were given at birth?)

Yes No Prefer not to answer

Please share your contact details below if you would like to be kept involved in the project, receive a copy of the engagement report and to see what people have said.

Your details will be stored in our system securely for one year and will only be used for the above purpose and any updates regarding this project.

Your personal information will be kept separate from the answers and your response to the questions will be anonymous.

What are your contact details?

Please note that you do not have to fill in your personal details to complete this survey.

Your name:

Address:
.....
.....

Email address:

Telephone:

GP practice:

- If you would like to find out more about any future changes to your local health services please tick this box to join our community network (Please note: if you tick the box, we will be in contact with you shortly after the engagement has closed).

How did you hear about this survey? (please select one option):

- Social media CCG website
- Voluntary sector organisation NHS trust
- At an event (such as a drop-in event)

Other:

You have completed this survey!

Thank you for taking the time to answer this survey.

At the end of the consultation, all the replies and comments will be analysed and published in a report. This report will be used by NHS Leeds Clinical Commissioning Group to make decisions about the Community Neurology Rehabilitation Service in Leeds. Your views will also be used to help understand the needs of local people and how any service changes in the future could impact on Community Neuro Rehabilitation Service.



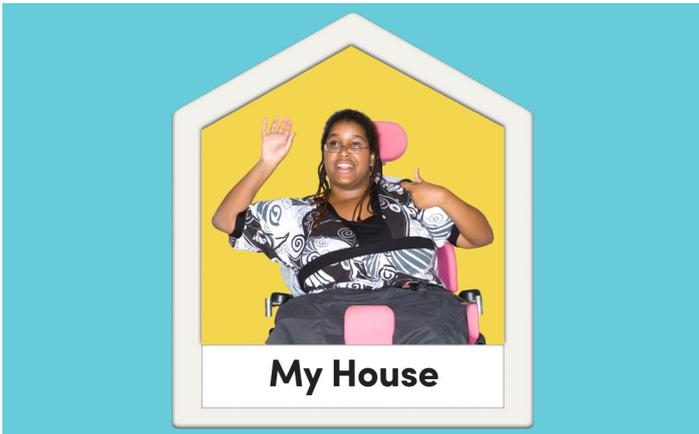
The NHS in Leeds want to involve you in changing the way the Community Neurological Rehabilitation Service (CNRS) is run.

Background Information



The Community Neurological Rehabilitation Service is called CNRS for short.

The service gives specialist support for adults in Leeds with neurological conditions like Multiple Sclerosis, Stroke and Parkinson's.



It also gives support to people who have had a trauma to their brain.

Rehabilitation is helping people to stay as independent as they can, so they can carry on living their lives.



Over the last few years more and more people have needed to use the service.

People have had to wait a long time for an appointment.



We are reviewing and looking at new ways of working to try and address these challenges.

The teams

There are 3 different teams and they work together to assess, plan and manage care.

They are:



Community Neurological Discharge Team

Works with patients to provide immediate Occupational Therapy.

This helps people with everyday tasks so they can be discharged from hospital earlier and go home.



Community Neurological Rehabilitation Team

Provides rehabilitation in a community setting.

This could be your home, workplace, community group, healthcare setting and so on.

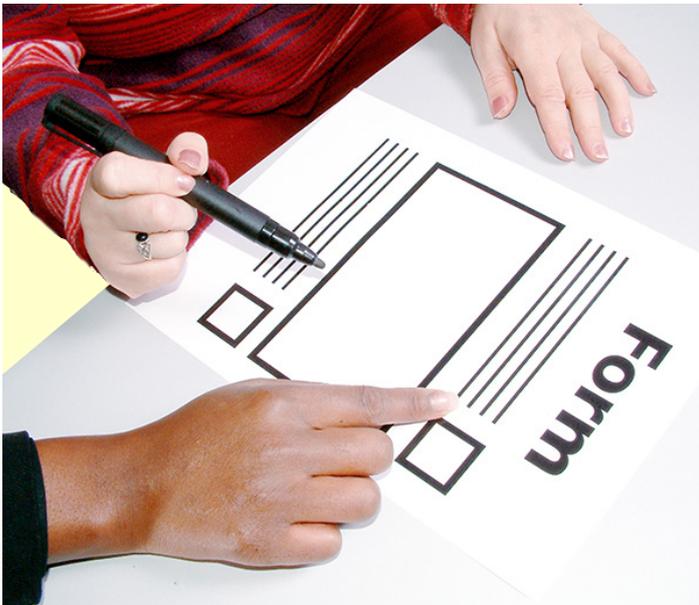


Community Neurological Rehabilitation Centre

This is the regional inpatient unit at St Mary's hospital.

It provides rehabilitation for anyone who might need more than can be offered in the community.

It offers a day service or short stays.



We are interested in hearing from everyone.

You don't have to have used the services before.

Your views can help us shape our plans.

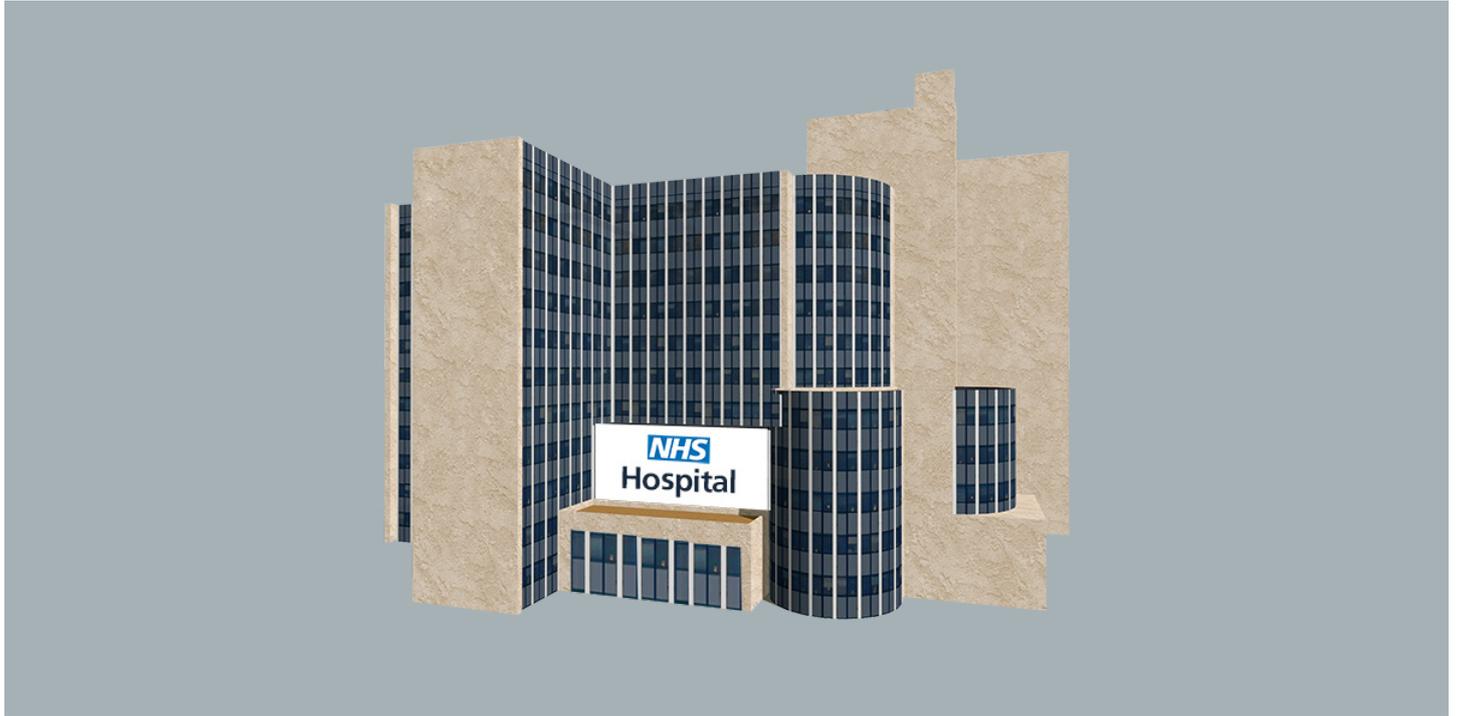


The survey closes on the 12th September 2021.

Please return the survey to

Helen Butters CNRS Survey
FREEPOST RTEG-JRZR-CLZG,
NHS Leeds CCG,
Suites 2-5 Wira House,
Wira Business Park,
West Park Ring
Road, Leeds, LS16 6EB

Please can you tell us a bit about who you are by ticking one of the boxes below:



- I have attended the CNRS
- I have not attended the CNRS
- I am a family member or carer of someone that has attended the CNRS
- I am a member of the public

• Other

1. Overnight stay in a healthcare setting



What is important to you, if you have to stay overnight, in a health care setting?

Please put the answers in order from 1 to 9 with the most important first.

For example if car parking is the most important to you put a 1 in that box and so on.

- The location of the healthcare setting

- Having your own room

- Car parking

• Being able to get there easily by public transport

• Outside space

• Location being in a smaller hospital

• Location being in a larger acute hospital

• Flexible visiting

• Relaxing and comfortable environment

• Other

2. Staff



Thinking about the service you have received or may receive, what matters most to you about the staff who care for and treat you?

Please put the answers in order, from 1 to 6 with the most important first.

For example if good communication is the most important to you put a 1 in that box and so on.

- Getting my therapy or care from the same therapist or nurse

- Getting my therapy or care from a range of different staff with the right skills

- Good communication

- Being seen in non-working hours, for example in the evening

- Being involved in your care

- Quality of care

- Other

3. Location



If you were unable to have your therapy at home, what would be important to you from a different venue?

Please put the answers in order with the most important first.

For example if a relaxing and comfortable environment is the most important to you put a 1 in that box and so on.

- A place close to where you live

- Central location

- Car parking

- Being able to get there easily by public transport
- Relaxing and comfortable environment
- Digital or virtual option, for example having a video call
- Not in a medical/clinical setting
- In a medical/clinical setting

• Other

4. Discharge

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

• Yes

• No

If yes can you tell us what would be most important to you by putting the answers in order.

For example if having a video or phone call is the most important to you put a 1 in that box and so on.

• Let me contact the service when I am ready

• Having a video or phone call

• Having a face to face review



Can you tell us when you would like the review?

• After 2 weeks

• After 6 weeks

• After 3 months.

If you don't want a review can you tell us why?

5. Current Day Service

Following a review of the service we have found out that it doesn't meet a patients clinical needs.

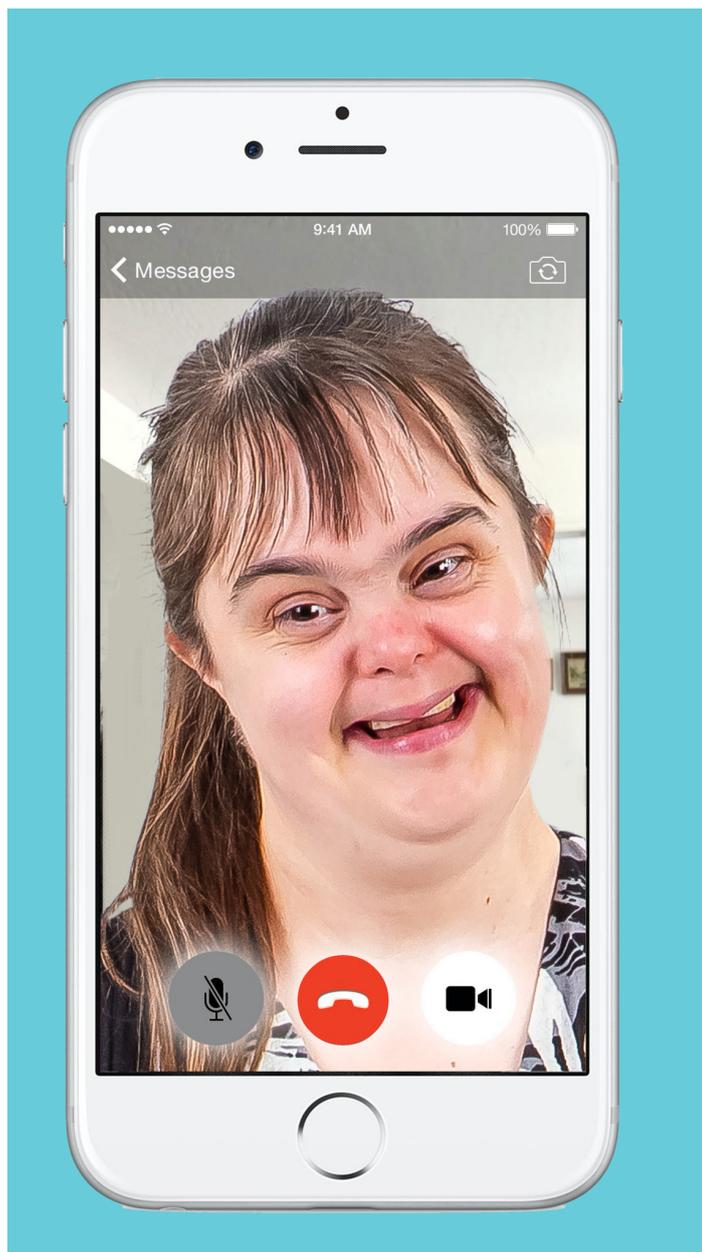
If you have used the service is there anything about it that you would like to say?

6. Managing your own condition

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

Please put the answers in order with the most important first.

For example if an advice line is the most important to you put a 1 in that box and so on.



• Written information

• Videos

• Digital option like video call

• Groups

• Advice line

• Other

7. Self-referral



What would make it easy for you to return to the service once you have been discharged.

Put the answers in order with the most important first.

For example if emailing the service is the most important to you put a 1 in that box and so on.

- Phoning the service

- Emailing the service

- Filling in an electronic form for example over the internet

- Other

8. Spasticity Service

This is a service that helps with severe muscle spasticity.

The treatments include injecting botulinum toxin into the muscles.

They also offer therapy support and guidance.

Which of the following would be important to you? Put the answers in order with the most important first.

For example if a central location is the most important to you put a 1 in that box and so on.

- Acute hospital setting
- Being seen in non-working hours, for example in the evening
- Community hospital setting
- A place close to where you live
- Central location



- Seeing the same therapist every time

- Seeing different therapists with the right skills

- Other

If you would like to receive a copy of the engagement report and see what people have said please fill in your contact details below.

Your details will be stored in our system securely for one year.

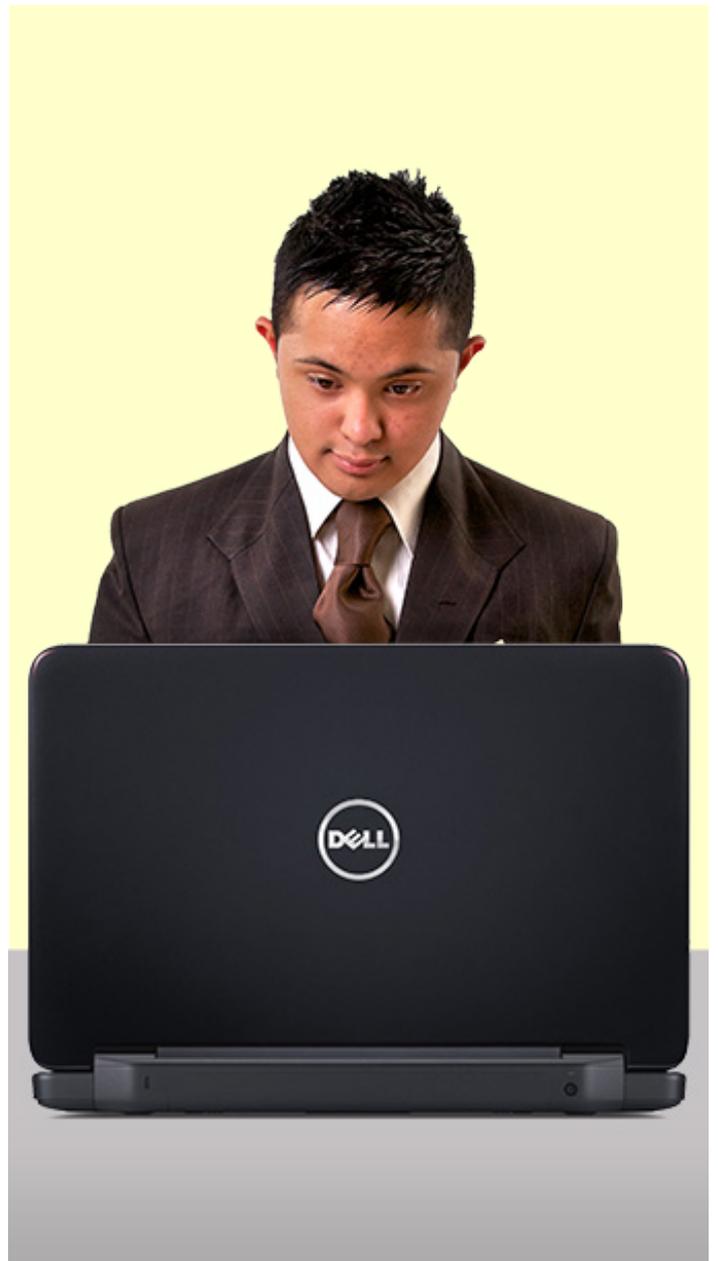
We will only use them for this project and to share anything we have found out.

Your personal information will be kept separately from your answers.

This means anything you say will be anonymous.

If you put any personal information in your answers, we cannot keep this anonymous.

You don't have to give us your contact details if you don't want to.



Name: _____

Address: _____

Email: _____

Telephone: _____

GP Practice: _____

We deliver a wide range of services and we need to know who is benefiting from our services and who might be missing out. We would really appreciate you answering the questions below by ticking the boxes that you feel most describes you. Some questions may feel personal, but the information we collect will be kept confidential, secure and kept separately from any personal information you might have provided elsewhere.

Please tick here if you would prefer to not answer any of the equality monitoring questions

I would prefer not to answer any of the equality monitoring questions

What is your postcode? E.g. LS12, LS13

What is your age?

- | | | | | | | | |
|--------------------------|----------|--------------------------|-------|--------------------------|--------------------------|--------------------------|-------|
| <input type="checkbox"/> | Under 16 | <input type="checkbox"/> | 16-25 | <input type="checkbox"/> | 26-35 | <input type="checkbox"/> | 36-45 |
| <input type="checkbox"/> | 46-55 | <input type="checkbox"/> | 56-65 | <input type="checkbox"/> | 66-75 | <input type="checkbox"/> | 76-85 |
| <input type="checkbox"/> | 86+ | | | | <input type="checkbox"/> | Prefer not to say | |

Do you consider yourself to be disabled?

(The Equality Act 2010 defines disability as 'a physical, sensory or mental impairment which has, or had a substantial and long-term adverse effect on a person's ability to carry out normal day to day activities'.)

- Yes No Prefer not to say

If yes, what type of impairment? (tick all that apply)

- Long standing illness
- Physical impairment
- Learning disability
- Mental health condition
- Hearing impairment (such as deaf or hard of hearing)
- Visual impairment (such as blind or partially sighted)
- Prefer not to answer
- Other (please specify):

What is your ethnic group?

Prefer not to say

White

- British (English, Welsh, Scottish, Northern Irish)
- Irish
- Gypsy or Traveller
- European
- Any other White background (please state):

Mixed or Multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed or Multiple ethnic (please state):

Asian or Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background (please state):

Black, African, Caribbean or Black British

- African
- Caribbean
- Any other Black, African or Caribbean background (please state):

Other ethnic group

- Arab
- Any other ethnic group (please state):

What is your sex?

- Female Male Other (please state):

Are you transgender? *(Is your gender different to the gender you were given at birth?)*

- Yes No Prefer not to say

Pregnancy and maternity

(The Equality Act 2010 protects women who are pregnant or have given birth within a 26 week period)

Are you pregnant at this time?

- Yes No Prefer not to say

Have you recently given birth (within a 26 week period)?

- Yes No Prefer not to say

What is your religion or belief?

- | | | | |
|--------------------------|-------------------------|--------------------------|-------------------|
| <input type="checkbox"/> | Buddhism | <input type="checkbox"/> | Judaism |
| <input type="checkbox"/> | Christianity | <input type="checkbox"/> | Sikhism |
| <input type="checkbox"/> | Hinduism | <input type="checkbox"/> | No religion |
| <input type="checkbox"/> | Islam | <input type="checkbox"/> | Prefer not to say |
| <input type="checkbox"/> | Other (please specify): | <input type="text"/> | |

What is your sexual orientation?

- Bisexual (both sexes)
 Gay man (same-sex)
 Gay woman/lesbian (same-sex)
 Straight/heterosexual (opposite sex)
 Prefer not to say
 Other (please specify):

What is your relationship status?

- Civil Partnership
 Co-habiting (live with partner)
 Divorced
 Married
 Single
 Widowed
 Prefer not to say
 Other (please specify):

What is your employment status (please tick all that apply)?

- Student – Further education (Sixth Form, College)
 Student – Higher Education (University)
 Employed - Full time
 Employed - Part time
 In receipt of state benefits (e.g. Personal Independence Payment, Universal Credit)
 Not in employment – Looking for work
 Not in employment – Unable to work
 Not in employment – Not looking for work
 Apprenticeship/training
 Retired
 Prefer not to say
 Other (please specify):

Are you a carer?

(A carer is someone who provides unpaid support/care for a family member, friend, etc. who needs help with their day to day life; because they are disabled, have a long term illness or they are elderly.)

- Yes No Prefer not to answer

Would you describe yourself as homeless?

Yes

No

Prefer not to say

Have your say on improving Community Neurological Services

Do you or someone you care for have a neurological condition which could include Stroke, Parkinsons, MS or Brain Injury?



We want to hear your views on the
Community Neurological Rehabilitation Service
in Leeds

This will help to reshape the service in the
best way for you.



£10

Shopping Voucher
for focus group

**We value your
contributions**

£5

Shopping Voucher
for telephone
survey

Email Leedsvoices@val.org.uk or fill in this [quick form](#) to
take part in a survey or focus group this summer.

A Patient Journey in The Community Neurological Rehabilitation Service pre COVID

'this example of a patient journey reflects a number of different peoples lived experiences of the service. It does not show one person's single journey'

Jozef is a 34 year old man who has experienced a Traumatic Brain Injury as a result of a car accident. Jozef lives with his wife and 2 daughters who are 10 and 8. He works full time as a manager of a small team.



*This example is different from what happens during Covid



Jozef is referred to the Community Neurological Rehabilitation Service (CNRS) by the hospital as he is being discharged home. He is physically mobile but is suffering with cognitive, memory and behavioral issues

The referral is picked up by the Community Neurological Discharge Team (CNDT) shortly before Jozef is discharged. One of the Occupational Therapists visits Jozef in hospital for an initial assessment. As part of the assessment they introduce themselves and they go with Jozef to the hospital coffee shop to observe how he copes.



Jozef is discharged 3 days later. The Occupational Therapist who saw him in hospital visits him at home the following day to start a full initial assessment and establish his therapy goals and any risks for him.

Together they make the following goals



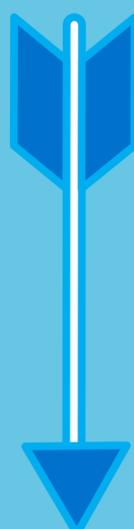
Jozef's goals are:

- 🎯 To be alone at home for a short period this includes keeping himself safe and being able to make drinks and snacks.
- 🎯 Helping bath children and put to bed,
- 🎯 To be able to take his children to school
- 🎯 To be able to look after children alone for approx. 2 hours
- 🎯 To be able to go to the local shop safely and manage to buy a small list of items.
- 🎯 A longer term goal for him is to return to work – this will require him to use public transport as he will be unable to drive for at least 6 months.



The CNDT immediately starts to work with him – They are only able to work on goals relating to Occupational Therapy as they only have Occupational Therapists and Rehabilitation Assistants in the team.

Jozef has Occupational Therapy visits 3 times a week for the first 2 weeks and then weekly Occupational Therapy visits and twice weekly Rehabilitation Assistant visits for the remaining 6 weeks. They work on his immediate goal and also provide education and advice for Jozef and his family (including the children) and link Jozef's wife in with Carer's Leeds for support.



At the end of 8 weeks Jozef has met the following goals:



- ✓ To be able to go to the local shop safely and manage to buy a small list of items
- ✓ To be able to look after children alone for approx. 2 hours
- ✓ To be able to take his children to school- this remains with the help of his wife
- ✓ Helping bath children and put to bed
- ✓ To be alone at home for a short period this includes keeping himself safe and being able to make drinks and snacks.

Jozef is more aware of his difficulties and he is more able to express these however he continues to struggle to accept and accommodate these difficulties.

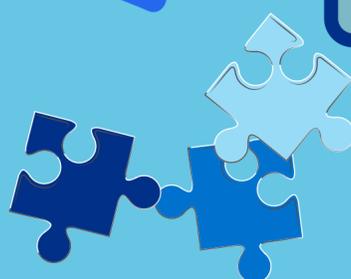
Outstanding goals for Jozef are:

- ✓ To return to work - this will require him to use public transport as he will be unable to drive for at least 6 months.
- ✓ Continued support around accepting and accommodating his ongoing difficulties

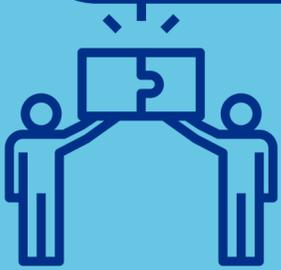
He has not been able to work on the return to work goal it requires psychological input to assess his cognition in full to understand his cognitive abilities and any adjustments that need to be made and psychologists are not part of the CNDT.

Jozef is referred onto the Community Neurological Rehabilitation Team (CNRT) for longer term community support. He is put on the Psychology and Occupational Therapy individual waiting lists. He is put on a priority due to his need to return to work.

After waiting 12 weeks Jozef is seen by the Occupational Therapist but they are limited with what they can offer as a psychology assessment is required first to assess Jozef's cognitive skills.



The Psychologist is able to offer an appointment 4 weeks later. The Psychologist and Occupational Therapist then work together to support Jozef, his family and his work place to enable Jozef to return to work using public transport. Jozef is finally back in work 9 months after his car accident.



3 months after this Jozef has a review appointment to check how he is getting on. Jozef and his family report that although there are occasionally bad days generally work is going really well and they are so happy that he has been able to get to this point considering how serious his injuries were. He appears well-adjusted and aware of his ongoing limitations and he is able to communicate about these.

Jozef is discharged at this point and told he can come back to the service for further support in the future if needed.



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 different staff with appropriate skills
 - Good communication
 - Being involved in your care
 - Quality of care
 - other

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

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

4. Discharge

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

If yes what would good look like to you?

- Let the patient contact the service when ready
 - digital/phone review
 - face to face review
- how long would you be happy to wait - 2, 6 weeks or 3 months

What would help you self-manage your condition in between therapies?

- Written information
 - Videos
 - Digital option
 - Advice line
 - Other

7 Self-referral

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

- Telephone request
- Filling in a form
- Other

8. If you oversaw the service, which type of service would you allocate NHS money to?

- A service where patients receive never-ending therapy services but there are long waits for new patients to access the service
- A service which incorporates fixed therapy services together with self-management which would mean shorter waiting times for new patients

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

Relaxing comfortable environment

Car parking

Your own room

Public transport links

Outside space

Acute hospital

Anything else

A smaller 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



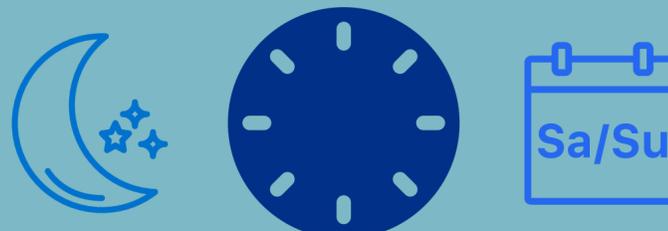
Being involved in your care



Quality of care



Receiving my therapy/care in non-working hours



Anything else



3

Location

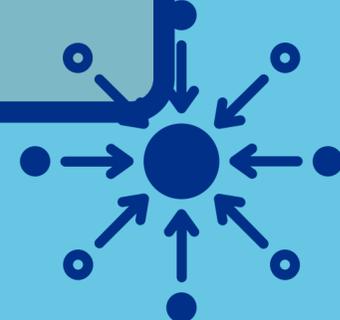
If you were unable to receive your therapy at home, what would be important to you from an alternative venue?



Close to home



Central location



Car parking



Good public transport links



Relaxing comfortable environment



In a medical/clinical setting



Digital/virtual option



~~Not in a medical/clinical setting~~



? Anything else ?

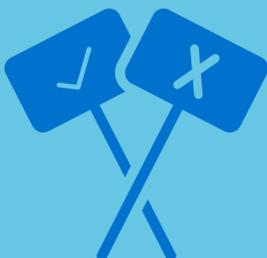
4

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

What would a 'good' final review look like?

Let the patient contact the service when ready



OR

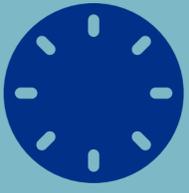
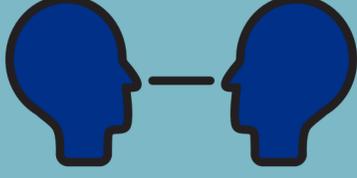
After 2 weeks
6 weeks
3 months



Digital/phone review

Review in non-working hours

Face to face review

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



5

Improvements to day service



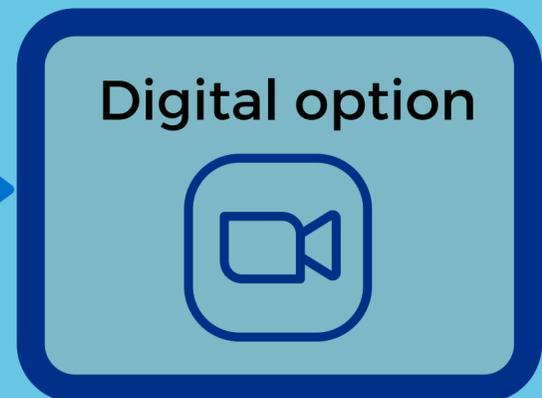
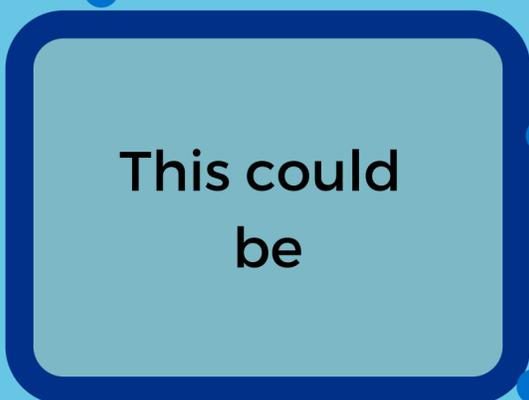
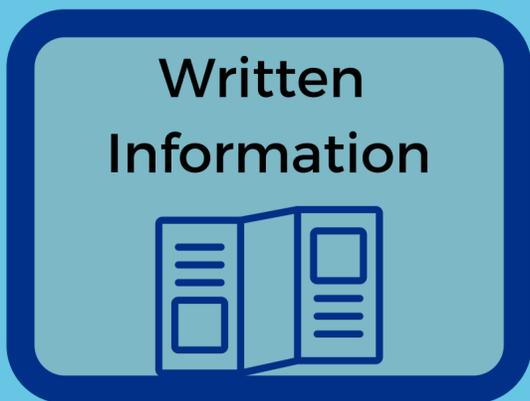
Current Day Service

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?

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?

Telephone request



Emailing the service



Filling in an electronic form



Any other way you would like to refer yourself back to the service



Which of the following are important to you?

The Spacidity 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

Community hospital



Acute hospital



Seeing the same therapist/nurse



Seeing a range of different staff with appropriate skills



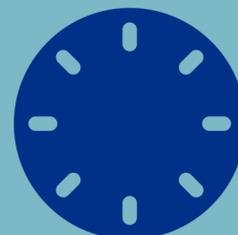
Close to home



Central location



Receiving my therapy/ care in non-working hours



Hospital



Community Neurological Rehabilitation Service

Separate waiting lists :

550 referrals a year

Community Neurological Rehabilitation Team

Only accepts referrals from hospital
provide rehabilitation in a community setting

Team consists of

Psychologist
Nurses
Occupational Therapist
Dietetics
Rehab Doctor
Rehab assistant

30 week waiting time

Community Neurological Discharge Team

support for patients with traumatic brain
injury to make
sure they have a smooth transfer from
hospital to home.

Team consists of

Community Occupational
Therapist
Rehab Assistant

· Can influence

Hospital stays

- Managing their own care in-between treatments
 - What a new service could look like