

# **Spasticity Management Project** (August 2022 – January 2023)

## **Engagement Report – February 2023**

## Executive Summary

### Background

Some patients with neurological conditions experience muscle spasticity. Interventions include injecting botulinum toxin into the muscles as well as therapy support and guidance which take place in a spasticity management clinic.

Currently patients who need spasticity management appointments are seen by a consultant in rehabilitation medicine and these clinics are held at both Leeds Teaching Hospital Trust and Leeds Community Care Trust. Sometimes patients also see an Occupational Therapist or a Physiotherapist but outside this clinic appointment.

We wanted to review how these clinic appointments were running. One area we are considering changing is for a Physiotherapist with a specialist understanding of spasticity and movement to join the clinic as currently there can be a wait to see a therapist. We ran a 6-month pilot to assess if having both a consultant and a specialist physiotherapist working together in clinic would lead to an improvement in care. Patient/carer and staff feedback was crucial.

The pilot ran between August and December 2022 and around 70 patients were seen in clinic by two health professionals together as opposed to one.

### Reason for involvement

We asked people to share their thoughts and experiences of using the spasticity clinic during the pilot. We asked whether patients felt that having a specialist physiotherapist together with the doctor in clinic was working well, and for their ideas of what could make it better.

### How we engaged

As this was a targeted piece of engagement, we needed permission to contact patients who had been seen in clinic. A letter explaining the pilot (Appendix B) was given to the patient or carer together with a consent form (Appendix A) giving us permission to ring them. We devised an online survey (Appendix C) and carried out 1-1 telephone calls using the survey as a guide. During the life of the pilot the clinical team passed details of 11 patients to us, and we spoke to nine. We were unable, after several attempts, to contact two people.

### What did people tell us?

We spoke to five patients and four carers. Everyone was aware that they were being referred to the clinic and knew what they were being treated for. Six people didn't know what was going to be discussed and three felt they did. Eight people did not feel they needed more information in advance of the appointment and one person did: If communication was needed, letter was the preferred communication method followed by email. Everyone found it a positive experience seeing a doctor and physiotherapist together at the appointment. This is what they said:

“Having both together was good. To hear them discuss things between them and I got to ask questions”.

“It was great – everyone working together as a team, and we got answers straight away”.

“Found it useful because you could ask questions together so good”

“Very good - things I wasn't aware of but never asked questions about the stroke, the clinic gave me the opportunity to ask those questions - great having two people who could answer questions”

“Great - worked well together”

“Very helpful - all on the same page - getting answers from everyone at the same time”

“Thought it was good, far better because of physio, they could understand what the problem was with my foot”

“Worked fine”

“Yes absolutely, all in one - nice that all three of them were there together and all played their own part - no one overlapping - all had their own benefits”

Everyone felt seeing two professionals together made their experience better:

“Yes - two things done at once”

“Good having two people: one watching me walk: I hadn't seen a physio for a while”

“More welcoming”.

“Input from all of them and they answered questions”

“Whenever we've been there only seen a doctor - not seen a physio”

“More areas covered with two professionals”

“A definite yes - it was a very pleasant experience”

Everyone was aware of what they wanted to achieve at the appointment and eight people felt their goal was clear to them and they were on the right path. One person felt it wasn't clear.

On asking the question whether the clinic helped with this, seven people said yes and two were unsure.

On asking what would make this clinic better, people said:

“Parking”

“Nothing - if he does have his finger removed - it's not an urgent operation so will have to wait. It was nice to see a doctor in real life as that hasn't happened due to covid - it was a long session - really good”

“Good balance between the physio doctor and myself”

“Nothing - very satisfied”

“Nothing, very good, improvement with physio is a good idea”

“Nothing”

“Nothing got seen straight away - a cup of tea would have been nice - nice and quiet hospital”

Five people were not seeing any other health professionals and three people were seeing physiotherapists.

On asking if there was anything else the patients/carers would like to tell us. People said:

“Really pleased with it and hoping this will help and improve her arm. when she walks her arm rides up and when she sits down her thumb is very painful - I said I would ask Christy if there is anything she can do to ease this”

“Happy with them telling us what they were going to do – she can now move her fingers a lot easier”

“Clinic is very near to where mum lives - personable, not in a big hospital - got transport which was wonderful, St Mary's is great”

“A warm cup of tea”

## Staff conversations

We attended two staff meetings with around 30 staff members in total. Three members of staff had experience of using the new pilot spasticity clinic. A full report of what they said can be seen in Appendix D. In summary, everyone felt having a specialist physio in the clinic was a positive move, both for the patient and for staff development. As some physios wanted to attend the clinic with their patients for a variety of reasons, there could be a danger that the clinic becomes highly resourced, but most staff did not feel that would be an issue.

### Main Themes:

- Patients and carers felt their experience in the clinic was positive and valued the opportunity of seeing a doctor and physiotherapist together.
- Most people understood their goal and felt that they were on the right path to achieve it.
- Staff were also very positive about the MDT approach and felt that it benefitted both patients and staff.

## What next?

The report will be discussed with the ICB volunteer on the project and the team to decide next steps of how we will feed back to the staff, patients and carers who gave us their thoughts. This report will be discussed with the Spasticity working group and be included in the evidence going forward.

## Contact

For further information or if you need to receive this information in alternative formats, please contact Helen Butters at the Leeds Office of the NHS West Yorkshire Integrated Care Board (ICB) at [hbutters@nhs.net](mailto:hbutters@nhs.net)

Appendix A

<b>CONSENT FORM</b>	
	<b>Please initial</b>
I have read the accompanying letter explaining why the Spasticity Service is conducting/gathering feedback/interviews with patients/carers/parents/families and I have had the opportunity to ask questions about this.	<p><b>Yes</b>      <b>No</b></p> <input type="checkbox"/> <input type="checkbox"/>
I understand that information I/we provide will be collated alongside other peoples' feedback to provide general information for staff teams and the purpose of improving the service.	<p><b>Yes</b>      <b>No</b></p> <input type="checkbox"/> <input type="checkbox"/>
I understand that whilst I/we will not be directly named within the feedback to staff teams, it may be possible to identify me/us from the content of what is said.	<p><b>Yes</b>      <b>No</b></p> <input type="checkbox"/> <input type="checkbox"/>
I understand that any paperwork involved in this feedback/exercise will be stored safely in accordance with Leeds Community Healthcare NHS Trust Data Protection requirements and the NHS Leeds Clinical Commissioning Group.	<p><b>Yes</b>      <b>No</b></p> <input type="checkbox"/> <input type="checkbox"/>
<b>I agree to take part in this feedback exercise</b>	<p><b>Yes</b>      <b>No</b></p> <input type="checkbox"/> <input type="checkbox"/>
<p>Name: .....</p> <p>Signed: .....</p> <p>Date: .....</p> <p>Name of Staff member: .....</p> <p>Signed:.....</p> <p>Date: .....</p>	



## Spasticity Clinic at St Mary's Hospital

During your spasticity management appointments, you are seen by a doctor in rehabilitation medicine. Sometimes if you are already seeing an occupational therapist or a physiotherapist, they may also attend the appointment with you.

We are reviewing how these clinic appointments are run, and one area we are considering changing is for a physiotherapist with a specialist understanding of spasticity and movement to join the clinic.

We are running a 6-month pilot to assess if having both a doctor and a specialist physiotherapist working together in clinic will lead to an improvement in your care.

As part of the pilot your feedback is crucial, and we would love to hear what you think. To facilitate that we would like to pass your details onto a member of the NHS team for them to contact you to have a telephone chat. It shouldn't take more than 20 minutes. If you would be happy for this to happen, the clinician will ask you to sign a consent form.

Please note that your contact details will not be shared with any third parties only with the team who will be conducting the interviews.

## Appendix C

### Spasticity Clinic at St Mary's Hospital

During your spasticity management appointments, you are seen by a consultant in rehabilitation medicine. Sometimes if you are already seeing an occupational therapist or a physiotherapist, they may also attend the appointment with you.

We are reviewing how these clinic appointments are run, and one area we are considering changing is for a physiotherapist with a specialist understanding of spasticity and movement to join the clinic.

We are running a six-month trial to assess if having both a consultant and a specialist physiotherapist working together in clinic will lead to an improvement in your care.

As part of the trial your feedback is crucial. We would love to hear what you think and would be grateful if you could complete the survey below.

1. I am filling in this survey as
  - a. patient
  - b. a carer/family member
  - c. other
  
2. Is this your first appointment with the spasticity clinic?
  - Yes
  - No
  
3. Before your appointment, were you aware you were being referred to the spasticity clinic?
  
4. Did you know what this appointment was for?
  
5. How much did you know about what was going to be discussed and did you have any ideas about the sorts of treatments that would be used?
  
6. Would you have wanted more information in advance of the appointment? If so, about what and how would you prefer to receive this kind of information?  
e.g. letter, leaflet, email, video, other
  
7. How did you find seeing a doctor and a physiotherapist together at one appointment?
  
8. Do you think it made your experience better, compared to seeing just one health care professional?  
In what way?



## Spasticity CNRS staff meeting -18 January 2023

Around 3 people in the meeting had patients attend the pilot clinic.

### 1. **Benefits / challenges of physio in an MDT clinic: people said:**

- I like going to the spasticity clinic with my patients who I have been seeing in the community - I find it helpful to understand where the doctors are injecting and what the goals are and what the patient needs to work on functionally. I haven't had any patients attending the new pilot.
- I have had a few patients going through the pilot clinic – The first one I didn't attend – they were injected and Christy has communicated and shared information directly: I haven't felt I needed to be there – I had another patient where I did want to be in clinic and it was nice to have a clinical reasoning discussion from a physio perspective which resulted in the best course of action for that patient – felt it was helpful and benefitted the patient as well as a learning opportunity for the physio. Attending with the patient has its pros and cons.

Helen Knight asked the physios whether they felt having a highly specialist physio in clinic was of benefit or whether they think it's better to have the treating physio.

- Somebody queried whether the 8a physio would become the injector? Helen answered that Injecting is not off the cards but the specialist physio would be working alongside the consultant. Currently Christy does have a prescribing role so that's why its 8A.
- It is useful to have peer discussion around patients. We feel having a physio at that level is a good thing to pull up others not just for patients but for staff.
- I felt I learnt something when I attended the clinic – the plan that we thought we had ended up being different after the discussion we had. There is a benefit to having someone with a high skill level and the opportunity to learn.

### 2. **If you have experienced the new clinic – how did you find communication and handover? People said:**

- It was fine
- It sounds like people have been involved in the clinic, so handover has not been an issue
- My patient had been to clinic and Christy had emailed her about an issue. She had had the same email from Steve 6 months before and she did feel she had to justify herself – a little frustrating but good communication as they did get in touch with the right person
- Feels now there is a lot of staff in the clinic – heavily resourced – can we make it a bit slicker?

### **3. Would you use the clinic differently because there is a physio there? People said:**

- I like to go into clinic with my patients – as I know how they move and what is important to them – they can often forget information - only thing I can't do in the home is the botox injection that's the only reason I would send a patient - I don't care who does the injection
- Important to note that not all patients who go to the spasticity clinic are seeing a physio
- Historically when the unit was open there was more flexibility of the therapists going into the clinic as they were there all the time, and we would naturally want to be there to give information and continuity of care. The pilot was looking at LTHT services that also work differently of accessing therapists at the time of clinic.
- I may not go into the clinic if felt handover was clear
- When we had the clinic on the ward previously and the consultants felt physio input was needed, they would pull the ward physios into clinic: we were not commissioned to do that so it would take the physios off the ward. Where the consultant does need some physio input the new model does work

### **4. Should the 8a do specialist training and education outside the clinic? People said:**

- In relation to training and education it may lose some value as there is no patient there

In summary

Staff did feel the new model worked due to benefits of having a specialist physio in clinic and staff enjoyed the learning for themselves and felt the patient benefited from the MDT discussion – As some physios wanted to attend the clinic with their patients for a variety of reasons, there could be a danger that the clinic becomes highly resourced.

## **Stroke Staff Meeting - 14 February 2023**

Nobody at the meeting had experienced using the Spasticity pilot clinic.

### **1. Benefits/Challenges of physio in an MDT clinic – people said:**

- We have gone with the patient in the past to clarify what the patient needs, and it would be good to have a discussion with the specialised physio and get their opinion on the pros and cons.
- I have worked with specialised spasticity physios in other roles - physios have a different approach to doctors they are more therapeutic and more focused on goals – they are a really good resource for us to have to bounce ideas off.

### **2. Would you want to go into the clinic with your patient? – people said:**

- From a development point of view, I would want to go the clinic with my patient
- Good development opportunity for staff to learn from the physio and from a patient perspective they have someone there who knows them and can advocate for them.
- Useful to go in seeing what can be done especially lower limb issues.

- A lot of us haven't referred into the spasticity clinic as we don't always know when it is appropriate so it would be useful to go in with the patient.
  - It's important for the usual therapists to be there – you know the patient really well to discuss problems but then continuing with the rehab afterwards – it's really important for us to know what they are doing and the best way to manage it.
  - We need to be there as some of our patients can't communicate and we know their compliance and story - continuity of care is important.
  - Physio does need to be there to carry on with the treatment afterwards. Would the specialist physio be able to do the clinic on her own? Could this be a potential for the future?
- 3. Do you feel the specialist physio should have responsibility for education and training? People said:**
- Welcome more training on spasticity for sure.
  - Having more knowledge of when it's appropriate of when to refer would be useful
  - Training of what we can do in the community and when is the right time to refer into the clinic.
  - Provide training would be helpful for the rest of the MDT if they are not going to the clinic.

In summary everyone felt having a specialist physio in the clinic was a positive move. Both for the patient and for the staff's development.