A Quality Review of a Specialist Multidisciplinary Service Caring for People with Long-term Neurological Conditions/Spasticity

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Summary
The multidisciplinary spasticity management team at the National Hospital for Neurology and Neurosurgery provides local and national care for patients with chronic long-term conditions and specialist care for ‘People with Spasticity’. There are many elements to the management of spasticity and an intrathecal baclofen pump is one option. The project was driven by a desire to improve the quality and care that patients receive from the specialist multidisciplinary spasticity service, especially with regard to the experience of living with a pump.

Over the course of this service evaluation, various members of the multidisciplinary spasticity management team and neuro-rehabilitation ward staff worked together with patients and their carers to explore the experience of staff, patients and carers. Many of the methodologies and techniques learnt through the Patients First Programme were put into practice to enable the project to move forward. The project lead and core project group also learnt a lot personally.

Many challenges were encountered, including structural change and staffing challenges, however the project created interest in all staff groups and users with a desire to get involved and engage in the process to design future service changes for others.

Implications for practice:
- Whilst it is useful to develop a shared purpose or goal, the nature of practice development is that it requires open-mindedness and flexibility as new ideas and directions might emerge
- Moving from a directive to facilitative leadership involves the development of new skills and knowledge to use in practice
- Evoke cards may be useful as prompts for patients or staff to tell their own stories, giving a reminder of past feelings or as permission to express a variety of emotions

Introduction and background
The project lead works at the National Hospital for Neurology and Neurosurgery (NHNN) in a specialist multidisciplinary spasticity team. This multidisciplinary spasticity management team provides local and national care for patients with chronic long-term conditions and specialist care for ‘People with Spasticity’ (PWS). This group of people have complex needs and if admitted, come to the rehabilitation unit where a team of nurses are familiar with caring for people with complex needs. There are many elements to the management of spasticity for those people with severe spasticity and an intrathecal baclofen (ITB) pump is one option that can be life changing. ITB is a management option that is used when oral spasticity medications are ineffective or cause too many side effects for patients. An ITB pump is a programmable device that is surgically implanted into the abdomen. It has a catheter attached that is tunnelled under the skin around the lumbar spine where it sits in the intrathecal space, delivering the prescribed baclofen medication into the cerebral spinal fluid. It is implanted under general anaesthetic and patients have two wounds, one in the abdomen and one in the lumbar spine. Following insertion of an ITB pump, patients and their carers receive information, education and support on all aspects of the pump function and their ongoing care while at the hospital. It is hoped that this information will support
The patient and their carer(s) to be aware of the ongoing care of the ITB pump and of how to contact the team in case of problems.

The project lead, in conjunction with the multidisciplinary team, wanted to understand the impact that the intrathecal baclofen pump has on the quality of life of patients and their carers. It was hoped that this would also result in collaborative working with patients to agree how education and support can best be provided to patients themselves and their carers or families who are living with an ITB pump in the future. To support this work a successful application was made to the Patients First Programme at the Foundation of Nursing Studies (FoNS) in September 2013. The Patients First Programme provides the support of a dedicated experienced practice development facilitator, workshop days with other teams and a small bursary. Project teams also have full access to the FoNS library and website, the Centre for Nursing Innovation (www.fons.org). The programme was invaluable in providing practice development methods and approaches such as the values clarification exercise and the claims, concerns and issues exercise, which helped to engage the wider team and increased confidence in the use of the methods for the project team.

**Aim of the project**

The aim of the project was to evaluate the impact of an intrathecal baclofen pump on the quality of life of patients who have spasticity and their carers.

**Objectives**

1. To engage key stakeholders in the project
2. To capture patient stories
3. To undertake a workshop with the ward nursing staff to gather and capture their involvement in the patient pathway
4. To understand how a practice development framework will help implement changes in practice for patients and carers
5. To plan how the patient and staff experiences will help co-design a more user-friendly service

**Methods and approaches**

A mixed method approach was used including the following methods: emotional touchpoints; patient and staff focus groups and an on-line Survey Monkey questionnaire to inform and evaluate our current practice, ending with a celebration event for patients, carers and staff. Below is a summary of the methods and approaches used.

<table>
<thead>
<tr>
<th>Table 1: Summary of time line and methods and approaches used</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>When</strong></td>
</tr>
<tr>
<td>October-December 2013</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
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<td></td>
</tr>
</tbody>
</table>
| November – December 2013 | Explored the need for ethical approval | What we did – the project lead contacted the local ethics department  
What was the outcome – project was deemed to be service evaluation  
What we did next – registered the project with the local audit department  
What we will do next – share findings and present at a governance day in the hospital to demonstrate our experience of practice development in a small service improvement project in particular with the neuro-rehabilitation unit |
| January – June 2014 | Patient narratives | What we did – conducted interviews asking 4 key questions  
Who we did it with – service users  
How we did it – users selected words and used these words to tell their unique story  
When we did it – planned in line with hospital visit  
Where we did it – booked a room next door to the clinic  
How we displayed findings – we developed a presentation and poster of the findings for the Rehabilitation in Multiple Sclerosis (RIMS)  
FoNS project discussed at weekly group meeting with the core practice group (CPG) |
| June 2014 | Staff workshop | How we did it – organised a workshop day with nursing staff from the neuro-rehabilitation unit  
What we did – values clarification exercise along with ice-breaker exercises: ‘big bus tour exercise’ and Evoke cards  
Who we did it with – nursing staff. We provided lunch and got agency nurses to cover the unit  
Where we displayed findings – we developed a poster which highlighted the project and illustrated our plans for involvement in particular with the neuro-rehabilitation unit |
| June 2014 | Carer questionnaire | What we did – designed a Survey Monkey to complete on-line  
Who was it with – carers of people receiving ITB  
What was the outcome – carers also wanted to have any opportunity to meet up  
What we will do next – we organised a CPG meeting to discuss the findings |
| October – December 2014 | Celebration event | How did we organise it – we undertook a claims, concerns and issues exercise as a planning tool with the CPG and identified key jobs for all the members of stakeholder group  
Why we decided to do this event – we decided to pull all the strands of the project together  
Who was the event for – a joint party for patients, carers and staff  
How did we evaluate it – CCI with group  
What we will do next – set up an email cascade led by 3 key users who volunteered |

**Engagement with the stakeholders**

A multidisciplinary stakeholder group was set up by the project lead with the aim of looking at the current education provision for patients who received an intrathecal baclofen pump
At the first FoNs workshop day the project lead reviewed the main stakeholder group and realised that the management team and the ward nursing staff needed to be included. Members of this group included two consultant neurologists, a specialist registrar, two physiotherapists, two clinical nurse specialists and administration staff. Nursing staff from the neuro-rehabilitation unit where patients are also admitted (patients who are fitted with an intrathecal baclofen pump are admitted to the neuro-rehabilitation unit, although it isn’t a specialist MS or spasticity ward), were invited too. The stakeholder group met each month for a feedback session and had some designated time during the clinical governance day at the hospital. The stakeholder group considered the model of participation for the project.

**Values clarification exercise**

The first step was a values clarification exercise which was conducted with the steering group in order to develop an initial project statement. The values clarification exercise (Warfield and Manley, 1990) asked:

- I believe the ultimate purpose of caring for people with spasticity is …
- I believe this purpose can be achieved by …
- I believe the factors that help us achieve this purpose are …
- I believe the factors that hinder us from achieving this purpose are …
- Other values and beliefs I consider important in relation to caring for people with spasticity are …

Initially, members of the steering group completed the exercise on paper (see Appendix 2), independently. Then as a group each question was explored in a shared group exercise. Sticky notes were used for individuals to note down their answers. This was a great grounding exercise as it helped identify what the next steps would be, how the group would achieve these and who the group needed to engage. It was important to have clear goals and hopes of a shared vision and what the group wanted to achieve aligned the project. The aim of the project was agreed:

*to evaluate the impact of an intrathecal baclofen pump on the quality of life of patients who have spasticity and their carers*

Manley (2000) suggests that by completing a values clarification exercise we can compare ‘what we say we believe and what we do’, and this is one of the ‘hallmarks of effective individuals, teams and organisations’. This is echoed in health literature which talks about having a yard-stick that can help healthcare professionals to measure what counts, ensuring a patient-centred approach in clinical practice and the importance of teams having time to consider this (Collins, 2014; Da Silva, 2013).

The group felt this exercise helped them focus on the project and demonstrated that there were many similar and overarching themes around the patient and the importance of their involvement in order for us to help improve their quality of life. The project lead themed the findings which can be seen below.
Table 2: Values and beliefs

<table>
<thead>
<tr>
<th>Improve quality of life</th>
<th>Kindness</th>
<th>Lacking time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Holistic care</td>
<td>Education</td>
<td>Patient choice</td>
</tr>
<tr>
<td>Involvement</td>
<td>Reduce pain</td>
<td>Timely manner</td>
</tr>
<tr>
<td>Multidisciplinary working</td>
<td>Shared skills</td>
<td>Communication</td>
</tr>
<tr>
<td>Equal access</td>
<td>Lacking resources</td>
<td>Future pressure</td>
</tr>
</tbody>
</table>

It was planned to run a workshop with the staff on the ward and then pull everyone’s views together at an event.

A second outcome from this stage of the project was the creation of a core project group (CPG), consisting of the consultant neurologist, consultant physiotherapist and clinical nurse specialist. Initially, the CPG felt it was ideal to have everyone from the stakeholder group involved in all the meetings however this proved challenging for the project lead. Hence, the CPG was largely responsible for the day-to-day decision making for the project.

The CPG developed the following SWOT analysis to help them think about the project.

Patient interviews/stories

Ethics

The project lead approached the local ethics committee at the hospital who, following a review of the project, deemed it to be a service evaluation which would provide local understanding of how ITB impacts on users and their carers. No ethical approval is required
for service improvements initiatives. The project lead felt the process of approaching the ethics committee was daunting, but felt that there were supportive processes within the hospital including guidelines the project lead found helpful. Even though ethical approval was not required, the project lead felt understanding the principles of ethics was vital in order to ensure the safety and protection of human subjects and to widen the concept of informed consent and outline the provisions for withdrawal from the project (Polit and Hungler 1999; Royal College of Nurses, 2011). The project lead was also aware that the participants could find the questions distressing and that they might be vulnerable subjects, however, she believed that the information gained would help future education programmes. It was made clear to participants that the project lead would stop the interview at any time if it was causing distress to the participant and this would not in any way affect future care or management.

The project lead was aware of the Code of Professional Conduct (Nursing and Midwifery Council, 2002) which stipulates that there is a professional duty to promote healthcare environments that are conductive to safe, therapeutic and ethical practice. The project lead wanted to ensure that all participants received clear information about their involvement and were given sufficient time to consider involvement. It was also important that participants understood that criticism of the current information provision was necessary in order that improvements could be made. In addition, participants were reassured that the aim of the study was to learn from their personal experiences.

The project lead designed an information leaflet (see Appendix 3) and consent form (see Appendix 4).

Patient recruitment
The CPG decided that patients who had experience of intrathecal baclofen for longer than 6 months would be contacted. Patients were initially approached in clinic and asked to verbally agree to participate in the project. This was followed up by a telephone call and if the person was still interested in the project, the patient information leaflet (Appendix 3) was emailed so they had sufficient time to consider involvement. Once verbal agreement was established, an appointment was made to meet. Meeting times were organised to coincide with the participant’s existing hospital appointment to make it less disruptive. All the participants were wheelchair users and had hospital transport organised for their hospital visits so no additional costs were incurred.

The process for the patient interviews
The CPG agreed that the project lead would use an adapted version of the emotional touchpoint approach to conduct the patient interviews. The emotional touchpoint approach (Dewar et al., 2010) is a way of systematically gathering patients’ experiences of receiving healthcare. The CPG discussed the potential questions that would help focus the project and agreed the questions to be asked at the interview.

The questions to be asked were:
1. Tell us about yourself
2. Tell us how you feel about living with your condition
3. Tell us how you feel about your pump
4. How can we work with you better to help you?

The project lead organised a room next to where participants would be having their pump refilled, refreshments were offered and the project and the Patients First Programme explained in detail. A ‘do not disturb’ sign was on the door, which was very helpful.

The interview started with the project lead checking that the participant had received the information leaflet and addressing any outstanding questions, this was followed by the participant signing to give consent. The project lead then explained how the interview would work, that participants would be encouraged to answer questions by selecting any of a series of cards depicting emotional words which were laid out on the table (see Figure 1 below).

**Figure 1: Emotion words**

![Emotion words](image)

With the support and involvement of the FoNS facilitator the first interviews were organised with the patients. Having observed the FoNS facilitator, the project lead was more confident completing interviews. In conducting patient interviews, it is important to allow the user to tell their unique story and to avoid ‘rescuing the quiet moments’, that is stepping in, as the patient reflected on their unique journey.

**Results**

**Seven** people with ITB pumps were interviewed face to face. The age range was from 50-62 years with the length of ITB experience differing hugely: the longest experience being over 20 years and the least experience 10 months. This was seen to be a benefit as it demonstrated the varying opinions over a longer and shorter periods of ITB experience.

The project lead looked closely at the narratives and pooled the themes and comments that arose from the interviews.
<table>
<thead>
<tr>
<th>Questions</th>
<th>Themes people talked about and words used:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tell us about yourself</td>
<td>• Work, family&lt;br&gt;• Loss of career, diagnosis&lt;br&gt;• Family, pain with spasm, adapted house&lt;br&gt;• Diagnosis&lt;br&gt;• Accident was a pivotal moment in my life, paralysed, loss&lt;br&gt;• Loss of my job, change of dynamics at home&lt;br&gt;• Diagnosis, walking and unable to walk, wheelchair dependent, depression</td>
</tr>
<tr>
<td>2. Tell us how you feel about living with your condition</td>
<td>• Curious, sad, fortunate with care, helpless with disease, hopeful because spasticity is better managed and I can work&lt;br&gt;• Resentful, out of control, worried, needing help from others, guilty, [I want to believe] my MS does not exist&lt;br&gt;• Thankful as thing could be worse, sad, effect on relationships, money worries, thankful to family, depression&lt;br&gt;• Angry, crashed while on my scooter as fell asleep, embarrassed about being in a wheelchair&lt;br&gt;• Very helpless, alone, worried about the future but more hopeful now, meeting new people and thinking about future work&lt;br&gt;• Frustrating, reduced social contact, hard running a team of carers, fortunate with family, tears before bedtime, freedom to be active&lt;br&gt;• Cared for, calm, thankful, happy, fortunate</td>
</tr>
<tr>
<td>3. Tell us how you feel about your pump</td>
<td>• Calm, relieved, brave, nervous about size of pump, staff helped me to be calm and not worry about operation&lt;br&gt;• Happy, relieved, grateful, pleased, fortunate&lt;br&gt;• Appreciative, fortunate, happy, cared for&lt;br&gt;• Calm, full of life, upbeat, fortunate, pleased, safe&lt;br&gt;• Grateful, enthusiastic, encouraged, appreciative&lt;br&gt;• Wonderful, accepted it, thankful, safe, trust in the team, makes me more capable people are curious about it appreciative, calm, pleased&lt;br&gt;• Relieved and peaceful</td>
</tr>
<tr>
<td>4. How can we work with you better to help you?</td>
<td>• More intensive physiotherapy after the pump&lt;br&gt;• I always challenge myself to do things better, post operation advise on low pressure headache&lt;br&gt;• Outpatient environment not very inviting, so much to take on board at the time, I want to talk to others about my experience, articles in MS Trust magazine should be handed out, information about what happens for the period in hospital&lt;br&gt;• I get support and reassurance from personal contact, this is crucial to me&lt;br&gt;• Meeting and talking to the team&lt;br&gt;• Meeting others that have pumps, putting articles in MS magazines&lt;br&gt;• I have all contact and telephone numbers and support I feel informed, the NRU experience is beyond good, that is how they make you feel, I would like to see the consultant again</td>
</tr>
</tbody>
</table>
What was overwhelmingly obvious was that people wanted to meet up and get the opportunity to share their stories and discuss their experiences (these were individual interviews). They were happy to be involved which was great. People also felt valued and were happy to be asked for their opinion. While not many suggested huge changes with the pathway, they were keen to discuss the significant difference having their spasticity managed had on their quality of life.

**Evaluation of the session**
At the end of the session, participants were asked how they felt about selecting cards and the process of using emotional touchpoints. The response was very positive:

<table>
<thead>
<tr>
<th>Comment</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>‘It’s quite nice to have a label to put to something because if you had said ‘well how do you feel?’ ‘I’m fine’, which is not a very meaningful word but to have these words which actually I can say describe why it makes me happy that I have a pump is very good’</td>
<td></td>
<td></td>
</tr>
<tr>
<td>‘a bit of fun, it was good – good way of doing it’</td>
<td></td>
<td></td>
</tr>
<tr>
<td>‘you forget sometimes of how you actually felt at the time and you see the word it reminds you gosh, I did feel like that’</td>
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<td></td>
</tr>
</tbody>
</table>

**Rehabilitation unit staff workshops**
The project lead was not experienced with facilitating workshops so had developed the key questions and the structure of the workshop in discussion with the FoNS facilitator. The bursary money was used to ‘back fill’ the ward staff and get agency nurses in order to get the staff off the unit. The workshop was advertised so attendance was encouraged.

There were two workshops, one in the morning and one in the afternoon, each workshop lasted two and a half hours. In total, nine members of staff were involved in the workshops. One of the first questions asked was ‘Where were the therapists?’ as the staff had assumed the therapists would be involved, they were surprised that the workshop was for them alone. The second question: ‘Was this a meeting about a complaint!’ clearly morale was low on the unit.

The following groups attended

<table>
<thead>
<tr>
<th>Staff nurses</th>
<th>Healthcare assistants</th>
<th>Charge nurses</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>3</td>
<td>1</td>
</tr>
</tbody>
</table>

Some basic ground rules were established and an exercise was conducted to explore staff expectations around the workshop using the ‘Emotion words’ (Evoke cards www.evokedcards.com) (see Figure 1 above) to help this process. This started the conversation and helped staff to relax and engage in the workshop, equally it helped the facilitator to relax into non defensive, listening role and avoid rescuing the discussion by allowing it to ‘flow freely’. Following this, the project lead used the adapted emotional touchpoint technique to describe how staff felt about caring from someone with spasticity. Emotional touchpoints have been described by the Scottish Health Council (2014) as a tool.
where ‘the person recalls being touched emotionally’ (feelings are cognitively lasting memory). Dewar et al. (2010) also suggests it can be used as a tool to record a key moment in the person’s experience. The 48 cards were displayed and participants were asked to select cards that they felt best described how they felt about caring for someone with spasticity (see Appendix 1).

**Values and beliefs clarification exercise**

Participants were asked to complete the following statements:

1. I believe the ultimate purpose of caring for people with spasticity is...
2. I believe the purpose can be achieved by...
3. I believe the factors that help me achieve this purpose are...
4. I believe the factors that hinder us from achieving this purpose are...
5. Other values beliefs I consider important in relation to caring for people with spasticity...

The answers were written down on paper and then shared with all members in the group. This structured way enabled staff to voice their values and beliefs around caring for people with a long term neurological condition such as spasticity. Once this had been achieved, the responses were used to develop a ‘we’ statement:

*We believe the purpose of caring for people with spasticity is to help improve the quality of life for people with spasticity*

**Claims, concerns and issues**

The staff on the rehabilitation ward are not specialists in spasticity, so the project lead was keen to find out what staff felt about caring for people with spasticity. She wanted to look at what they felt were the strengths and what the concerns were and decided to use the claims, concerns and issues tool, based on Fourth Generation evaluation (Guba and Lincoln, 1989). Claims are favourable ideas about a topic, concerns are unfavourable and issues are questions that arise from the concerns expressed. The staff were invited to write down their claims, concerns and issues on sticky notes and put them up on three flip charts. Different coloured notes were used for different areas. The results were collated by the project lead and displayed below in table 4:
Table 4: Claims, concerns and issues

<table>
<thead>
<tr>
<th>Claims</th>
<th>Concerns</th>
<th>Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>complex needs</td>
<td>time of surgery</td>
<td>How can we manage behavioural and cognitive challenged patients?</td>
</tr>
<tr>
<td>nursing assessment</td>
<td>education on time assessment</td>
<td>How can we ensure the best nursing care?</td>
</tr>
<tr>
<td>environment/ side room</td>
<td>access out of hours</td>
<td>Can we get an opportunity to debrief and know what happened after discharge?</td>
</tr>
<tr>
<td>quality of life impact</td>
<td>SHO on call not understanding PWS</td>
<td>How can we help ensure that care is planned as much as possible?</td>
</tr>
<tr>
<td>more independence</td>
<td>having a 'expert nurse' on the ward that has the experience</td>
<td>Can we have more patient / staff friendly information on spasticity?</td>
</tr>
<tr>
<td>confidence of understanding complex needs</td>
<td>preparation before trial and check list</td>
<td></td>
</tr>
<tr>
<td>general medication problems</td>
<td>concern about operation at the weekend</td>
<td></td>
</tr>
<tr>
<td>flexibility for visiting</td>
<td>staffing level</td>
<td></td>
</tr>
<tr>
<td>access to team M-F</td>
<td>patient needs can be uncommon and 'new territory'</td>
<td></td>
</tr>
<tr>
<td>good bladder and bowel management</td>
<td>high dependency</td>
<td></td>
</tr>
<tr>
<td>learning experiences</td>
<td>compliance with care</td>
<td></td>
</tr>
<tr>
<td>new challenges</td>
<td>physically demanding on staff</td>
<td></td>
</tr>
<tr>
<td>pre assessment preparation</td>
<td>ensuring plan is in place for home</td>
<td></td>
</tr>
<tr>
<td>plan what the patient is coming in for</td>
<td>ongoing management of care</td>
<td></td>
</tr>
<tr>
<td>good communication between teams (NRU/Spasticity team)</td>
<td>patient developing complications</td>
<td></td>
</tr>
<tr>
<td>improve skills</td>
<td>difficulties with family</td>
<td></td>
</tr>
<tr>
<td>learning new things</td>
<td>there is always room to improve</td>
<td></td>
</tr>
<tr>
<td>support spasticity team</td>
<td>dealing with demanding patients</td>
<td></td>
</tr>
<tr>
<td>good knowledge and skills</td>
<td>pre/post op care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>simple information e.g. how should patient transfer; what meds have changed</td>
<td></td>
</tr>
</tbody>
</table>

This exercise sparked discussion with all those attending the workshop. The project lead made notes of the discussion so it could be fed back to the steering group and ensure all members were informed.

The project lead reviewed the claims, concerns and issues exercise and themed the responses. There were three main themes:

- **Education and adjustment** - to the complex needs of the patient and ensuring the best nursing care
- **Improving quality of life** – this intervention may help give the patient hope for the future with less pain and better management of their unpredictable spasticity and spasm
- **Support of the patient once discharged** – ensure follow up is in place and that the community teams are aware and that the patient has the support from the spasticity team once discharged.
**Evaluation of the workshop**

The nursing group were asked to evaluate the workshop using the following questions:

What did you like?
What was a challenge?
What will you take away?

The evaluation was very positive as can be seen from the evaluation findings below:

<table>
<thead>
<tr>
<th>What did you like?</th>
<th>What was a challenge?</th>
<th>What will you take away?</th>
</tr>
</thead>
<tbody>
<tr>
<td>having a voice, open forum</td>
<td>doing the reflection</td>
<td>we are all in it together</td>
</tr>
<tr>
<td>being involved and reflecting</td>
<td>considering the challenges</td>
<td>new knowledge gaining from</td>
</tr>
<tr>
<td>relaxed atmosphere,</td>
<td>the patient have</td>
<td>talking and listening</td>
</tr>
<tr>
<td>happy to talk honestly and the opportunity to come together and share</td>
<td>worried it was a complaint</td>
<td>good team spirit</td>
</tr>
<tr>
<td>the idea of improving</td>
<td>doing some of the exercises</td>
<td>ideas about thinking of</td>
</tr>
<tr>
<td>and maintaining care, can we do this again</td>
<td>thinking differently</td>
<td>managing complex patients</td>
</tr>
<tr>
<td>feels supported by spasticity team</td>
<td>to relax, stop and thinking</td>
<td>to be assertive</td>
</tr>
<tr>
<td>informative / enjoyable</td>
<td>about work for a while</td>
<td>increased confidence and</td>
</tr>
<tr>
<td>better understanding of how</td>
<td>opportunity to reflect and share</td>
<td>support</td>
</tr>
<tr>
<td>to manage PWS</td>
<td>completing the exercises</td>
<td>thinking about the ward and</td>
</tr>
<tr>
<td>everything</td>
<td></td>
<td>making it relaxed for patients</td>
</tr>
</tbody>
</table>

**Carer’s questionnaire**

From the outset of this project, the project lead was keen to use a mixed methods qualitative and quantitative approach. This was ambitious and as the project progressed, needed some adjusting. A carers questionnaire was used. The questionnaire was posted online using the website Survey Monkey and carers were invited to complete it. It consisted of a series of questions with drop down options. There was no free text option. This questionnaire was evaluated prior to being used by the carer of a patient receiving intrathecal baclofen. The carer highlighted some key issues, in particular, the importance of how we would supply ongoing support to carers if it was highlighted as an area that we needed to expand.

The quality of life carer questionnaire proved useful and gave insights into carers’ experiences of ‘Health and Social care’ and ‘Caregiver Strain Index’ when caring for someone with a long term condition, such as spasticity, who is receiving ITB. The questionnaire results along with the carer information leaflets were presented to the stakeholder group at a later meeting. Some of the questionnaire data was used in the rehabilitation poster that was designed for the MS conference (see Appendix 5). On reflection, the tool was useful, however it may have proved more valuable if it had asked for direct open comments from the carer group.
Celebration event

A meeting of the CPG was organised to discuss the findings so far and consider the next steps. Following reviews of the patient and staff feedback it was decided to hold a celebration event to give an opportunity for everyone to come together to share their stories, to pull all the strands of the project together and provide a valuable pause for all to reflect on what had been achieved.

The project lead set up a planning meeting with the CPG to plan the event. Initially, the administration staff had not been keen on being involved as they didn’t feel they could contribute, however once the feedback was examined more, they realised how valuable their contribution would be. At the planning meeting it was decided to use a claims, concerns and issues exercise to explore the celebration event. The exercise was immensely helpful and straight away people were suggesting solutions and being incredibly creative around how we could make it happen (Table 6).

<table>
<thead>
<tr>
<th>Table 6: Celebration event planning</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Claims</strong></td>
</tr>
<tr>
<td>Time to run event</td>
</tr>
<tr>
<td>Ideas around what users want</td>
</tr>
<tr>
<td>Ensuring involvement from all the team</td>
</tr>
<tr>
<td>Making sure all users can access the event</td>
</tr>
<tr>
<td>Communication</td>
</tr>
</tbody>
</table>

There were lots of practical details that needed organising.

- The invitation (see Appendix 6) was designed by the consultant physiotherapist and a designated telephone contact number was set up so patients/carers could call and leave a message to confirm their attendance
- The clinic nurse specialists planned the timing of the clinic slots so that patients could be seen in clinic and have enough time to attend one of the events (two events were held over the course of the day so patients and carers had the flexibility of attending and contributing, at a convenient time)
- It was decided to request an extra two rooms which were organised with sufficient space for twenty wheelchair users and their carers
- Food, decorations and music were planned
- There was discussion around tokens of appreciation for attendees. As the event was planned for close to Christmas, something festive was suggested. However, there was concern that this might offend people that were not celebrating Christmas. Eventually it was agreed that a card with a picturesque water colour picture would be a token of our appreciation of attendance. This was personalised, signed and dated by the team and was a huge success as people were pleased to have the card
as a memory of the day. The project lead felt relieved that this had worked, despite it being a small gesture - it was very person-centred and as a result worked well

- The CPG started to look at the staff needed to run the day. The neurologist organised for herself and two medical colleagues to be available on the day. Each team ensured that all their teams were available to help on the day. The project coordinator invited the communication team and the clinical management team to the event so that they could meet the patients and carers, invitations were also sent to the rehabilitation ward managers and the staff so they could meet patients/users and carers in a different environment.

Attendance on the day was good and all staff groups were hugely supportive and helped coordinate the event ensuring that everything was ready.

The follow attended:

<table>
<thead>
<tr>
<th>Patient and carers</th>
<th>Stakeholder and administration group</th>
<th>Nursing, therapy and management staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>45</td>
<td>15</td>
<td>4</td>
</tr>
</tbody>
</table>

There were some problems with staff being released as staffing levels were poor, so working creatively, it was decided that staff would be invited during their lunch break and food was provided. The posters from the project were displayed so patients and staff could see the findings. Sharing the feedback from the interviews was really helpful and showed a creative way of gathering feedback from users.

**Evaluation of the celebration event**

The patients and carers were asked to evaluate the event at the end. The evaluations were powerful with attendees delighted to have been asked and very interested in hearing how the day came about. There were posters of the project, reflecting the journey with the ‘Patients First Programme’ and there were also A4 size hand-outs of the poster from RiMS (June 2014) (see Appendix 5) available for people to take away and examine at their convenience.

**Table 7: Celebration event evaluation**

<table>
<thead>
<tr>
<th>Great day</th>
<th>Good food</th>
<th>When is the next one?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delighted to see the poster and my picture</td>
<td>Lovely meeting the team</td>
<td>Interesting to chat to others</td>
</tr>
<tr>
<td>Glad I could help with the interviews</td>
<td>Now have a ‘face’ to the name</td>
<td>Can we email each other?</td>
</tr>
<tr>
<td>Thank you for organising</td>
<td>Happy to coordinate</td>
<td>What happens next?</td>
</tr>
<tr>
<td>Glad I made it</td>
<td>How can I get involved?</td>
<td>Have you had these events before?</td>
</tr>
</tbody>
</table>
Discussion

What worked well?

The main elements of this project that worked well were the input and facilitation from FoNS, the use of practice development tools and the teamwork which ensured the success of the celebration event. The project was driven by a common desire to review and improve the quality of care that patients receive in the ITB service. This service evaluation allowed the team to reflect, with enthusiasm, about the current service and identify areas to work on. The team work within the stakeholder group and CPG allowed the project keep its momentum. The skills and practice development tools gained from the FoNS workshop days allowed the project to move forward.

The input and facilitation from FoNS ensured that the PD tools learnt could be ‘live in practice’ and successful in a neurological setting. Learning from the FoNS workshops demonstrated the importance of getting staff feedback and ensuring this is reflected in future service design. FoNS workshop days provided the CPG with the confidence and tools necessary to carry out the patient interviews and to hold the staff workshops. The opportunity to network and share practice was invaluable and despite there being many varied projects at the FoNS workshops, the knowledge gained with running patient and staff events is transferable in any setting. The use of the tools from the FoNS workshops demonstrated a ‘ripple effect’ in clinical practice giving the project lead, as facilitator, and the team, the confidence in the process. Similarly gaining confidence and encouragement from the Patients First Practice Development Facilitator during the staff workshop and interviews, guaranteed that that project was on the correct trajectory. Learning to trust the PD tools and avoid rescuing a situation was challenging but allowed the findings to guide the team.

The team were able to use many practice development tools during the project and the project lead continues to use the PD tools and see the benefit and value in engaging staff. The opportunity to stand back and look at the service and listen to patients and staff was hugely helpful. The project lead used situational facilitation model as an outlined by Hersey and Blanchard (1996) to reflect on how she would facilitate the staff workshop and continues to use this style in the new ward. This model describes four distinct domains.

![Situational Facilitation](image)

*Hersey and Blanchard, 1996*
In order to facilitate the staff workshop the project lead had organised backfill nurse staff on the unit. This was funded by the bursary from FoNS. The project lead felt that providing some food and refreshments helped the staff to relax and enjoy their experience of being away from the unit and being asked for their contribution. People felt valued as the staff that care for a hugely complex group. This felt like a light bulb for the project lead as staff seldom get an opportunity to sit back, reflect and evaluate what is done on a busy rehabilitation unit. The project lead was careful to ‘facilitate’ this workshop and avoided ‘directing’ it. The staff workshop may have worked better away from the clinical setting. Equally the time was limited and staff didn’t get the opportunity to hear about all of the aspects of the service evaluation, in particular, the patients’ narratives.

Using the adapted emotional touchpoints method was another success for the project. It provided a valuable narrative as people were invited to share their experiences and ‘tell their story’, it provided an opportunity for sharing negative and positive experiences of their spasticity pathway and identified areas of improvement and a platform for discussion with all involved in the spasticity pathway.

However, there are challenges for people new to practice development. The project lead felt it was difficult for the staff to see her as a ‘facilitator’ and not as a senior nurse on the ward. On reflection the project lead felt she should have spent more time with the group and been able to offer more to nurses on an ongoing basis. It was also a challenge to use a ‘complete’ experience based design (EBD) approach. It was felt that this should be explored in the future. An EBD approach helps capture the experiences of those involved in that service; patients, carers and staff. The main core element of EBD have been described by Bate and Roberts (2007a; b) as focusing on the whole experience of a service from patients perspective and involving users to participate in the design /redesign and service development. The CPG would like to use an EBD approach in the future as is was felt the elements could be mapped to the ITB service and make a significant difference.

The celebration was received very well by all. The teamwork required to coordinate this event was huge and its success a credit to the dedication and hard work of all involved: patients, staff and carers. It also provided a launch-pad for an email cascade within the patient group.

**What didn't work so well?**
Unfortunately after the staff workshops, a decision was made independently, that patients receiving ITB would be cared for on another ward. Whilst this was very disappointing as a lot of time had been invested in the staff on the rehabilitation unit, the CPG felt that there were many PD tools that could be used and started with the staff on the new ward. The project lead started this process and completed a values clarification exercise in April 2015 with the new staff as part of their education programme. This process is ever evolving and the PD tools will assist with keeping the ITB patient in the forefront.

In addition, there were time pressures. Keeping to the time line was difficult, however once the strands were pulled together in a PowerPoint presentation (see attached PowerPoint) it was easier to action plan the celebration event. Trying to have protected time was difficult
as all the clinical staff groups are very busy so creative and innovative ways to figure a way forward were needed.

The carers’ questionnaire needs to be looked at. Whilst it asked useful questions, it is didn’t give carers the opportunity to tell their whole story.

Finally, the stakeholder group was multidisciplinary however it was felt that the involvement of a clinical psychologist would have provided valuable insight from the beginning of the project.

What did you learn?
The project lead had approached two other funding sources before being successful with FoNS. This was disappointing at the time however fortuitous as the FoNS ‘Patient First Programme’ fit best with the service evaluation needed in the ITB service, it provided the opportunity to:

- Recognise the importance of getting time to look at the service
- Explore and value the huge impact the service can have on people’s lives and the importance of having this user experience in a service
- Recognise how powerful patient stories are
- Get feedback from the staff involved in caring for the patients

Achievements

- Getting funding for the project from FoNS was a great achievement for the team
- Getting an opportunity to present a poster on the values clarification exercise completed with the nurses on the ward
- A poster was presented in June 2014 at the rehabilitation in multiple sclerosis (RiMS) conference which was held in Brighton outlining our project and feedback we had received from the patients. This included pictures and some narrative comments that had been collected at interviews (see Appendix 5)
- Poster displayed at the National Intrathecal Baclofen conference in June 2014

Conclusions and implication for practice
Service evaluation continues to be at the forefront of practice for the spasticity team at the National Hospital for Neurology and Neurosurgery and remains an ever evolving model. Many of the objectives were achieved because the PD tools engaged patients to open up and tell their unique story. Stories are very powerful and feedback from RiMS and the ITB Forum suggested that often patient views are overlooked, this needs to be addressed and considered in this service going forward. By raised awareness of 'patient experience' in our service we have managed to start a user group that is invaluable to current users and people that are considering management of their spasticity with ITB.

This project gathered valuable information on the unique impact ITB can have on a group of patients however did not accurately assess the impact for carers. Many of the practice development tools could be used to help capture the impact on carers and this needs further discussing. By presenting the service in a transparent way to patients and staff the
team can question current pathways, evaluating the educational support and allow us to
design change.

Many challenges were encountered; moving ward and difficulties in setting up the staff
workshops for example, were addressed with good teamwork and open ‘can-do’
discussions. It was apparent that the project created interest in all staff groups and patients
with a desire to get involved and engage in the process to help shape a service change in the
future for others. People valued being asked and participating.

**Implications for practice:**

- Whilst it is useful to develop a shared purpose or goal, the nature of practice
development is that it requires open-mindedness and flexibility as new ideas and
directions might emerge
- Moving from a directive to facilitative leadership involves the development of new
skills and knowledge to use in practice
- Evoke cards may be useful as prompts for patients or staff to tell their own stories,
giving a reminder of past feelings or as permission to express a variety of emotions

**References**

Bate, S.P. and Robert, G. (2007a) *Bringing user experience to healthcare improvement: the
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Publications.


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London UK

Philadelphia


**Appendices**

Appendix 1  Steering Group Values Clarification

Appendix 2  Values and beliefs template

Appendix 3  Patient Information Leaflet on Participation

Appendix 4  Consent form

Appendix 5  RiMS Poster June 2014

Appendix 6  Invitation to celebration event
Appendix 1

UCLH nursing conference

Title: Values clarification exercise on the Neurorehabilitation Unit (NRU) as part of a bigger Spasticity Service Evaluation

Authors: Keenan, E., Lee, H. (Clinical nurse Specialists in Spasticity Management) Minioza, D., (Charge Nurse NRU), Sorianosos, R. & Swamy, J. (Spasticity link nurses NRU)

Aim This poster aims to describe a values clarification exercise with the nursing staff on a neuro rehabilitation unit (NRU) when caring for people with spasticity that are receiving intrathecal baclofen (ITB). This is part of a bigger spasticity evaluation which is looking at the experience of people receiving intrathecal baclofen (ITB) treatment for their spasticity. There are three strands to this spasticity service evaluation: patient evaluation, carer feedback and brainstorming values clarification exercise with the nursing staff on the NRU.

Background The multidisciplinary spasticity team at the National Hospital for Neurology and Neurosurgery (NHNN) provides a national service for patients with long-term conditions and specialist care for People with Spasticity (PWS). There are many elements to the management of spasticity, but in those people with severe spasticity an ITB pump can be life changing. ITB is used when oral spasticity medications are ineffective or cause too many side effects. Following careful patient selection, admission is organised to the NRU for an ITB trial and if trial is positive then insertion of an ITB pump. Patients and their carers receive support and education from the spasticity team and the ward nurses.

The service evaluation is being supported by the Patients First Programme at the Foundation of Nursing Studies (FoNS), a registered charity dedicated to working with nurses and healthcare teams to develop and share innovative ways of improving practice. The programme provides support via an expert external facilitator, networking days and a bursary of £5,000.

Method We will organise a values exercise with the nurses on the unit using the template by Warfield & Manley (1990) which outline key questions that we have adapted for our service:

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>I believe the ultimate purpose of caring for people with spasticity is?</td>
<td></td>
</tr>
<tr>
<td>I believe this purpose can be achieved by:</td>
<td></td>
</tr>
<tr>
<td>I believe the factors that help us achieve this purpose are:</td>
<td></td>
</tr>
<tr>
<td>I believe the factors that hinder us from achieving this purpose are:</td>
<td></td>
</tr>
<tr>
<td>Other values and beliefs I consider important in relation to caring for people with spasticity are:</td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 2

### Values and beliefs template

*(Warfield and Manley, 1990)* and beliefs template

<table>
<thead>
<tr>
<th>I believe the ultimate purpose of caring for people with spasticity is?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I believe this purpose can be achieved by:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I believe the factors that help us achieve this purpose are:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I believe the factors that hinder us from achieving this purpose are:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other values and beliefs I consider important in relation to caring for people with spasticity are:</th>
</tr>
</thead>
</table>
Appendix 3

Project title: Spasticity Service evaluation of the Intrathecal Baclofen service

Project lead: Liz Keenan

Participant Information Leaflet – Patients

We would like to invite you to take part in an evaluation of the service, which the spasticity team are completing at the National Hospital of Neurology and Neurosurgery (NHNN)

What is the purpose of the Project?
The overall aim is to explore the patient experience of the Intrathecal Baclofen service

What are we trying to find out and why?
Through undertaking this evaluation we hope to find out more about your experiences, living with your condition, and the current education that we provide in practice, for people receiving Intrathecal Baclofen

What does the study mean for me?
The Principal Investigator, Liz Keenan, with the support of Jo Odell, Practice Development Facilitator at the Foundation for Nursing Studies (FoNS) will interview you ask you to tell your story. This short interview (40 minutes maximum) will be recorded and transcribed verbatim for the sole purpose of this project.

Do I have to take part in the project?
It is up to you, if you want to take part in the project. You do not have to agree to take part.

How will I be treated if I do not take part?
You will not be treated differently if you do not take part in the study. The standard of care you receive will not be affected.

What are the benefits of taking part?
There will be no direct benefits to you from this project. However, the information gained from this study will help us to evaluate our service in this future.

What if I have concerns relating to this study?
If you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Investigator. The normal National Health Service complaints mechanisms are also available to you.

What will happen if I don’t want to carry on with the study?
You can choose to withdraw from the study at any time during the study. If you decide to withdraw from the study you can do so by informing the Investigator.
What will happen to the results of the study?
The results of the project will be published so that others can learn from what we find out from the evaluation. All published data will remain anonymous unless you specifically consent to photographs or audio material being used.

Who is organising and funding the evaluation?
The project is being funded by the Foundation of Nursing Studies, a registered charity who are dedicated to the working with nurses and healthcare teams to develop and share innovation ways of improving practice. This project is a multidisciplinary initiative.

Who has reviewed the study?
The service evaluation has been reviewed within the NHNN spasticity team and registered with the audit and clinical governance team at NHNN

What if I do have any questions?
You can contact us during working hours by ringing the phone number below or by writing by e-mail. We will be happy to answer any questions or address any concerns that you have.

What now?
If you agree to take part in the project please give your verbal and written consent to the Principal Investigator.

Thank you for taking time to read this information leaflet

Contact numbers:

Patient Advice and Liaison Service (PALS) is xxx
Appendix 4

Written Consent Form

Full Title of Project: **Spasticity Service evaluation of the Intrathecal Baclofen service**

Name of Project lead:

1. I confirm that I have read and understand the subject information leaflet for the above study and have had the opportunity to ask questions which have been answered fully.

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I give permission for these individuals to access my records that are relevant to this project

4. The compensation arrangements have been discussed with me. I understand there is no compensation for taking part to this study.

5. I agree to take part in the above project.

Name of Patient

________________________

Date

Signature

________________________

Name of Person taking consent

________________________

Date

Signature

Service Evaluation, Spasticity team, NHNN
Consent form: version 1, 9th Jan 2014
Appendix 5

Evaluate the experience of people receiving intrathecal baclofen (ITB) treatment for their spasticity, and capture the quality of life impact ITB treatment has on carers

Liz Keenan, Jo Odell, Kat Buchanan, Hyesook Lee, Laura Balfour, Dr Val Stevenson

Aim
To evaluate the experience of people receiving Intrathecal Baclofen (ITB) treatment for their spasticity, and capture the quality of life impact ITB treatment has on carers.

Method
A mixed method approach was used. Emotional touch points were used to structure user interviews to gather experiences of living with ITB and Seven users with ITB pumps were interviewed face to face. Carers were invited to complete a survey on line which looked at Caregiver Strain Index.

Process
An information leaflet was emailed, inviting users to participate in this evaluation. Following consent, people were encouraged to answer the following questions by selecting a series of cards that depict emotional words: Tell us about yourself? Tell us how you feel about living with your condition? Tell us how you feel about your pump? How can we work with you better to help you?

What did we learn?
1.  Comment: “It was probably the most difficult thing in my life to get from the front door to that clinic”
   - Words selected: Appreciative, Fortunate, Happy, Cared for, Calm, Thankful
2.  Comment: “The pump has changed my life again for the better, so I have a much more positive view of my future”
   - Words selected: Appreciative, Enthusiastic, Encouraged
3.  Comment: “I think it makes me more capable because I don’t have to worry so much about so many drugs”
   - Words selected: Appreciative, Comfortable, Calm, Curious, Accepted

Comments on the process of using emotional touch points as a method:
“you forgot sometimes of how you actually felt at the time and you see the word it reminds you gosh, I did feel like that”

“What did the carer’s report?”
1.  Over 80% reported that their sleep was disturbed and a greater physical effort needed
2.  60% of carer’s reported emotional strain and needing to adjust future plans
3.  Not being able to complete all their daily tasks, was reported by over 80%

Key findings and next steps
- Emotional touch point method is easy to use and can generate very valuable user narratives
- These negative and positive experiences need to be shared with a stakeholder group
- Further analysis of narratives will guide future patient education programmes
- To organise a focus group with the ward staff as this evaluation has provided us with a platform for discussion of the spasticity pathway

References

Acknowledgement
Thank you to all the users and carers for their time and contribution to this service evaluation.
Appendix 6

The National Hospital ITB Pump Service would like to invite you to

A Christmas Celebration

Friday 19th December 1.30 - 3.00 pm or 3.00 - 4.30 pm

Venue: 2nd Floor, Albany Wing, The National Hospital

As well as eating, drinking & chatting we would very much like to find out whether as a group of patients you would like to set up some kind of support network. We would also like to share with you some service developments. Numbers are limited so please RSVP by the 21st Nov to Bernice Saunders by calling 0203 448 3312 or email bernice.saunders@uclh.nhs.uk

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